

**Outline for Families
regarding the:**

**“Early Intervention Colorado Autism Guidelines for Infants
and Toddlers”**

By the Colorado Division for Developmental Disabilities

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In 2010, the Division for Developmental Disabilities of the Colorado Department of Human Services created and adopted a document titled “Early Intervention Colorado Autism Guidelines for Infants and Toddlers” (Autism Guidelines). The Autism Guidelines outline how Part C services under the Individuals with Disabilities Education Act (IDEA) of 2004 will be implemented in Colorado. You probably know these services as your “Part C” or “IFSP” services.

It is important for you to understand what is in the Autism Guidelines. It is 42 pages long and the information can be complex. This summary should help you understand the document and your rights.

- The full document can be found at (http://www.eicolorado.org/Files/EIColorado%20Autism%20Guidelines%2010-21-10_FINAL.pdf).
- An executive summary can be found at (http://www.eicolorado.org/Files/EI%20Colorado%20Autism%20Guidelines%20Exec%20Summ%2010-8-10_FINAL.pdf).
- The Early Intervention Colorado website can be found at (www.eicolorado.org).

This summary is in outline form to aid you in accessing the information. We encourage families to please read the entire Autism Guidelines document in order to better understand Early Intervention services and the state’s thoughts about interventions. Additional contact information is at the bottom of the document. This summary has not been reviewed or authorized by the state.

Purpose:

Purpose of Autism Guidelines: “to ensure that infants and toddlers, birth through three years of age, who have a diagnosis of, or characteristics of Autism Spectrum Disorders (ASD), receive early intervention services based on their individualized identified need, and not on a prescriptive curriculum or treatment model.” Guidelines are also meant to help early intervention (EI) programs provide services based on evidenced based practices and newest research and recommendations.

Guiding Principles:

1. Services must be individualized for each child and family
 - Parent’s are EI team members and have a decision making role for components of the Individualized Family Service Plans (IFSP) – (who, what, when, how often) services will be provided. The IFSP is a process that uses a written plan to: document current levels of development; identify functional learning objectives for child and family; and specify early intervention therapy/educational/support services
 - A specific curriculum (for example, playing appropriately with toys, making choices, or reciprocal interactions) may be chosen for the child, but the plan must still be individualized to meet the needs of the family based on life circumstances (ex: family structure, income stability, informal supports, coordination with other relevant services)
2. Family involvement and participation is critical
 - Families are the constant in a child’s life and the ones who know their child’s needs the best
 - Families must help with: deciding services; developing strategies to address needs of child; evaluating child’s progress
 - Families and service providers learn from one another
3. Early delivery of intervention must be encouraged
 - Early intervention is important, so parents and providers suspecting ASD should insist on early screening (M-CHAT)
 - Do not wait for formal diagnosis to begin EI services
4. Families have a right to evidence-based practices
 - All EI services delivered should be based on up-to-date, scientifically based research
 - Families have a right to services that address all the core deficits of ASD and services that can be expected to have positive long-term outcomes

- Once methods are selected, EI professionals should collect data to determine effectiveness
- Interventions must be delivered correctly (providers must have proper training; adequate resources; ongoing feedback with families)

5. Intervention is based on a developmental curriculum designed to address the specialized needs of a child with ASD

- Curriculum must address the areas of language, social interaction, and play skills and interests
- Targets of ASD therapy: (1) attending to and staying engaged in the environment, including people and developmentally appropriate play materials; (2) using verbal and non-verbal communication, such as gestures, vocalizations and words; (3) understanding and using language to communicate; (4) playing appropriately with toys; (5) playful interactions with others; (6) reciprocal interactions; (7) spontaneous interactions; (8) making choices; (9) following daily routines and variations in routines; (10) addressing atypical sensory preferences and aversions

6. Intervention is Planned and Systematic

- Intervention must involve assessing, planning, teaching, and consistent measuring of progress each step of the way
- Intervention must target behaviors or goals which are most important to family, even if they are not as easy to measure (ex: reduction in tantrums)
- Data must be collected to measure outcomes
- A list of the components for an effective assessment can be found on page 4
- Regularly scheduled meetings with all providers and family members are recommended to review data and assess intervention's effectiveness
- Interventions deemed inadequate or not helpful should be discontinued

7. Infants and toddlers with ASD should have regular and deliberate exposure to typically developing peers

- Children with ASD should participate in preschool/child care settings, play dates, or planned interactions with siblings, so EI providers can facilitate peer training scenarios

8. Challenging behaviors are addressed using positive behavioral interventions and supports (PBIS)

- To practice PBIS means getting to know the whole child and assuming behavior has meaning and is a form of communication
- EI providers should complete a Functional Behavior Analysis (FBA) to better understand why a behavior is occurring and what function it is playing
- Once the FBA is complete, a PBIS plan should be developed and added to the IFSP to help the child develop new skills and alternative behaviors

9. Intervention should focus on developing communication skills

- Alternative or augmentative communication systems should be considered as an option for children with limited language, but specific type of communication system should be chosen based on individual need of child
- A list of the types of functional communication that should be addressed in the IFSP can be found at the top of page 6

