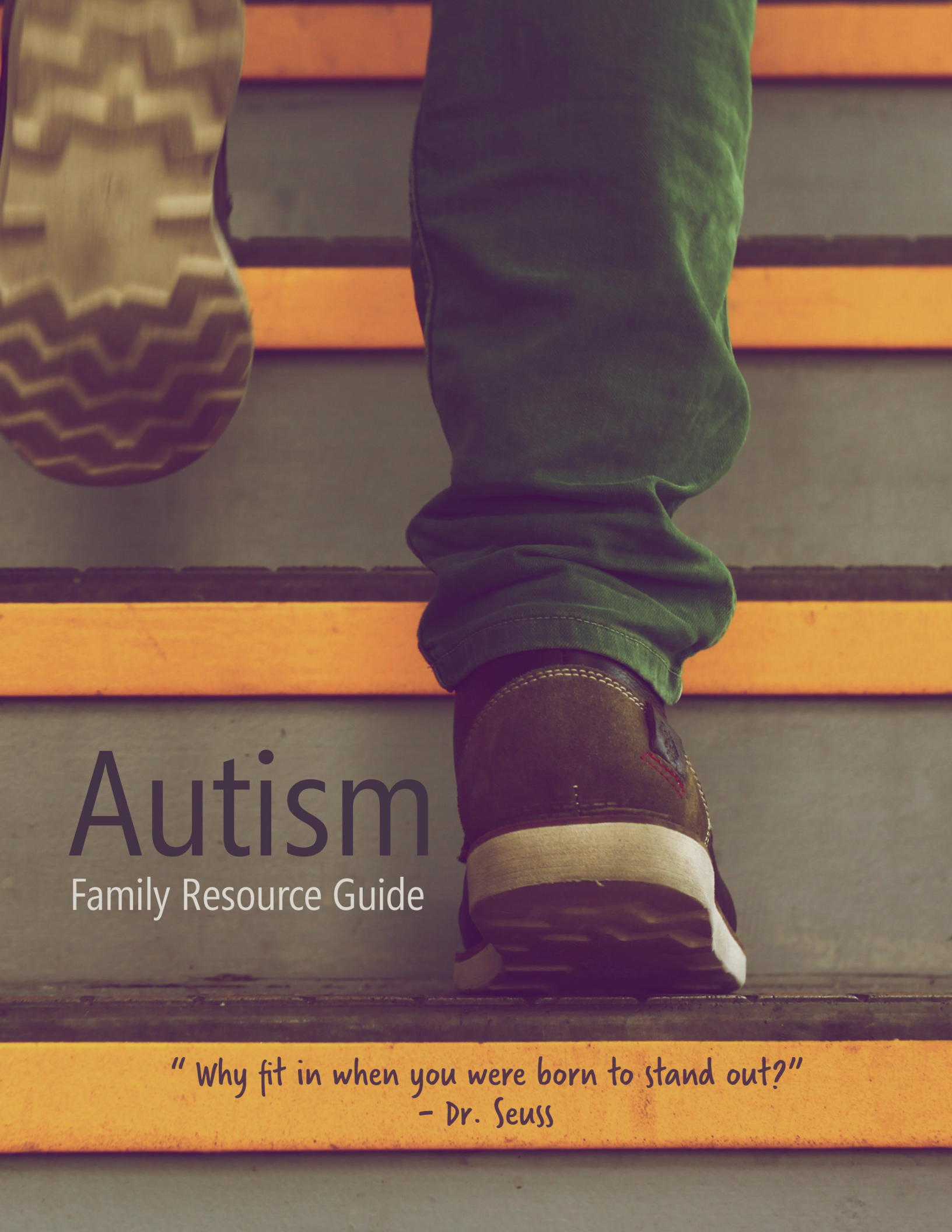


Autism

Family Resource Guide

" Why fit in when you were born to stand out?"
- Dr. Seuss

Smart Start™

Mecklenburg Partnership for Children

www.smartstartofmeck.org

601 E. 5th St., Suite 500
Charlotte, NC 28202
704.377.6588

Join Us - We Are Social!

@SmartStartMeck

The Purpose of This Book

This guide has been developed to help parents navigate the challenging and often confusing journey of parenting a child with autism.

In an effort to raise awareness of autism spectrum disorder (ASD) and the importance of early intervention in the Charlotte-Mecklenburg area, the Autism Spectrum Disorder Collaborative was created. This group of local organizations has worked together to develop outreach programs and initiatives to educate, inform, support, and encourage everyone affected by autism. The outcomes are as follows:

Targeted outreach to both healthcare and child care professionals to educate them about the lifelong value of early intervention for young children exhibiting signs of autism.

Presentations, workshops, articles, and brochures that encourage physicians to perform autism-specific developmental tests on babies at 18 and 24 months of age, and refer parents for an assessment if necessary.

Autism-related books were provided to the Spangler Library located at ImaginOn to help families understand autism and assist them in learning more about becoming an advocate for both their child's and their family's needs.

This **Autism Family Resource Guide** was also an outcome of the ASD Collaborative. It was developed to help explain how to navigate Mecklenburg County agencies that provide developmental and autism-related services.

We hope you find this guide helpful.

Dear Concerned Parent,

Child rearing can be a challenge since all children develop somewhat differently. Milestones are not always met on time or in a specific order. Delays can create concerns, especially if they involve speech or are paired with unusual behaviors. You may be reading this resource guide because you have noticed some developmental delays in your child and are concerned that they may be showing early signs of autism. Please know that if autism is found to be the reason for your child's differences, there are useful resources to help them better develop age-appropriate skills in order to lead a happy, meaningful life. Also, please note that some differences in children of a very young age may look like autism, but with early intervention, you may find that your child can, in time, acquire the missing skills without further concern of autism. Because early intervention is crucial for reaching the best outcome, seeking a professional diagnosis is the best thing you can do for your child, regardless of whether or not autism is present. The information provided in this guide will lead you to professionals who will diagnose the cause of your child's delays and prescribe therapies that will help.

Realizing that your child has developmental differences can be overwhelming. This guide will introduce you to resources in Mecklenburg County that can provide you with ways to create the best environment for your child's development. Some of this information is available online, and the resources in this guide will connect you with knowledgeable professionals.

Additionally, this guide contains information about support groups, which will allow you to connect with others who understand your challenges. Raising a child who is socially different can be a lonely job, but surrounding yourself with others who understand your situation can help you take positive actions more quickly, make necessary changes, and find peace in order to help your child. You are not alone! Welcome to the world of many families in Charlotte and Mecklenburg County who are working to help their child with special needs become the best young person possible. You are entering a community of support, knowledge, motivation, and hope. I hope that this guide will make your life easier and give you the tools you need to quickly move forward with your life.

Sincerely,

Nancy Nestor
Support Coordinator for the Regional Chapter of the Autism Society of NC
and parent of a son with autism spectrum disorder

Table of Contents

1 Signs of Autism Spectrum Disorder (ASD)

Are you wondering if your child has autism? As the prevalence of **autism spectrum disorders** increases, the number of parents facing the prospect of raising a child with autism also increases, and so does the need for information about what ASD looks like in young children.

Autism spectrum disorders are developmental disorders that affect brain development and cause differences in three main areas: 1) **social interaction,** 2) **communication**, and 3) **interests and behaviors**. The degree of difficulty in each of these core areas can range from very mild to severe, and each child will show individual differences regarding when symptoms start and what exactly they look like.

