



**Supporting Young
Children with
Autism Spectrum
Disorders
and their Families**
**Infant & Toddler Connection of
Virginia Guidance Document**

January 2012



Infant & Toddler
Connection of Virginia

Dana C Childress, MEd
Maureen A. Conroy, PhD
Corinne F. Hill, MEd

Acknowledgements

This document is a publication of the Partnership for People with Disabilities at Virginia Commonwealth University.

We would like to acknowledge the efforts of the Autism Guidance Document Committee members who collaborated on the development of this document. The committee members represented a variety of agencies and groups including:

- Virginia Department of Behavioral Health and Developmental Services (VDBHDS)
- Partnership for People with Disabilities at Virginia Commonwealth University
- Virginia Department of Education (VDOE)
- The ARC of Virginia, and
- Local Early Intervention Providers

We would also like to extend a special thank you to the Perry family for contributing the cover photo of their beautiful daughter, Elyssa.

Table of Contents

| | |
|---|----|
| Introduction and Purpose | 5 |
| Autism Spectrum Disorders: Signs and Symptoms | 7 |
| Case Study: Kaylee | |
| What are Autism Spectrum Disorders? | 8 |
| Virginia’s Definition of Autism | |
| What are Early Signs of Autism Spectrum Disorders? | 9 |
| Symptoms of Communication, Social Skills, and Behavior in Young Children with ASD | |
| <i>Communication</i> | |
| <i>Social Skills</i> | |
| <i>Restricted, Repetitive, and Stereotypical Patterns of Behavior</i> | |
| <i>Additional Symptoms and Characteristics</i> | |
| Summary | 11 |
| The Early Intervention Process | 13 |
| Referral and Intake | 13 |
| Screening and Eligibility Determination | 14 |
| Assessment for Service Planning | 16 |
| Referring for Further Diagnostic Evaluation | |
| <i>Screening and Diagnostic Tools</i> | |
| Developing the Individualized Family Service Plan (IFSP) | 20 |
| Summary | 21 |
| Early Intervention Supports and Services | 22 |
| Infant & Toddler Connection of VA Supports and Services | 22 |
| Evidence-based Practices for Working with Young Children with ASD | 23 |
| General Guidelines | |

| | |
|---|----|
| Focused Practices and Comprehensive Intervention Models | |
| Deciding Which EBP to Use and With Whom | |
| Complementary Alternative Interventions | |
| Monitoring Child and Family Progress | 28 |
| Transition from Early Intervention | 28 |
| Summary | 29 |
| References | 30 |
| Other Websites and Resources | 31 |
| Appendices | |
| Appendix A - Screening & Diagnostic Tools for Toddlers with ASD | 33 |
| Appendix B - Focused Practices and Comprehensive Intervention Models | 34 |

Introduction and Purpose

According to the Centers for Disease Control (2010), 1 in 110 children will be diagnosed with an autism spectrum disorder (ASD). Families and medical personnel are beginning to recognize signs of autism spectrum disorders (ASD) earlier, often within the first or second year of life. Although many children who show early signs of ASD are not officially diagnosed until later in their preschool years, we know that the earlier signs are recognized, the earlier intervention can begin. When intervention begins within the first three years of life, young children with ASD can make quite promising developmental gains.

Early intervention supports and services are available to families of eligible infants and toddlers (ages birth to 36 months) through the *Infant & Toddler Connection of Virginia*. Part C of the Individuals with Disabilities Education Act (2004) describes this system of supports and services. In Virginia, local Infant & Toddler Connection programs cover every locality across the state and provide intervention supports in families' homes and other natural community settings. When an infant or toddler in Virginia has a diagnosis of an autism spectrum disorder, he or she is automatically eligible for intervention. The early intervention process will be described in detail in this document to help families understand what to expect and how they can access and participate in their local program. To find out how to contact your local early intervention program, visit <http://www.infantva.org/> or call 1-800-234-1448.

The Infant & Toddler Connection of Virginia is committed to working closely with families of young children with ASD to provide individualized supports and services that help families promote the development of their children. This guidance document has been developed to serve as a resource for early intervention practitioners (e.g., service coordinators, educators, speech language pathologists, physical therapists, occupational therapists), family members, and other service providers (e.g., medical personal) who work with infants or toddlers who have signs of or who have been diagnosed with ASD. Information is presented in this document that relates to the early identification of young children with ASD as well as their progression through Virginia's early intervention process. Readers are encouraged to remember that early identification is an individual process for each child and family, as is the early intervention experience. This document is intended to help families and early intervention practitioners work together so that children and families receive the supports and services they need to work towards their goals.

This document also provides information related to recommended practices for working with infants and toddlers with ASD. As with all information about recommended practices, the information presented should be considered with respect to an individual child's and family's strengths and needs. Simply put, not all of the information presented in this document is applicable to all young children who demonstrate characteristics on the spectrum. Although children with ASD display similarities, each child and family present a unique set of skills and characteristics.

The information presented within this guidance document is based on the most up-to-date evidence available focusing on early identification and intervention. However, new

evidence and information is being revealed almost daily. Therefore, the reader is cautioned that there may be new approaches that are not included within the document.

Autism Spectrum Disorders: Signs and Symptoms

Kaylee

Kaylee is 30 months old and is the youngest child in her family. Her mother, Alaina, has been concerned about her development for quite a while, worrying that she is not talking or playing like her older brother did when he was Kaylee's age. She often describes Kaylee as "Miss Independent" because she seems to prefer to play by herself. When Alaina and her older son try to engage Kaylee to play trains or roll a ball, Kaylee will usually leave the play area. She loves to wrestle and swing with her daddy, but will sometimes get too excited and the play will end in a tantrum. Kaylee says a few words, such as car, daddy, light, and doggie, but she does not use these words to request or label; she tends to say them spontaneously while she is babbling or to herself as she plays. She does use a lot of jargon as she plays but her mother is not able to find meaning in it. When Kaylee wants something, she will take her mother's or father's hand and pull her or him to what she wants, such as pulling her father to the back door when she wants to go outside to swing. Kaylee will also put something in her mother's hand to indicate that she needs something, such as her empty juice cup when she needs a drink.

Alaina has been concerned that Kaylee does not follow any directions or turn when her name is called. Her pediatrician recommended a hearing test, which indicated that Kaylee's hearing was fine. Kaylee doesn't use eye contact to connect with her family and will only occasionally look at them. Usually, when she does, her mother says that it feels like Kaylee is looking past her. Alaina has been working with Kaylee to try to get Kaylee to look at her and to say more words, but she tends to ignore the games and walk away. She will, however, come to her mother for comfort and will lean on her or touch her hair. She likes quick bear hugs and being picked up and swung around, but otherwise she is not as affectionate as her older brother, according to her mom.

Kaylee's favorite things to do at home are to watch cartoons, swing on the swingset outside, play chase with her brother, and roll spice jars across the coffee table then watch them fall to the floor. Alaina says that Kaylee can play with the spice jars for hours if she lets her and that Kaylee will cry if she cannot get in the pantry each morning to get them. When Kaylee gets upset, she has recently started to bang her head on the floor, which is very alarming to her parents. This behavior has made it hard for Kaylee's family to take her out of the house and difficult to get through the day, because if her routine changes in any way, Kaylee will become upset and bang her head.

What are Autism Spectrum Disorders?

Autism Spectrum Disorders (ASD) are a group of developmental disabilities that cause children to display social and communication skill deficits and behavioral challenges. As suggested by the title, ASD is part of a “spectrum” with characteristics and symptoms that fall along a continuum from “mild” to “severe.” All children with ASD share some similar characteristics; however, ASD is expressed differently in individual children, with varying symptoms and degrees of severity. For some children, symptoms begin within the first year of life. Whereas, for other children, symptoms might not be apparent until they are two - three years old. For a small percentage of children (20 – 30%), they appear to be developing “normally” until approximately 2 years old and then their development begins to slow and some believe they lose their existing skills. Regardless of when the early warning signs begin to appear, research has shown that the majority of parents were concerned about their child by 24 months.