10. The development of social relationships is integral to successful outcomes

- Intervention and IFSP should promote social development by having – regular access to typical peers; meaningful social interactions imbedded throughout day; use of ‘social toys’; ability to practice social skills in multiple settings; intensive data collection

11. Getting to quality outcomes is not just about hours of direct services

- There is not a specific type or amount of treatment that fits all children with ASD (25 recommended hours per week is disputed on page 7)
- A list of evidence-based factors for considering type and amount of treatment can be found on pages 7 and 8
- Type and amount of treatment needs to be considered carefully to create a strong, well-functioning IFSP

12. The transition from early intervention program to preschool special education and related services should be well planned

- Toddlers with ASD have a hard time with change, so transitioning to preschool may be particularly difficult and should be a major focus of IFSPs and EI providers
- EI staff should try to complete earliest possible referrals to Child Find, alert schools of EI services being provided and specific strategies that have been helpful, as well as support child and family throughout transition process

Detailed Guidance for Key Practice Issues:

Strategies for Designing IFSPs

- IFSPs should: document current developmental levels; identify functional learning objectives; and state specific early intervention services needed
- A list of 15 key ingredients for a good IFSP can be found on page 9
- A list of questions EI staff should ask themselves to ensure a strong IFSP is created can be found on pages 10 and 11

A Tiered Model for Thinking About Specific Needed Early Intervention Services

- Time is of the essence – a Three Tier Model should be considered to quickly identify target behaviors to address strategies for prevention, and intensity of treatment (Figure of Three Tier Model can be found on page 13)
- The Tiered Model has a primary emphasis on prevention – utilizing Levels 1 & 2 can help prevent the need for Level 3 interventions

Level 1: Building Positive Relationships, Supportive Environments, and Healthy Physiologies

- Intended for all children with ASD
- Referred to as “primary prevention, involving universal applications”
- Examples: (1) to build strong parent/child relationships; (2) provision of safe, comprehensible, stimulating environment; (3) insuring child’s physical health is sound; (4) locate functional communication options
- A detailed list of examples of Level 1 interventions can be found on pages 13-15

Level 2: Building Social and Communicative Competencies Inconsistent with Problem Behavior

- It is likely that a substantial portion of the population will have to access Level 2 strategies
- Referred to as “secondary prevention” for children for whom Level 1 is insufficient and who are at risk for or already have problematic behaviors
- Level 2 strategies are typically based on the science of Applied Behavior Analysis (ABA)
- Examples: incidental teaching; Pivotal Response Training, antecedent prompting; and discrete trail instruction
- A detailed list of Level 2 interventions can be found on pages 15-16

Level 3: Individualized Intensive Interventions

- Intended for children who are already displaying target/disruptive behaviors which pose a threat to the physical/emotional safety of the child or family
- Referred to as “tertiary prevention, with individualized and intensive intervention”
- Not just one level of intensity, but rather is a set of procedures on a continuum based on the intensity of the behavior problems
- Examples: FBA performed when severe behavior problems occur over several months which will require considerable investment of time and resources – PBIS put into place
- Level 3 is discussed in detail on page 16

Evidenced Based Interventions and Measuring Outcomes

There are more interventions marketed to families than research to support them, resulting in poor outcomes, lost dollars, and lost hope. The guidelines publish what we do know, based on the most extensive review to date (National Standards Project (NSP), 2009, www.nationalautismcenter.org/affiliates/model.php), and press providers to deliver services that comport to this list. Communication and social/emotion challenges must be addressed with all interventions.

Established Interventions in the National Standards Project (i.e., those which consistently were most effective across multiple research models with the widest variety of persons and symptom concerns):

- A list of the **eleven** Established Interventions identified by NSP can be found on page 17 – **nine** of which are covered in detail in the EI Guidelines
 - Comprehensive Behavioral Treatment for young children with autism: combined, intensive applications of many of the other 10 intervention types, typically administered 10-30 hours per week, and “are not generally available” (pg. 18) in Colorado. As such, they were not discussed.
 - Self-management and Story-based Intervention Package are not covered in detail because it is unlikely to use these strategies with children under the age of 3 years (these therapies are briefly discussed on pages 17-18)
 - NSP identified some interventions as ‘emerging’ and ‘un-established’; for these groups the data are sparse, mixed, unclear or entirely lacking for interventions. Based on the limited number of interventions listed above, many marketed approaches fit into these categories.
 - Augmentative and Alternative Communication is an ‘emerging’ strategy that is covered in detail
1. **Antecedent treatments:** alterations to the environment before a behavior occurs, increasing the likelihood of the positive behavioral choice occurring instead of the negative choice. There are numerous types of these, and the guidelines provide special emphasis on those regarding prompting (cues, supports or hints) on what to do next. The best way to manage a poor choice is to keep it from occurring and antecedent treatments work in that manner.
 2. **Behavioral intervention packages:** interventions are based on the Applied Behavior Analysis model of antecedents, behaviors, and consequences, with special emphasis on two techniques.
 - a. *Discrete Trial Training:* learning small chunks of behavior through repetition or repeated practice. To minimize the learning of incorrect ways of doing things, an errorless learning model will be used. This is usually a most to least prompting hierarchy. Though simple sounding, a skilled

practitioner is needed to ensure the event does not become unpleasant for the child. Practice makes perfect, especially if each practice is perfect.

