



Early Intervention for Young Children on the Autism spectrum: Parent's Perspective

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The importance of early intervention (services for children zero-three years) and early childhood education programs (services for those three-five years) for young children with autism spectrum disorder (ASD) has been well documented in the literature (National Research Council, 2001; Rogers, 1999, 1996). The need for effective early intervention (EI) has been highlighted as a priority in legislation as well. The National Institutes for Health Interagency Autism Coordinating Committee (IACC) developed a research roadmap and matrix that encompasses goals and activities for autism research across the next 10 years. Research exploring and confirming the successful elements of early intervention is a critical component of the plan (IACC, 2003).

Despite the widespread support for the necessity of early intervention services for young children on the autism spectrum, families and professionals may be overwhelmed when attempting to navigate through the early intervention literature. What are the most effective ingredients in an early intervention or early childhood program? How many hours of services should a child receive? Where should the intervention take place? What elements of an intervention are parents most likely to find helpful? These questions and others have become controversial in the autism community.

In an effort to begin to answer those questions for Indiana families, the Indiana Resource Center for Autism (IRCA) conducted a state-wide survey of families with young children with ASD. Respondents to the survey represented 50 of the 92 counties in Indiana, and were distributed across rural, suburban and urban areas. 586 surveys were sent and 198 returned (33.7% return rate). The ages of the children represented were 2-8 with an average age of 5.44 years. The purpose of the survey was to gauge the accessibility of services for young children with ASD in Indiana as well as understand family's perceptions of Indiana's programs for young children with ASD. The following questions were addressed:

- What early intervention services are available to children with autism spectrum disorder and their families?
- Where/How are those services accessed?
- How are Indiana's early intervention programs succeeding or failing in meeting the needs of children with autism spectrum disorder and their families?

Settings and Services Received

Young children with ASD in Indiana are most likely to be served in public preschool settings (73.8%) and home programs (16.4%). Residential centers (1.0%) and Head Start programs (4.1%) are the early intervention settings used least to serve young children with ASD. In terms of services, speech therapy is used most frequently (89.2%), followed by occupational therapy (83.1%), classroom aides (46.7%), and augmentative communication (43.1%). Recreational therapy is used least by families (12.8%), followed by supports to assist in inclusion (15.9%), and supports to assist in social skills development (15.9%). 59% of families strongly agreed that parent participation was encouraged in their child's setting, and 47.7% of parents strongly agreed that regular reports of progress were provided to them about their child. The fewest number of parents (25.6%) strongly agreed that integration opportunities were provided to their child.

Hours of Intervention

Hours of intervention varied across participants, however 66% reported receiving less than the recommended 25 hours per week (National Research Council, 2001). Families using applied behavior analysis (26.2%) used the intervention the highest number of hours per week (16.2), followed by those utilizing a classroom aide (15.4). Parents using augmentative communication, which was defined as supports to enhance a child's ability to give and receive messages such as Picture Exchange Communication or communication devices, used the intervention 11.6 hours per week. Physical therapy (1.1 hours per week), consultation from specialists (1.6 hours per week), and speech therapy (2 hours per week) were used the fewest number of hours per week. The average number of hours of intervention was 25.5 with some children receiving less and some receiving in excess of 40 hours. While the majority of comments show strong support for the school system and the progress children have made, one mother noted the importance "of more intervention than the school's 12 ½ hours a week."

Payment Sources for Interventions

Families reported that public schools were the primary funding source for interventions, and out-of-pocket funds were the second most cited source. First Steps and private insurance were noted next, followed by the Medicaid waiver, which funded the fewest number of services for Indiana families. This funding trend reflects the availability of resources in the state. For example, there is a lengthy waiting list for Medicaid Waivers and insurance is often difficult to access. One family states the importance of "better funding available to special preschools and public schools so that children of all income brackets can receive intense intervention at an early age." Another parent asks: "Why is this burden put on the schools so much instead of being funded through Medicaid waiver programs?"