Fortunately for Kaylee and her family, there is a growing national public awareness of the early warning signs of autism spectrum disorders and acknowledgement of the importance of early identification, diagnosis, and intervention.

According to the Infant & Toddler Connection of Virginia Practice Manual (2011), autism spectrum disorder is defined as impairment in social interaction, impairment in communication skills, and a restricted and repetitive repertoire of activities and interests.

Virginia’s Definition of Autism

In the Infant & Toddler Connection of Virginia, young children who have a diagnosis of an autism spectrum disorder are automatically eligible for early intervention supports and services. Virginia’s definition includes the diagnoses of Autism, Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), Asperger’s Disorder, Rett’s Disorder, and Childhood Disintegrative Disorder. For more information about the types of autism spectrum disorders referenced in this definition, please visit First Signs.org at <http://www.firstsigns.org/screening/DSM4.htm>

Many young children receive early intervention services without having a formal diagnosis. For toddlers who, like Kaylee, do not have the diagnosis but appear to have signs and symptoms of ASD, they may qualify in other ways, such as by demonstrating a developmental delay in one or more areas of development or atypical development (i.e., a child may have atypical sensory processing or differences in his social-emotional development). Under the category of atypical development, infants and toddlers who demonstrate “impairment in social interaction and communication skills along with

restricted and repetitive behaviors” without a formal diagnosis also qualify for intervention.

What are Early Signs of Autism Spectrum Disorders?

While most early intervention practitioners are not diagnosticians, it is important for them to be aware of early signs of ASD so that children who are referred will receive appropriate eligibility determination, assessment, and intervention. There are a number of early warning signs that may indicate an infant or toddler is at risk for being diagnosed with ASD. First Signs¹ has suggested the following indicators might be early warning signs:

- No big smiles or other warm, joyful expressions by 6 months or later
- No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter
- No babbling by 12 months
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- No words by 16 months
- No two-word meaningful phrases (without imitating or repeating) by 24 months
- Loss of speech or babbling or social skills at any age

The Centers for Disease Control have also identified the following early signs:

- 12 months
 - Unresponsive to name
- 14 months
 - Lack of pointing at objects to comment or show interest
- 18 months
 - Lack of pretend play
 - Avoidance of eye contact
 - Inability to recognize feelings of others
 - Delays in speech and language skills
 - Repetitive use of words
 - Difficulty with change of routine
 - Obsessive interests
 - Unusual sensory responses to objects (e.g., smells, tastes, visual input)
 - Unusual and repetitive body movements (e.g., rocking, hand flapping)²

Remember that even if a child displays any of these early warning signs, it does not necessarily mean that the child has ASD.

Although all of these behaviors are early warning signs of ASD, it is important to remember that if a child displays them, it does not necessarily mean that the child has ASD. Children

¹ First Signs (<http://www.firstsigns.org/>)

² Centers for Disease Control, 2011

with ASD are not likely to exhibit all of these early warning signs and some may exhibit them at different times. These early warning signs are just the first indicators that a child might have ASD. Probably the most common indicators recognized by parents are delays in speech, language, and communication skills. When parents express concerns related to possible ASD, further assessment is needed prior to making a diagnosis.

Symptoms of Communication, Social Skills, and Behavior in Young Children with ASD

ASD affects young children's development across three main areas: communication, social skills, and atypical patterns of behavior.

Communication

One of the most commonly recognized symptoms of ASD is a delay in communication, speech, and language skills. As with all symptoms, communication abilities vary across children with ASD. Some children have no language and may communicate primarily through gestures (e.g., pulling a caregiver's hand to make a request) or challenging behaviors (e.g., tantrum in response to a request or to make a request); others have some limited words; and some can speak well, but have delays in their pragmatic use of language – that is, they use language in a socially unusual manner. Common communication symptoms and characteristics displayed by infants and toddlers with ASD are:

- Speech and language skill delays
- Echolalic speech (repetition of words)
- Pronoun reversal (child referring to himself using incorrect pronoun, such as saying "You're here" instead of "I'm here" or "Kaylee want it" instead of "I want it")
- Difficulty staying on topic
- Lack of pointing or responding to others' pointing
- Limited use of gestures
- Unusual intonation (robotic speech or "sing-song" speech)
- Lack of sense of humor

Social Skills

By nature, infants and toddlers are social beings and interact with their caregivers and others in their immediate environment from birth. It is through these early interactions that they gain an understanding of their world, develop relationships and learn new skills. They often play "games" with their caregivers, imitate their actions and approximate their words. These early relationships serve as the foundation for the development of further relationships and learning. Unfortunately, young children with ASD have difficulty socially interacting with others. Many young children may be extremely socially withdrawn, preferring to play alone or avoid contact with others. Other children may display unusual social behaviors, such as inappropriate response to another's feelings. Regardless, social skill deficits can have a significant negative impact on a child's development and well-being.

Common social skill symptoms and characteristics displayed by infants and toddlers with ASD are:

- Avoids eye contact
- Unresponsive to name
- Prefers to play alone
- Lack of interest in others
- Absence of appropriate facial expressions
- Invades others' personal space
- Avoids or is distressed by physical contact
- Does not seek comfort when hurt or injured
- Lack of empathy or understanding of others' feelings

Restricted, Repetitive, and Stereotypical Patterns of Behavior

Infants and toddlers use their motor skills to explore and learn from their environment. Although this is also true for infants and toddlers with ASD, young children with ASD may demonstrate some unusual motor behaviors. Often, these behavioral symptoms are displayed in the form of repetitive motor actions, such as rocking, hand flapping, or spinning wheels on a toy car. In addition to repetitive motor patterns, many young children with ASD engage in consistent routines, many of which may be unusual. For instance, they might want to follow the same path when traveling from one place to another. Changes in these routines can be particularly difficult or upsetting to them. Common restricted, repetitive, and stereotypical patterns of behavior displayed by infants and toddlers with ASD are:

- Repetitive play with a toy
- Following the same routine over and over
- Repetitive motor movements (rocking, spinning)
- Intense focus on an object or activities

Additional Symptoms and Characteristics

Many children with ASD also experience other disorders or display other symptoms and characteristics. These include (but are not limited to): hyperactivity and brief attention span; self-injury; unusual reactions to smell, taste, visual and auditory stimuli; lack of appropriate response to pain or fear; unusual food preferences; and abnormal sleeping habits.

Summary

Early signs, symptoms, and characteristics of ASD present themselves differently across children and with varying degrees of severity and needs. Each child with ASD is unique, with differing strengths and needs. The important point for service providers and family members to remember is that recognizing early warning signs and providing the child and

family with needed supports and services as early as possible may help to lessen the severity of the symptoms of ASD³.

Recognizing early warning signs and providing the child and family with needed supports and services as early as possible may help to lessen the severity of the symptoms of ASD.

Further information on early warning signs and characteristics can be found at the Centers for Disease Control and Prevention at www.cdc.gov/ncbddd/autism/signs.html.

To learn more about autism in infants and toddlers, take the free online module, *Autism in Infants & Toddlers: What Every Early Interventionist Needs to Know* at www.eipd.vcu.edu.

³ Volkmar, Chawarska, & Klin, 2008

The Early Intervention Process

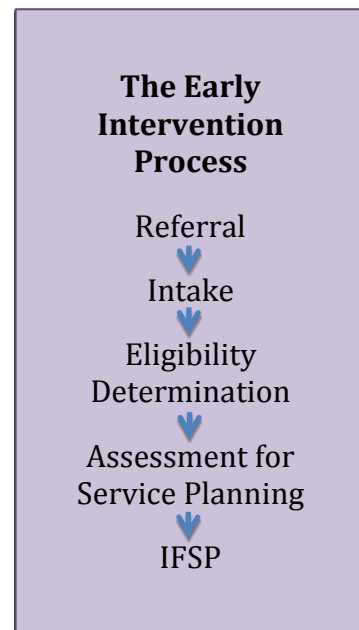
Referral and Intake

At Kaylee's 24 month well-child check-up, Alaina discusses her concerns with the pediatrician again. She had mentioned them at a sick visit about 2 months ago, which prompted the referral to the audiologist to have Kaylee's hearing tested. Kaylee's pediatrician completes the M-CHAT (an ASD screening tool) with Alaina's assistance and notes concerns for possible autism spectrum disorder. He recommends that Alaina call the local early intervention program and refers Kaylee for a consultation with the developmental pediatrician at the local children's hospital for further testing.