In general, core impairments in these areas result in the following "**red flags**":

Social interaction

- Lack of appropriate eye gaze (child may avoid looking at faces or eyes)
- Lack of warm, joyful expressions (child may not smile at you to communicate happiness)
- Lack of sharing interest or enjoyment (child may have strong interests and enjoy them very much but may not share them with others)
- Lack of response when called by name

Communication

- Lack of showing gestures (child may not hold up an object of interest for others to see)
- Lack of coordination of nonverbal communication (absent or unusual use of gestures, expression, or vocal quality to communicate)
- Unusual **prosody** (little variation in pitch, odd intonation, irregular rhythm, unusual voice quality sometimes called robotic)

Repetitive behaviors and limited interests

- Repetitive movements with objects (child may not use an object for its intended purpose)
- Repetitive movements or posturing of body, arms, hands, or fingers

The impairments associated with the core deficits of ASD may also appear in your child in the following areas:

Socialization

- Prefers to be alone; appears aloof
- Has difficulty interacting with other children
- Does not want physical contact (cuddling, touching, hugging)
- Makes little or no eye contact

Communication

- Has difficulty initiating conversation or play with others
- Does not demonstrate **joint attention** (showing or sharing something with another person; this is typically demonstrated by using eye gaze and gestures, particularly pointing) during social interaction
- Has difficulty interpreting **facial expressions** and/or body language
- Has difficulty understanding and interpreting emotions (of self and/or others)
- Has difficulty in expressing needs (may use negative behavior instead of words)
- Laughs, cries, or shows distress for reasons not always apparent to others
- Has little or no speech
- Has difficulty processing language and may not understand instructions and/or may take longer to respond to questions)
- **Echolalia** (immediate or delayed repetition of the words of another person such as a family member, peer, TV character, singer, etc.)
- Not responsive to verbal cues – acts as if deaf although tests prove hearing is in normal range
- Acts or speaks in socially inappropriate manner (such as speaking too loudly or for too long)

Behavior

- Has difficulty transitioning from one activity or setting to another
- Has **tantrums** or "meltdowns"
- Spins and/or lines up objects repetitively or obsessively
- Develops inappropriate attachments to objects
- Frequently walks on tiptoes (toe walking)
- Displays stereotypical or self-stimulatory behaviors (repetitive movement of the body or other objects such as hand flapping, rocking, flicking fingers in front of face.)
- Has restricted and persistent interests

- Insists on sameness and is resistant to change
- Engages in self-injurious behaviors

Other Areas

- Has uneven gross-/fine-motor skills
- Has sensory processing issues or responds to sensory input in usual ways
- Seems over-sensitive or under-sensitive to pain
- Displays noticeable signs of physical over-activity or under-activity
- Eats limited food choices and/or textures
- Seems only minimally aware of physical danger

If your child is on the autism spectrum, you might describe his or her behaviors with words like these:

Social behaviors

- "It's hard to get his attention."
- "She seems to be in her own world."
- "Everything she does is on her own terms."
- "He completely ignores his baby sister."

Communication behaviors

- "She gets things by herself."
- "He can't tell me what he wants."
- "She takes my hand and pulls me to whatever it is she wants."
- "He repeats lines and songs from TV and videos but doesn't use words to ask for things."

Behaviors/restricted activities

- "She plays with all of her toys by lining them up."
- "He studies things very carefully."
- "She plays by dumping her blocks and then putting them back again – over and over."
- "He'll watch his favorite video over and over again…and over and over again."

Source: Warren, Z. (2008, October). Early assessment and diagnosis of autism spectrum disorders. Presentation at the First International Autism Summit, Cleveland, OH.

2 Developmental Differences

The social, communicative, and behavioral characteristics of ASD will look different depending on your child's age and development. For example, an eight-month-old would not be expected to use words or point to show you something that interests them.

There may be reasons for concern if your child demonstrates the following differences at the ages of:

6 to 9 months

- Gaze aversion (child avoids looking at faces or eyes)
- Decreased social smiling
- Absent facial expression
- Poor emotional modulation (child is unable to calm themselves)
- Delayed **babbling**
- Infrequent vocalizations (child rarely makes the sounds of speech)
- Abnormal pattern of focus or attention (child spends most of their time attending to unusual objects or patterns)

9 to 12 months

- Tends not to turn to someone calling their name
- Seems to hear environmental sounds better than human voices
- Decreased monitoring of others' gazes (child does not look to faces or look where another is looking)
- Inability to follow a point (child fails to look to where someone is pointing)
- Abnormalities in arousal to stimuli (child over- or under-reacts)
- Infrequent babbling

12 to 15 months

- Rarely or never points
- Rarely or never shows something of interest to another person
- Delayed speech

- Repetitive or perseverative play with objects (child repeats a movement or routine over and over)
- Does not wave bye-bye

15 to 18 months

- Limited or scripted **pretend play** (play routines are limited to a single action or are imitations always completed in the same way)
- Lack of imitation
- Reduced variety of play acts
- Early signs of developmental regression (child loses skills previously demonstrated)

Source: Plauche Johnson, Recognition of Autism Before Age 2 Years, Pediatrics in Review (March 2008; 29:86-96)

3 Truths About ASD

It is important to remember that:

- A complete and accurate diagnosis of autism requires more than a brief observation in a single setting.
- People with autism have needs and strengths that should be addressed within programs individualized to meet their profile of abilities.
- Autism is not caused by cold or unemotional mothers.
- The MMR vaccine protects children from diseases; it does not cause autism.
- A child may be able to look at your face or eyes and still have autism.
- Individuals on the autism spectrum may not have a special or outstanding talent.
- Children with autism can be emotional and affectionate.
- Autistic people are able to build relationships.
- Individuals with autism frequently speak and communicate.
- Some people with autism have limited intellectual abilities; some have high intellectual abilities.
- Teasing and bullying can affect a person with autism just as much as a person without autism.
- People with autism are able to learn and develop new skills.
- Self-stimulatory behaviors may serve several purposes. They may be used to communicate that the child is overstimulated or bored, or that they may want or not want something.

4 Referral Information
Who to Contact If Your Child Shows "Red Flags"

If you want to learn more about ASD, Autism Speaks has an excellent website that will provide useful information. It is loaded with autism "current events," facts and explanations about ASD, and "tool kits" designed to address specific situations or events. The site may seem overwhelming at first, but it's worth the effort to explore it. (www.autismspeaks.org)

A good first step, if you are worried about your child, is to contact your healthcare provider for a discussion about your concerns. Next, you could contact the Autism Coordinator for Smart Start's Guiding Parents to Services for a conversation about your child and to learn about services in Mecklenburg County that may help.

Guiding Parents to Services (GPS)

A free program offered by Smart Start of Mecklenburg County designed to help parents begin the process of understanding autism spectrum disorders and find local services. The GPS Coordinator will listen to your story and concerns, will help you understand the process for finding appropriate services, and can guide you to accessing them. This program is dedicated to helping you start your journey – GPS is a place where you can regain your balance, expand your capabilities, and be in a better position to support your child.

- **704-943-9416 o 704-806-5123**
- **GPS@smartstartofmeck.org**
- For children from birth to 5 years of age
- Telephone or in-person consultations will help you make sense of your child's behaviors, introduce you to service options and help you plan your next steps
- Services are offered at no cost

GPS will guide you to services and programs available in Mecklenburg County. On the following pages, there are additional programs listed. Be sure to read the description of services each organization provides. You are welcome to contact any of these programs.

1. The Mecklenburg County Children's Developmental Services Agency (CDSA)

Location: Carlton G. Watkins Center • 3500 Ellington Street • Charlotte, NC 28211
Website: http://charmeck.org/mecklenburg/county/PSO/cds/Pages/default.aspx

Serves children (and their families) from birth to age three with a developmental delay or established condition, including ASD.

