



# **Autism Spectrum Disorders (ASD) Frequently Asked Questions By Families**

**My child's service provider has shared her concerns regarding my son's development and behaviors. We recognize that he has delays and is different from other two year olds. We think he is too young to be brought to a specialist for a label or a diagnosis. We would prefer to wait another year or so to see how he develops. Is there any harm in waiting?**

The research is very clear that intervention should begin as early as possible to be most successful. However, it is important that families make the decision with which they are most comfortable for their child. Evaluations for diagnosis of ASD are not physically painful for the child. They consist of behavioral observations, educational testing, and family interviews. Most families report a feeling of relief after the evaluation because they know whether or not their child has a diagnosis and are able to begin appropriate services if needed.

Early intervention services identified as appropriate by the local Babies Can't Wait (BCW) early intervention team can be initiated with or without a formal diagnosis. There are many different techniques and strategies that may be implemented. Some techniques are more directive, whereas others require more family participation. What is most important is that the specific outcomes identified by the family are addressed and that an appropriate program is developed. However, the evaluation can be very helpful to the team and the family as they determine the types of services, techniques, and strategies that will be most effective. While a diagnosis is not required for services, the evaluation and subsequent intervention recommendations can be very beneficial to program development.

**My child has been evaluated by BCW and the team has a concern about the possibility of ASD. Will BCW pay for an evaluation to determine if my child has ASD?**

When the BCW team determines that pursuing a diagnosis is appropriate, then the evaluation may be included as a BCW service on the child's Individualized Family Service Plan (IFSP). This means that the program is responsible for providing payment for this diagnostic service. It is essential that any diagnostic evaluations be done in collaboration with the child's primary care physician.

## **Can early intervention cure Autism Spectrum Disorders?**

There is no nationally recognized program that has adequate research data on young children that can claim a cure for autism. Autism is, by definition, a life-long disability. Because of its link to biological or neurological differences in the child's brain, there is no "cure", in the medical sense, for these differences. With appropriate intervention, many behaviors associated with ASD can be positively changed. Research does indicate that with early and intensive intervention, many children make substantial gains and enter preschool programs with varying levels of support.

## **What are the most effective approaches?**

No one approach is effective for all children. Research has shown that a structured, specialized education program that emphasizes communication and social interaction skills designed for the individual child will produce positive results. Family members must also consider their role in the program when evaluating effectiveness. Questions such as "How much time and resources will be necessary from the family in order to implement a specific approach?" should be considered. The approaches found to be the most effective include a coordinated program involving the child and the family. Programs must be reflective of family concerns, priorities, and values, and consistently implemented by all providers, including family members.

## **How do I know which treatment approach is best for my child?**

This is the most difficult question for families to answer and one that may change over time. Often, the best approach is a combination of approaches. What works for one child may not work for another. What works one month may not work six months later for the same child. Parents are advised to be good consumers of the intervention their child receives. This includes ongoing discussion of the treatment options and approaches their child receives. When considering treatment approaches, family members need to ask and expect answers to questions like these:

- What positive effects of treatment would I hope to see?
- Are there any harmful side effects associated with this treatment?
- What short-term and long-term effects might I see with this treatment?
- Can this treatment be integrated into my child's current program?
- 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 required time to the treatment?
- What do my pediatrician and other professionals involved with my child think about the treatment's appropriateness?
- Is there widely accepted research that provides scientific evidence that supports the use of this treatment?

## **How do I know if my child is making progress? What do I do if I don't feel my child is making progress? What do I do if I'm not satisfied?**

The IFSP is designed to state what changes you expect to see in a child, how the change will be measured, and what the timelines are for the change. As a family member, you are a very important part of the identification of outcomes, development of activities and strategies to achieve the outcomes, and determination of where those activities would best fit into your family's and child's daily routine. Minimally, each outcome on the IFSP must be reviewed every six months and be rewritten annually. For children with ASD, this may need to be done more frequently, such as every three months. In addition, each outcome on the IFSP should be broken down into measurable steps so progress towards outcomes can be measured during each intervention opportunity. As a family member and a member of the team, you should be included in frequent discussions of your child's status. Consultants are available and can be included in a program review if you have concerns about progress.

