



Autism Spectrum Disorder: Developing State Guidelines for Services

IDEA Infant & Toddler Coordinators Association (ITCA)

Position Statement

February 2021

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Purpose and Background

The purpose of this position statement is to support states in developing appropriate services for all families of infants and toddlers with disabilities, including those children diagnosed with Autism Spectrum Disorder (ASD). The Infant and Toddler Coordinators Association (ITCA) asserts that services designed for children with ASD must be consistent with and uphold (1) the requirements of the Individuals with Disability Education Act (IDEA) Part C, (2) evidence-based practices and (3) the foundational principles of early intervention.

This position statement was developed by a task force appointed by the ITCA Board to examine best practices and draft recommendations for supporting infants and toddlers diagnosed with ASD, and their families. The task force reviewed existing literature and state-level work, consulted with the Early Childhood Technical Assistance Center (ECTA), and solicited ITCA general membership input. The ITCA Board endorsed this position statement on February 1, 2021. ITCA greatly appreciates the task force members and ECTA for their time and conscientious efforts on this important work.

Foundational Principles of Early Intervention

Agreed-upon and widely accepted principles of early intervention serve as the foundation and guide for evidence-based service delivery across children and families receiving Part C services, regardless of an individual child's disability or diagnosis (DEC, 2014; IDEA, 2004; Workgroup on Principles and Practices in Natural Environments, 2008). The following key principles from the Workgroup on Principles and Practices in Natural Environments (2008) remain essential when working with families of children under three years with diagnosed or suspected ASD.

- 1. Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.** By embedding intervention strategies into family life, routines, and activities, caregivers of young children with ASD can support generalization within their natural environments and across their existing routines. Because children with ASD can show difficulty generalizing skills to different contexts (NRC, 2001), this concept is critical when working with this population.
- 2. All families, with the necessary supports and resources, can enhance their children's learning and development.** By creatively adapting caregiving methods to facilitate the development of the child, while balancing the needs of the rest of the family, caregivers of young children with ASD can feasibly achieve the recommended 25 hours of developmentally appropriate services per week (National Research Council, 2001; Woods & Brown, 2011).

- 3. The primary role of a service provider in early intervention is to work with and support family members and caregivers in children's lives.** Coaching is a common method of promoting caregiver-implemented intervention when working with families of young children with ASD (e.g., Siller & Morgan, 2018; Tomeny et al., 2020). Coaching builds caregivers' capacity to promote the child's optimal development and to facilitate participation in family and community activities.
- 4. The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child's and family members' preferences, learning styles and cultural beliefs.** Regardless of disability, this requires a collaborative relationship between families and professionals and is recommended when working with families of young children with ASD (Zwaigenbaum et al., 2015).
- 5. IFSP outcomes must be functional and based on children's and families' needs and family-identified priorities.** Even though outcomes for young children with ASD are likely to address core features of ASD, such as language, social communication or behaviors, it is essential that the outcomes continue to address the family's priorities in a functional manner (Schreibman et al., 2015). Interventions should be linked to specific, individualized goals that target child functioning and family needs instead of a focus on isolated and discrete skills.
- 6. The family's priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.** The primary service provider approach is considered best practice in early intervention (e.g., Sheldon & Rush, 2013; Marturana et al., 2011; McWilliam, 2010). A diagnosis of ASD should not negate this recommended approach to service delivery, but rather encourage its use to ensure highest success in achieving outcomes.
- 7. Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations.** Part C of IDEA (2004) requires the use of evidence-based practice in early intervention service delivery. This expectation holds true when working with all children and families in Part C services, including children with ASD.

As Schreibman and colleagues (2015) note, "application of developmentally-informed principles in early intervention is also designed to promote generalization throughout the intervention process as well as socially appropriate and functional use of new skills and knowledge" (p. 2414). Many ASD-specific interventions for very young children, however, address only a small number of early intervention principles in their practice (Schertz et al., 2011). It is essential that the full range of foundational principles remain at the forefront of

early intervention services for young children with ASD and their families to best meet their needs and improve outcomes.

Evidence-based Practices

The following five early intervention practices align with empirical evidence and Part C system core values (Alabama’s Early Intervention System, 2018). These practices can be implemented across a range of service frequency, length and settings and address areas such as social communication, challenging behaviors, and other symptoms of ASD.

