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Coaching Parents of Young Children with Autism: Promoting Connection, Communication, and Learning.
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Chapter 2

Key Practices in Coaching Parents in Parent-Implemented Interventions

The current emphasis on parent-implemented interventions for early ASD is fueled by (1) new findings from the studies of infant–toddler development of ASD symptoms, (2) new tools for early diagnosis of autism, (3) and recent research funded by the National Institutes of Health and advocacy groups, especially Autism Speaks, on effective interventions for very young children with ASD.

Key Practice: Parents Working with Their Children at Home

Before the early 1970s, children with autism were very often treated in treatment centers, institutions, and psychiatric settings by therapists. The work of two men, Eric Schopler and Ivar Lovaas, had tremendous influence on the development of parent-implemented intervention for ASD.

Eric Schopler (1971), a student of Bruno Bettelheim's, reacted strongly to Bettelheim's destructive and inaccurate suggestions that autism was caused by rejecting parents. Convinced that autism was a biological condition, Schopler showed in his doctoral thesis (personal communication to G. Dawson, 1983) that children with ASD have unusual ways of processing information. Soon thereafter, he made a radical proposal: Parents can and should provide therapy directly to their children, at home. He led a pioneering effort to mobilize home- and community-based services for children with ASD and spearheaded an intervention called Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH; Mesibov, 2005), still in use today. He provided four completely new ideas about how children and adults with ASD should be treated, ideas that have had lasting influence (Schopler, Reichler, & Lansing, 1980). The first idea involves a generalist approach: that autism therapists need to bring generalized knowledge of autism treatment to families and children, knowledge developed within an interdisciplinary team in which professionals from a wide range of disciplines learn from each other and pool their knowledge, with each taking on the role of primary therapist for children with ASD and their families. The second idea promotes working with parents and children in a home setting as a crucial part of intervention. Schopler's third novel idea is the need for parents to have a strong voice in their child's treatment and to work as partners with professionals in all aspects of assessment, diagnosis, and treatment of children with autism. Fourth, ASD interventions need to respect people with ASD, supporting their preferences, strengths, and needs rather than working to eliminate or hide their symptoms and individual differences. TEACCH achieves these goals by building on individual preferences and strengths as well as needs, delivering interventions whose methods and content best support an individual's personal learning styles and needs, and simultaneously supporting the independence, comfort, and community participation of those with ASD (Mesibov, Shea, & Schopler, 2005).

The influence of the TEACCH generalist model is clear in interventions such as ESDM, in which one member of an interdisciplinary team takes on the role of team leader, partnering with parents in the design, implementation, and oversight of their child's intervention. Other professionals on the team serve as consultants to the team leader and parent, rather than as direct interventionists with the child. This model has three major effects on service delivery. First, responsibilities for team leadership and decision making are shared by parents and the team leader. Second, the generalist team leader helps integrate information from all available sources for parents to apply to the child's intervention; in so doing, the generalist

The Generalist Model Developed by TEACCH

1. Various disciplinary therapists have unique knowledge of autism.
2. Generalists learn and use the core principles/practices from each discipline.
3. The interdisciplinary team knows the child and supports each generalist's work.
4. A primary generalist helps parents work with their child at home.
5. Parents have a strong voice on the team and work as partners with professionals.
6. Intervention needs to respect the unique strengths and needs of each child with ASD.

is in a position much like that of parents, who need to make decisions about their child based on information from many resources. Third, the generalist team leader uses the interdisciplinary intervention knowledge acquired to coach the parents and to help develop a practical and effective approach to their work at home.

Lovaas, approached autism as a problem of learning. Lovaas, like Schopler, began his work with older children, 6- to 10-year-olds, since autism was not yet recognized or diagnosed in early childhood. Building on the work of his colleagues, the early leaders in ABA—Sidney Bijou, Donald Baer, Montrose Wolf, and Todd Risley, among others—Lovaas commenced his independent work by creating a teaching environment based on the principles of operant learning in a hospital setting and taught his staff to work intensively with children with autism using the principles of ABA throughout the children's waking hours. While these children made considerable progress, return to their previous settings after the study ended resulted in a loss of new skills and the resumption of their previous patterns of behaving. Learning from this experience, Lovaas and colleagues (1973) shifted their focus to beginning interventions as early as possible and carrying them out using trained interventionists at home, with the family and in the community. Parents were taught the same intervention strategies that the intervention team used. The curriculum itself was comprehensive (Lovaas, 1981, 2003), providing systematic teaching programs to address children's behavioral deficits and excesses across developmental and behavioral domains and embedding needed supports in community activities to assure child participation and learning (Lovaas, Koegel, Simmons, & Long, 1993).