The Mecklenburg Children's Developmental Services Agency (CDSA) is the local early intervention agency in our community, and it is part of the statewide NC Infant-Toddler Program. The CDSA provides services to families with very young children (newborn to three years of age) who may have delays in the way they are developing. The program also supports families whose children have certain medical conditions that may be affecting their development. The CDSA provides support to children and families through a variety of services and emphasizes the powerful learning opportunities that occur as part of a child's participation in everyday family and community life. Early intervention professionals work with caregivers to build their capacity to enhance their child's development. They help you meet the developmental needs of your infant or toddler.

All it takes to initiate a referral is concern on the part of the parent or caregiver. You or your doctor may make a referral by phone call, fax, a mailed letter or an in-person request.

To make a referral, please call 704-336-7130 or fax 704-336-7112
Para Hacer una referencia, por favor llá menos al 704-336-7452

No family is ever denied services because of their inability to pay. Evaluations and service coordination are provided at no charge to families. Other services are provided on a sliding scale fee. Medicaid and private insurance are billed with family permission.

2. The Charlotte-Mecklenburg School (CMS) Preschool for Exceptional Children Program

Call **980-343-2720** if you have concerns about your child's development and, if he/she is older than 3 to request an evaluation to be considered for Exceptional Children services. It is a good idea to begin the enrollment process before the 3rd birthday when possible.

- Children receiving services through early intervention programs associated with the CDSA may transition to CMS as they approach their third birthday. CDSA service coordinators and CMS case managers collaborate and assist parents in the transition process.
- Children may be referred to CMS by a parent or a physician. Physician referrals alone, however, will not begin the evaluation process. Parents must communicate with a CMS Preschool Exceptional Children intake specialist to indicate their desire for services.
- Parents will be required to provide an original certified copy of their child's birth certificate and two copies of proof of residence in Mecklenburg County.
- Parents will be required to provide case history information and signed consent for testing.
- Children will be provided with special education and related services based on their eligibility and the agreed-upon **Individual Education Program (IEP)** goals.

- Children do not have to attend CMS schools to receive therapy.

CMS special education services may be delivered in the following ways:

- **Drive-in services** - special education and related services are provided at a designated CMS site.
- **Community-based preschool and/or child care program** - special education and related services that are provided at the child's preschool or child care facility.

CMS Pre-K programs for children who will be four years old on or before August 31 include:

- **Itinerant Services** - special education and related services that are provided within the Bright Beginnings or NC Pre-K Program. Minimal levels of support are typically required.
- **Inclusive Practices Model** - special education and related services that are provided within a Bright Beginnings Inclusion Classroom in collaboration with Exceptional Children staff. Increased levels of support may be required.
- **Exceptional Children Preschool Classes** special education and related services that are provided to students with disabilities (most students are three-years-old) either two or three days a week. An increased level of support and a smaller student-to-teacher ratio is required.
- **Metro School** - special education and related services that are provided at a separate school with peers who exhibit disabilities. Maximum levels of support and a smaller student-to-teacher ratio are required. Students may need specialized equipment and materials.

3. The Polliwog Project

The Polliwog Project is a Smart Start funded program at Thompson Child & Family Focus Center that provides therapies to children who need support and services.

- **704-817-1607**
- Children ages zero to five whose therapeutic needs do not qualify them for developmental therapies through CDSA or the CMS Preschool Exceptional Children Program may be eligible to receive speech-language, physical, or occupational therapies.
- Children ages zero to five whose challenging behavior impacts their child care placement may be eligible to receive behavioral intervention including support for families and teacher coaching.
- Behavioral support services are free. Therapeutic services are fee based. Insurance and Medicaid coverage are accepted and sliding scale fees are available.

4. The Autism Society of North Carolina - Mecklenburg County Chapter

The Autism Society exists to improve the lives of people of all ages who are affected by autism through increasing awareness of the day-to-day issues faced by people on the spectrum, advocating for appropriate services and providing information on research, treatment, advocacy and education.

The Autism Society of North Carolina (ASNC) offers the services of parent advocates who help families find the resources and support they need by providing information and referrals; presenting training classes and workshops; helping families navigate early intervention issues, schools, communities and transitions; and providing support to families in crisis.

For more information about the Autism Society of North Carolina, or to find contact information for Parent Advocates or the Chapter Support Coordinator, please visit:

www.autismsociety-nc.org Or call 704-894-9678

The Mecklenburg County Chapter of the Autism Society is the local arm of ASNC. It provides a calendar of events, support groups, training, and meetings of interest to individuals with ASD and people who care about them. The chapter is run by parent volunteers and is designed for parents facing similar challenges to:

- Offer each other support and encouragement
- Share experiences, information and resources
- Raise awareness about the needs and strengths of individuals with ASD
- Learn realistic, practical solutions for autism-related concerns
- Have a place where they feel welcome, accepted and understood

For more information about the Mecklenburg Chapter go to **www.asncmeck.org**

LifeLong Interventions is a service delivery model that provides comprehensive treatment for ASD, across skill domains and the lifespan of the individual. The service is rooted in the principles of applied behavior analysis (ABA) and involves intensive teaching and training using evidence-based practices to promote appropriate skills and behaviors in the home and community.

Clients are accepted at any age, and treatment plans are developed based on the results of intake and formal assessments. ASNC currently offers the LifeLong Interventions service in the greater Charlotte area. For a more complete description or to enroll, please call 919-865-5070 or 880-442-2762 (ext. 1118).

5. TEACCH Charlotte

The UNC TEACCH Autism Program (Charlotte Center) is part of a regional university-based system of community centers offering a set of core services along with demonstration programs meeting the clinical, training, and research needs of individuals with ASD, their families, and professionals across the state of North Carolina. (www.teacch.com)

- **704-563-4103**
- Previous evaluation results will be requested.
- A history form asking for information about your child can either be mailed to you or you can access the form online. When it is completed and returned, an initial consultation meeting at TEACCH will be scheduled.
- The initial consultation is carried out either in person or over the phone. The focus of this meeting is to discuss the family's needs and to direct the family to appropriate TEACCH services and other available services in the community. The initial consultation is the first step to receiving services. There is no fee for this consultation.
- Following the initial consultation parents are invited to attend a three-hour *Parent Class* that offers general information about autism using visual supports and various approaches to behavior management. There is no fee for this class.
- Children younger than three are placed on a waiting list for Early Intervention Parent Teaching sessions for children and parents together at the center in order to:
    - Introduce the child and parent to a *beginning learning environment*
    - Develop and expand their curriculum goals in the areas of communication, pre-academic and cognitive skills, work behaviors, play skills, and social development and/or
    - Clarify diagnostic impressions
- Fees for certain services are out of pocket
- Children older than three are eligible to receive diagnostic evaluations (if they have not yet received an ASD diagnosis from another provider).
- Evaluations are typically made during a half- or full-day appointment at the clinic and focus on diagnosis and educational programming and intervention. There is a fee for this evaluation.
- The evaluation typically includes a caregiver interview; a review of medical, social, academic, and developmental history; caregiver questionnaires; and testing sessions.
- Results of the evaluation are shared with parents during a conference that is usually held at the end of the diagnostic day
- Individual *Parent-Child* teaching sessions are available to parents of children with autism who are three years of age and older following attendance of the Parent Class. The sessions provide an opportunity for parents to learn ways of teaching their child at home and to help deal with behavior problems, self-help, and other skills including communication and social skills. Sessions are time-limited and scheduled once a week, typically for four to six sessions.
- Fees for certain services are out of pocket