1. Caregiver-Implemented Intervention

Effective early ASD interventions actively involve caregivers, utilize developmental approaches, and target social communication (Zwaigenbaum et al., 2015). In caregiver-implemented interventions, the caregiver is a primary intervention facilitator and the provider focuses on coaching the caregiver as both they work with the child.

2. Following Child’s Lead

Caregivers are taught that following their child’s focus of attention creates teaching opportunities. That is, when the child demonstrates interest in an activity or engages in a familiar routine, the caregiver presents a natural teaching opportunity which increases the child’s motivation to participate (Schreibman et al., 2015).

3. Naturalistic Teaching

This practice refers to a combination of strategies used to teach within naturally occurring activities and routines (NAC, 2015), supporting generalization of skills across natural contexts. Teaching opportunities are created when caregivers follow their child’s focus of attention.

4. Modeling

Caregivers are coached to model a desired target behavior that results in the independent use of the behavior by the child (Steinbrenner et al., 2020). Target behaviors can include particular actions, gestures, words, etc.

5. Natural Reinforcement

Natural reinforcement is intrinsic to the child’s goal rather than extrinsic or external reinforcement (Schreibman et al., 2015). Such reinforcement naturally reinforces a child’s attempt at a targeted behavior.

IDEA Part C Requirements

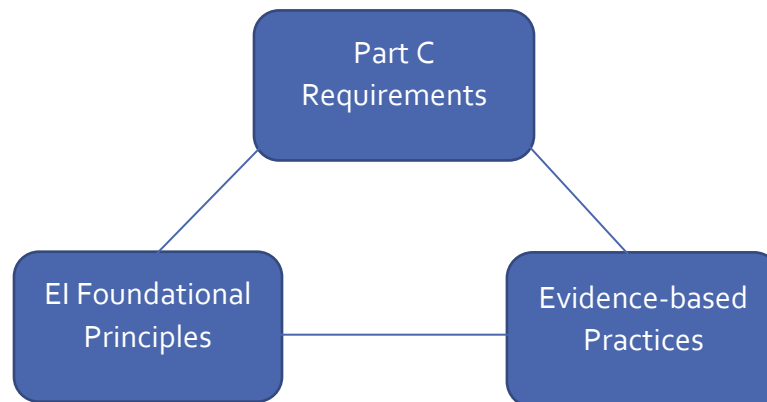
While there are no specific references to services for children with ASD in the regulations, there are several provisions that support the process of determining and providing services for children with ASD and their families. The Part C regulations at 34 CFR Part 303

emphasize the overall requirement that all decisions be individualized for each child and for their family. Services must be determined by the IFSP team based on the evaluation and assessment of the child and the parent's concerns, priorities, and resources. Any standardized level of service intensity based on diagnosis is inherently noncompliant with the statute and regulations of IDEA. A number of the most relevant regulations are listed below:

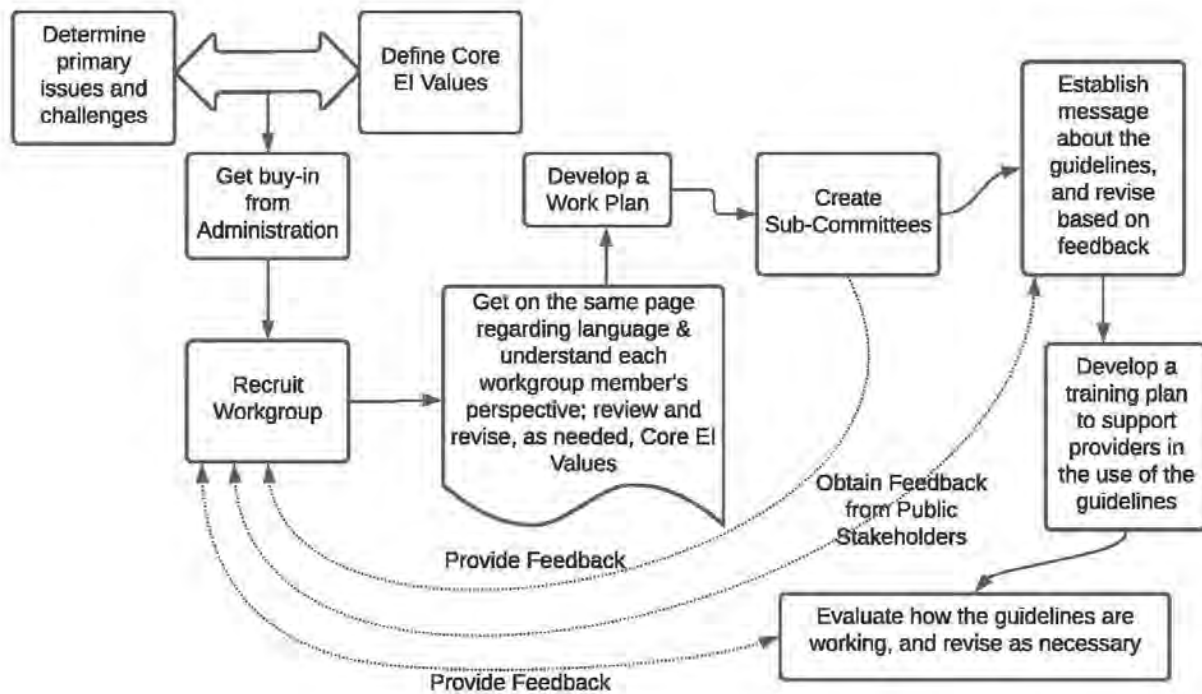
- 303.12 Early intervention services.
- 303.167 Individualized family service plans.
- 303.340 General.
- 303.342 Procedures for IFSP development, review, and evaluation.
- 303.343 Participants in IFSP meetings and periodic reviews.
- 303.344 Content of an IFSP.

