

With Autism, as with All Special Needs,
Each Child and Family is Unique!

By Amy Cocorikis

Moving to Illinois last year after a lifetime in New Jersey was an unsettling experience...So far from family and friends, we needed to adjust to a new house, new schools, new doctors, and new jobs. Thankfully, my new job working for the Illinois Early Intervention Training Project actually made me feel less homesick.

Many of the issues families and providers face here in Illinois are ones that I had experienced during my years in NJ's early intervention system. One of the areas we have in common involves service provision for young children with Autistic Spectrum Disorder (ASD) and their families. I have always been a direct service provider for children with ASD birth to three and their families. I then worked as an administrator of specialized programming for children birth to five with ASD as well as an early intervention (EI) system representative who participated in statewide training and policy development.

The people who come to my trainings in Illinois tell me that it seems as if there are so many more children with autism now than in the past. Providers in New Jersey (and everywhere else for that matter) noticed the same rise in numbers of children diagnosed before the age of three. The incidence of autism is increasing at a rate of 10-17% each year, and systems struggle with the many issues and implications of those rising numbers. Along with noticing more children being identified earlier, providers in New Jersey and Illinois also have questions on the various approaches, methods, and philosophies of how best to work with very young children with ASD.

EI systems are gathering all of the information on treatment, determining how it relates to the mission and vision of early intervention, defining the roles of providers and family members within each approach, providing training and supervision, and monitoring the process. Systems are also working to ensure that even within a diagnostic category such as ASD, each child and family is viewed as, and treated as, unique individuals whose strengths, needs, and priorities differ from every other child with ASD and the family members who nurture that child.

At the same time, families are struggling with their own personal issues related to their young child with ASD. During this process, they are interfacing with different professionals from different systems and sorting through massive amounts of information.

When I sit around the "Individual Family Service Plan (IFSP) table," I try to take a moment to consider the different perspectives and viewpoints each of us may represent. I am someone who has chosen the field I am in and who has developed my experience with ASD over time after working with many children and families. My knowledge about autism, my perceptions and expectations, my philosophical approach have all changed dramatically over time.

The family who sits across from me at their **very first** IFSP meeting has been thrust into this situation and is attempting to take in and process information, not about ASD, but about **their child with ASD!**

Each family has different levels of information and perception about the diagnosis itself. Each family has very different feelings, reactions, and beliefs about how this diagnosis pertains to and impacts their child and family. What many families share is an understandable sense of urgency, a need to proceed as quickly as possible from the information gathering stage to the intervention stage.

While I understand and acknowledge this sense of urgency, I also know that in early intervention families are equal team members. Informed collaborative decision making is crucial to the IFSP development process. Diagnosis alone cannot drive the process any faster. We cannot make assumptions or streamline decision-making about services based solely on a diagnosis. Information about a diagnosis is important, but it does not offer much insight into an individual child.

Families are not developing outcomes or making service delivery decisions for any child with ASD, they are doing it for their child who is unique and different from any other child with or without a diagnosis.

In order to ensure that I have tailored the process to each child and family I check in with the other members of the IFSP development team. Have we gathered and shared with the family information about how their child's individual developmental profile is or is not impacted by the diagnosis? Have we helped them to understand that even within a diagnostic category there are strengths and needs that can assist in the decision making process for their child and family? Have we provided families with the information and resources on the broad range of philosophies, approaches, and methods of working with young children with ASD so they can decide which approach might be a good fit for their child and family?

One of the many resources I share in my trainings is the Autism Society of America's Web site, which summarizes some of my key points, and also supports my perspective on working with families.

“Individuals with autism, like everyone, are individuals first and foremost. They have unique strengths and weaknesses. What people with autism have in common is a developmental disability, a disorder of communication, which manifests itself differently in each person. Just as there is no one symptom or behavior that identifies autistic children, there is no single treatment. It is important that you gather information concerning various options before making decisions concerning your child's treatment. As a parent, it's natural to want to do something immediately. However, it is important not to rush in with changes. Your child may have already learned to cope with his or her current environment and changes can be stressful. You will encounter numerous accounts from parents about successes and failures with many of the treatment approaches mentioned. You will also discover that professionals differ in their theories of what they feel is the most successful treatment for autism. It can be frustrating! But, you can learn to sift through them, and make rational, educated decisions on what is appropriate for **your child**. You live with your child day by day. You know his/her needs, and you will come to know his/her autism. Trust your instincts as you explore various options.”

For additional information, visit www.autism-society.org.