Impact on Developmental Growth Related to Specific Interventions

Family members rated the impact of each service used on its value and contribution to their child's growth. The majority of family members strongly agreed that each intervention was effective and contributed to growth; however the percentage varied from 50% to 78.2%. Parent training was perceived as making the greatest contribution to growth with 78.2%. This issue is discussed more in depth below. Parents strongly supported speech therapy (76%), sensory integration (69%), applied behavior analysis (68.4%) and social supports (67.5%) as effective contributors to their child's development. One mother states the need to "add ABA or similar low student/teacher ratio instruction. Having him sit to listen to a story in a preschool class seems pointless when he doesn't understand the stories." Table 1 below illustrates data related to percentage of those who used a specific service, how many hours a week it was used, and whether it was perceived as contributing to growth and improvement.

Use of Evidence-Based Practices

There is an indication that several of the evidence-based practices described by the literature (Hurth, 1999; National Research Council, 2001; Rogers, 1999) are being used by families and service providers in Indiana. The National Research Council (NRC) recommends low student teacher ratios, which is apparent in the high rate of classroom aides (46.7% of respondents) found in these EI settings. A curricular focus on functional communication and motor skills, as suggested by the NRC, is evident in the high rates of speech therapy, augmentative communication, and occupational therapy provided to the respondent's children.

Table 1

Early Intervention/Early Childhood Education Usage Practices in the State of Indiana

	% Families Who Used this Service	Hours Per Week	Contribution to Growth*
Speech Therapy	89.2	2.0	76
Occupational Therapy	83.1	1.7	65.6
Classroom Aide	46.7	15.4	65.9
Consultation	45.1	1.6	46.7
Augmentative Communication	43.1	11.6	62.7
Sensory Integration	40.0	3.1	69
Behavior Supports	30.8	7.8	50
Physical Therapy	29.7	1.1	51.7
Medical Treatment	27.7	9.1	57.1
Applied Behavior Analysis	26.2	16.2	68.4
Music Therapy	23.1	2.4	50
Counseling/Psychotherapy	22.6	2.3	60.8
Parent Training	21.0	3.5	78.2
Floor Time	20.5	5.5	51.1
Social Skills	15.9	3.8	67.5
Recreational Therapy	12.8	3.4	57.9
Other (Includes TEACCH)	25.5	5.3	63

*Indicates the percentage of families that Strongly Agreed with the statement: "This service was effective and contributed to my child's growth"

The high percentage of families that agreed that parent participation was encouraged (89.8%) indicates that family involvement was a priority with most EI programs. This is aligned with current evidence-based literature which acknowledges the importance of family-centered service delivery (Hurth, Shaw, Izeman, Whaley, & Rogers, 1999). Over 90% of families noted that regular reports of progress were provided for their child as suggested by the National Research Council (2001).

However, there are some practices recommended in the literature that are not frequently being utilized by families or by early interventionists. The NRC (2001) recommends curricula addressing social skills development, through the use of adult and peer mediated social supports, such as social stories, peer modeling, and pivotal response training. Only 15.9% of families report using such strategies. Hurth et al. (1999) reports that intervention in settings with typical children is an important element of early intervention programs, however, only 15.9% of families report receiving inclusion support. Similarly, only 25.6% of families strongly agreed that integration opportunities were provided for their child.

Though parents reported that family involvement was encouraged, few parents (21%) reported receiving parent training. This is a particularly troubling finding given the fact that parents in this study rated parent training as the most effective practice in contributing to their child's developmental growth. Parent training for those receiving EI services has been recognized to positively affect the knowledge and attitudes of parents, as well as reduce stress and increase confidence (Wehman, 1998). The NRC (2001) reports that when parents can learn techniques for teaching skills and managing their child's behavior, child learning is maximized and the quality of the family's life is improved. One parent notes that "it has been most beneficial that I have learned new techniques to help control behavior and (the school) has also educated us more about his disorder as well, so that we can improve our child as he continues to grow and develop."

