

# Assessment of Screening, Diagnosis and Identification of Autism Spectrum Disorder in Virginia



A VCU-ACE WHITE PAPER

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## EXECUTIVE SUMMARY

It is well documented that ASD can be accurately diagnosed between ages two and three. Identifying and diagnosing ASD at young ages enables children to begin receiving ASD-specific early intervention services, which research shows can produce favorable outcomes. Throughout Virginia, a number of services and supports are available to support individuals with ASD and their families. Despite the range of services available, it is clear that the current service delivery system is not keeping pace with the growing needs for diagnosing, treating, and managing ASD. In 2008, the Virginia General Assembly asked the Joint Legislative Audit and Review Commission (JLARC) to assess availability and delivery of ASD services in the Commonwealth, examine the provision of these services in other states, and identify better ways to serve individuals with ASD. While the JLARC report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, noted many findings, the final conclusion specifically outlined a need for massive improvement in the domain of diagnosis and identification of ASD.

To help improve services for those with ASD and their family members, the Virginia Commonwealth University Autism Center for Excellence (VCU-ACE) convened an interdisciplinary Task Force of stakeholders across the Commonwealth to study issues related to medical and educational assessment. The Task Force, composed of educational, medical, and community based providers, convened for 18 months beginning in 2011. Also involved were family members of persons with ASD. The task force evaluated three different topics related to identification of ASD: screening, diagnosis, and systems change. A subcommittee was formed for each topic, with an equal representation of members who identified research questions and completed evaluation activities. Upon completion of the evaluation, recommendations were made to improve services related to screening, diagnosis and identification of ASD in Virginia.

### Recommendations:

1. Increase the occurrence of and access to recommended screenings.
  - a. Develop a Virginia based website or webpage providing information related to recommended practice in screening and diagnosis of ASD as delineated in the literature and through CDC and APA, so parents, medical professionals, early interventionists and educational teams can access evidence based information.

The website should include:

- i. Recommendations for screening
- ii. A list and description of appropriate screening tools for children of different ages (e.g. CSBS-6-24 months; M-CHAT-16-30 months; SCQ [24months +])

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- iii. A list and description of appropriate diagnostic tools for children with different characteristics
    - iv. Guidelines for screening
    - v. Procedures for diagnosis
    - vi. A directory for tier 2 or 3 evaluations that characterize the services that are available at specific clinics across Virginia
  - b. Target medical residents and medical students and provide training related to the characteristics of ASD and screening so new pediatricians are aware of the importance of screening as well as how and when to provide screening.
  - c. Target pediatricians, including physician assistants and nurse practitioners, by providing a brief tutorial [2-3 minutes] or announcement which can be viewed online or delivered in person which highlights the need for screening, provides a link to the M-CHAT and other screening tools, emphasizes the cost effectiveness of screening, and describes how to bill for services
  - d. Target early interventionists and provide training related to the characteristics of ASD, importance of an early diagnosis, importance of specialized services and intervention, and provides information related to talking to and supporting parents
2. Expedite the diagnostic process by increasing the supply of trained professionals.
- a. Develop a state guidance document that outlines recommendations in the areas of screening, diagnosis and educational identification of ASD. Guidance documents developed by other states can be referenced to determine content.

- At a minimum, the document should provide:
- i. References to key research in screening, diagnosis, and educational identification
  - ii. Recommendations for screening
  - iii. A list and description of appropriate screening tools for children of different ages (e.g. M-CHAT-16-30 months; SCQ [24months +])
  - iv. A list and description of appropriate diagnostic tools for children with different characteristics
  - v. Guidelines for screening
  - vi. Procedures for diagnosis
  - vii. Recommendations on who can provide a diagnosis
  - viii. Critical areas to measure (e.g. adaptive behavior, neuropsychological, audiological) and recommendations of assessments to complete when conducting a diagnostic evaluation
  - ix. Procedures for educational identification
  - x. Recommendations on members of the educational team and those who should conduct the assessments
  - xi. Critical areas to measure (e.g. adaptive behavior, cognitive performance, communication, social, audiological) and recommendations of assessments to complete when conducting an educational evaluation
  - xii. Steps and procedures to move a child from diagnosis or identification to service delivery
  - xiii. Recommendations on how to work with parents and maintain sensitivity as well as respect cultural characteristics

- b. Develop and promote a tiered system for a medical diagnosis of ASD so the simplest, shortest assessment which produces the desired outcome and is tailored to the circumstances is provided so those children with prominent, clear symptomology can be diagnosed and move quickly to intervention and those with more subtle characteristics receive more comprehensive assessment
  - c. Develop and promote a tiered system for educational identification of ASD so the simplest, shortest assessment which produces the desired outcome and is tailored to the circumstances is provided
  - d. Provide state-wide training to school divisions in the use of gold-standard diagnostic tools including the ADOS-2 and ADI-R
  - e. Since the school psychologist and speech therapist are considered to be 2 of the most critical school team members, provide state-wide training to school psychologists and speech therapists targeting assessment of students considered to have ASD and emphasize characteristics of those students who are higher functioning
  - f. Develop a directory for clinics across Virginia providing tier 2 or 3 evaluations and characterize the services that are available at specific clinics
3. Improve the information and referrals parents receive once they begin the identification and diagnostic process.
- a. Since parents who have a child with ASD will likely gather information on their own (e.g. Internet, books), Virginia should create a website and series of documents for parents providing essential information related to receiving a diagnosis of ASD. Information can be disseminated at the time of the assessment or diagnosis.
    - Information provided could include:
      - i. Characteristics of ASD
      - ii. Information related to insurance coverage for young children with autism
      - iii. Early Intervention
      - iv. School age services
      - v. Medicaid
      - vi. Medicaid Waivers
      - vii. Evidence based interventions
      - viii. Strategies to support a child with ASD in the home
      - ix. Support Groups
  - b. In the state guidance document, provide recommendations for practitioners related to information to provide to parents at the time of assessment, time of diagnosis, and on an ongoing basis
  - c. Since many clinics provide a report with a diagnosis, provide several sample reports which delineate appropriate information to include
  - d. Target early interventionists and provide training related to specialized services and intervention, how to support parents emotional journey, and how to coach parents in effective interventions for children with ASD
4. Raise public awareness.
- a. Work with the Learn the Signs. Act Early! Ambassador of Virginia (Deana Buck) to distribute CDC materials to child care centers, Head Start and other programs serving young children
  - b. Support the creation of a coalition of state agencies and professional groups who have a stake in the health and well-being of young children including DBHDS, the VA Department of Health.



In the past decade, Virginia has experienced a dramatic increase in the number of children diagnosed with Autism Spectrum Disorder (ASD). According to data released in 2012 by the Center for Disease Control and Prevention (CDC), autism spectrum disorder affects 1 in every 88 children in the United States. This represents a 23% increase since the CDC's last report in 2009. Based on the CDC report, ASD appears to affect children of different racial, ethnic, and socioeconomic backgrounds at similar rates. However, males are four times as likely to be affected as females. While the CDC estimates are the best available prevalence rates for the United States, in Virginia, the Department of Education reports an increase of more than 400% in the past 10 years. The latest data from the Individuals with Disabilities Education Act reveals 13,137 children ages 3-22 have been identified with an ASD in public schools.

Virginia operates several publicly supported programs designed to serve those with ASD and their families. Various agencies provide an array of services ranging from diagnosing the disorder to offering intervention and treatment. At the very core of service delivery, are the procedures required to accurately and reliably identify those who have ASD and move them seamlessly into intervention services. It is well documented that ASD can be accurately diagnosed between ages two and three. Identifying and diagnosing ASD at young ages enables children to begin receiving ASD-specific early intervention services, which research shows can produce favorable outcomes. Children receiving these services experience improved functioning, IQ gains, more frequent general education placement and require fewer supports over time. Additionally, there is a significant cost savings to the Commonwealth, as there are estimated savings of \$137,400 in special education costs per student with an ASD, if intensive early intervention services are consistently provided for a period of two to three years if delivered before the age of six (Educating Children with Autism , 2006).

Years of extant research clearly concludes that identification of ASD at a young age is a critical component of providing lifelong services to those who are on the spectrum. Early identification allows the child to receive intervention services at a pivotal period of development. Further, early identification can supply much needed information to family members who observe differences in their child's development and provide a direction for treatment. Identifying children at younger ages has become so critical that it is now a national priority to lower the age of diagnosis. In response to the crisis, the CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD), in collaboration with a number of national partners, launched a public awareness campaign called "Learn the Signs. Act Early." The campaign aims to educate parents doctors and other caretakers about the early warning signs of autism spectrum disorder and encourages screening and intervention.