Recommendations for States; Guidelines for a Stepwise Process

State guidelines and policies must be in accordance with IDEA requirements and support the implementation of evidence-based practices in alignment with the early intervention foundational principles.



States should use a systematic, stepwise process, which includes stakeholder input, to develop guidance specific to the state's needs. A suggested flow chart for a multi-step state process is provided below.



ITCA recognizes that each state’s Part C system has different needs and resources and recommends individual states launch their own initiatives to meet their unique needs. In 2018, Alabama’s Early Intervention System launched a statewide initiative to address Part C service delivery for infants and toddlers with, or at risk for, ASD and their families. A brief description of Alabama’s process is presented here as an example of one state’s process.

Determine Primary Challenges

When considering the development of guidelines on serving infants and toddlers with a diagnosis of ASD, or a suspected ASD diagnosis, an important first step is to determine the primary challenges the state faces.

Define State EI Core Values

Identify the state’s core values regarding providing early intervention.

Alabama’s Early Intervention System has identified eight core values: family-centered, developmentally appropriate, individualized, natural environments, equip/train the caregiver, collaborative, and routines-based. These values lay the foundation for developing best practices appropriate for Alabama Early Intervention providers.

Get Administrative Buy-In

Any system-wide guidance or changes require the full support of administration at all levels. This support ensures that whatever the work group decided is the most appropriate

path forward will be supported. Early Intervention was created to be a system of services and supports. This requires commitment and investment from all partners to be the most effective. The early “buy-in” and endorsement from the leadership of the lead agency, the ICC membership and other stakeholders will guide the way to effective implementation.

Form a Work Group

Establish a diverse group of stakeholders, representative of state demographics. Include service providers from different disciplines, state leaders who specialize in working with infants and toddlers with ASD and their families, higher education professionals, childcare representatives, physicians, families, and other critical partners. Selection of a strong chairperson who is a leader in the field and adept at group facilitation is key to managing differing viewpoints, priorities, and practices.

Alabama Part C formed a workgroup consisting of community stakeholders, agency leaders, parents and researchers across disciplines to identify state resources and needs, examine evidence-based practices for young children with suspected ASD and gather stakeholder input.

Get on the Same Page

A first step for the workgroup is to ensure that all members have a common understanding of the group’s shared purpose, along with respect for the unique perspectives of each workgroup member. Consensus-building requires strong relationships, effort, and commitment over time. Throughout the process, open communication and continuous feedback with all stakeholders and policy makers is critical.

Develop a Work Plan

Develop a plan with goals, outcomes, and timelines. Convene subcommittees, as appropriate. Subcommittees might collect and analyze state and national data, create a crosswalk aligning ASD evidence-based practices for infants and toddlers with the state’s core values, explore screening strategies, create a professional development plan for providers, and other priorities identified by the workgroup.