6. The Charlotte Speech and Hearing Center - (CSHC)

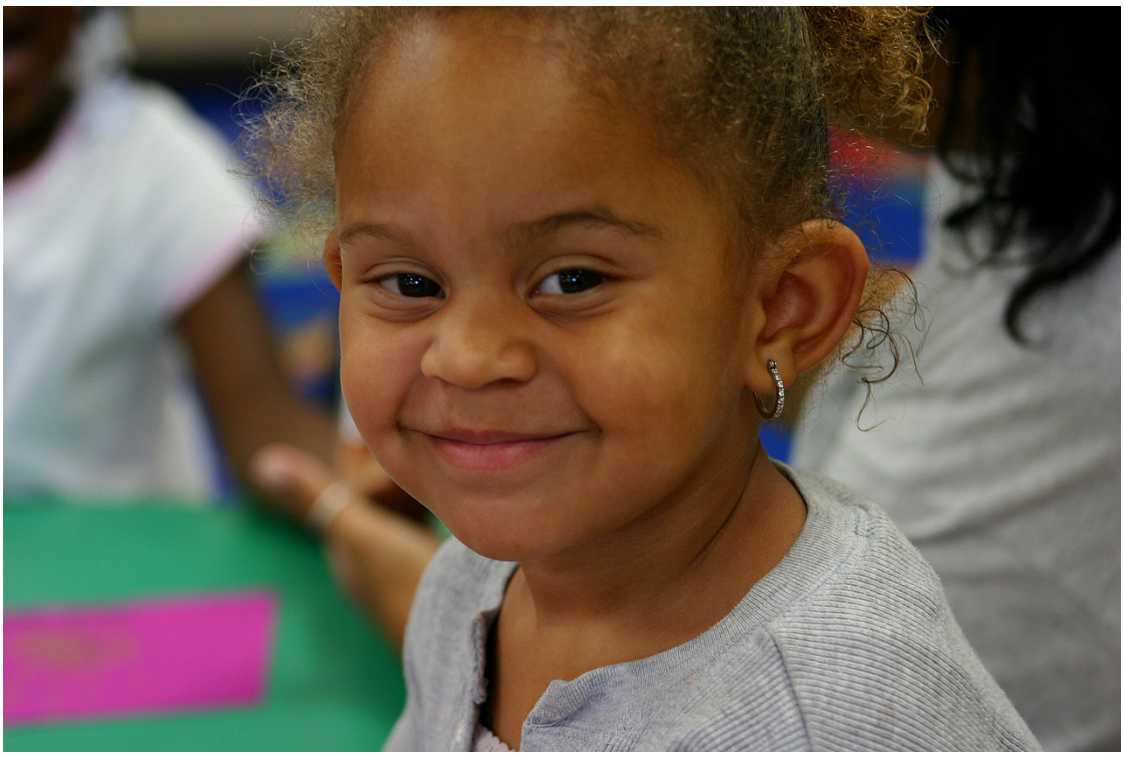
Charlotte Speech and Hearing Center is a non-profit organization offering speech-language services beginning at infancy and stretching throughout the life span of the individual.

- **704-523-8027 (ext. 25)**
- **www.charlottespeechhearing.com**
- CSHC offers free speech-language and hearing screenings conducted by therapists experienced in working with ASD.
- Complete community referral services including speech-language evaluations and follow-up therapy are available.
- CSHC accepts many insurances, including Medicaid, but also has an assistance fund for individuals who are uninsured/underinsured (must meet eligibility requirements).

7. The Exceptional Children Assistance Center (ECAC)

ECAC will provide support and information regarding your child's access to an appropriate education or to available services.

- **704-892-1321**
- **www.ecac-parentcenter.org**
- The primary mission of ECAC is to help parents understand their rights as they access services for developmental disabilities and healthcare.
- ECAC offers resources, workshops, and materials created to teach parents how to advocate for their child with a disability in order to access services and attain an effective individualized education plan (IEP).



5 What to Do if Your Child Shows Signs of Autism

Parents and professionals sometimes want to "wait and see" when there are concerns about a child's development. There are pressures not to label and there are hopes that the child is a late bloomer and will catch up.

Waiting for a child to catch up, however, wastes valuable time, and we know that early intervention is the best way to help your child catch up; it is the best hope for the future of any child with ASD. Early intervention will provide benefits that will not be gained if a wait-and-see approach is taken. A good early intervention approach will:

- Provide your child with instruction that will build on his strengths to teach new skills, improve behaviors, and remediate areas of weakness
- Provide you with information that will help you better understand your child's behavior and needs
- Provide you with resources, support and training that will enable you to work and play with your child more effectively; and
- Improve your child's overall outcome

(Source: "Does My Child Have Autism?" Wendy L. Stone, PhD, with Theresa Foy DiGeromino, MEd)

Best Practice Information

In 2001, the US Department of Education's Office of Special Education Programs requested the National Research Council to form a Committee on Educational Interventions for Children with Autism and asked the committee to integrate scientific, theoretical and policy literature to create a framework for evaluating the effects and features of educational interventions for young children with autism.

The committee agreed that education provided to children, parents and teachers is the primary form of treatment for autistic spectrum disorders. The following conclusions were published in "Educating Children with Autism" (National Research Council, 2001):

> Effective programs for young children with ASD support the following philosophies:
>
> - Early is better - intervention by three-and-a-half years may be more effective than intervention after five years
> - Goals need to be individualized and monitored regularly
> - Intensity matters - active student **engagement** for 25 hours per week with low student/teacher ratio (no more than 2:1) is necessary
> - Family participation is essential

Effective programs for young children with ASD prioritize six kinds of instruction:

- **Functional, spontaneous communication,** which means that children communicate for real, useful reasons, without being prompted
- **Social instruction in various settings** where a particular social skill is used
- **Teaching of play** focusing on toys and appropriate play with peers
- **Instruction leading to generalization and maintenance of cognitive goals** in natural contexts, which means that the skills that a child learns in one setting are demonstrated in a variety of settings and with a variety of people
- **Positive approaches to problem behaviors**, which means that the reason for the problem behavior is understood so that replacement behaviors can be taught
- **Functional academic skills** when appropriate, which means that academic information is taught within a meaningful context (ex., counting is not a rote activity but used to give four pencils to four children).

6 Questions About Getting a Diagnosis

Does my child need a diagnosis to receive intervention?

In Mecklenburg County it is not necessary to have a formal diagnosis in order to receive early intervention through the CDSA or specialized educational services through CMS.

How does my child receive services in Mecklenburg County without a diagnosis?

CDSA, the agency that provides early intervention services for children birth to three years of age, will provide an assessment of your child to determine if he or she is eligible to receive services. The identification of developmental delays or patterns of delay will start the delivery of services.

Once your child reaches age three, CMS will conduct an assessment to establish your child's eligibility for special education and to gather information to assist in planning an individualized program for your child.

Access to other intervention services and therapies through insurance, Medicaid, or private pay will depend on the funding source's requirements for a formal diagnosis.

What are the differences between a screening, an eligibility assessment and a formal diagnosis?

Screenings usually occur in a doctor's office and are the first step. They provide a quick and simple way to monitor a baby's healthy development. Monitoring includes clinical observations and the charting of **developmental milestones.**

If concerns about your child are raised by a developmental screening, further screenings for hearing loss or lead poisoning, or the **M-CHAT** (a screening for ASD) may be completed.

If screening results suggest that your child is at risk for ASD, you may decide to seek services and/or a diagnosis.

Eligibility assessments are conducted by CDSA and CMS for the purpose of establishing eligibility for specialized services and are based on federal legislation, The Individuals with Disabilities Education Improvement Act (IDEIA), Part C of the IDEIA for infants and toddlers, and Part B for school children.