## **Should my child be enrolled in a special "autism" program and participate in a curriculum designed for children diagnosed with autism?**

Special programs may not meet the legislative criterion of "natural environment" or be located where children without disabilities are typically found. Children with ASD benefit from access to peers who are age-appropriate and typically developing. Each child is an individual with individualized needs. Because of the spectrum nature of ASD and the many behavior combinations which can occur, no one curriculum approach or program will be effective for all children. Providing services to children with ASD in a group assumes they all need a similar program and similar services. A curriculum that supports the achievement of individual outcomes should be adopted.

## **Will the Babies Can't Wait Program pay for an alternative therapy such as auditory training, vision therapy, or cranial sacral therapy for my child?**

No. BCW will assist families in finding information and resources on alternative treatments, but will not pay for these alternative services. Often these are considered medical interventions which are not covered by BCW. BCW will not provide payment for any treatment that has not been proven effective based on research studies. BCW staff, in collaboration with consultants, will advise providers and families of techniques or approaches that fall into this category.

### **Will Babies Can't Wait pay for a "name brand" program for my child such as Discrete Trial, Greenspan, TEACCH, or Little Walden?**

The approach determined to be the most appropriate by the IFSP team, based on evaluation/assessment information, will be implemented and may include programs such as those listed above. The IFSP team will assist families with implementing a specific special instruction program if it is considered to be the most effective treatment option. The amount of time for special instruction paid for by BCW will be determined by the team and included on the IFSP. This program will typically be only one component of a child's plan that also includes opportunities for the child to generalize skills to other natural environments and to have interaction with typically developing peers.

### **My child was diagnosed by an expert in the field who recommended we hire a consultant outside the Babies Can't Wait Program to consult with us on our child's programming. Will BCW pay for this?**

Babies Can't Wait is not obligated to hire or pay for outside consultants if the program has the expertise available to implement the requirements of the IFSP. BCW has trained and experienced consultants available to assist with program development. Parents are welcome to invite anyone to participate in the IFSP meeting. As part of the development of the IFSP, appropriate staff and supports are discussed and identified.

### **Who is qualified to work with a young child with ASD?**

There is no specific credential or discipline that qualifies an individual to work with a child with ASD. We find that the complexity of behaviors and needs for children with ASD often requires a team of individuals who work with the family. The team may include any or all of the following: an educator who is an early intervention specialist, early interventionist, or an early intervention assistant; a speech/language pathologist; an occupational therapist; a psychologist; and/or a social worker. It is important that members of the team have adequate training and experience in working with children with ASD. Frequently, our programs will have experienced staff as part of the comprehensive program to deal with all the components of a family's plan. If the program does not have staff experienced in a specific strategy or technique, BCW will assist in identifying consultants who may provide technical assistance or training to the program for the family.

## **What will happen to my child when he turns three and will no longer be receiving services through Babies Can't Wait?**

BCW is required to assist your family in planning for changes in service delivery a minimum of six months prior to your child's third birthday. Possible program options include public school preschool special education programs and other community programs. Your service coordinator will assist you in identifying available options in your community.

It is important for you to know that all school districts in Georgia are required to provide children with disabilities ages 3 through 21, a free and appropriate public education to meet their individual needs. In order to ensure that children with disabilities are provided services and supports through their school district by the age of three, planning and communication between your child's early intervention program and school district personnel must take place as early as possible. It is recommended that you begin to investigate options when your child turns two.

Early activities that are essential to the transition process include:

- Meeting with BCW, school personnel, and other community programs to discuss the plan for gathering information needed to make the transition;
- Sharing relevant and recent information, such as current evaluations, assessments, and IFSPs by all parties working with your child;
- Completing a formal referral of your child to his or her school district. Once the referral is made, school system personnel, along with you, can begin the process of determining if your child is eligible for special education services, and if so, what those services might be.

Adapted from *Connecticut Birth to Three, Service Guideline #1: PDD/Autism* and Fields V. *Autism Advocacy in Lane County: Oregon: A Handbook for Parents and Professionals*. Eugene, OR: University of Oregon: 1993. Thesis.

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