Establish Key Guidelines and Practices

Following a multi-step process that included an extensive review of the existing literature and established treatments (e.g., NAC, 2015; NPDC, 2017, 2020), Alabama’s workgroup agreed upon five intervention practices that aligned with empirical evidence and Alabama’s core values in order to address areas such as social communication, challenging behaviors, and other symptoms of ASD. The five identified intervention practices include:

- (1) caregiver-implemented intervention
- (2) following child’s lead

- (3) naturalistic teaching
- (4) modeling
- (5) natural reinforcement.

These practices are found across the ASD literature and intervention models for very young children (e.g., Schreibman et al., 2015), and can be embedded naturally within the Part C system while remaining in alignment with recommended practice in early intervention (Workgroup on Principles and Practices in Natural Environments, 2008). The work of this initiative resulted in statewide guidance that Part C early interventionists and families use these five intervention strategies when ASD is first suspected.

Consistent Messaging and Provider Training

Once guidelines and practices have been developed, the workgroup should establish consistent messaging about the state guidelines to share with referral sources, childcare, physicians, providers, and families.

The next step is to develop a training plan for early intervention providers, including coaching and mentoring, to learn about and implement the identified practices to fidelity. The training plan must include strategies for statewide implementation and ensure scaling-up practice and professional support over time. Alabama's Early Intervention System has created a multi-tiered training and coaching program to build a sustainable system of care for families of infants and toddlers with, or at risk for, ASD in their state.

Primary Resources

This paper includes multiple resources in Appendix B. To assist state lead agencies in identifying key timely resources for themselves and their stakeholders, the members of the task force prioritized these and found the following to be most critical for state's consideration when developing guidance.

Minjarez, M. B., Bruinsma, Y., & Stahmer, A. C. (2020). *Considering NDBI Models*. In Y. Bruinsma, M. B. Minjarez, L. Schreibman, & A. C. Stahmer (Eds.), *Naturalistic developmental behavioral interventions for autism spectrum disorder* (p. 21–42). Paul H. Brookes Publishing Co.

Minjarez, M. B., Karp, E. A., Stahmer, A. C., & Brookman-Frazee, L. (2020). Empowering parents through parent training and coaching. In *Naturalistic developmental behavioral interventions for autism spectrum disorder* (p. 77–98). Paul H. Brookes Publishing Co.

Naturalistic Developmental Behavioral Interventions in the Treatment of Children of Autism Spectrum Disorder (2020) Edited by: Yvonne E.M. Bruinsma Ph.D., BCBA-D,

Mendy B. Minjarez, Laura Schreibman Ph.D., Aubyn C. Stahmer Ph.D., Paul H. Brookes Publishing, Baltimore, MD. See Chapters 2 and 4 as listed below.

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Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Kasari, C., Carter, A., Granpeesheh, D., . . . Pierce, K. (2015). Early intervention for children with autism spectrum disorder under 3 years of age: Recommendations for practice and research. *Pediatrics, 136* (Supplement 1), S60-S81.

Overall ITCA Recommendations

It is strongly recommended that State Part C Lead Agencies:

1. Develop and implement plans to help practitioners and families understand:
 - The importance of individualized interventions for all children;
 - That individualized decision-making for Birth to Three is not only evidence-based practice but is also required under IDEA;
 - Intensity of services must be based on the needs of the child and family, and on the developmental appropriateness for very young children; and
 - Evidence-based practices for all young children, including behavioral techniques, are a foundation for all interventions.
2. Create and implement accountability activities to:
 - Review and analyze data on current IFSP decisions and intensity of services provided throughout the state;

- Consider how service decisions are made currently and if these are individualized and determined by the IFSP team or prescribed based on diagnosis; and
 - Plan activities and professional development strategies to address the importance of planning individualized, evidence-based practices and services based on the needs of the child and family.
3. Review and share the prioritized resources in this paper and remaining aware of the ever-changing evidence base for intervention for children with ASD.
 4. Establish and implement a planning process, as described in this paper, with stakeholder input to develop state guidelines for determining and implementing services for children with ASD.

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Appendices

Appendix A	Task Force Members
Appendix B	Resources

Appendix A: Task Force Members

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Appendix B: Resources

Recommended Practices for Young Children with ASD and their Families

- Boyd, B. A., Odom, S. L., Humphreys, B. P., & Sam, A. M. (2010). Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention, 32*(2), 75-98.
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