Despite the range of services available in Virginia to support individuals with ASD and their families, it is clear that the current service delivery system is not keeping pace with the growing needs for diagnosing, treating, and managing ASD. In 2008, the Virginia General Assembly asked the Joint Legislative Audit and Review Commission (JLARC) to assess availability and delivery of ASD services in the

Commonwealth, examine the provision of these services in other states, and identify better ways to serve individuals with ASD. While the JLARC report, *Assessment of Services for Virginians with Autism Spectrum Disorders*, noted many findings, the final conclusion was that programs in the Commonwealth do not form a comprehensive system of care for Virginia residents living with ASD. The JLARC report also outlined a need for massive improvement in the domain of diagnosis and identification of ASD.

The report has shown that Virginia's efforts in diagnosis and identification are appalling, as diagnosis of ASD is happening far too late. It is widely known that children can be reliably diagnosed with ASD by three years of age. However, in Virginia, children are often diagnosed much later, with the average age of diagnosis being six to seven years of age. Of course, if a child is not diagnosed until the age of six, then critical intervention opportunities have passed.

According to the report, delays in diagnosis occur due to a multitude of reasons. First, parents are unsure how to proceed when they first notice signs of atypical development. Physicians also do not consistently use recommended tools to screen for ASD or provide ongoing surveillance. Additionally, there is a limited capacity to formally diagnose ASD throughout the entire state. There are few professionals trained and able to make an accurate, differential diagnosis. This results in parents often receiving misinformation or being placed on extensive waiting lists. Because there are extreme delays in diagnosis, moving to intervention is further delayed for the child. When a diagnosis is made, both parents and providers, also report not knowing the necessary steps to obtain services.

## **JLARC Recommendations**

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The JLARC report indicates several recommendations that will facilitate earlier identification and diagnosis of ASD.

- These options address four main issues:
1. Raise public awareness about child development and ASD as this will facilitate earlier recognition of ASD characteristics and allow families to pursue diagnosis at younger ages.
  2. Increase the occurrence of recommended ASD screenings by providing training on performing screenings to medical and non-medical personnel.
  3. Expedite the diagnostic process by increasing the supply of trained professionals and creating regional capacity to provide multidisciplinary diagnoses.
  4. Improve the information and referrals parents receive once they begin the identification and diagnostic process.

Reducing the age of identification and ensuring children receive intervention services as early as possible is a serious need that will require Commonwealth wide involvement. This requires the development of local capacity throughout the entire



state and requires efforts aimed at both the medical and educational fields. On the medical front, physicians, including pediatricians, family physicians, developmental pediatricians, psychologists, and neurologists need significant improvement in identifying early signs of ASD, screening at regular intervals, diagnosing ASD across all ages (using sound clinical models and gold standard tools), and providing recommendations to parents for movement into service delivery. For educational services, educators need improvement in the identification of the early signs of ASD. Further, improvement among school psychologists and other educational team members is needed in terms of eligibility determination for special education services under the disability category of autism, including the use of sound data and gold standard evaluation tools, as well as, incorporating appropriate individualized interventions and supports.

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## Virginia Commonwealth University Autism Center for Excellence (VCU-ACE)

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The VCU-ACE is a university-based technical assistance, professional development, and educational research center. It is dedicated to improving services to individuals with ASD and to the implementation of evidence-based practices in schools and the community. The ACE mission is to build state-wide capacity to improve outcomes of individuals with ASD by improving the knowledge, skills and understanding of families, educators, and professionals who support someone with a spectrum disorder.

ACE strives to accomplish this through four activities:

- **Training** - Training increases knowledge and understanding of ASD and interventions throughout the entire state.
- **Technical Assistance** - Technical Assistance promotes the implementation of best practice in targeted school divisions.
- **Collaboration** - Collaboration helps provide a comprehensive array of services and supports by working with stakeholders who share the ACE mission and passion.
- **Research** - Research helps identify effective practices for individuals with ASD.

## VCU-ACE Screening, Diagnosis, and Identification Task Force

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One core goal of VCU-ACE is to facilitate statewide planning to increase capacity and take the critical first steps towards identification, diagnosis, and intervention planning. ACE has a vision for infants, toddlers, and young children with ASD and their families to be provided with quality screening and assessments, which are delivered in a timely and culturally competent manner. In 2011, VCU-ACE convened an interdisciplinary Task Force of stakeholders across the Commonwealth to study issues related to medical and educational assessment. The Task

Research  
Conducted

Force, composed of educational, medical, and community based providers, convened for 18 months. The Task Force also asked family members of persons with ASD to share their unique perspective. The Task Force evaluated three different topics related to identification of ASD. A subcommittee evaluated each topic. Each subcommittee contained a chair and co-chair with an equal representation of members from the Task Force who completed evaluation activities. The following is a description of each subcommittee. It includes members, research questions asked, and a summary of the evaluations conducted.

### SCREENING

Chair: Dr. Maria Urbano of Eastern Virginia Medical School

Co-chair: Staci Carr of VCU-ACE

Members: Dr. John Harrington, Dr. Donald Lewis, Dr. Sean McKenna, and Dr. Carol Schall.

- Research Questions:
- ❑ What are the recommendations for screening for ASD?
  - ❑ What are the recommended tools for screening a child for ASD?
  - ❑ Who is the first to notice atypical signs of development in an individual with ASD in Virginia?
  - ❑ Do pediatricians in Virginia conduct screening for ASD? If so, what screening tools are used?
  - ❑ Do school divisions in Virginia conduct screening for ASD?

- Evaluation Methods:
- ❑ Survey administered to school divisions across the state including Hampton, Newport News, Lancaster, Northumberland, Richmond County, Town of Colonial Beach Public Schools, Wise, Richmond, and Arlington. Responses: 8
  - ❑ Survey administered to pediatricians across the state. Responses: 55
  - ❑ Survey administered to parents of children with ASD across the state. Responses: 79

### DIAGNOSIS

Chair: Dr. Donald Oswald of Commonwealth Autism Services

Co-chair: Dr. Dawn Hendricks of VCU-ACE

Members: Carol Burke, Adam Dreyfus, Dr. Tracy Fatzinger, Dr. Tony Gentry, Dr. Donna Gilles, Dr. Colleen Kraft, Dr. Rachel Mathews, Jennifer Rabung, and Dr. Lissa Power-deFur.

- Research Questions:
- ❑ What are the essential features of the medical diagnostic process?
  - ❑ Who may conduct a diagnostic evaluation for ASD?
  - ❑ What are the recommended tools for diagnosing a person with ASD?
  - ❑ What additional testing is recommended when evaluating for ASD?

- ❑ What is the parents' perspective of the medical diagnostic process?
- ❑ What does a medical diagnosis of ASD look like in Virginia?
- ❑ What is the role of early intervention in relation to diagnosis/identification of young children?
- ❑ What do early intervention providers in Virginia need to know to lower the age of identification?
- ❑ How is service delivery and diagnosis connected?
- ❑ How is service delivery and diagnosis connected in Virginia?

- Evaluation Methods:
- ❑ Survey administered to medical practices and child development clinics that provide ASD diagnostic evaluation across the state. Responses: 14
  - ❑ Review of literature
  - ❑ Review of state guidelines and resource documents
  - ❑ Interview with Virginia early intervention representatives from Infant and Toddler Connection

#### SYSTEMS CHANGE

Chair: Dr. Heather Applegate of Loudon County Public Schools

Co-chair: Joy Engstrom of VCU-ACE

Members: Maria Beck, Joy Engstrom, Cindy Gwinn, Jennifer Sherry, and Janet Willis.

- Research Questions:
- ❑ What guidelines exist regarding screening, diagnosis and identification of ASD?
  - ❑ What information is provided in state level guidance documents for screening and diagnosis of ASD?
  - ❑ What guidelines exist regarding identification of autism in schools?
  - ❑ What are the essential features of the evaluation process to identify a child with autism in schools?
  - ❑ What guidelines exist in Virginia regarding educational identification of autism in the public schools in Virginia?
  - ❑ What does an eligibility evaluation for ASD look like in Virginia?
  - ❑ What are the tools used in school divisions when conducting an eligibility evaluation for ASD?
  - ❑ What do educators / educational teams in Virginia need to know to lower the age of identification?

- Evaluation Methods:
- ❑ Surveys administered to lead school psychologists in school divisions across Virginia. Responses: 67
  - ❑ Review of state guidelines and resource documents

The results of the Task Force are outlined below and are arranged according to research questions.

## Systems Change

### Question 1. What guidelines exist regarding screening, diagnosis and identification of ASD?

Several resources exist regarding guidelines for screening, diagnosis and identification of ASD. Resources include articles found in the research literature, as well as, developed guidance or procedural documents. Guidance documents are found at the national level, as well as, the individual state level.

In the research literature, there are a number of resources that clearly delineate early identification recommendations.

The primary sources on this topic include,

but are not limited to, the following:

- Filipek et al. (2000)
- Freeman & Cronin (2002)
- Ozonoff, Goodlin-Jones, & Solomon (2005)
- Johnson, Myers, & the Council on Children with Disabilities (2007)
- Matson, Beighley, & Turygin (2012)

Nationally, there are a number of agencies and associations providing recommendations on identification of ASD. For example, Autism Speaks, the Autism Society of America and the American Speech-Language-Hearing Association all provide such guidelines. However, there are two primary sources providing information at the national level. The American Association of Pediatrics (AAP) has guidance documents and resources designed to assist in the recognition, evaluation, and ongoing management of ASD throughout a child's life span. The CDC, as noted previously, has an active public awareness campaign called "Learn the Signs. Act Early." This campaign provides guidelines, as well as, resources and training activities to educate family members and medical personnel.