Case management, an aspect of service delivery recommended by Kohler (1999) in an effort to coordinate the various services young children with ASD receive, was not provided for more than one-fourth of the respondents. This service is considered critical to many families who are attempting to negotiate the maze of services. Case management is connected with overall quality of life—possibly indicating the positive developmental impact of coordinated services.

Reported Efficacy of Early Intervention Services

Parents using Floor Time perceived favorable outcomes in the areas of social, cognitive, and speech development. Floor Time emphasizes engagement, problem solving, and intentional communication (Wieder & Greenspan, 2003) which are likely related to the perceived outcomes. Children receiving recreation therapy were also perceived to have greater social outcomes. Parents reported that the use of a classroom aide was inversely related to adaptive behavior outcomes. This may be due to the large role paraprofessionals play in the personal care of students (Downing, Ryndak, & Clark, 2000). In other words, the support of a paraprofessional may impede the independent development of adaptive behavior.

Families also reported relationships between service delivery methods and outcomes across developmental areas. Opportunities for integration linked positively with social, emotional, cognitive, and speech development, as well as adaptive behavior and overall quality of life. This is consistent with the findings of Harrower and Dunlap (2001) who report that students with autism who are included have higher rates of social engagement and interaction, as well as developmentally more advanced IEP goals than their peers in segregated settings. Understanding what services families are receiving, as well as the impact those services are having on the family and child with ASD, is an important step for lawmakers, service providers, and family members as decisions about funding, access, and educational outcomes are made. While this article is an important first step in articulating the state of services in

Indiana, the IRCA realizes the importance of gathering input from educators and others as critical decisions are made about future options.

Recognizing the importance of family training, the IRCA is in the final stages of developing a family training module. This module will be field tested with a group of families and then a "train the trainer" model will be used to train autism mentors in school districts and parent groups to deliver the training to families. For more information, contact Cathy Pratt via email at prattc@indiana.edu or via phone at 1-812-855-6508.

The full study is published as follows:

Hume, K., Bellini, S., & Pratt, C. (2006). The usage and perceived outcomes of early intervention and early childhood programs for young children with autism spectrum disorder. *Topics in Early Childhood Special Education*.

References

Downing, J., Ryndak, D., & Clark, D. (2000). Paraeducators in inclusive classrooms: Their own perceptions. *Remedial and Special Education*, 21, 171-81.

Harrower, J. & Dunlap, G. (2001). Including children with autism in general education classrooms: A review of effective strategies. *Behavior Modification*, 25, 762-784.

Hurth, J., Shaw, E., Izeman, S., Whaley, K., & Rogers, S. (1999). Areas of agreement about effective practices serving young children with autism spectrum disorders. *Infants and Young Children*, 12, 17-26.

Interagency Autism Coordinating Committee. (November 2003). IACC autism research matrix. Retrieved on October 1, 2004 from <http://www.nimh.nih.gov/autismiacc/CongApprCommRep.pdf>.

Kohler, F. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disorders*, 14, 150-159.

National Research Council. (2001). *Educating Children with Autism*. Committee on Educational Interventions for Children with Autism. Cathernie Lord and James P. McGee, eds. Division of Behavioral and Social Sciences and Education. Washington DC: National Academy Press.

Rogers, S. (1996). Brief report: Early intervention in autism. *Journal of Autism and Developmental Disorders*, 26, 243-246.

Rogers, S. (1999). Intervention for young children with autism: From research to practice. *Infants and Young Children*, 12, 1-16.

Wehman, T. (1998). Family centered early intervention services: Factors contributing to increased parent involvement and participation. *Focus on Autism and Other Developmental Disabilities*, 13, 80-87.

Wieder, S. & Greenspan, S. (2003). Climbing the symbolic ladder in the DIR model through floor time/interactive play. *Autism: The International Journal of Research and Practice*, 7, 425-435.

Bellini, S., Hume, K., & Pratt, C. (2006). Early intervention for young children on the autism spectrum: Parent's perspective. *The Reporter*, 11(2), 1-4, 18.