CMS's evaluation team will consider whether your child's symptoms adversely affect his or her educational performance and whether specialized educational services are appropriate.

Formal diagnoses of ASD are most often made through assessments conducted in the private sector by a psychologist, psychiatrist, neurologist or physician using criteria from the Diagnostic and Statistical Manual of Mental Disorders.

- A formal diagnosis uses specific evaluation tools to assess strengths and weaknesses and provides recommendations for intervention strategies
- A formal diagnosis may be required to meet insurance coverage requirements or to access certain services
- A formal diagnosis is not required to access early intervention or special education, nor does it automatically guarantee identification for enrollment into services

Why would I seek a diagnosis for my child?

There are some good reasons for getting a diagnosis. A thorough and detailed diagnosis:

- Will provide important information and answers to your questions about your child's behavior and development
- Will replace your worries with a solid understanding of the nature of your child's challenges
- Will create a road map for treatment by identifying your child's specific strengths and challenges and providing useful information about which needs and skills should be targeted for effective intervention
- May be required for insurance coverage of certain services

It can be frightening to think about "labeling" your child, but remember that a label does not limit. It does not determine outcomes. It does not change who your child is. However, a label can help your child receive services that are appropriate for the unique pattern of his or her development.

How do I get a diagnosis for my child in Mecklenburg County?

If your child is younger than three-years-old, you may contact Mecklenburg County Children's Developmental Services (704-336-7130) for a multidisciplinary evaluation, which may include therapists from various professions (speech, occupational therapy, physical therapy, psychology, or social work) interacting with your child to assess his or her overall development. This evaluation determines your child's eligibility for the Infant Toddler Program. If eligible, subsequent evaluations can be offered to address questions specific to autism and to provide you with information, a diagnosis (if appropriate) and options for services to support your family's individualized plan.

A formal diagnosis is available (for a fee) through TEACCH or through private practices and is made by professionals experienced in administering evaluations such as the Autism Diagnostic Observation Schedule or the Autism Diagnostic Interview.

7 Intervention Options

> *"A treatment method or an educational method that will work for one child may not work for another child. The one common denominator for all of the young children is that early intervention does work, and it seems to improve the prognosis."*
>
> *~Temple Grandin~*

Early intervention and special education services are the first steps for addressing the needs of a child on the autism spectrum. In addition, many children with ASD benefit from the traditional therapies listed below.

Speech Therapy

One of the core deficits associated with ASD is communication impairment. The National Institute on Deafness and Other Communication Disorders states that children with ASD:

- May have difficulty developing language skills and understanding what others say to them
- May also have difficulty communicating nonverbally (through gestures, eye contact and facial expressions)
- May be unable to speak, while others may have rich vocabularies
- Will likely have difficulty using language effectively
- May have problems with the meaning and rhythm of words and sentences
- May be unable to understand body language and the nuances of vocal tones

Some patterns of language use and behaviors associated with ASD include:

- Rigid or repetitive language
- Narrow interests and exceptional abilities
- Uneven language development
- Poor nonverbal language skills

A speech-language pathologist will evaluate your child's communication profile and identify areas that are causing difficulties. It is important to know if your child understands words as well as they say them and whether your child's problems are associated with differences in his desire to communicate, deficits in language abilities, or with the demands of conversation.

Speech-language therapy will target any problem areas, teach missing skills, and provide opportunities to practice and generalize recently acquired abilities.

To find a speech-language pathologist or for more information about the role of speech-language pathologists in the treatment of ASD, visit the American Speech-Language Hearing Association (ASHA) at www.asha.org, or call **800-498-2071.**

Occupational Therapy (OT)

The American Occupational Therapy Association estimates that 80 percent of children with ASD have sensory processing problems. This means that they can't filter out extraneous sensory stimulation or don't process sensory stimulation in the same way typically developing children do.

Sensory features that often occur in children with ASD can interfere with their daily life. The following four sensory patterns correlate with autism severity:

- **Hyper-responsiveness** (overreacting)
- **Hypo-responsiveness** (underreacting)
- Sensory interests and repetitions
- Enhanced perception

(National Survey of Sensory Features in Children with ASD: Sensory Patterns Measured by the Sensory Experience Questionnaire, Ausderau, K, et al.)

Occupational therapists use their expertise to identify sensory issues and provide interventions to facilitate effective self-regulation (wake-sleep cycles, level of alertness, self-quieting), sensory processing, motor development and adaptive behavior.

In addition to providing interventions that remediate the sensory integration issues influencing behaviors in the home, occupational therapy practitioners also make modifications to the classroom environment in order to assist children with participating and progressing at school, playing, making friends, and focusing in order to learn.

Examples of these modifications may include managing sensory information during school routines like riding the school bus, tolerating smells and noise in the cafeteria, and playing on the playground with others.

Occupational therapy strategies may help reduce stress and inappropriate or disorganized behavior caused by poor sensory integration, **sensory defensiveness**, sensory overload, and poor **praxis**. Occupational therapy practitioners who provide therapy services using sensory processing approaches work with children to remediate the underlying sensory integration and **praxis** factors affecting a child's home and community life.

To find an occupational therapist or for more information about the role of cccupational therapists in the treatment of ASD, you can visit the American Occupational Therapy Association, Inc. at www.aota.org or call **800-377-8555.**

Applied Behavior Analysis Therapy

Applied Behavior Analysis (ABA) focuses on principles of learning that include the idea that people are more likely to repeat behaviors that are rewarded than behaviors that are not recognized or are ignored. Applied Behavior Analysis can help children with autism by teaching them to develop a number of skill sets at the same time as it works to reduce the likelihood of their engaging in problematic behaviors.

A trained therapist works one on one with a child 20 to 40 hours a week or in conjunction with other therapists (such as speech or occupational therapists) for a "modified" approach for 10 to 15 hours a week. Treatment begins with an assessment to determine the child's existing skills and the development of an individualized program to increase skills. (www.WebMD.com)

Autism Speaks offers a tool kit explaining ABA therapy that can be downloaded. A list of dos and don'ts from the Autism Speaks website (www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba) includes the following points:

- ABA should never be a canned program; one size does not fit all. A skilled therapist should customize treatment to each learner's skills, needs, interests, preferences, and family situations.

- A qualified and trained behavior analyst should design and directly oversee the intervention.

- The analyst's development of treatment goals should stem from a detailed assessment of each learner's skills and preferences and may also include family goals.

- Treatment goals and instruction should be developmentally appropriate and target a broad range of skill areas such as communication, sociability, self-care, play and leisure, motor development and academic skills.

- Goals should emphasize skills that will enable learners to become independent and successful in both the short term and the long term.

- The instruction plan should break down desired skills into manageable steps to be taught from the simplest (e.g. imitating single sounds) to the more complex (e.g. carrying on a conversation).

- The intervention should involve ongoing objective measurement of the learner's progress.

- The behavior analyst should review information on the learner's progress frequently and should use this to adjust procedures and goals as needed.

- The analyst should meet regularly with family members and program staff to plan ahead, review progress and make adjustments as needed.

- The instructor should use a variety of behavior analytic procedures, some of which are directed by the instructor and others initiated by the learner.

• Parents and/or other family members and caregivers should receive training so they can support learning and skill practice throughout the day.

• The learner's day should be structured to provide many opportunities – both planned and naturally occurring - to acquire and practice skills in both structured and unstructured situations.

• The learner should receive an abundance of positive reinforcement for demonstrating useful skills and socially appropriate behaviors. The emphasis should be on positive social interactions and enjoyable learning.

• The learner should receive no reinforcement for behaviors that pose harm or prevent learning.