- b. *Positive Behavioral Interventions and Supports (PBIS)*: a form of ABA with 5 essential elements, to include 1) establishment of a team around the child and their family to determine his/her strengths, needs, and goals for intervention, 2) conducting a functional assessment of any problem behaviors to determine how they work, and hence what alternative positive behaviors need to be taught or supported to compete against the unhelpful, current choice, 3) designing the plan, 4) implementing the plan, and 5) evaluating the effectiveness of the plan through data collection and then altering the plan as needed. The data are always right, so if a plan is not working, changes need to occur.
3. **Joint attention interventions**: teaching the child to do simple things like look at what you're looking at, make eye contact, share their interests with others, share toys through interactive play, get attention through positive means, and learning to read and share facial expressions are immediately impacting to your child's health. These are foundational skills to life and learning.
4. **Modeling**: demonstrating how to do something, sometimes over and over again. Many children with autism need repeated modeling to learn from this approach.
5. **Naturalistic teaching strategies**: life is full of teaching opportunities, where we do things that work and don't work. This strategy teaches parents and others to identify the 'teachable moments' and use the natural motivation and reinforcers tied to those situations. It is similar to the concept of giving a person a fish and they will eat for a day, but teaching a person to fish and they will eat for a lifetime.
6. **Peer teaching strategies**: if we want a child to interact with their peers, they must be given access to them. Through thoughtful planning, teaching, monitoring, and structuring of the social situation, we can enhance social skills by including real peers. Teaching social skills without peers often results in kids who may know the right answer, but can't do the skill when it counts.
7. **Pivotal Response treatments**: an ABA approach based on targeting a core set of skills and behaviors, to 'unlock' or effect a larger set of skills. Overlapping with some other established interventions, targets often include language skills, social interactions, joint attention, increased establishment of reinforcers, time on task, and self management to name a few.
8. **Schedules**: use of typically visual items to assist with daily schedules, routines, transitions, time-telling skills, and changes in the day.
9. **Augmentative and Alternative Communication (AAC)**: Breaking from NSP, the guidelines support the use of one emerging intervention, AAC tools for children with little functional speech. Widely accepted and supported by professionals, these practices range from signs and gestures to computer generated voice production. Please consult with a Speech Pathologist or other communication specialist to determine if these approaches may be of use to your child.

Not all of these are needed for each person, nor will each of these be equally effective for any given child due to age, symptoms, and access to appropriately trained providers in Colorado. This is why a well functioning, highly trained team including the child's parents is needed.

One missing category, 'iatrogenic' or likely to be harmful to the person undergoing treatment, was missing from the report due to a lack of data. This makes sense as no one would want to harm children to prove something is harmful; this may unfortunately allow some practitioners to unknowingly providing such treatments. Consult your physician or psychologist to learn more about such risks.

Case Studies

- A series of useful case studies are presented to show how to use pieces of the aforementioned interventions on pages 28-33.

Monitoring Progress

- Selection of any or all of the evidence-based procedures does not guarantee success. It is unethical to treat without measuring the effects of the treatment. All interventions must be assessed via objective data (outcomes that two or more people can agree on through measurement). This does not diminish the usefulness of thoughts, opinions, and feelings about a treatment as useful supplements.
- The authors provide some useful and simple models to gain objective data collection on pages 34-36.

Appendix A: Questions to guide the individualized family service plan planning process for children with autism spectrum disorders can be found on page 41 and provides a nice checklist to enhance your child's treatment process.

Appendix B: About our child can be found on page 42 and provides a well organized model to collect information to be used in the treatment planning process. Items include domains of functioning and prioritization of skills desired.

Key Components of Autism Guidelines for 'real-life' use:

1. Parent's are an important and MANDATORY part of the EI team
2. Families and EI providers should have regular meetings/communication to assess progress and make changes as needed
3. Data collection is essential to success and should be gathered throughout
4. IFSPs need to be specific – outline (who, what, where, when, and how often) of services
5. Families should receive help and guidance with how to reduce a child's challenging behaviors – an FBA should be completed to better understand the specifics of a behavior
6. Providers should be qualified and have specific training in autism strategies

7. Increasing communication and developing social skills should be a focus of EI services for children with autism – including EI facilitated time with typical peers
8. Transitioning to special education/preschool should happen early and families should be supported throughout process
9. Level of services should be assessed and agreed upon with family members

If you feel that one or more components of the Autism Guidelines are not being addressed properly for your child, please contact: Lenita Hartman with the Division of Developmental Disabilities/ Early Intervention @ 303-866-7262 for assistance.