At the state level, a number of states have recognized the need to develop standard procedures for identification of ASD. The subcommittee performed a comprehensive review of state guidelines related to systems change. This review yielded 31 existing state guidelines or recommendations. A list of the states with such documents is in appendix A.

### Question 2. What information is provided in state level guidance documents for screening and diagnosis of ASD?

The information provided in state level documents varies considerably. Approximately half of the documents address issues related to screening young children. In these documents, recommendations are provided for screening children from birth to five and standardized screening instruments are given. Approximately 25% ad-

dress screening in individuals age 6 and older.

The review also included the type and level of information available regarding diagnostic evaluations. Despite the literature providing clear guidelines on how to best conduct an evaluation, recommendations in this area are surprisingly different and in many cases, sparse. When outlining the components of an evaluation, the most common strategy listed is the use of a developmental history (42%). The least common is the use of adaptive behavior assessments (24%). Other components, such as observations, parent interview, rating scales, and the use of gold standard tools, are infrequently addressed. Guidelines regarding who can or should conduct an evaluation are inconsistently provided. Twenty-one percent make specific team evaluation recommendations, while a slightly smaller group lists qualified medical personnel. Other evaluation factors are often provided. Most frequently addressed are the need for community collaboration in lowering the age of diagnosis (46%) and family collaboration and communication (46%). Written reports or provisions describing evaluations results (8%) and issues specific to young girls and women (4%) are the least frequently addressed considerations.

## Screening

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### General Information

#### **Question 3. What are the recommendations for screening for ASD?**

While there are recommendations on screening found in the literature, the best source for outlining screening recommendations is from the CDC. According to the CDC, children should be screened for both developmental delays and disabilities, as well as, specifically for ASD (2012). Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening, the doctor might ask the parent some questions or talk and play with the child during an exam to see how the child learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem. Screening is needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons. All children should be screened for developmental delays and disabilities during regular well-child doctor visits at the ages of:

- 9 months
- 18 months
- 24 or 30 months

Further, all children should be screened specifically for ASD during regular well-child doctor visits. Additional screening and evaluation is needed if a child is at high risk for ASD (e.g., having a sister, brother or other family member with an ASD) or if behaviors sometimes associated with ASD are present. All children should be screened for ASD during well-child visits at:

- 18 months
- 24 months

#### **Question 4. What are the recommended tools for screening a child for ASD?**

There are many different screening tools available. The CDC does not approve or endorse any specific tools for screening purposes. The National Professional De-

velopment Center on Autism Spectrum Disorders (2011) provides a list of recommended screening tools:

- ❑ Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999)
- ❑ Pervasive Developmental Disorders Screening Test-II (PDDST-II; Siegel, 2004)
- ❑ Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003)
- ❑ Social Responsiveness Scale (SRS2; Constantino & Gruber, 2012)

### Virginia Information

**Question 5. Who is the first to notice atypical signs of development in an individual with ASD in Virginia?**

Screening group survey results indicate that a number of individuals may first identify atypical signs of development. Parents most often identify atypical signs of development, followed by the pediatrician, family physician, early intervention provider, educator, and finally, child care provider. It is important to realize, the literature notes that parents are usually correct in their concerns about their child's development (Glascoe, 1994; Glascoe & Dworkin, 1995). Parents may not be completely accurate regarding the qualitative and quantitative characteristics present in their young child. However, if parents express a concern, there is indeed a problem in some aspect of the child's development.

**Question 6. Do pediatricians in Virginia conduct screening for ASD? If so, what screening tools are used?**

Forty percent of pediatricians surveyed indicate they do not conduct screening for ASD. Those who do screen for ASD, use a standardized tool. These tools include the Ages and Stages Questionnaire (Squires & Bricker, 2009) and the M-CHAT. The Ages and Stages Questionnaire is a general developmental screening tool and is not specifically designed to screen for ASD.

**Question 7. Do school divisions in Virginia conduct screening for ASD?**

According to survey results, school divisions do not currently conduct screening for ASD but instead rely on teacher referral for Child Study.

## Diagnosis

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### General Information

**Question 8. What are the essential features of the medical diagnostic process?**

The literature regarding diagnostic process provides substantial and consistent information (Filipek et al., 2000; Johnson et al., 2007; Matson, et al., 2012, Ozonoff, et al., 2005). A medical diagnostic evaluation for ASD consists of three primary goals. A medical evaluation provides a determination of the child's overall level of functioning and makes the categorical diagnosis of an ASD. The evaluation ultimately ensures treatment and determines the best means of intervention based on the child's profile of strengths and weaknesses.



There are several key characteristics of a quality medical assessment. The first characteristic is to maintain a developmental perspective (Ozonoff, et al., 2005). Development is integrated in complex ways across domains. Familiarity with early child development and areas of interconnection will improve the ability of professionals to appropriately diagnose and intervene with young children with ASD.

The second characteristic of a quality medical assessment includes incorporating information from multiple sources and contexts (Filipek et al., 2000; Johnson et al., 2007; Matson, et al., 2012; Ozonoff, et al., 2005). Individuals intimately involved in the care of the child add tremendous depth to understanding how the child functions in different environments and with different people and their input should be included in the assessment. Early intervention providers and school personnel have a role in the diagnostic assessment of children for possible ASD. In addition to being a source of referral for diagnostic evaluation, educational professionals can assist by providing accounts of behavioral observations and academic and psychological testing information. Additionally, the family is an essential member of the diagnostic team. Family members contribute by providing important historical information. They can optimize their roles by becoming familiar with the features of ASD and helping the diagnostic team recognize the features that may or may not be present in the child.

The literature outlines a 'core' assessment battery for conducting a quality evaluation of suspected ASD (Johnson et al., 2007; Ozonoff, et al., 2005). The core battery is as follows:

1. Conduct a thorough interview of the parents to review the child's early developmental history and ascertain concerns the parents have about their child.
2. Review all available records from sources thoroughly familiar with the child (e.g., schools, teachers, physicians, daycare providers, and early childhood intervention providers). Also included in the record review are any results of testing already conducted.
3. Provide direct observation of and interaction with the child by the assessment team.

The third and final characteristic of a high-quality assessment includes those measures and activities designed to move the child toward treatment. The ability to direct parents immediately to services and supports is a core issue impacting children and families. Referral networks and information received at the time of diagnosis or shortly thereafter can foster movement to intervention. Follow-up, where ongoing evaluation and additional information on ASD and services and supports is provided, is critical to maximizing positive outcomes (Ozonoff, 2005). When a diagnosis is made, clinicians must include an assessment of parents' knowledge of ASDs, coping skills, and available resources and supports and determine the intensity of follow-up (Johnson et al., 2007).

How each step of a high-quality assessment is carried out will vary depending on the child (Matson, et al., 2012). The age, presenting characteristics and symptomology, and previous evaluations may impact the assessment process. For some children, this may be a streamlined, timely process while others may require much more time and consideration. When it comes to assessment, more is not necessarily better. More can mean more stress for both the child and the family. The simplest,

shortest assessment which produces the desired outcome and is tailored to the circumstances, goals, and needs of the family should be used (Matson et al., 2012). Therefore, diagnosticians will need to use informed clinical judgment to determine what is necessary to make or rule out an initial ASD diagnosis.

**Question 9. Who may conduct a diagnostic evaluation for ASD?**

According to the literature, a clinician experienced in the diagnosis and treatment of autism is usually necessary for accurate and appropriate diagnosis and the general consensus is that a diagnostic evaluation is best conducted by an interdisciplinary team of child specialists with expertise in ASD (Filipek et al., 2000; Johnson et al., 2007). Although the use of teams is desirable in diagnosing ASD, they are not essential for accurate diagnosis in all cases. When teams of practitioners are not available, individual practitioners can provide diagnostic evaluations including pediatricians, developmental/behavioral pediatricians, pediatric neurologists, child psychiatrist, or child psychologists. Speech/language pathologists with expertise in ASD may be qualified to diagnose these disorders according to the American Speech-Language-Hearing Association.

Because of the complexity of ASD, it is not possible for any single clinician to maintain expertise about the full range of issues that present in every case. Therefore, a diagnostician must be aware of the limits of his or her own clinical competencies. The diagnostician must be able to determine when he or she is able to make a diagnosis independently or when input from other professionals is needed to inform diagnostic decision making.

While individual practitioners may complete diagnostic evaluations, the interdisciplinary team is valuable to the evaluation and assessment of older children and adolescents. In children and adolescents ages 6 and older, the challenges and difficulties are diverse and complex requiring a coordinated team approach. It is unrealistic to expect that individual practitioners have expertise in ASD and the multitude of concomitant and coexisting psychiatric and medical conditions that are often in question. Therefore, a team approach is critical to provide a comprehensive evaluation and assessment for children in this age group. Repeated referrals to multiple professionals increase the number of potential interventions, which is difficult and frustrating for the child and family.