Music Therapy

Many families have found music therapy to be a useful way to scaffold communication, as well as social and behavioral goals, onto the fun of musical play.

Music therapy is a well-established professional health discipline that uses music as a therapeutic stimulus to achieve non-musical treatment goals. Research supports connections between speech and singing, rhythm and motor behavior, memory for song and memory for academic material, and the overall ability of preferred music to enhance mood, attention, and behavior in order to optimize the student's ability to learn and interact.

Effects of music therapy are believed to include increased attention, improved behavior, decreased self-stimulation, enhanced auditory processing, improved cognitive functioning, decreased agitation, increased socialization, improved verbal skills, successful and safe self-expression, and enhanced sensory-motor skills.

To find a music therapist or for more information about the role of music therapists in the treatment of ASD, you can visit the American Music Therapy Association at **www.musictherapy.org** or call **301-589-3300. Please Note that music therapy is typically not covered by insurance.**

Physical Therapy

Autism is a **pervasive developmental disorder.** This means that most people on the autism spectrum have delays, differences or disorders in many areas -- including gross and fine motor skills . Children on the spectrum may also have low muscle tone, or have a tough time with coordination and sports. These issues can interfere with basic day-to-day functioning and are almost certain to interfere with social and physical development.

Children with autism would rarely be termed physically disabled (though there are some autistic children with very low muscle tone, which may make it difficult to sit or walk for long periods). Most children with autism do, however, have physical limitations.

Physical therapists (often called "PTs") are trained to work with people to build or rebuild strength, mobility and motor skills. Physical therapists may work with very young children on basic motor skills such as sitting, rolling, standing and playing. They may also work with parents to teach them some techniques for helping their child build muscle strength, coordination and skills.

To find a physical therapist or for more information about the role of physical therapists in the treatment of ASD, you can visit the American Physical Therapy Association at **www.apta.org** or call **800-999-2782.**

Additional Intervention Options

Families have a confusingly large number of treatment options from which to choose. The Autism Society website states that "the dramatic increase in the number of individuals identified with ASD has focused increased attention on the types of interventions that can lead to opportunities for a high quality of life for those with unlimited potential." TARGET, a resource for families seeking information about treatments and programs for ASD, will help identify appropriate intervention choices.

The Texas Statewide Leadership for Autism has compiled the Texas Autism Resource Guide for Effective Teaching (TARGET) at **txautism.net/target.** This guide is an alphabetized list of researched interventions which includes named programs and teaching methods. Clicking on a program opens pages of information including an introduction to the approach, a description, steps of implementation, examples of usage, a summary, and research information.

Questions to Consider

The large number of programs available to choose from suggests the need for parental caution and informed decision making. The National Institute of Mental Health suggests a list of questions for parents to consider when choosing a placement or a program:

- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- What is the cost, time commitment, and location of the program?

Biomedical Training

Biomedical interventions focus on the physical needs of the person by addressing deficits or system weaknesses in the body (digestive, respiratory, muscular, etc.) through medical or chemical means. Examples of biomedical interventions include the gluten-casein-free diet, addressing food sensitivities, use of supplements, gut treatments and immune system regulation.

The Ohio Center for Autism and the Autism Society of America offer the following questions for parents to consider before choosing medical interventions for their child:

- What characteristic behaviors of ASD am I trying to target?
- Does the program/therapy and anticipated outcomes address these targeted concerns?
- Does the method meet the unique strengths/challenges/goals for my child?
- Are there any harmful side effects associated with this treatment? What are the potential risks? Is there any risk in discontinuing the intervention?
- Are any activities, foods, etc. restricted during treatment?
- What positive effects of treatment would I hope to see?
- What are the short-term and long-term effects?
- Can the treatment be integrated into my child's current program?
- How will goals/outcomes be evaluated? How will I know if my child is making progress toward desired outcomes? What method will be used to evaluate my child's progress?
- What is the cost of treatment? Will my insurance company pay for the treatment?
- How much time does the treatment take? Can I realistically devote the time required to the treatment?
- Has this treatment been validated scientifically? Have I collected information about this from a variety of sources?
- Was I able to interview other parents and professionals about the treatment? If so, what are the pros and cons?
- Do proponents of the treatment claim that this procedure can help nearly everyone? If so, this should be seen as a "red flag" to slow down and be more careful, and consider the wide range of abilities represented on the autism spectrum.
- What do my pediatrician and other professionals involved with my child think about the treatment's appropriateness?
- Are there alternatives that are less restrictive or better researched?
- How will the failure of the treatment affect my child and family?

8 Useful Websites

Local Sites

Autism Society-Mecklenburg Chapter
www.autismsociety-nc.org
www.asncmeck.org

CDSA
www.beearly.nc.gov

Exceptional Children Assistance Center
www.ecac/parentcenter.org

THE MAP (Mecklenburg Access Portal)
www.the-map.net

Smart Start of Mecklenburg County
www.smartstartofmeck.org

For information on family support groups in Mecklenburg County, visit the Smart Start website (www.smartstartofmeck.org)

TEACCH
www.teacch.com

National Sites

Autism Internet Modules
(Discusses evidence-based practice modules developed by
the National Professional Development Center on Autism Spectrum Disorders.)
www.autisminternetmodules.org

Autism Navigator
About Autism in Toddlers
www.autismnavigator.com/resources-and-tools/

Autism Society
www.autism-society.org

Autism Speaks
www.autismspeaks.org

Center for Disease Control (CDC)
www.cdc.gov/actearly
www.cdc.gov/ncbddd/autism

Diagnosis Info
www.autismspeaks.org/what-autism/diagnosis

FAQs
www.autismspeaks.org/what-autism/faq

First Signs
www.firstsigns.org

The National Information Center for Children and Youth with Disabilities
www.nichcy.org

National Institute of Child Health and Human Development:
Autism Site
www.nichd.nih.gov

Ohio Center for Autism and Low Incidence
www.ocali.org

Positive Beginnings: Supporting Young Children with Challenging Behavior
pbs.fsu.edu/PBS.html

Spanish Resources
www.theautismprogram.org/autism-resources-resources/spanish-resources

Video Glossary
www.autismspeaks.org/what-autism/video-glossary

Zero to Three: National Center for Infants, Toddlers and Families
www.zerotothree.org

9 Glossary of Terms

Taken from First Signs© and www.firstsigns.org

Autism Diagnostic Observation Schedule (ADOS) is the assessment instrument typically used to diagnose ASD.

Autism Spectrum Disorders, or ASD are a group of neurobiological disorders that affect a child's ability to interact, communicate, relate, play, imagine and learn. The term spectrum is important to understanding ASD because of the wide range of intensity, symptoms and behaviors, types of disorders and considerable individual variation. Children with ASD may have a noticeable lack of interest and ability to interact, limited ability to communicate and show repetitive behaviors and distress over changes. On the other end of the spectrum are children with a high-functioning form who may have unusual social, language and play skills.

Babbling *(p. 4)* is the repetition of consonant-vowel combinations made by babies, typically 6 to 9 months of age. Babbling precedes speech and is necessary in the process of learning to talk.

Body Postures are movements or positions of the body used as nonverbal ways of conveying information or expressing emotions without the use of words.

Communication *(pp. 1,2,3,10,11,13,16,18,19))* is the use of nonverbal (eye gaze, facial expression, body posture, gestures) and verbal (spoken language) behavior to share ideas, exchange information and regulate interactions.

Developmental Milestones *(p. 14)* are markers that enable the monitoring of a baby's learning, behavior and development and consist of skills or behaviors that most children are able to do by a certain age.