Several aspects of Lovaas's practices are apparent in many parent coaching approaches in ASD, including ESDM, today: (1) Young children with ASD need to engage with others in typical activities throughout their waking hours; (2) the home, family, and community provide optimum contexts for supporting the learning of young children with ASD; (3) children with ASD (and all of the rest of us) learn when the learning content is broken down into small steps and taught systematically; (4) intervention should begin as soon as possible; and (5) children with ASD are adaptable and need to learn within the everyday environments of family, typically developing peers, and community members. (Although these were the principles that Lovaas and his close colleagues espoused and demonstrated, it is often the case that they are not the aspects of his practice that we associate with some community discrete trial training [DTT] services.)

Key Practice: Attending to the Positive Parent–Child Relationship in Young Children with ASD

There was a long period of time in which professionals assumed that the attachment relationship in ASD was either disturbed or nonexistent. These assumptions were eventually proven wrong. Beginning with the landmark contributions of Marian Sigman and her students and colleagues (Sigman & Ungerer, 1984; Capps, Sigman, & Mundy, 1994; Sigman & Mundy, 1989; Rogers, Ozonoff, & Maslin-Cole, 1991; Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2009), autism researchers demonstrated that young children with ASD can, in fact, form secure attachments with their caregivers. Evidence from these group studies showed that children with ASD experience their parents as secure bases, that they know and prefer familiar to unfamiliar people, and that they are negatively affected by separation from their parents and by interactions with strangers. These findings provided solid evidence for focusing on adults' sensitive and responsive interactions (parent behaviors that mediate secure attachments in toddlers) with young children with ASD and focusing on supporting parental roles and competencies as key emotional figures and teachers in their young autistic children's lives.

In addition to the attachment studies in ASD, studies focused on parent–child patterns of interaction in ASD have demonstrated many similarities between parent–child interactions in ASD, those in other neurodevelopmental disorders, and those in typical development (Kasari, Sigman, Mundy, & Yirmiya, 1988; Meirsschaut, Warreyn, & Roeyers, 2011). They have also defined differences in key communication behaviors, such as the ability to share attention with others or *joint attention* (Mundy, Sigman, Ungerer, & Sherman, 1986; Sigman, Mundy, Sherman, & Ungerer, 1986; McEvoy, Rogers, & Pennington, 1993). Kasari reported that parents and children with ASD interact very similarly to children with other developmental delays, with the main differences arising from the need for increased parent support for the child's attention to the parent (Kasari et al., 1988). Dawson and colleagues demonstrated that children with ASD readily increased their eye contact and joint attention behavior when the caregivers closely followed and responded contingently to the behavior of the child (Dawson & Adams, 1984b; Lewy & Dawson, 1992). We also learned that young children with ASD desire social interaction and respond more positively when social interactions are predictable and understandable. We saw that parents typically scaffolded their children's learning in ways that supported positive parent–child interactions, while also supporting the child's social attention and engagement in activities and interactions.

Sadly, and against all evidence, there is still a tendency to question the skills of parents with children on the spectrum, fueled by layperson notions of autism as well as the topic of the *broader autism phenotype*. The latter leads some to question whether the ASD-related genetic backgrounds of parents may result in parenting differences. Very important studies recently examined this question by looking at parent–child interactions among a large group of infants who had an older sibling with ASD (Talbott, Nelson, & Tager-Flusberg, 2016; Wan, Green, & Scott, 2019). Contrary to the hypothesis that parents of children with ASD may interact differently with their children due to the presence of autism risk genes, no significant differences were found between the group of parents who had a child with

ASD (and thus were assumed to have more autism risk genes) and those who had children exhibiting typical development. Thus, 30-plus years of studying parent–child interactions in ASD have not reported significant parenting differences that might be responsible for any ASD symptom development in their children.

Perhaps someday science and advocacy will be able to put this destructive idea to rest once and for all. The critical findings suggest the opposite: Children with ASD and parents generally develop close ties; children with ASD know and prefer their family members and caregivers and feel safe with them, although they may use different behaviors than other children to express these feelings (Rogers et al., 1991); and parents of children with ASD interact with them in ways that demonstrate their understanding and support for their children's unique needs.