**Question 10. What are the recommended tools for diagnosing a person with ASD?**

Filipek et al. (2000) recommends the use of a diagnostic instrument with at least moderate sensitivity and good specificity for autism. The parent-interview Autism Diagnostic Interview-Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003) and the performance-based Autism Diagnostic Observation Schedule-Generic (ADOS-G; Lord, et al., 2000) are considered to be the “gold standard” for the diagnosis of autism spectrum disorder (Ozonoff et al., 2005). However, the National Professional Development Center also recommends the Autism Observation Scale for Infants (AOSI; Bryson, Zwaigenbaum, McDermott,, Rombough, & Brian, 2008) and the Childhood Autism Rating Scale (CARS; Schopler, Reichler, & Renner, 1988). The CDC also recommends the Gilliam Autism Rating Scale-2 (GARS-2; Gilliam, 2006).



### **Question 11. What additional testing is recommended when evaluating for ASD?**

When conducting an evaluation, further measures beyond the core assessment may provide information needed for a differential diagnosis or to determine intervention services. Adaptive behavior, language, and neuropsychological evaluations will be helpful when determining if the child meets criteria (Ozonoff, et al., 2005). According to Johnson et al. (2007) it is generally accepted that a child who has screened positive for an ASD should undergo an audiological evaluation even if the neonatal screening result was normal.

Specific activities of the diagnostic evaluation will vary depending on the child's age, history, previous evaluations or assessments, and referral questions. For individuals aged six and older, the recommendation includes such additional measures as psychological, adaptive behavior, attention, language and cognitive assessments (Johnson, et al., 2007).

A medical evaluation may also include a search for an associated etiology (Johnson, 2007). In this case, the first step is the completion of a thorough health history. Administering a physical examination includes a thorough search for dysmorphic features and neurological abnormalities and a laboratory investigation to search for a known etiology or coexisting condition. The most commonly tested etiology, and the test with the best empirical support, is for Fragile X, particularly if intellectual disability is present (Filipek et al., 2000). With respect to other genetic tests, Johnson et al. (2007) concluded that current data does not support extensive testing of all children with ASD; however, the rapidly-developing literature in this area may render this conclusion outdated at any time. Further medical tests are recommended with caution. EEGs are only recommended for children who demonstrate clinical signs of seizure activity or for those with clear language regression. Testing for Rett's syndrome should be provided for any girl who presents with microcephaly and a global delay.

### **Question 12. What is the parents' perspective of the medical diagnostic process?**

Few formal studies address how parents perceive the diagnostic process and their level of satisfaction. There are some studies, from a variety of countries, which provide a parent's perspective. Results of these studies suggest that parents' experiences of the diagnostic process vary. Some are quite satisfied with the process of arriving at a final diagnosis, education received about the diagnosis, and treatment recommendations. Others find the diagnostic process lacking in various aspects. Factors possibly related to satisfaction are the number of professionals visited to get a diagnosis, wait time to get a final diagnosis, the amount of collaboration the parent perceives with the diagnosing professional, and the amount of stress a parent feels during the diagnostic process.

A North-Carolina specific study (Gaspar de Alba & Bodfish, 2011) assessed how well parents' concerns about symptoms were addressed during the diagnostic process. The authors conducted an Internet-based survey and offered it to all families listed in the North Carolina Autism Registry. There was a final response of 438. The

survey asked which of seven areas (receptive language, expressive language, social problems, unusual/unwanted behaviors, sleep problems, eating problems, gastrointestinal problems) were of foremost concern for parents at diagnosis and how well they felt those concerns were addressed. Survey participants also rated a list of secondary concerns in terms of how important it was to discuss these issues at time of diagnosis. Results indicated that core deficits of social problems (33%), expressive language (36%), and unusual/unwanted behaviors (22%) were of most concern, but parents considered them well-addressed only about half the time. Sleep, eating, and gastrointestinal problems, or non-core symptoms, were rated as significant concerns for only 6% or less of respondents. In terms of secondary issues, survey participants indicated that it would be 'very important' to discuss treatment options and available therapy services. Available therapy included such services as behavioral, speech and other therapies, medication options, and other medical or psychological services, and the best educational environment. They also indicated that information about expectations for the child's future, where to find more information about autism spectrum disorders, and local support or parent groups would be helpful. Overall, the authors suggested that as many as half of all parents were leaving the initial diagnosis encounter feeling that their concerns about their child's core ASD symptoms had not been fully addressed. Additionally, many felt unsatisfied with the process because neither core nor secondary issues are properly addressed.

In another survey of parents' view of the diagnostic and recommendation process, Keenan, Dillenburger, Doherty, Byrne, and Gallagher (2010) questioned 95 parents of a child with ASD about the process of obtaining a diagnostic evaluation and an educational program in Northern Ireland or the Republic of Ireland. Participants were recruited by distributing survey invitations at conferences, special schools, school districts, and health boards, and listed on websites of autism-specific entities. Survey results indicated that about half of the sample (49%) did not think they received clear information about their child's diagnosis. Furthermore, 77% of respondents did not think the advice from providers was sufficient for their child and family and they did not receive clear advice on how to proceed after diagnosis.

Results from a study of 70 southeastern English parents by Osborne and Reed (2008) are similar to results reported above. Parents of children diagnosed with ASD were invited to participate in focus group discussions about the diagnostic process. Twenty-five to thirty percent of the sample reported that they had been given no to very little information, advice or support about understanding the nature of ASD at the time of diagnosis. Most reported finding some benefit in receiving the diagnosis such as relief, confirmation of their concerns, or increasing others' understanding regarding their challenges with their child. However, a significant proportion of parents reported that 'nothing' was helpful about receiving a diagnosis and they had not achieved better understanding of their child or that they may have been in the grieving process about their child's future development.

Moh and Magiati's 2012 study also focused on parents' experience in a specific country, Singapore. Parents of children with ASD from ages two to 17 completed a survey regarding the diagnostic process, satisfaction, and stress. Results indicated that higher parental satisfaction was associated with higher perceived collaboration with professionals, higher perceived helpfulness of received information, and lower levels of stress. Parents reported feeling most collaborative with professionals

who took their concerns seriously, gave them specific information about autism, explained the process of gathering information from multiple perspectives and the reasons for the diagnosis, and made them feel like partners in decision-making.

### Virginia Information

#### Question 13. What does a medical diagnosis of ASD look like in Virginia?

The VCU-ACE Task Force conducted surveys of medical personnel, as well as, family members to examine practices regarding a medical diagnosis of ASD in Virginia. Because the first step of the diagnostic process is the referral for an assessment, the survey asked medical personnel to indicate from whom they get referrals for assessment.

Below is the ranking in order from highest number of referrals to the lowest number of referrals provided:

1. Parents
2. Pediatrician/Primary Care Physician
3. Educator
4. Medical Specialist (e.g. Neurologist, Psychiatrist)
5. Early intervention Provider
6. Mental Health Care Providers/Social Workers
7. Department of Social Services

Medical personnel were asked about the diagnostic procedures employed. First respondents answered questions about diagnostic tools used. One hundred percent of responders indicate that a clinical interview with the parent combined with direct observation / interaction assessment are used as diagnostic components. Eighty-six percent of the survey responders have parents complete a diagnostic checklist.

Next respondents answered questions related to the individuals who complete the diagnostic evaluation and make the diagnostic decision. Thirty-six responders indicate that assessment is completed with only a single provider. Of those who use a team approach, 43% of responders indicate diagnosis is reached through a transdisciplinary or multidisciplinary team consensus while 21% of responders note that 2-4 multidisciplinary providers conduct assessments, and diagnosis is then formed by a single provider after a review of those reports. For those responders who use a transdisciplinary or multidisciplinary team approach, Table 1 on the following page lists team members who may be incorporated as part of a diagnostic team, and indicates the percentage of responders who include that member as part of the diagnostic process. For both groups a clinical psychologist was the most common member of the team.

|                                        | Team of providers conduct assessment, diagnostic decision is made by team consensus | Team of providers conduct assessment, diagnostic decision made by single provider |
|----------------------------------------|-------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|
| Clinical Psychologist                  | 88%                                                                                 | 88%                                                                               |
| Social Worker                          | 88%                                                                                 | 63%                                                                               |
| Developmental/ Behavioral Pediatrician | 63%                                                                                 | 63%                                                                               |

(continued)

**Table 1:  
Team Members  
According to Role  
Who are Included  
in the Diagnostic  
Assessment**

|                             | Team of providers conduct assessment, diagnostic decision is made by team consensus | Team of providers conduct assessment, diagnostic decision made by single provider |
|-----------------------------|-------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|
| Educator                    | 75%                                                                                 | 63%                                                                               |
| Child Psychiatrist          | 25%                                                                                 | 13%                                                                               |
| Speech / Language Therapist | 13%                                                                                 | 25%                                                                               |
| Occupational Therapist      | 13%                                                                                 | 0%                                                                                |
| Behavior Analyst            | 13%                                                                                 | 0%                                                                                |

Lengthy waiting lists are a major concern throughout the Commonwealth. When asked about the length of time a family waited for an assessment, respondents indicate a range from two weeks to six months with the predominant answer indicating a wait of three to six months. This is indeed a very long time for a parent with a child with challenges indicative of ASD.