Diagnosis *(pp. 6,11,14,15,23)* should include information about the child's developmental and medical history, current activities, and behaviors, and is often performed by an inter- or multi-disciplinary team of professionals from several different specialties. Since there is no biological way of confirming a diagnosis of ASD at this point in time, diagnosis should be based on the observation of the behavioral features using the DSM framework.

Diagnostic and Statistical Manual of Mental Disorders, or DSM *(p. 14)* is the handbook widely used by professionals to diagnose and categorize mental and developmental disorders. It provides the framework for identifying autism spectrum disorders.

Echolalia, or scripting *(p. 2)* is the repetition of words, phrases, intonation, or sounds of the speech of others. Children with ASD often display echolalia in the process of learning to talk. Immediate echolalia is the exact repetition of someone else's speech, immediately or soon after the child hears it. Delayed echolalia may occur several minutes, hours, days, or even weeks or years after the original speech was heard. Echolalia sometimes sounds like the child is repeating a movie script. Echolalia was once thought to be non-functional, but is now understood to often serve a communicative or regulatory purpose for the child.

Emotional Regulation is a child's ability to notice and respond to internal and external sensory input, and then adjust his emotions and behavior to the demands of his surroundings. Emotional regulation includes the body's involuntary reactions (heart rate, respiratory rate, etc.) to events or perceptions, as well as voluntary responses. Voluntary responses may be behaviors that the child engages in to soothe, or excite him or herself, such as spinning the wheel of a toy car, rubbing a

smooth surface, rocking, or hand flapping. This may also include the use of communication to get help modulating emotion, such as reaching to request comfort when afraid. Many children with ASD have difficulties with emotional regulation and often have abnormal or inappropriate responses to the ordinary demands of their surroundings. They may also have problems adjusting to change, and transitioning from one activity to another, responding with strong negative emotions, tantrums, stereotyped, or even self-injurious behaviors.

Engagement *(p. 12)* refers to a child's interest in being with and interacting with adults or other children by looking at them, smiling and communicating in verbal and nonverbal ways. A child with ASD may show more interest in objects and toys than in engaging in interactions with people.

Expressive Language is the use of verbal behavior, or speech, to communicate thoughts, ideas, and feelings to others.

Eye Gaze *(pp. 1, 2)* is looking at the face of others to check and see what they are looking at and to signal interest in interacting. It is a nonverbal behavior used to convey or exchange information or express emotions without the use of words.

Facial Expressions *(pp. 2, 16)* are movements of the face used to express emotion and communicate with others. Facial expression is a nonverbal behavior used to convey information.

Functional Play happens when a child uses a toy or object for its appropriate or usual purpose, like rolling a car, stirring with a spoon, or giving a doll a bottle.

Gestures *(pp. 1, 2, 16)* are hand and head movements used to signal to someone else, such as a give, reach, wave, point, or head shake. These are nonverbal behaviors used to convey or exchange information or express emotions.

Hyper-Responsiveness *(p. 17)* is abnormal sensitivity or over-reactivity to sensory input which produces a feeling of being overwhelmed by what most would consider ordinary stimuli of sounds, sights, smells, tastes, or touch. Many children with ASD are hyper-responsive to input and react with sensory defensiveness which involves a strong negative response to their overload by screaming or tantrumming.

Hypo-Responsiveness *(p. 17)* is an abnormal insensitivity or under reactivity to sensory input in which the brain fails to register incoming sensory input appropriately so that the child fails to respond to the sensory stimulation. A child with normal hearing but appears deaf or one who craves sensation, seeks sensory input, has a high tolerance for pain, acts aggressively or clumsily may be hypo-responsive to sensory input.

Individualized Education Plan, or IEP *(pp. 8, 11)* is a legal document that spells out the child's learning needs, the services the school will provide and how progress will be measured. The IEP is a written statement of the special educational program designed to meet a child's individual needs.

Insistence on Sameness is a rigid adherence to a routine or activity carried out in a specific way which then becomes a ritual or nonfunctional routine. Children with ASD may insist on sameness and may react with distress or tantrums to even small changes or disruptions in routines. Young children with ASD may also show some repetitive movements with objects, such as lining things up, collecting objects, or clutching similar small toys.

Joint Attention *(p. 2)* is an early social-communicative ability whose absence is a hallmark symptom of ASD. Impairment in joint attention is a core deficit of ASD. Typically developing children seek to share attention with others spontaneously during the first year of life. Joint attention or shared attention is first accomplished by the caregiver looking at what the infant is looking at. Infants learn early to seek joint attention spontaneously by shifting their gaze between an object of interest and another person and back to the object (also called three-point gaze), following the gaze or point of others, and using gestures to draw others' attention to objects (e.g., holding out and showing an object, pointing to it, or by eye gaze). This desire to share attention on objects builds to sharing enjoyment by looking at others and smiling when enjoying an activity, drawing others attention to things that are interesting, and checking to see if others notice an achievement (e.g., after building a tower of blocks, looking up and clapping and smiling to share the achievement). Ultimately, children learn to talk and use language to share enjoyment, interests, and achievements and later to share ideas and experiences.

Nonfunctional Routines are specific, sequential and apparently purposeless repeated actions or behaviors that a child engages in, such as lining up toys in a certain order instead of playing with them.

Nonverbal Behaviors are the things people do to convey information or express emotion without using words, such as eye gaze, facial expressions, body postures, gestures, and tone of voice.

Perseveration refers to repeating or "getting stuck" carrying out a behavior (e.g., putting in and taking out a puzzle piece) when it is no longer appropriate.

Perseverative Speech refers to the repeating of a word or phrase over and over or bringing up the same topic incessantly with a sense of "getting stuck."

Pervasive Developmental Disorder (PDD) *(p. 19)* is an umbrella term for a wide spectrum of disorders referred to as Autism or Autism Spectrum Disorders (ASD). The terms PDD and ASD are used interchangeably.

Pointing *(pp. 2, 4)* is an important gesture of the index finger used to request an object (called protoimperative pointing) or to draw attention to an object to comment on it or share interest in it (called protodeclarative pointing). The ability to make pointing gestures typically develops by the age of 12 months.

Pragmatics are social rules for using spoken language in a meaningful context or conversation. Challenges in pragmatics are a common feature of the spoken language difficulties of children with ASD.

Praxis *(p. 17)* is the neurological process by which cognition directs motor action (Ayres, 1985). Put simply, it involves planning what to do and how to do it. In order to know what to do, we must first conceive an idea of what to do (ideation), then plan how we are going to do it (motor organization, or motor planning), perform the movement correctly (execution) and then be able to reflect on feedback so we can adapt our movements in the future (feedback and adaptation).

Preoccupation with Parts of Objects is a persistent, unusual interest in one aspect of something that usually interferes with interest in using the object in a functional or appropriate manner, or interferes with interest in socially interacting. The preoccupation may be related to anxiety.

Pretend Play *(p. 5)* is the same as make-believe play or symbolic play. It occurs when children use their imagination to do things and to be something or someone else.

Prosody *(p. 1)* is the "melody" and rhythm of speech expressed through rate, intonation, pitch, stress and inflection. Usually, children with ASD speak with odd intonation (flat, monotonous, stiff, or "sing songy" without emphasis on important words), and those who do not yet talk may make unusual sounds.

Receptive Language is the ability to understand the meaning of words and sentences that others use. Typically, by 12 months of age a child begins to understand words and will respond to his or her name, and may be able to respond to familiar words in context. By 18 to 20 months, a child will be able to identify familiar people by looking when named (e.g., "Where's mommy?"), give familiar objects when named (e.g., "Where's the ball?"), and point to a few body parts (e.g., "Where's your nose?", "Where's your mouth?"). Children with ASD may appear to understand words when, in fact, they are following the routine that is attached to the words.