Alaina calls the early intervention program, shares her concerns and her pediatrician's recommendations, and refers Kaylee to the program. The person answering the phone welcomes Alaina, explains the early intervention process and tells her that a service coordinator will be contacting her shortly to schedule an intake visit. Alaina asks a few questions then hangs up, eager to hear from the service coordinator and start receiving help for Kaylee.

The next day, Alaina speaks with the service coordinator, who schedules to come out to the family's home to meet the family later that week. Alaina is nervous but relieved to begin the process.

The referral begins the early intervention process for families of young children with ASD (or those who are suspected of having ASD). Children are most often referred to early intervention by their parents or guardians, or by their physicians. Those who are referred to the early intervention system with documentation of a diagnosis of ASD (i.e., documented in a report from the diagnostician or the child's medical record) will be found to be automatically eligible for early intervention. Children who enter the system without a formal diagnosis may have been referred due to concerns for communication and social interaction, limited play skills, and questions related to atypical sensory processing (e.g., child looks out of the corner of his eyes rather than making direct eye contact or child walks up on his toes all of the time). Regardless of the reason for



referral, all children have the right to eligibility determination to see if they qualify to receive early intervention supports and services.

Soon after the early intervention program receives the referral, the intake visit is scheduled with the child's family to gather information about the child's development, medical history, and his or her ability to participate in daily family routines and activities. Written parental consent is obtained from the family to request medical and other records. For children who have already been screened, like Kaylee, the early intervention staff will request records and review any screening information conducted outside of the early intervention system (such as a screening conducted by the child's pediatrician) and use this information as part of the eligibility determination process. If the child was referred without a previous screening or diagnosis, a developmental screening will be conducted by an early intervention practitioner that will provide valuable information to the team of professionals who determine the child's eligibility for early intervention.

Screening and Eligibility Determination

During the intake visit, Alaina shares with the service coordinator a copy of the M-CHAT screening that was completed at the pediatrician's office. The service coordinator reviews this screening and informs Alaina that she can use the results of this screening to help determine if Kaylee will be eligible for early intervention. The service coordinator also completes another developmental screening to check areas of development not addressed by the M-CHAT. Following the screening, she and Alaina discuss the early intervention process in detail, including eligibility determination, which is the next step. Paperwork is completed, including the signing of an authorization to disclose information to Kaylee's pediatrician. After talking with Alaina about Kaylee's strengths and areas of concern and observing Kaylee's play during the intake, the service coordinator completes the intake and prepares to leave. The service coordinator thanks Alaina for her time and tells her that she will call with the results of the eligibility determination later in the week.

The early intervention service coordinator or other practitioner typically conducts a general developmental screening of the child's development at the intake visit. The purpose of the screening is to determine if the child is demonstrating any delays. For children who are suspected of having ASD, the screening is also conducted to identify any early warning signs in the areas of communication, socialization, and problematic behavior. If a child is referred to early intervention with a previous screening already completed, and the results of this screening provide information that can be used to determine the child's eligibility, then completing a general developmental screening might not be required.

Several specific screening tools have been designed to help with the early identification of ASD. These include:

- *Modified Checklist for Autism in Toddlers (M-CHAT)*⁴: The M-CHAT is most appropriately used for children who are approximately 18 months old. It may be completed by the parent or caregiver or by the physician or other professional in collaboration with the parent.
- *Communication and Symbolic Behavior Scales - Developmental Profile (CSBS-DP)*⁵: Although not specifically developed to screen for ASD, the CSBS-DP is designed to identify children from 6 – 24 months with communication difficulties. The parent or caregiver completes a brief questionnaire about the child's development.
- *Pervasive Developmental Disorders Screening Test – II (PDDST- II)*⁶: The PDDST-II offers two screening levels for children ages 18 months to 6 years old. The parent or caregiver completes the general questionnaire.

Parents are fully involved in the early intervention screening process. They assist with the screening by answering questions related to their child's development and by sharing their insights into their child's behavior. Family members may also participate by interacting with their child in ways that help the early intervention practitioner see the child's abilities related to items on the screening.

Back at the office, information from Kaylee's screenings, her medical records, the service coordinator's observations and information shared by her mother are reviewed by a team of two other professionals from different disciplines to determine if Kaylee is eligible for early intervention. The occupational therapist and educator on the team decide that, based on the information, Kaylee is eligible for early intervention due to her developmental delays in communication and social-emotional skills as well as atypical development. The service coordinator calls Alaina with the news and plans with her to schedule the assessment for service planning. Alaina requests that the assessment be scheduled at a time when her husband can participate. The service coordinator offers several options for days and times for the assessment, and they find a time that suits the family's schedule. In the meantime, Alaina calls the service coordinator to let her know that the appointment with the developmental pediatrician has been scheduled to occur in a few weeks.

⁴ Robins, Fein, Barton, & Green, 2001

⁵ Wetherby & Prizant, 2002

⁶ Seigel, 1996; 2004

Immediately following any screening, the early intervention practitioner discusses the results of the screening with the family. It is important to remember that the results of any screening do not necessarily mean that the child has ASD. No screening is 100% reliable, meaning that some children may “fail” the screening and have nothing wrong, while other children may “pass” the screening and later be diagnosed. Early intervention practitioners should explain this to families and encourage them to use the screening results to make informed decisions about future assessment and services. Screening results are also combined with information from the child’s medical record, input from the family, and clinical observations from the early intervention practitioner to determine the child’s initial eligibility for early intervention services.

If, following the screening or eligibility determination, the parent requests assistance linking to a professional for further diagnostic evaluation of the child, the early intervention service coordinator is available to assist with this process. Parents who wish to pursue further evaluation might find that sharing the results of the early intervention screening and eligibility determination with their pediatrician is helpful in discussing the need for further evaluation.

Assessment for Service Planning

On the day of Kaylee’s assessment for service planning, her parents are nervous about what the assessment team will find. When the assessment team arrives, Martin, Kaylee’s father, welcomes them at the door. An occupational therapist, a speech therapist, and the service coordinator join the family in the living room. The speech therapist tries to engage Kaylee in play, but she runs to the kitchen to hide. After spending some time playing with Kaylee with her spice jars to help her warm up, the speech therapist tries a variety of assessment activities. As they play, the occupational therapist and service coordinator talk with Alaina and Martin about Kaylee’s development. The information gathered during the assessment for service planning about Kaylee’s strengths and areas of need will be used to develop her Individualized Family Service Plan, or IFSP.

When a child is determined eligible for early intervention, the next step in the process is assessment for service planning. An assessment of the child’s development is conducted by a team that includes the child’s family and professionals from different disciplines (i.e., educator and speech-language pathologist). Information is gathered about the child’s strengths and needs in all areas of development, including:

- Cognition (how a child thinks and solves problems)
- Communication (how a child lets others know what he wants and what he understands)
- Social Emotional (how a child interacts with others)
- Motor (how a child uses his large and small muscles)
- Adaptive (how a child helps himself by eating, sleeping, dressing, etc.)

Information is also gathered to determine how the child interacts with others and his environment during daily routines and family activities. This information helps put the child's development into the context of his daily life. The IFSP team will also use this information when developing the Individualized Family Service Plan (IFSP) and when planning intervention strategies and activities.

For those children who have been assessed by a professional outside of the early intervention system, medical records will be requested (with parental consent) and the results of the outside assessment will be reviewed. Whenever possible, these results will be used to inform the service planning process to avoid having the child undergo multiple assessments.