Practices were asked to indicate the deliberate steps taken to provide family-centered diagnostic assessments. The practices surveyed report (100%) that they provide a gracious and welcoming environment with multiple opportunities for families to express their main concerns, listen carefully to family concerns and follow up until the concerns are clearly understood as deliberate steps needed to provide family-centered diagnostic evaluations. Eighty-six percent report actively involving families in the discussion of the diagnosis by regularly soliciting their input and 57% provide an integrated, comprehensive, multidisciplinary written evaluation report in a timely fashion.

Sixty-two percent of practices indicate that in an effort to improve evaluation processes, they solicit input from school personnel or local early intervention personnel or others who know the child well. Fifty-four percent indicate evaluation improvement would increase the number of discipline representatives participating in the process while 46% would incorporate the use of more or different diagnostic instruments. Thirty-nine percent indicate a need to provide an opportunity for discipline representatives to meet together in order to establish a diagnosis conjointly. Practices also report an additional time to observe and interact with the child and the family (31%) with others indicating they would not change their current evaluation process (15%). The primary barriers to improvement among practices include time constraints and additional expense (64%) and an inability to bill for services (43%).

In regards to practices in obtaining a medical diagnosis of ASD in Virginia, family members were asked to report the age of the child when the diagnosis was made. Parents indicate an age range of diagnosis from one year to seventeen years old, with the majority diagnosed between the ages of two and seven. See Figure 1 on the following page for the breakdown of child age.

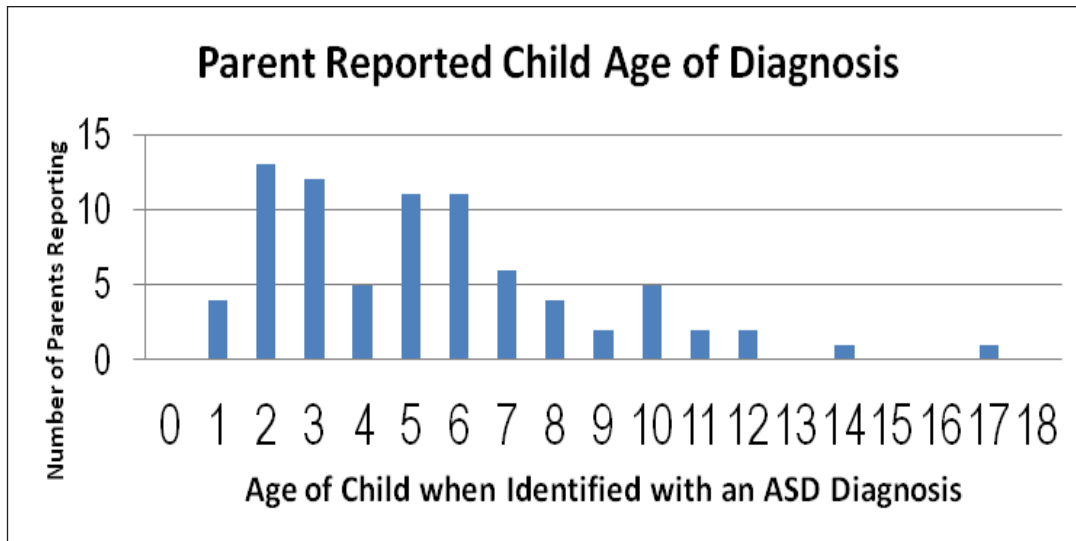


Figure 1:  
Age of Diagnosis

One quarter of parents report seeing five or more, professionals prior to the child receiving a diagnosis on the autism spectrum. Over half see 4 or more, while 74 percent indicate seeing three or more professionals. Figure 2 below provides a graph indicating the number of professionals seen by parents before a diagnosis is made. As indicated in the figure, only 26% of parents report seeing 2 or less before the diagnosis is made. It is reasonable that some parents may need to visit more than one professional, however, visiting three or more is not a good use of the family’s time and reduces time the child can be receiving needed intervention services.

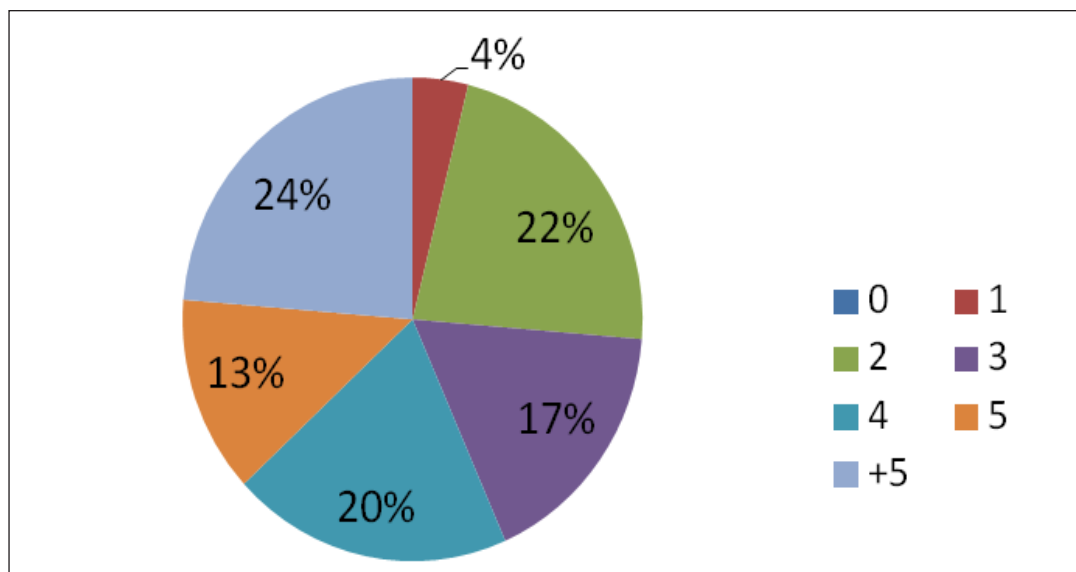


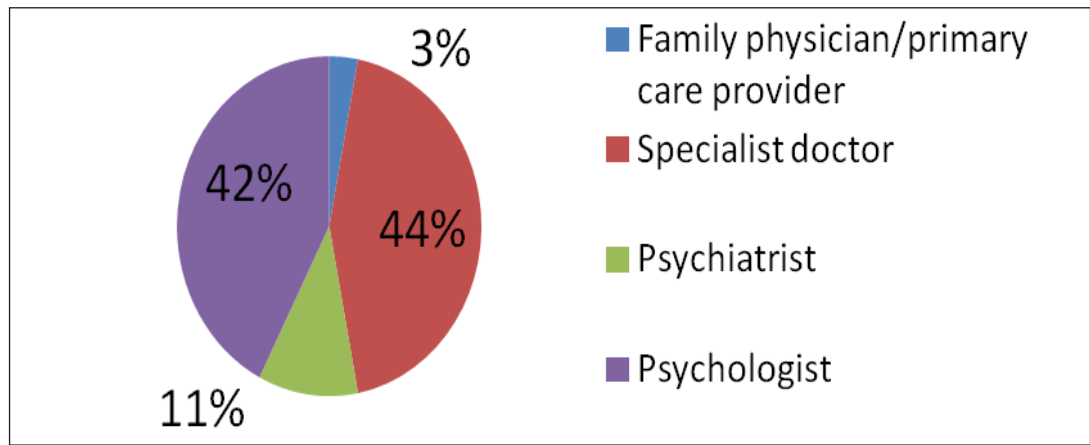
Figure 2:  
Number of Professionals Seen Prior to Child Receiving a Diagnosis

A specialist doctor or psychologist most frequently provides the diagnosis while a family physician or primary care provider least frequently provides the diagnosis. Figure 3 on the following page provides more information.



Figure 3:

Provider Making the Formal Diagnosis



When asked about the diagnostic experience, over fifty percent of the parents surveyed indicate they were not satisfied with the process. Only 16% indicate being extremely satisfied. Parents were asked to report about the information they found to be most helpful when receiving the diagnosis. Forty-one percent report they receive no helpful information. Eight percent report that the diagnosis is the only helpful information provided. Only 40% report receiving referrals or resources. Of those, books, websites are provided to some while referrals for social groups, speech therapy, and/or occupational therapy are provided to the majority.

