First Steps After an Autism Diagnosis

CHAPTER 1
EASTER SEALS SOUTHEAST WISCONSIN
START EARLY, START STRONG PROGRAM
What is Autism?

- Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain. Scientists do not know yet exactly what causes these differences for most people with ASD. However, some people with ASD have a known difference, such as a genetic condition. There are multiple causes of ASD, although most are not yet known.

- There is often nothing about how people with ASD look that sets them apart from other people, but they may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.
What is Autism?

New Diagnostic Criteria for Autism Spectrum Disorder (DSM-V)

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder. Severity is based on social communication impairments and restricted, repetitive patterns of behavior.
How Common is Autism?

- Current estimate is 1 in 68 children
- ASD is reported to occur in all racial, ethnic, and socioeconomic groups.
- ASD is almost 5 times more common among boys (1 in 42) than among girls (1 in 189).

CDC.Gov
What Causes Autism?

- Research is currently in progress – no known specific cause
  - Many theories

- Different levels of severity

- Different variables
  - Genetic components
  - Environmental Factors
Developmental Milestones

Children with ASD might:

- not point at objects to show interest (for example, not point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people’s feelings or talking about their own feelings
- prefer not to be held or cuddled, or might cuddle only when they want to
- appear to be unaware when people talk to them, but respond to other sounds
- be very interested in people, but not know how to talk, play, or relate to them
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language
- have trouble expressing their needs using typical words or motions
- not play “pretend” games (for example, not pretend to “feed” a doll)
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had (for example, stop saying words they were using)
Developmental Milestones

Resources:

- CDC.gov - Developmental Milestones
- Pediatrician: Developmental screening and checklists
- Developmental Screening Tools: Ages and Stages Questionnaire (ASQ) - Available free online Makethefirstfivecount.com
- Local Early Intervention Providers (Birth to Three Program)
Symptoms of Autism

- Social symptoms
- Communication deficits
- Sensory issues
  - Challenges with time with lights/sound/textures
- Behavioral Concerns or issues
- Repetitive Behaviors
  - Stereotypic Behaviors (Physical, Object, Vocal)
How is Autism diagnosed?

- Usually parent, teacher or pediatrician has concerns
- Based on observed behavior, educational & psychological testing
- A visit with a Developmental Pediatrician, Neurologist, Psychiatrist or License Psychologist
How do I Deal With This?

- Parents often report experiencing stages of grief:
  - **Shock**
    - Not ready to accept – even if you were initially the one with concerns
  - **Sadness and Grief**
    - Time of mourning but not depression
    - Crying is okay
  - **Anger**
    - Can be directed at ones you love, perhaps not directly over Autism
    - Express how you are feeling to those who care about you!!
How do I Deal With This?

• Denial
  ○ Natural part of coping, but don’t lose focus
  ○ Try not to “shoot the messenger”

• Loneliness
  ○ Don’t be afraid to reach out – you are not alone

• Acceptance
  ○ Ready to advocate and learn about Autism
  ○ Your child is still the same child they were before the diagnosis.
How do I Deal With This?

- Take care of yourself
- Try to get rest and nutrition – help yourself
- Use your support system, or find one – online can be a great start
- Use a journal or blog
- Whatever you are feeling is OKAY
The Internet

- Can be a great tool to reach out and to educate yourself but be careful

- Ask:
  - Is what I’m reading relevant to MY child?
  - Is this new information?
  - Is this a reliable source?
  - Is this someone’s theory, or is there evidence?
Which Intervention do I use?

- Seek Research based interventions
- Talk to providers and ask them to explain what they do
- Individualized to your child
- YOU know your child best
What is “ABA??”

- **Applied Behavior Analysis**

- **APPLIED**
  - Focuses on Behaviors that are meaningful and significant, or are bridges to those behaviors

- **BEHAVIOR**
  - Identifies SPECIFIC behaviors for change

- **ANALYSIS**
  - Through the use of objective data, changes are tracked to assess growth
How will ABA help?

- Increase communication and social behavior
- Teach self help skills to promote independence
- Help maintain new behaviors
- Help generalize or transfer behaviors
- Help identify and modify conditions that may prevent learning or behavior change
- Reduce problem behavior
Why ABA?

- 50+ years of sound research
- Rigorous monitoring of professional credentials
- Each program customized for the individual