Referring for Further Diagnostic Evaluation

When the day finally arrives for the visit to the developmental pediatrician for further testing, Kaylee's family is in the midst of the early intervention process. When they meet with this new doctor, they share the results of the assessment that was conducted by the early intervention program. The developmental pediatrician listens as Kaylee's parents describe their concerns. He also reviews the initial screening information as well as the assessment information provided by the early intervention service coordinator. He conducts further testing with Kaylee using the ADOS and determines that Kaylee does meet the criteria for a diagnosis of autism spectrum disorder. He discusses the diagnosis, answers Alaina's and Martin's questions, and reviews options for intervention services in the community. He also gives them a resource booklet related to supports and services for children with ASD. Further medical testing is recommended to rule out genetic causes, such as Fragile X syndrome. Kaylee's family is also referred to a psychologist for assistance with Kaylee's behavior. When Kaylee's father asks if Kaylee will ever be able to talk like other children, the developmental pediatrician said that he doesn't know for sure, but he encourages them to work with Kaylee throughout the day using the intervention strategies they will learn from the early intervention service provider. The doctor says that with early intervention, many children make good progress so the family is doing the right thing by getting Kaylee help while she is so young.

At any point in the early intervention process, a family may request assistance from the early intervention team with finding a specialist who can conduct further evaluation of their child to rule out or confirm a diagnosis of ASD. Or, families may be referred for further testing by their pediatrician, as was the case with Kaylee. It is important for families to understand that currently, there is no medical test that can be used to diagnose a young child with ASD. Diagnosis (as well as screening) is based on observation of the individual child's behavioral profile – that is, the presence of social, communicative, and behavioral characteristics that might be indicative of ASD. Diagnosis of ASD is most commonly made by a trained clinician (e.g., psychologist or psychiatrist), but other medical professionals may also be able to conduct the evaluation, such as developmental pediatricians or

neurologists. While we know that many children are not actually diagnosed with ASD until after the age of 3 (and after they leave early intervention), recent research has indicated that for many children a reliable and stable diagnosis can be made by a trained clinician by approximately 18 months⁷. The research indicates that the earlier children receive an appropriate ASD diagnosis, the earlier they are likely to begin receiving intervention supports and services, so assisting families with referrals for further evaluation (when families are ready) is extremely important.

Screening and Diagnostic Tools

With the increasing attention to early identification, a number of screening and diagnostic tools are becoming available to assist with early identification of these very young children. These tools are more likely to be used by professionals outside of the early intervention system, but early intervention practitioners can benefit from being familiar with them to help families through the comprehensive evaluation process.

The screenings listed here are more in-depth than the screenings mentioned previously. These screenings may be conducted by professionals after the initial screening has been completed to gather more information to determine if further comprehensive evaluation is needed.

- *Communication and Symbolic Behavior Scales - Scale of Red Flags (CSBS/SORF)*⁸: The CSBS/SORF is a Level II screener that is used to directly observe and evaluate children's behaviors that may suggest ASD and/or a communication delay. The SORF has been demonstrated to be effective in differentiating between children with language disorders and those with ASD.
- *PDDST-II Stage 2*⁹: The PDDST-Stage 2 screener is designed for children 18 months – 3 years old. At this level, the PDDST-2 is administered by a professional to children who do not pass the initial screener.
- *Screening Test for Autism in Two-Year-Olds (STAT)*¹⁰: The STAT uses a brief and direct assessment of a child's play, communication, and imitation skills. Research has demonstrated its effectiveness in differentiating children with ASD from children who do not have ASD.
- *Childhood Autism Rating Scale - 2 (CARS- 2)*¹¹: THE CARS-2 is a screener that is most applicable to children 2 years of age and older. Using a Likert rating scale that indicates severity of symptoms, a professional rates the child on ASD characteristics and symptoms.

⁷ Lord, Risi, DiLavore, Shulman, Thurm, & Pickles, 2006

⁸ Wetherby & Woods, 2002

⁹ Siegel, 1996, 2004

¹⁰ Stone, Coonrod, & Ousley, 2000

¹¹ Schopler, Van Bourgondien, Wellman, & Love, 2010

Many children move directly to a comprehensive diagnostic assessment by a multidisciplinary team, which should include a professional who specializes in early diagnosis of developmental disabilities, including ASD. This diagnostic assessment process should be comprised of a:

- Medical examination including hearing and vision screenings
- Parent or caregiver interview including a developmental history
- Observation of the child interacting with his or her environment with attention to the child's use of communication, play, and repetitive behaviors
- Direct developmental assessment including communication, social, cognitive, adaptive behavior, and motor skills

For some children, additional evaluations may also be important to include, such as a neurological examination, sensory processing assessment by an occupational therapist or other qualified professional, etc.

The following diagnostic instruments have been developed to assist professionals with diagnosing children with ASD. Early intervention practitioners may not necessarily administer these assessments, but some familiarity with these tools might help practitioners be prepared to answer questions from families.

- *Autism Diagnostic Observation Schedule-Generic (ADOS-G)*¹² is a structured observational tool that provides opportunities for observation of a child's social, communication, and play behaviors. Some research indicates that the ADOS-G can be reliably used with children 24 months and older; however, clinicians and family members should view the outcomes with caution, since the ADOS-G was not designed for use with this population. A new toddler module for the ADOS-G is currently being developed to examine children ages 12 – 20 months who are suspected of having ASD.
- *Autism Observation Scale for Infants (AOSI)*¹³ is specifically designed for children under 18 months old. The AOSI is a play-based assessment, similar to the ADOS-G. Children are observed across a variety of play-based activities for early ASD warning signs.

Appendix A provides an overview and comparison of the different tools described in this section. It is important to remember that findings from several sources and different tools should be used in the identification and diagnostic process.

¹² Lord et al., 2000

¹³ Bryson, Zwaigenbaum, McDermott, Rombough, & Brian, 2007

Development of the Individualized Family Service Plan (IFSP)

At the IFSP meeting, Alaina and Martin share the diagnosis with the service coordinator and speech therapist and discuss their hopes and dreams for Kaylee. Based on information learned about Kaylee at her assessment and her parents' priorities for her development, the team (including Alaina and Martin) develops the IFSP outcomes and goals that will guide intervention. IFSP outcomes include Kaylee learning to use words to communicate and improve her ability to interact with her family during play and other daily routines. Kaylee's IFSP outcomes also address her tantrums, as her parents hope that as Kaylee learns to communicate more clearly what she wants and what she feels, the frequency and intensity of the tantrums will decrease.

After the IFSP outcomes are developed, early intervention supports and services are discussed. The team, including Kaylee's family, decides that weekly speech therapy services will be the primary early intervention service offered to support Kaylee's family. Monthly occupational therapy is also included on the IFSP to give Kaylee's parents and the speech therapist suggestions for activities to address Kaylee's sensory processing and fine motor needs. At the end of the meeting, the IFSP is signed so that services can begin as soon as possible.

Following the IFSP meeting, Alaina and Michael are excited to begin early intervention services to help Kaylee. Since the assessment, they have been working with Kaylee to help her learn to say "open" to get the pantry door open each morning to get her spice jars, and recently she said "opa-" several times. They are eager to learn more strategies that they could use with Kaylee every day to encourage her development.

Following the assessment for service planning, or the review of outside assessment results, families may proceed with the development of the child's IFSP. The IFSP must be developed within 45 calendar days of the date of the child's referral to the early intervention system. The IFSP is developed through collaboration between the family, the service coordinator, and the service provider(s) who were involved in eligibility determination and/or assessment, as appropriate, and those who may be providing supports and services, depending on the child's strengths and needs and the family's priorities for their child.

For young children with ASD, as with any child, the IFSP acts as the foundation for the early intervention supports and services that will be provided.