In a Virginia-specific study, Rhoades, Scarpa, and Salley (2007) conducted an Internet-based survey regarding the process of evaluation and the types of actions or information provided by the diagnosing professional after the diagnosis was made. Parents reported that 41% of professionals spent time talking about autism and that 45% of diagnosing professionals handed out literature about autism while an equal amount (45%) handed out information on available resources. Parents also reported that 34% of diagnosing professionals advised them on educational programs whereas only 15% advised them on medical programs. Ten percent of parents were referred to a support group and 6% were referred to an autism specialist. Eighteen percent of parents reported that the diagnosing professional provided them with no additional information. This is an appalling finding as parents who receive such upsetting news are in immediate need of services and supports for both their child and family unit.

Data indicate that developmental pediatricians were most likely to provide additional information to parents with 97% doing so. Neurologists were the least likely with only 56% providing additional information to parents. Parents were also asked what other sources they used to gain information about their child's diagnosis. The most widely used resources were the Internet; books, magazines or videotapes; conferences and workshops; other parents of children with autism. Very few turned to healthcare professionals, education professionals, parent resource centers or early intervention specialists.

# Identification of Autism in Schools through Eligibility Evaluation

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## General Information

### **Question 14. What guidelines exist regarding identification of autism in schools?**

It stands to reason that the diagnostic process will be different when it comes to making a medical diagnosis of ASD versus evaluating a child in a public school to determine eligibility for special education services under the disability category of autism. The literature focuses on medical diagnosis rather than educational eligibility; therefore, there is a scarcity of information on this topic. A review of educational guidelines for autism evaluation from Connecticut, Missouri, Ohio, Oregon, Wisconsin and Tennessee reveals that scope and detail in the evaluation process varies greatly. Common components of the guidelines include the purpose of assessment, the assessment process, general knowledge needed by the educational team, characteristics of the disorder, and information regarding other disability conditions.

### **Question 15. What are the essential features of the evaluation process that a school aged child experiences to become eligible for special education services under the category of autism? with autism in schools?**

The purpose of the educational evaluation is to determine whether the child has an impairment that adversely affects the student's learning and educational performance. The secondary purpose is to then identify the disability category which best fits the student's profile and ultimately determine whether the student meets the educational eligibility criteria for autism. Given this purpose, the first core feature of the evaluation process is to define 'educational performance.' Some of the guidelines documents provide a detailed list of elements of educational performance which extend beyond the core curriculum. This is important given the characteristics of ASD and pervasive impact across developmental domains.

For example, one such document included the following:

- Cognitive performance, including academic and pre-academic skills,
- Communication skills,
- Personal/Social skills,
- Sensory processing and motor planning skills, and
- Adaptive skills, including self-help skills and activities of daily living.

The first core feature of the evaluation process must also define 'adversely impacts.' This is described in some guidelines documents because the impact for a student with ASD may not be overt and easily recognized. For example, one document

noted that there may be changes observed as the child ages, since he or she may experience significant challenges later due to the effort required to manage the communication, social, academic and sensory expectations of a typical school day.

The second feature of the evaluation must provide a definition of autism and criteria the student must meet. Both the definition and criteria vary from state to state. In some cases, the definition provided by the Diagnostic and Statistical Manual of Mental Disorders is utilized. In others, the guidelines provide a different definition. However, the core characteristics of impairment in communication; impairment in social functioning; and presence of restricted, repetitive and stereotypical patterns of behavior is present in each.

Outlining the team members is a third important component of the evaluation. The evaluation of a school-age child should occur through a multidisciplinary team. There are specific team members considered to be critical when evaluating for autism eligibility:

- Parents and guardians are considered essential members of the team and provide important historical information and help the team recognize the features that may or may not be present in the child.
- A school psychologist experienced in evaluating children with autism may provide important information about the student's social functioning, neurological functioning, developmental rates and sequences, etc. and are able to interpret the instructional implications of evaluation results.
- Speech and language therapists with expertise in assessing children with autism may conduct assessments of the student's communication abilities and needs and examine social and pragmatic skills.

Other school professionals are often recommended as participants.

- For example:
- Occupational therapists may assess the effects of the environment and the demands of an activity on the student's ability to perform functional skills, such as the effects of noise or touch on social interaction.
  - Physical therapists may assess the student's motor skills.
  - School nurses may bring expertise to evaluation of complex health needs.
  - School social workers may provide insight into the student's developmental history and how the student functions and interacts in home, school and community environments.

A fourth core element of evaluation includes the consideration of assessments and measures needed to complete a comprehensive evaluation. Gathering information from multiple sources using a variety of methods is a common recommendation.

- These measures include:
- A developmental profile that describes the child's historical and current characteristics that are associated with ASD;
  - Observations of the child's behavior, conducted across multiple natural environments and involving direct interactions with the child;



- ❑ Behavior rating tools, to include observation and interview based tools, designed to identify the characteristics associated with an autism spectrum disorder;
- ❑ Assessments to address the communication, social and behavioral characteristics of ASD;
- ❑ Assessments to determine the impact of the suspected disability on the educational and/or developmental performance of the child;
- ❑ Assessments needed to identify the child’s educational needs.

In some cases, recommendations in the guidelines documents included areas or domains to be measured while others outlined specific assessments appropriate for this group.

- Specific areas to be measured include:
- ❑ Cognitive skills or developmental level,
  - ❑ Adaptive skills,
  - ❑ Communication skills,
  - ❑ Social interaction skills,
  - ❑ Social/emotional functioning,
  - ❑ Motor development,
  - ❑ Academic achievement levels,
  - ❑ Vocational skills, and
  - ❑ Sensory functioning.

As a component for the evaluation, the use of well-recognized diagnostic tools is recommended due to the presence of less obvious symptoms in some children with ASD. The diagnostic tool should be given by a trained professional. The gold standard tools outlined above, the ADOS-G and the ADI-R, as well as the CARS and the GARS are recommended specifically for use in approximately half of the guidelines documents. Others do not make specific recommendations on tools to use.

Special assessment procedural considerations are provided in many cases, however, the considerations vary. One state’s document noted that use of standardized or norm–referenced instruments may not be reliable or valid and that alternative means of evaluation, such as criterion–referenced assessments, achievement assessments, observation, and work samples, should be considered. Test users should ensure that they are aware of the validity and reliability when assessing students with ASD and take these limitations into account when forming opinions and reporting results.

Since there is no absolute test for ASD, it is essential for evaluators to complete a comprehensive evaluation when a child is being assessed and fully consider other possible diagnoses such as:

- ❑ Hearing impairment
- ❑ Specific language disorder
- ❑ Semantic pragmatic language disorder
- ❑ Dyspraxia
- ❑ Intellectual disability
- ❑ Attention deficit hyperactivity disorder
- ❑ Conduct disorder in the older child
- ❑ Abuse, trauma, neglect.

Many states stress the need to individualize the evaluation based on the child; however, not all techniques need to be used in all cases. Rather, IEP teams should carefully consider what information is needed and select appropriate methods. In one case, a tiered evaluation system was presented, where the number and intensity of measures varied depending on the presenting characteristics and age of the child.

The final core feature of the evaluation is a statement about the relationship of educational eligibility and medical diagnosis. There is agreement that a medical diagnosis of ASD alone does not determine educational eligibility. A medical diagnosis can provide data about the characteristics evidenced to be important in determining eligibility for special education services under the disability category of autism. The team will make the final determination about whether or not the child meets the educational criteria established.

### Virginia Information

#### **Question 16. What guidelines exist in Virginia regarding educational identification of autism in the public schools in Virginia?**

Virginia does not have a guidance document or specific procedures outlined for evaluating students suspected of being on the autism spectrum. Virginia does have the Regulations Governing Special Education Programs for Children with Disabilities in Virginia, which outlines special education policy and procedures and includes eligibility. This document provides a brief description of the criteria an educational team should consider when determining if a child has autism. This section is essentially an expansion the definition of autism and includes a description regarding how the disability may impact communication and social functioning. The Regulations provides such a description for each disability category recognized by the stated DOE.

#### **Question 17. What does an eligibility evaluation for ASD look like in Virginia?**

In one of the surveys conducted by the VCU-ACE Task Force, school psychologists were asked to report on behalf of the division. Psychologists were asked to indicate whether their division was equipped to identify students with autism. Responding school divisions report that 70% are well equipped to identify students with autism while 25% are partially equipped. The reason school divisions report being only partially equipped is related to the lack of experience with autism in small divisions and the reliance on outside diagnosis for identification.

Reporting school divisions indicate the percentage of special education students identified under the autism category ranges from .02%- 19%. The majority report identifying students in the kindergarten through third grade range. Those students with Asperger's Disorder are often identified later. School divisions identify pre-school children with a medical diagnosis of autism under a variety of categories. The category of developmentally delayed and speech language impaired is reported to be used by 53%. A category of autism is used with 38%. For those students with a medical diagnosis of Asperger's Disorder, a range of disability categories are also utilized. Ninety-two percent of divisions report they identify these students under the autism category. Eight percent of divisions report using emotionally disabled, Other Health Impaired, and Learning Disabled.