Red Flags for ASD *(pp. 1, 4)* are early indicators or warning signs for ASD.

Regulatory and Sensory Systems controls a child's ability to take in or "register" and respond to internal sensory input (such as thoughts and feelings, heart rate, etc.), and external stimuli (sights, sounds, tastes, smells, touch, and balance), and then adjust his or her emotional and behavioral response to those stimuli and the demands of his or her surroundings. Many children with ASD have regulatory and sensory deficits, but other children do as well, so the presence of this kind of impairment is not part of the criteria for a diagnosis of an ASD. Regulatory and sensory deficits are associated features that are common in children with ASD, but not necessarily indicative of the disorder.

Repetitive Behaviors and limited Interests *(p. 1)* are common in children with ASD. Children with ASD may appear to have odd or unusual behaviors such as a very strong interest in a particular kind of object (e.g., lint, people's hair) or parts of objects, or certain activities. They may have repetitive and unusual movements with their body or with objects, or repetitive thoughts about specific, unusual topics.

Repetitive Motor Mannerisms are stereotyped or repetitive movements or posturing of the body and are common among children with ASD. They include mannerisms of the hands (such as hand flapping, finger twisting or flicking, rubbing, or wringing hands), body (such as rocking, swaying, or pacing), and odd posturing (such as posturing of the fingers, hands, or arms). These mannerisms may appear not to have any meaning, or function, although they may have significance for the child.

Restricted Patterns of Interest refer to a limited range of interests that are intense in focus. This may also be referred to as stereotyped or circumscribed patterns of interests because of the rigidity and narrowness of these interests.

Rituals are specific and seemingly meaningless behaviors that a child performs repeatedly in certain situations or circumstances, such as turning the lights on and off several times when entering a room.

Screening *(pp. 11, 14)* is a quick and simple way to monitor a child's typical development. The American Academy of Pediatrics (AAP) recommends routine developmental screening and surveillance of all children from birth through school age to identify those at risk for atypical development. Screening tools are brief measures (often in the form of a parent questionnaire) that distinguish children who are at risk for developmental delay or disorders, such as ASD, from those who are not. A screening is not a diagnosis but may indicate a child's need for further assessment and follow-up.

Scripting, or echolalia *(p. 2)* is the repetition of words, phrases, intonation, or sounds of the speech of others, sometimes taken from movies, but also sometimes taken from other sources such as favorite books or something someone else has said.

Self-Injurious Behavior *(p. 3)* - about 10 to 15 percent of individuals with ASD engage in some form of self-injurious behavior (SIB), causing self-inflicted bodily harm, such as bruises, redness, or cuts. The most common forms of SIB include head banging, hitting the face, biting the hand or arm, and excessive scratching or rubbing. SIB can range from mild to severe, and can potentially be life threatening. A child who engages in SIB may be seeking attention, feeling overwhelmed and frustrated, seeking self-stimulation, or may be hypersensitive to certain sounds. SIB may be biologically or neurologically based.

Self-Stimulatory Behavior, or "stimming" *(pp. 2, 6)* are stereotyped or repetitive movements or posturing of the body. They include mannerisms of the hands (such as hand flapping, finger twisting or flicking, rubbing, or wringing hands), body (such as rocking, swaying, or pacing), and odd posturing (such as posturing of the fingers, hands, or arms). Sometimes they involve objects, such as tossing a string in the air or twisting pieces of lint. These mannerisms may appear to have no meaning or function, although they may have significance for the child, such as providing sensory stimulation (also referred to as self-stimulating behavior), communicating to avoid demands or to request a desired object or attention, or self-soothing when wary or anxious. These repetitive mannerisms are common in children with ASD.

Sensory Defensiveness *(p. 17)* is an abnormal reaction to ordinary sensory input. Children who are overly reactive may display strong negative emotions to stimuli.

Sensory Input *(p. 3)* includes both internal (e.g., heart rate, temperature) and external (e.g., sights, sounds, tastes, smells, touch, and balance) sensations. A child's response to sensory input depends on their ability to regulate and understand these stimuli and to adjust their emotions to the demands of their surroundings.

Shared Attention *(p. 2)* is the same behavior as joint attention.

Social-Imitative Play is pretending to act out the actions of daily routines (e.g., stirring food or brushing hair) or the actions of others (e.g., a parent talking on the telephone) in the context of play. In typical development, by about 18 - 24 months of age a child should be engaging in simple pretend play, like feeding a doll, or putting it to bed. This forms the foundation for make-believe play. A lack of spontaneous social imitative or make-believe play appropriate to a child's age or developmental level is one of the criteria for a diagnosis of ASD. Children with ASD may become preoccupied with the toy itself or parts of a toy or object (like spinning the wheels on a car over and over) rather than engaging in pretend play or social imitation.

Social Interaction *(pp. 1, 2, 19)* is the use of nonverbal or verbal behavior to engage in interaction with people. This can involve eye gaze, speech, gestures, and facial expressions used to initiate and respond to interactions with others.

Social Reciprocity is the back-and-forth flow of social interaction. The term reciprocity refers to how the behavior of one person influences and is influenced by the behavior of another person and vice versa. Social reciprocity is the dance of social interaction and involves partners working together on a common goal of successful interaction. Adjustments are made by both partners until success is achieved. Impairment in social reciprocity may be seen as not taking an active role in social games, preferring solitary activities, or using a person's hand as a tool or a person as if they are mechanical objects. This may lead to not noticing another person's distress or lack of interest in the focus or topic of conversation.

Stereotyped Behaviors refer to an abnormal or excessive repetition of an action carried out in the same way over time.

Stereotyped Language, or stereotypy refers to an abnormal or excessive repetition of an action or phrase over time.

Stereotyped Patterns of interest or restricted patterns of interest refer to a pattern of preoccupation with a narrow range of interests and activities.

Tactile Defensiveness - Many children with ASD are overly reactive to ordinary sensory input and may exhibit sensory defensiveness, a strong negative response to a sensation that would not ordinarily be upsetting, such as touching something sticky or gooey or the feeling of soft foods in the mouth. Tactile defensiveness is specific to being touched or touching something or someone.

Tantrums *(p. 2)* for most typically developing children are expressions of intense, immediate frustration that occur most often at an age when a child is unable to express his or her emotions due to inadequate verbal skills. However, many children who have ASD are unable to communicate in a way most typically developing children do. Instead, they may develop inappropriate ways to communicate – through aggression, self-injurious behavior (SIB), or tantrums. The tantrums may be much more intense and more frequent than those of typically developing children. Often, a tantrum may be due to a child seeking attention, or feeling overwhelmed, frustrated or hypersensitive to their environment, or the child may be trying to escape from a difficult task, protesting against a change in routine or schedule, or trying to regulate him or herself in a more predictable way.

Many thanks to the members of the ASD Collaborative for their dedicated efforts in the creation of this resource guide for Mecklenburg County families.

THE UNIVERSITY of NORTH CAROLINA
TEACCH
Autism Program
Services Across the Lifespan

Smart Start
Mecklenburg Partnership for Children

N W E S GPS

cms
Charlotte-Mecklenburg Schools

child care resources inc.

THOMPSON
Child & Family Focus

CDSA
Children's Developmental Services Agency
MECKLENBURG COUNTY
Supporting Child Development Through Family Centered Learning

Family Support Network
Charlotte

Dreamweavers Unlimited
www.dreamweaversNC.com

Autism Society of NORTH CAROLINA

CHARLOTTE SPEECH & HEARING CENTER

Easter Seals DISABILITY SERVICES
UCP United Cerebral Palsy
Easter Seals UCP North Carolina