Each child's IFSP includes information about:

- The child's and family's daily routines and activities;
- Family resources, priorities, and concerns related to the child's development (included if the family chooses to share this information);

- Summary information about the child’s medical history and his or her functional strengths and needs as determined during the assessment;
- Outcomes and goals for the child’s development;
- The supports and services that will be provided to help the family encourage the child’s development within the context of daily activities in order to achieve the outcomes and goals identified on the IFSP; and
- A plan for transition to supports and services outside of the early intervention system after the child is no longer participating in early intervention.

The goal of the IFSP process is to develop a plan that is meaningful to the family and individualized to the unique strengths and needs of the child. The IFSP is a legal document and acts as a guide to the family and early intervention practitioners so that all team members are working together for the benefit of the child and family.

Throughout its implementation, the IFSP will be reviewed at least every six months. Annually, the IFSP will be re-evaluated and a new IFSP will be developed. The IFSP is a flexible document that should change as children make progress, as outcomes and goals change, and as family priorities and daily activities evolve. The IFSP should reflect the developmental progress children make during their participation in early intervention supports and services.

Summary

Individualized supports for young children with ASD are based on the information that is gathered throughout the early intervention process. As each child moves through the process, the family and early intervention practitioners collaborate on the completion of the screening, the determination of the child’s eligibility, gathering of assessment information, and the development of the IFSP. It is through this collaborative partnership that a meaningful system of early intervention supports and services is developed to address the unique needs of the child with ASD.

If you would like more information about the Infant and Toddler Connection of Virginia, visit www.infantva.org. For a visual representation of Virginia’s Service Pathway, visit www.infantva.org/documents/ovw-ccED-ServicePathChart.pdf.

For more information about family-centered practices in early intervention or about the Individualized Family Service Plan (IFSP), two online modules are available:

Family-Centered Practices in Early Intervention
www.eitraining.vcu.edu

IFSP 101: Introduction to the Infant & Toddler Connection of Virginia’s IFSP Development Process
www.eipd.vcu.edu

Early Intervention Supports and Services

During the first visit with the speech therapist, Kaylee takes a while to warm up, but eventually plays with her with the spice jars and on a trampoline. She also enjoys popping bubbles that her mother blows for her during the visit, and eventually says “pop” to get more bubbles. During their weekly visits, the speech therapist works closely with Alaina so that she will know how to use intervention strategies with Kaylee when the therapist is not in the home. By practicing strategies during visits and receiving coaching support from the therapist, Alaina learns ways to help Kaylee learn to make better eye contact, pay attention to what others say, follow a few simple directions, and use early sounds and some single words to communicate. Alaina also learns strategies from the occupational therapist that help Kaylee’s sensory processing so that she can be more focused and engaged with her family. By combining what her family knows about Kaylee’s daily routines and favorite activities with the information provided by the professional team members, Alaina, Martin, and the therapists work together as partners to support Kaylee’s development towards her IFSP goals.

Infant & Toddler Connection of VA Supports and Services

Once the IFSP is in place, early intervention supports and services must begin within 30-calendar days of the date the family signs the plan. There are no mandates or requirements for specific frequency or intensity of supports and services, regardless of disability or diagnosis. The types of supports and services a child receives will depend on the child’s unique constellation of strengths and needs and his IFSP outcomes and goals. How much early intervention support a child and family receive is determined by the IFSP team, which includes the family.

Each child and family will receive service coordination, which is provided by a service coordinator who acts as the single point of contact for the family and links them to needed resources. The service coordinator also monitors the implementation of the IFSP and coordinates all early intervention services. The goal of service coordination is to ensure that the child and family receive the support they need to encourage the child’s development within the context of family interactions and daily routines.

A variety of other supports and services are available to infants and toddlers with ASD. These services may include, but are not limited to:

Assistive technology devices & services
Audiology
Developmental services
Counseling services

Physical therapy
Psychological services
Service coordination
Social work services

Health services
Medical evaluations
Occupational therapy

Speech-language pathology
Transportation & related costs
Vision services

Services such as developmental services, occupational therapy, physical therapy, and speech-language pathology are among the most common services that young children with ASD receive. Not all children with ASD will need all of these services; service type, frequency, and intensity are determined during the IFSP development process and are based on the outcomes and goals written into the plan. Regardless of which of these intervention services a child receives, early intervention services will focus on supporting the family's efforts to interact with their child during daily family routines and activities that actually occur between intervention visits. Service providers use methods such as coaching and modeling of intervention strategies with families so that they are prepared to support the development of their children when the service provider is *not present with the family*.

EI services focus on supporting the family's efforts to interact with their child during daily family routines and activities that actually occur between intervention visits.

Evidence-based Practices for Working with Young Children with ASD

Using evidence-based practices (EBP) when working with young children with ASD and their families is not only a legal mandate, but is also the most efficient and effective means for promoting positive outcomes for young children and their families. Evidence-based practices are those practices that are grounded in science and have empirical evidence of their effectiveness. These practices are scientifically sound and should be used by early intervention practitioners to inform their practices with children and families. It is important to understand, though, that which practices are used and how they are implemented might look different when they are individualized to each child's specific strengths and needs and embedded within the context of each family's unique daily routines. See Appendix B for information about specific evidence-based practices.

General Guidelines

The National Research Council (2001) provides overall guidance for implementing effective interventions with children with ASD. In general, they suggest:

- Instructional interactions should occur for approximately 25 hours per week
- Intervention opportunities should be planned and embedded throughout the day to provide sufficient opportunities for learning

- Family members or caregivers should be a part of the intervention planning process and should be active participants in the delivery of supports and services
- If children are enrolled in a classroom setting, a low child to teacher ratio should be provided
- A mechanism should be developed for program evaluation and ongoing child assessment and monitoring to support desired outcomes and inform decision-making¹⁴

The Infant & Toddler Connection of Virginia’s approach to providing individualized early intervention supports and services is aligned with the NRC recommendations. The 25 hours per week of intervention support recommended by NRC can include support by the service provider during the intervention visit as well as the support family members and caregivers provide as they implement intervention strategies into their daily routines. If service providers are working closely with families and other caregivers to ensure that they are able to use effective strategies to address IFSP outcomes during daily routines, then children could potentially be receiving much more than 25 hours per week of support. In fact, children would be receiving intervention every day throughout the day during their interactions with their loved ones in the context of the daily activities that they enjoy most and where they learn best. During intervention sessions, service providers help families and caregivers understand how to identify learning opportunities and embed intervention strategies in natural daily routines and activities to encourage the child’s development. Early intervention visits focus on how family members and other caregivers interact with the child during the rest of the week, when the provider is not present. This approach paves the way for the child to receive intervention supports that are individualized and meaningful, and provides for repeated practice of new and emerging skills and abilities. Families who are interested in receiving additional or supplemental services outside of the early intervention system may choose to explore other community options as well.

It is the goal of early intervention to ensure that family members, who are best suited to most directly impact the development of their children, have the knowledge and skills they need to feel confident and well-prepared to interact with their children in ways that support healthy development and progress towards IFSP outcomes and goals.