The process by which school divisions conduct evaluations varies across Virginia. Less than half of the reporting divisions (42%) have written guidelines and/or procedures for best practices in the evaluation of ASD. The state DOE definition is used by all reporting divisions and the DSM criterion is considered by 85%. When provided with an outside evaluation, 64% of the divisions will consider the evaluation, but will conduct their own evaluation of the child and will use such results to determine if the child qualifies for special education services. Only 6% of school divisions will accept an outside provider's diagnostic evaluation report and identify the child with autism based on that report. Some school divisions (30%) will accept the outside provider's diagnosis of autism but may consider another educational category or may not qualify the child for special education services.

Components that are used in the evaluation of a student suspected of an ASD vary. Observations of the child in naturalistic settings are most common with 88% requiring their use. Seventy-three percent require the use of a diagnostic rating scale such as the ADOS-G or the CARS-2 and 63% require a speech/language evaluation.

**Question 18. What are the tools used in school divisions when conducting an eligibility evaluation for ASD?**

The assessment tools used by school divisions include the CARS-2, GARS, Asperger Syndrome Diagnostic Scale (Myles, Jones-Bock, & Simpson, 2000), the ADI-R, and the ADOS-G. Thirty percent of responding school divisions require the use of the ADOS-G as a part of their autism evaluations.

**Question 19. What do educators / educational teams in Virginia need to know to lower the age of identification?**

As noted above, screening for ASD is not taking place in school divisions throughout Virginia and children are being identified at late ages. Therefore, it is critical for educators to be sufficiently knowledgeable to ensure any child on the spectrum who is adversely impacted is found eligible and receives appropriate services. The VCU-ACE Task Force outlined the basic information educators, including both special and general educators, should know. First, educators must have knowledge of typical child development. Educators should also be able to identify the continuum of ASDs and describe the differences among the continuum. Educators should be able to list the characteristics of ASD, define and identify examples of each, as well as, identify ways the characteristics may impact educational performance. It is also indicated that educators be able to describe the range of possible behaviors across the lifespan. Further, in regards to intervention, educators must understand the importance of early identification. Educators must be aware of how early identification can lead to beneficial services and supports, and how students with ASD benefit from specific evidence based strategies. Perhaps the most importantly educators should take parental inquiries regarding developmental concerns about their child very seriously and address them appropriately.

Since it is still common for school divisions to delay identification of students with autism and utilize other disability categories, the VCU-ACE Task Force also outlined information needed for those who conduct the evaluations. In addition to the information provided in the state guidelines documents, foundational information is needed. To move educational teams to providing an appropriate and meaningful evaluation, this group should be made aware of research related to identification.

- For example:
- ❑ There have been a number of barriers to early diagnosis. These include: failure to recognize symptoms, denial that there may be a problem, failure to get a referral, lengthy waiting time for an assessment, inadequately trained staff for evaluation (Howlin & Moore, 1997; Shattuck et al., 2009)
  - ❑ A valid clinical diagnosis and identification can often be made by the time the child is aged 2 to 3 years (Lord, et al., 2006).
  - ❑ Research supports educating a student with ASD under the disability category of autism if he or she meets criteria (National Research Council [NRC], 2001).
  - ❑ In many cases, a structured or familiar setting can hide the characteristics of ASD. Therefore, the behaviors and performance of the child should be considered across multiple settings and situations (Mandell, Novak, & Zubritsky, 2005; Matson, et al., 2012).

Other important considerations surround the family component. After all, the family is an essential part of the team. However, for the family, this is much more than an evaluation to determine special education services. Therefore, teams must take special care to provide useful and constructive information to the family.

- For example:
- ❑ Parents will enter the evaluation at various points holding different beliefs about their child. The evaluation team must assess the parents' knowledge and emotional level and provide the information, descriptions and specific examples needed to help parents understand why autism is being considered as a classification and why it is important to make this determination (Stoner, et al., 2005).
  - ❑ The evaluation process is overwhelming for parents and many report not being satisfied with the process and level of communication (Gaspar de Alba, et al., 2011; Keenan, et al., 2010). Teams must take care to provide a thorough description of the evaluation and steps of the process. Additionally, since teams are provided a certain number of days to complete the evaluation, parents should be kept abreast of progress throughout this lengthy process.
  - ❑ The parents are legally able to review the results of the evaluation prior to the team meeting. Every effort should be made to get these results to the parents in ample time to review the results and identify questions and comments.
  - ❑ Results must be interpreted in layman's terms ensuring parents fully understand and are in agreement. Sensitivity to parents' feelings and outlook must be taken into consideration as results may be disappointing and may paint a negative picture of the child that demonstrates abilities below or well-below age level.
  - ❑ If the child meets criteria for autism, this may be the first time the parents are hearing the 'A' word. The team should provide any information the parent needs in order to learn more about the disorder, understand the range of abilities of those on the spectrum, and realize that children with autism can and do learn and are able to lead successful, fulfilling lives (Gaspar de Alba, et al., 2011; Keenan, et al., 2010).
  - ❑ Teams should also provide families with recommendations for sources to gather more information about ASD and interventions

and provide referrals to appropriate agencies and services. For example, for children under the age of six, information on insurance coverage can be provided. For all children, information regarding Medicaid Waivers, case management, as well as, respite services would be beneficial.

## Early Intervention

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### Question 20. What is the role of early intervention in relation to diagnosis/identification of young children?

We have explored the medical diagnosis, as well as, identification of ASD in an effort to better understand how to lower the age of diagnosis. The VCU-ACE Task Force raised the question regarding the role of early intervention in the diagnosis/identification of young children. The Task Force consulted early intervention and the following responsibilities were outlined:

- Recognize the characteristics of ASD. Talk with families about these characteristics and what they might mean. Guide the family to talk further with their physician in order to discuss possible referrals for a formal evaluation.
- When the child is evaluated, provide information about the child's development with parental permission.
- Provide support and education about ASD to the family if a diagnosis is given.
- Provide resources and referrals for services and supports to the family if a diagnosis is given.
- Provide early intervention services that continue to be individualized and based on the child's needs.
- Train and coach parents in strategies that will help their child learn and develop.

### Question 21. What do early intervention providers in Virginia need to know to lower the age of identification?

The importance of early intervention cannot be stressed enough for this group. According to the seminal report by the NRC (2001), young children with ASD should receive 25 or more hours a week of intensive services. This, of course, first requires young children under the age of 3 to be identified. Early intervention plays a critical role in identification. While providers cannot diagnose, providers can give families the information and direction needed to act quickly and persistently. Additionally, there are considerations related to services and supports provided when a child is on the spectrum. The VCU-ACE Task Force outlined information providers must know to both help lower the age of diagnosis as well as ensure appropriate intervention services.



- ❑ Early identification is critical and can lead to appropriate and beneficial services and supports (NRC, 2001).
- ❑ There are a number of barriers to early diagnosis. These include failure to recognize symptoms, denial that there may be a problem, failure to get a referral, lengthy waiting time for an assessment, inadequately trained staff for evaluation (Goin-Kochel, Mackintosh & Myers, 2006; Howlin, et al., 1997; Shattuck et al., 2009)
- ❑ A valid clinical diagnosis or identification can often be made by the time the child is aged 2 to 3 years (Lord, et al., 2006).
- ❑ Identification is more difficult for children who are considered to be higher functioning (Goin-Kochel, et al., 2006).
- ❑ Children with ASD benefit from specific evidence based strategies and may not benefit from certain strategies employed with children with other disabilities (McEachin, Smith, & Lovaas, 1993; NRC, 2001; Sheinkopf & Siegel, 1998).
- ❑ A child with a pervasive disability impacting multiple areas of development benefits from intensive intervention services and supports with at least 25 hours of intervention provided weekly (McEachin, et al., 2006; NRC, 2001).
- ❑ Through the use of effective strategies effective and intensive delivery of services during the early years of development, the child's neurology can be impacted improving his or her outcome (Filipek, et al., 2000; Green, 1996).
- ❑ Parental inquiries regarding developmental concerns about their child must be taken seriously and addressed appropriately.
- ❑ Parents of children on the spectrum suffer from more stress than parents of any other children. (Sanders & Morgan, 1996).
- ❑ When a child is diagnosed with ASD, it is beneficial to determine the best route for service delivery and to consider both the child and the family (Aman, 2005; Reed & Osborne, 2012; Siegel, 2008). For some children, continued services with early intervention (Part C) may be the best course of action. For other children it is often beneficial to refer children as soon as possible to a school-age program (Part B). This is especially true for children requiring highly intensive intervention and/or families who are under extreme stress.

## Connecting Diagnosis/Identification and Service Delivery

### General Information

#### **Question 22. How is service delivery and diagnosis connected?**

Literature suggests there are many general resources available to both parents and professionals about recommended treatments and interventions for ASD. However, few formal studies have been conducted regarding how evaluators translate their diagnostic label and evaluation findings into specific recommendations for an individual child, or how evaluators turn treatment recommendations into active therapy. To answer this question, it is necessary to review several studies noted above which researched the parents' perspective of the diagnostic process. Several of these studies provided information regarding information and resources offered to parents at the time of or following the diagnosis, as well as, referrals to services. Based on results, it is clear that there is not a seamless transition from diagnosis to service delivery for most parents (Gaspar de Alba et al., 2011, Keenen et al., 2010). Conversely, there is a lack of information provided which would help family members move forward.