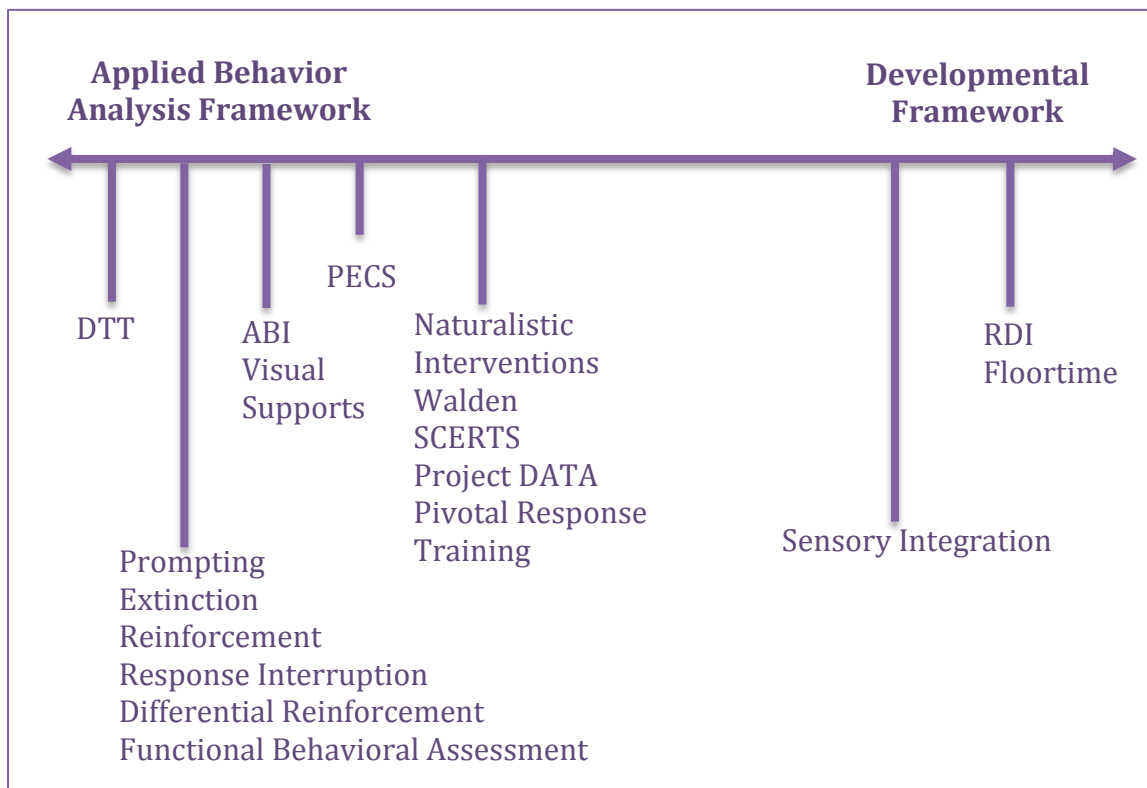
¹⁴ NRC, 2001

Focused Practices and Comprehensive Intervention Models

Early intervention practitioners may use a variety of practices and models of intervention when working with young children with ASD. Which practices and models are used depends on the practitioner's training, family preference, the individual child's development, and the IFSP outcomes and goals.

The conceptual foundations for various *focused practices* and *comprehensive intervention models (CIM)* vary along a continuum. On one end of the continuum, practices and CIM may be oriented toward applied behavior analysis. On the other end of the continuum, practices and CIM may have a developmental orientation. See the figure below for a visual representation of this continuum.

Focused Practices and Comprehensive Intervention Modules Continuum



NOTE: DTT: Discrete Trial Training; ABI: Antecedent-based Interventions; PECS: Picture Exchange Communication System; RDI: Relationship Development Intervention

An overview of *focused practices* and *comprehensive intervention models* is provided here so that all early intervention team members, including the family, have information about options that may be appropriate for encouraging the development of the child toward IFSP outcomes.

Focused practices. Focused practices are individualized intervention strategies that early intervention practitioners can use to promote or change a *specific* skill or set of skills or behaviors. Focused practices are typically used over a relatively short period of time (e.g., 3 months) and can be implemented in homes, classroom settings or community programs. A number of EBP focused practices exist for working with young children with ASD. Appendix B provides examples and an overview of these practices.

Comprehensive intervention models. Many of the focused practices described above have been combined into more comprehensive intervention models. Comprehensive intervention models are organized packages of focused practices and components and address a broad array of developmental skills for children. Typically, comprehensive intervention models are intensive and are used over an extended period of time. Several comprehensive intervention models have been developed for young children with ASD (see Appendix B). Although some of these comprehensive intervention models have been widely advertised, many of them lack evidence of their effectiveness, especially when comparing one program to another.¹⁵

Deciding Which EBP to Use and With Whom

An important part of using EBP is considering which practices are going to help the child and family achieve the outcomes and goals on the IFSP. Although some level of evidence exists for recommended and promising practices, it is important for early intervention practitioners to ask themselves the following questions prior to selecting a practice to use:

- What are the *anticipated outcomes* of using a particular practice and do the anticipated outcomes match the needs of the child and family?
- What are the *potential risks* associated with the practice?
- What are the most effective *means of evaluating* a particular method or approach for that child?¹⁶

The decision to choose a particular practice should be based not only on the evidence, but also on the outcomes associated with the intervention and the individual needs of the child with ASD.

It can be very helpful to discuss these questions with families so that they are part of the decision-making process for which practices they would like to try with their children. When families participate in this thought process, they offer needed insights into what may work for their child and learn skills that will help them

¹⁵ Odom, Boyd, Hall, & Hume, 2009

¹⁶ Simpson, 2005

make informed decisions for the child during the child's enrollment in early intervention and beyond.

Complementary Alternative Interventions (CAI)

A number of complementary alternative interventions (CAI) for children with ASD have appeared over the past 10 years. Many families who have children with ASD consider trying some complementary alternative interventions with their children. These interventions often receive a great deal of attention in the media; however, they are considered alternative interventions or therapies because they either lack any scientific evidence or have substantially less scientific evidence than more traditional approaches to intervention. Several of the most commonly used CAI are diets, vitamins and supplements, and manipulative and body-based therapies.

Diets, Vitamins and Other Supplements

The use of vitamin supplements and diet changes are the most commonly used CAI for individuals with ASD.¹⁷ Many families have suggested that their children improve on gluten-free and casein-free diets (GFCF); however, only several studies have examined the effects of GFCF diets on children with ASD and the findings are inconclusive.¹⁸ Likewise, research indicates that more than half the families of children with ASD use vitamins or supplements with their children. Although vitamin therapy is often used, very few research studies have been conducted to provide support for this practice.¹⁹

Manipulative and Body-based Therapies

Therapies such as chiropractic care, craniosacral manipulation, massage, yoga, music therapy, Reiki and so forth are also commonly accessed by families of children with ASD. Although many parents anecdotally report improvements in their children, there have not been any evidence-based studies that specifically examine the impact of these practices.²⁰

Considering the Use of CAI

When deciding whether to use a CAI with children with ASD, the same principles and levels of evidence as with all recommended practices should be applied. It is important to examine the potential and direct impact of the intervention on an individual child's growth and development. However, since CAI have little or no scientific evidence, families and practitioners should use caution and monitor for any counter-therapeutic side effects that may occur. Discussing the potential use of these interventions with the child's pediatrician is also recommended.

¹⁷ Brown & Patel, 2005

¹⁸ Hyman & Levy, 2011

¹⁹ Green et al., 2006

²⁰ Hyman & Levy, 2011

Monitoring Child and Family Progress

Regardless of the EBP that an early intervention practitioner might use with a child and family, the only way to know if that intervention is effective is through ongoing monitoring of child and family progress and outcomes. The most objective and efficient manner to monitor children's (and family's) progress is to collect data and evaluate progress. In early intervention, this is accomplished by tracking progress towards IFSP outcomes and goals.

IFSP outcomes and goals provide a framework for intervention by specifically describing skills that the child's needs to learn in the natural contexts where he or she will practice them. Outcomes and goals include a statement of what the child will do (i.e., Kaylee will use single words), a description of the context in which she will use the skills (i.e., while playing in the backyard with her brother), and a criterion for mastery, which is typically written in measurable terms that describe how the child will achieve the skill and be able to do it across a certain amount of time (i.e., 2 times a day for 2 weeks). Data can be collected from the family at each intervention visit through conversation about their routines and activities during the previous week. Families are not expected to actually keep a tally of their child's performance, but if they are using intervention strategies during their daily routines with their child, then their feedback should inform the service provider's data collection. The service provider then documents the child's progress in a contact note, and depending on the activities being addressed, may also collect data in other formats, such a helping the family keep a running list of words the child uses during the day or a list of the types of foods the child eats at each meal.

When collecting data and monitoring progress, it is very important that early intervention practitioners remember to combine their observations of the child's abilities during the intervention visit with the feedback they receive from the family about what the child does between visits.

Transition from Early Intervention

Transition from early intervention occurs when a child has made sufficient progress and he or she no longer meets the early intervention eligibility requirements or the child no longer meets early intervention age-eligibility requirements. An eligible toddler may continue to receive early intervention services until he or she turns 36 months of age, at which time the child becomes ineligible for early intervention due to age.

As a child nears the time for transition, the family's early intervention service coordinator will offer to assist with transition planning for supports and services outside of the early intervention system. Prior to the third birthday, the service coordinator will assist the child's family with considering other community options if the child continues to need

supports and the family is interested in pursuing other options. The transition process is individualized to the child's and family's needs and priorities and the local community. Transition planning for each child is documented on the IFSP and families are supported throughout the process. Transition options may include early childhood special education (ECSE) preschool services through the public school system; private speech, occupational, or physical therapy; private preschool; or other options that may be specific to a local community.

If a family decides to pursue transition to the early childhood special education preschool program in their local school system, the service coordinator will discuss with the family the timeframes for transition. In Virginia, the public school may accept a child who is found eligible under the local school division's eligibility criteria (which may differ from the early intervention system's eligibility criteria) if that child turns *2 years old on or before September 30th of a given school year*. Virginia is the *only state* that enrolls eligible 2 years olds into its early childhood special education preschool program. Families have the option of referring their children to the public schools, if their children meet this September 30th timeline, or waiting to transition to preschool once the child turns 36 months of age. Also in Virginia, referrals for ECSE preschool services are typically sent by April 1st of a given year, so that, if a child is found eligible, he or she may start preschool on the first day of the next school year. A child may be referred before or after the April 1st deadline, though, depending on circumstances such as when a family moves into the area after April 1st.

For more information about early childhood special education services in Virginia's public schools, visit the Virginia Department of Education's website at http://www.doe.virginia.gov/special_ed/early_childhood/index.shtml.

Summary

The Infant & Toddler Connection of Virginia is committed to providing the best quality supports and services to young children with ASD and their families. Early identification of signs and characteristics of ASD is extremely important to ensuring that children and families receive the supports and services they need. Whether a child has a formal diagnosis or is suspected of having ASD, the early intervention system will work closely with the child's family throughout the early intervention process to ensure that the child's strengths and needs are addressed and the family's priorities for their child are considered in all decisions. Collaboration between the child's family and the early intervention practitioners who support their efforts is critical to the provision of individualized, meaningful supports and services that are based on evidence-based practices.

Together, we can make a difference in the lives of infants and toddlers with autism spectrum disorders.

References

- Brown, K.A., & Patel, D.R. (2005). Complementary and alternative medicine in developmental disabilities. *Indian Journal of Pediatrics*, 72 (11), 949-952.
- Bryson, S.E., Zwaigenbaum, L., McDermott, C., Rombough, V., & Brian, J. (2007). The Autism Observational Scale for Infants: Scale development and reliability data. *Journal of Autism and Developmental Disorders*. Retrieved from www.springerlink.com/content/104757
- Hyman, S. L., & Levy, S.E. (2011) Dietary, complementary, and alternative therapies. In B. Reichow, P. Doehring, D.V. Cicchetti, & F.R. Volkmar (Eds.), *Evidence-based practices and treatments for children with autism*. New York: Springer.
- Green, V.A., Pituch, K.A., Itchon, J., Choi, A.O., Reilly, M., & Sigafos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27(1), 70-84.
- Lord, C., Risi, S., Lambrecht, L., Cook, E.H., Leventhal, B.L., DiLavore, P., et al. (2000). The Autism Diagnostic Observation Schedule-Generic: A standard measure of social and communication deficits associated with spectrum of autism. *Journal of Autism and Developmental Disorders*, 30, 205-223.
- Lord, C., Risi, S., DiLavore, P., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from two to nine. *Archives of General Psychiatry*, 63, 694-701.
- National Research Council (NRC) (2001). *Educating children with autism*. Committee on Educational Interventions for Children with Autism. C. Lord & J.P. McGee (Eds.). Division of behavioral and Social Sciences and Education. Washington, DC: National Academy Press.
- Odom, S. L., Boyd, B.A., Hall, L.J., & Hume, K. (2009). Evaluation of comprehensive treatment models for individuals with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 40 (4), 425-436.
- Rice, C. (2009). *Prevalence of autism spectrum disorders – Autism and developmental disabilities monitoring network, United States, 2006*. Morbidity and Mortality Weekly Report. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>
- Robins, D.L., Fein, D., Barton, M.L., & Green, J.A. (2001). The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 31, 131-144.
- Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R. (2010). *Childhood Autism Rating Scale* (2nd Ed.). Los Angeles, CA: Western Psychological Services.

- Seigel, B. (2004). *The Pervasive Developmental Disorders Screening Test II (PDDST-II)*. San Antonio, TX: Psychological Corporation.
- Simpson, R.L. (2005). Evidence-based practices and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 20*, 140-149.
- Stone, W.L., Coonrad, E.E., & Ousley, O.Y. (2000). Screening Tool for Autism in Two-Year-Olds (STAT): Development and preliminary data. *Journal of Autism and Developmental Disorders, 30*, 607-612.
- Volkmar, F., R., Chawarska, K., & Klin, A. (2008). Autism spectrum disorders in infants and toddlers: An introduction. In K. Chawarska, A. Klin, & F.R. Volkmar (Eds.) *Autism Spectrum Disorders in Infants and Toddlers: Diagnosis, Assessment, and Treatment* (pp. 1 – 22). New York: The Guilford Press.
- Wetherby, A.M., & Prizant, B.M. (2002). *Communication and Symbolic Behavior Scales Developmental Profile* (First Normed Ed.). Baltimore: Brookes.
- Wetherby, A.M., & Woods, J. (2002). *Systematic observation of red flags for autism spectrum disorders in young children*. Unpublished manual, Florida State University, Tallahassee.

Other Websites & Resources

Please note that there are far too many books and websites on autism spectrum disorders and related resources for this list to be complete. The resources you will find here are intended to be helpful when searching for more information beyond what is included in this document. There is space below this list for you to include additional resources of interest to you.

American Academy of Pediatrics
<http://www.aap.org>

Ball, J. (2008). *Early intervention and autism: Real-life questions, real-life answers*. Arlington, TX: Future Horizons.

Center for Disease Control
<http://www.cdc.gov/ncbddd/autism/research>

Infant & Toddler Connection of Virginia
<http://www.infantva.org>

Interagency Autism Coordinating Committee
<http://iacc.hhs.gov>

First 100 Days Kit
http://www.autismspeaks.org/community/family_services/100_day_kit.php

First Signs

<http://www.firstsigns.org/>

Ohio Center for Autism and Low Incidence (OCALI) Autism Internet Modules

<http://www.autisminternetmodules.org/>

Moor, J. (2008). Playing, laughing, and learning with children on the autism spectrum: A practical resource of play ideas for parents and carers. London: Jessica Kingsley Publishers.