Parent report seems to indicate that there are areas overall on which evaluators might wish to focus or improve in their diagnostic sessions. Evaluators should ensure that they have addressed all concerns presented by the parents, and have provided as much information about ASD as the parents require. Parents desire information on the core issues of ASD including social problems, expressive language, and unusual/unwanted behaviors (Gaspar de Alba et al., 2011; Osborne et al., 2008). They also want information about expectations for the child's future, where to find more information about ASD, and local support or parent groups.

Parents seem to be most focused on wanting to know the next steps to take for their child, especially in regards to treatment and education recommendations; merely receiving a diagnostic label is not sufficient. Parents want information on therapy services, including such services as behavioral, speech and other therapies, medication options, and other medical or psychological services, and the best educational environment.

Parents surveyed in the study by Osborne et al. (2008) made suggestions regarding the delivery of information. Parents of younger children wanted as much information as possible right after diagnosis, while parents of older children (secondary-aged, presumably middle school age and older) felt that providing information could be phased in over time, likely reflecting changes in the child's and family's needs over the lifespan course. They suggested providing general information sheets to parents following diagnosis, with information about ASD and interventions, support groups, and reputable providers of intervention and education, followed by more specific information as the family adapts to the diagnosis.

Parent responses also indicated that if they did not receive the information they desire from the evaluator or other professionals, they were quick to turn to other parents or support groups, or did their own research (e.g. Internet, books) to find answers. This can be of possible concern given that some sources of information are not as reliable or based on scientific observation as others. Thus, it appears important that evaluation (and other service) providers remain up to date about the most beneficial and sound treatment interventions for ASD in order to communicate that information to families for treatment planning purposes.

### Virginia Information

#### **Question 23. How is service delivery and diagnosis connected in Virginia?**

Connecting diagnosis and service delivery is noted by JLARC as a challenge across Virginia. The VCU-ACE Task Force also considered this issue and surveyed families. Nearly half of all responding parents indicate they received no helpful information at the time of diagnosis and only 40% indicate receiving referrals or resources. Of those, books, websites are provided to some while referrals for social groups, speech therapy, and/or occupational therapy are provided to the majority.

Surveys to medical practices provide some information on this topic. Medical practices were asked to indicate the level / type of recommendations made to a family when a diagnosis was given. The treatment/education recommendations are dominantly (64%) mid-level recommendations that specify skills or skill domains to address in the child's treatment or education. Thirty six percent of reports include

## Recommendations

only general service recommendations such as speech therapy or the provision of Applied Behavior Analysis. None of the respondents indicate providing specific goals or objectives for the child. Many practices offer follow-up services. Eighty-six percent of practices report that at the family's request, a copy of the evaluation report can be sent to other providers or to the child's school. Fifty-seven percent report that families can be seen regularly by the provider who gave the diagnosis for an episode of treatment (more than three times per year). Fifty percent report that an educator or other professional is available to meet with families to review proposed IEPs or offer suggestions regarding educational services.

Based on the findings from the VCU-ACE Task Force, the following recommendations are made. The recommendations are categorized according to those made in the JLARC report.

1. Increase the occurrence of and access to recommended screenings.
  - a. Develop a Virginia based website or webpage providing information related to recommended practice in screening and diagnosis of ASD as delineated in the literature and through CDC and APA, so parents, medical professionals, early interventionists and educational teams can access evidence based information.

The website should include:

    - i. Recommendations for screening
    - ii. A list and description of appropriate screening tools for children of different ages (e.g. CSBS-6-24 months; M-CHAT-16-30 months; SCQ (24 months +))
    - iii. A list and description of appropriate diagnostic tools for children with different characteristics
    - iv. Guidelines for screening
    - v. Procedures for diagnosis
    - vi. A directory for tier 2 or 3 evaluations that characterize the services that are available at specific clinics across Virginia
  - b. Target medical residents and medical students and provide training related to the characteristics of ASD and screening so new pediatricians are aware of the importance of screening as well as how and when to provide screening.
  - c. Target pediatricians, including physician assistants and nurse practitioners, by providing a brief tutorial (2-3 minutes) or announcement which can be viewed online or delivered in person which highlights the need for screening, provides a link to the M-CHAT and other screening tools, emphasizes the cost effectiveness of screening, and describes how to bill for services
  - d. Target early interventionists and provide training related to the characteristics of ASD, importance of an early diagnosis, importance of specialized services and intervention, and provides information related to talking to and supporting parents



2. Expedite the diagnostic process by increasing the supply of trained professionals.
  - a. Develop a state guidance document that outlines recommendations in the areas of screening, diagnosis and educational identification of ASD. Guidance documents developed by other states can be referenced. At a minimum, the document should provide:
    - i. References to key research in screening, diagnosis, and educational identification
    - ii. Recommendations for screening
    - iii. A list and description of appropriate screening tools for children of different ages (e.g. M-CHAT-16-30 months; SCQ [24months +])
    - iv. A list and description of appropriate diagnostic tools for children with different characteristics
    - v. Guidelines for screening
    - vi. Procedures for diagnosis
    - vii. Recommendations on who can provide a diagnosis
    - viii. Critical areas to measure (e.g. adaptive behavior, neuropsychological, audiological) and recommendations of assessments to complete when conducting a diagnostic evaluation
    - ix. Procedures for educational identification
    - x. Recommendations on members of the educational team and those who should conduct the assessments
    - xi. Critical areas to measure (e.g. adaptive behavior, cognitive performance, communication, social, audiological) and recommendations of assessments to complete when conducting an educational evaluation
    - xii. Steps and procedures to move a child from diagnosis or identification to service delivery
    - xiii. Recommendations on how to work with parents and maintain sensitivity as well as respect cultural characteristics
  - b. Develop and promote a tiered system for a medical diagnosis of ASD so the simplest, shortest assessment which produces the desired outcome and is tailored to the circumstances is provided so those children with prominent, clear symptomology can be diagnosed and move quickly to intervention and those with more subtle characteristics receive more comprehensive assessment
  - c. Develop and promote a tiered system for educational identification of ASD so the simplest, shortest assessment which produces the desired outcome and is tailored to the circumstances is provided
  - d. Provide state-wide training to school divisions in the use of gold-standard diagnostic tools including the ADOS-2 and ADI-R

- e. Since the school psychologist and speech therapist are considered to be 2 of the most critical school team members, provide state-wide training to school psychologists and speech therapists targeting assessment of students considered to have ASD and emphasize characteristics of those students who are higher functioning
  - f. Develop a directory for clinics across Virginia providing tier 2 or 3 evaluations and characterize the services that are available at specific clinics
3. Improve the information and referrals parents receive once they begin the identification and diagnostic process.
- a. Since parents who have a child with ASD will likely gather information on their own (e.g. Internet, books), Virginia should create a website and series of documents providing essential information related to receiving a diagnosis of ASD. Information can be disseminated at the time of the assessment or diagnosis. Information provided could include:
    - i. Characteristics of ASD
    - ii. Information related to insurance coverage for young children with autism
    - iii. Early Intervention
    - iv. School age services
    - v. Medicaid
    - vi. Medicaid Waivers
    - vii. Evidence based interventions
    - viii. Strategies to support a child with ASD in the home
    - ix. Support Groups
  - b. In the state guidance document, provide recommendations for practitioners related to information to provide to parents at the time of assessment, time of diagnosis, and on an ongoing basis
  - c. Since many clinics provide a report with a diagnosis, provide several sample reports which delineate appropriate information to include
  - d. Target early interventionists and provide training related to specialized services and intervention, how to support parents emotional journey, and how to coach parents in effective interventions for children with ASD
4. Raise public awareness.
- a. Work with the Learn the Signs. Act Early! Ambassador of Virginia (Deana Buck) to distribute CDC materials to child care centers, Head Start and other programs serving young children
  - b. Support the creation of a coalition of state agencies and professional groups who have a stake in the health and well-being of young children including DB-HDS, the VA Department of Health.

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States that have recognized the need to develop standard procedures for identification of ASD and have state guidelines or recommendations are:

1. Alabama
2. Alaska
3. Arkansas
4. California
5. Colorado
6. Connecticut
7. Florida
8. Illinois
9. Iowa
10. Indiana
11. Kansas
12. Maine
13. Maryland
14. Missouri
15. Nebraska
16. Nevada
17. New Hampshire
18. New Jersey
19. New Mexico
20. New York
21. North Carolina
22. North Dakota
23. Ohio
24. Oklahoma
25. Pennsylvania
26. Rhode island
27. Texas
28. Washington
29. West Virginia
30. Wisconsin
31. Wyoming









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