National Professional Development Center on Autism Spectrum Disorders

<http://www.fpg.unc.edu/~autismPDC>

National Autism Center

<http://www.nationalautismcenter.org>

Translating Autism

<http://www.translatingautism.com>

University of California MIND Institute

<http://www.ucdmc.ucdavis.edu/mindinstitute/>

Virginia Department of Education

http://www.doe.virginia.gov/special_ed/early_childhood/index.shtml

Virginia Early Intervention Professional Development Center

http://www.eipd.vcu.edu/sub_autism.html

Virginia Commonwealth University Autism Center for Excellence

<http://www.vcuautismcenter.org/>

Notes on Additional Resources:

Appendix A

Screening & Diagnostic Tools for Toddlers with ASD

| Screening or Diagnostic Assessment Tool | Ages | Who Completes Checklist | Time to Complete (Minutes) |
|---|-------------------|-------------------------|----------------------------|
| Screening Tools | | | |
| Modified Checklist for Autism in Toddlers (M-CHAT) | 16-30 months | Parent | 5-10 |
| Communication and Symbolic Behavior Scales – Developmental Profile (CSBS – DP) <i>Infant/Toddler Checklist</i> | 6-24 months | Professional | 5-10 |
| Pervasive Developmental Disorders Screening Test (PDDST) – Level 1 & 2 | 12–48 months | Professional | 10-20 |
| Screening Test for Autism in Two-Year Olds (STAT) | 24–36 months | Professional | 20 |
| Childhood Autism Rating Scale (CARS-2) | 2 years and older | Professional | 5-10 |
| Diagnostic Tools | | | |
| Autism Diagnostic Observation Schedule - Generic (ADOS- G) | 2+ years | Professional | 35-40 |
| Autism Observation Scale for Infants (ASOI) | 12-18 months | Professional | 20 |

Appendix B

Focused Practices and Comprehensive Intervention Models²¹

| Focused Practice/Comprehensive Intervention Model (CIM) | Description of the Practice or CIM | Developmental Skills/Symptoms | Setting | Level of Evidence ²² |
|---|---|---|--|---------------------------------|
| Focused Practices Evidence-based and Promising Practices | | | | |
| Antecedent-based Interventions (ABI) | Group of behavioral strategies that include the modification of environmental factors that “set the stage” for increasing and/or decreasing behaviors. Examples include: choice making, routines, task modification | Increasing appropriate behavior Decreasing problem behaviors | Individual or small group Classroom or home | Evidence-based Practice |
| Discrete Trial Training (DTT) | A behavioral strategy that includes highly controlled repeated trials with a discrete | Increasing cognitive, language, social, and | Individual setting | Evidence-based Practice |

²¹ Adapted from the National Professional Development Center on Autism Spectrum Disorders

²² Level of evidence is determined by the number and quality of research studies conducted on each practice or CIM. The term “evidence-based practice” indicates a sufficient amount of research indicating efficacy of the practice or model. “Promising or emerging practice” indicates that only limited research has been conducted indicating efficacy of the practice or model. “Limited evidence” indicates that there is not sufficient empirical evidence to indicate whether the practice is effective or not. Please note that research is continuing to be conducted on practices and CIM; thus levels of evidence will change as additional research is conducted.

| | | | | |
|----------------------------|---|--|--|-------------------------|
| | beginning and end | behavioral skills | | |
| Extinction | A behavioral strategy used to decrease behavior that involves discontinuing a reinforcer that is maintaining the behavior | Decreasing problem behaviors | Individual or small group Classroom or home setting | Evidence-based Practice |
| Naturalistic Interventions | A group of behavioral strategies that are oriented toward the child's focus and implemented during naturally occurring situations | Increasing cognitive, communication and social skills | Individual or small group Classroom or home setting | Evidence-based Practice |
| Prompting | A group of behavioral strategies that provide levels of support or assistance to a child when learning a new skills (e.g., least to most, graduated guidance) | Increasing cognitive, communication and social skills | Individual or small group Classroom or home setting | Evidence-based Practice |
| Reinforcement | A behavioral strategy that is used to increase future occurrence of a behavior | Increasing cognitive, communication and social skills | Individual or small group Classroom or home setting | Evidence-based Practice |
| Response Interruption | A behavioral strategy used to redirect a behavior that is interfering with learning (e.g., self-injurious, repetitive behavior) | Decreasing problem behaviors including repetitive or stereotypic or self-injurious behaviors | Individual Classroom or home setting | Evidence-based Practice |
| Visual Supports | A set of visual prompts or tools that are used to communicate | Increasing appropriate | Individual or small group | Evidence-based Practice |

| | | | | |
|--|---|--|--|-------------------------------------|
| | information to children | behaviors Decrease problem behaviors | Classroom or home setting | |
| Picture Exchange Communication System (PECS) | A pictorial instructional package designed to increase the use of communication skills | Increasing communication, social, and behavioral skills | Individual or small group Classroom or home setting | Evidence-based Practice |
| Differential Reinforcement | A group of behavioral strategies used to reinforce behaviors other than problem behaviors | Increasing communication, social, and behavioral skills | Individual or small group Classroom or home setting | Evidence-based Practice |
| Functional Behavioral Assessment (FBA) | A group of behavioral strategies used to identify the function of behavior | Increasing communication, social, play, and behavioral skills | Individual Classroom or home setting | Evidence-based Practice |
| Sensory Integration | A group of occupational therapy strategies designed to address children's over (or under) stimulation to the environment (e.g., swinging, brushing) | Increasing appropriate behaviors Decreasing problem behaviors | Individual Classroom or home setting | Promising Practice/Emerging Support |

| Comprehensive Intervention Models Evidence-based and Promising Practices | | | | |
|--|--|--|--|--------------------------------------|
| Pivotal Response Training (PRT®) http://www.koegelautism.com/ | A model comprised of naturalistic behavioral strategies designed to use the child's interests and follow the child's lead to increase appropriate behaviors | Increasing communication, social, play, and behavioral skills | Individual or small group Classroom or home setting | Evidence-based Practice |
| Project DATA (Developmentally Appropriate Treatment for Autism) http://education.washington.edu/research/projects/projectdata.html | A classroom-based model that includes inclusive early childhood services, extended instructional time, and family support and includes the use of social communication learning opportunities embedded using naturalistic instructional strategies | Increasing cognitive, communication, social, and behavioral skills | Classroom | Promising Practice/Emerging Evidence |
| Social Communication Emotional Regulation, Transaction Supports Model (SCERTS®) http://www.scerts.com/ | A comprehensive model that provides a scope and sequence of developmentally appropriate goals and a framework for teaching children with ASD through everyday activities | Increasing cognitive, communication, social, and behavioral skills | Home Classroom | Promising Practice/Emerging Evidence |
| Walden Program | A comprehensive model that uses naturalistic behavioral | Increasing cognitive, | Classroom | Promising Practice/Emerging |

| | | | | |
|--|---|--|--------------------|--------------------|
| http://www.psychiatry.emory.edu/PROGRAMS/autism/Childhood.html | practices and embedded learning opportunities to teacher children with ASD in an inclusive early childhood classroom setting | communication, social, and behavioral skills | | Evidence |
| Limited or No Evidence | | | | |
| Developmental Individual-Difference®/Floortime™ Model http://www.icdl.com/dirFloortime/overview/index.shtml | A framework that includes comprehensive assessment and development of an individualized intervention program which is based on the strengths and needs of the child | Social, emotional, and intellectual skills | Individual Home | Limited Evidence |
| Relationship Development Intervention® (RDI) http://www.rdiconnect.com/pages/RDI-Program-for-ASD.aspx | A developmental model designed to build reciprocal relationships between caregivers and children | Social/emotional | Individual Home | Limited Evidence |
| Son-Rise Program® http://www.autismtreatmentcenter.org/ | A comprehensive program designed to teach caregivers how to interact and motivate their child to learn | Learning and communication skills | Individual Home | No Evidence |
| Not Recommended: Empirical Evidence Indicates Counter-therapeutic Findings | | | | |
| Holding Therapy | A treatment where an adult uses | Attachment | Individual | Evidence indicates |

| | | | | |
|--------------------------------|---|---------------|------------|---|
| | physical restraint of a child, encourages the child to make eye contact, and provides tactile stimulation | behaviors | | counter-therapeutic outcomes |
| Facilitated Communication (FC) | A strategy designed to provide support for the learner as they use a keyboard to communicate | Communication | Individual | Evidence indicates counter-therapeutic outcomes |

Notes

The Partnership for People with Disabilities is a university center for excellence in developmental disabilities at Virginia Commonwealth University. VCU is an equal opportunity/affirmative action institution providing access to education and employment without regard to age, race, color, national origin, gender, religion, sexual orientation, veteran's status, political affiliation, or disability. If alternative formats of this document are needed, please contact Deana Buck at (804) 827-0198 or (800) 828-1120 (TTY Relay).