Key Practice: Building Language Interventions Based on Developmental Communication Science

Our understanding of the processes that young children use to develop spoken language has altered radically over the past few decades. Before the 1970s, the predominant theories of language development represented nativist and environmentalist viewpoints. The most well-known representative of the nativist position was Noam Chomsky; his hypothesized Language Acquisition Device (Chomsky, 1965, 1980) was a uniquely human brain mechanism that parsed language into its elemental parts and helped children acquire speech and language. The environmentalist view was best represented by B. F. Skinner's operant learning model, which posited that speech and language evolved from the same learning processes seen in all other aspects of learned behavior (Skinner, 1957). The operant learning approach to language is still embraced by many and is highlighted in the Verbal Behavior method of intervention (Sundberg & Partington, 1998).

In the 1970s, a new model of language development was articulated and began to be studied in infant developmental labs across the country. Known as the pragmatics approach and articulated by Jerome Bruner (1983), Elizabeth Bates (1976), Inge Bretherton and Bates (1979), and other key scientists, the pragmatic approach suggests that children decode and learn language by discerning the speaker's intent (the goal of the communication). Is the speaker making a request, offering or asking for help, directing a partner to act, seeking a social response, directing a partner's attention? Such intents are expressed by body language—gesture, posture, vocal tone, and facial expressions—as well as word meanings. Young children demonstrate their understanding of these intents toward the end of the first year of life, through their preverbal responses to partners and their own gestural production of these intents. A series of elegant experiments occurring across several decades have firmly supported the pragmatics foundation of infant speech and nonverbal communication. The experiments have changed the view of speech and language from behaviors learned via imitation and associative learning for the purpose of representing objects and actions in the world, to efforts to join a social partner in shared activities for the pleasure of social connectedness and social influence through shared meanings.

Early on, Ratner and Bruner (1978) highlighted the key roles of infant–adult play routines in infants' learning to anticipate and predict others' behaviors and intentions. They pointed out that first words were very often the cue words in social games like peekaboo, "uh-oh," "so big," rather than need-fulfilling words like *milk, food,* or *help.* Their insights about the impact of emotionally salient and highly pleasurable routines with favored social partners on early word learning have stood the test of time and formed the basis for the ESDM intervention.

The second contribution of pragmatics researchers was to examine what parents did that fostered word learning in their infants. In direct challenge to the operant learning theory of language learning, a large variety of studies have demonstrated that infants and toddlers benefited the most in the early stages of word learning from partners who used language to describe the focus of an infant's attention or goals, rather than using it to direct the infant's attention and to teach word labels.

Many studies have found that young children with autism learn spoken language using the same processes as do typically developing children (Lord & Schopler, 1989; Sigman & Ruskin, 1999; Tager-Flusberg et al., 1990). A milestone study by Michael Siller and Marian Sigman (2002) demonstrated the effect on language development of parents who use language to follow their autistic children's leads rather than to direct them, and this style positively affected their children's language learning not only in early childhood, but also all the way through adolescence.

Longitudinal findings by Mundy and colleagues and others demonstrated that a child's early joint attention gestures were strong predictors of later language acquisition (Mundy, Sigman, & Kasari, 1990). Such findings indicate that language interventions for preverbal toddlers should focus first on developing use and understanding of communicative gestures, especially the joint attention gestures involving initiating and following a partner's gaze, pointing, showing, and sharing/giving. These and many other research findings stress the importance of parents and other adults interacting with young autistic children by responding to and following such children's focus of attention and goals, talking with them about their activities, and joining them as play partners.

> *Studies have consistently found that young children with autism learn spoken language using most of the same processes as do typically developing children.*

Key Practice: Interdisciplinary Teams

On October 8, 1986, a federal law (Public Law 99-457) was passed that amended the 1975 Education for All Handicapped Children Act (Public Law 94-1142)—now known as the Individuals with Disabilities Education Act (IDEA)—to require public educational services be provided to children with disabilities from age 3 to 22. Public Law 99-457 also required that assessment, intervention, and family support for all infants and toddlers with or at risk of developmental delays be provided at little or no cost to families. This law cast a wide umbrella for infants and toddlers with difficulties in all spheres of development, including the social and behavioral domain. It called for interdisciplinary services from a wide range of disciplines, both educational and health-related, as well as case management services, home visits, parent training, counseling, and the full range of allied health benefits and educational benefits. It also mandated that a family service plan be developed and carried out.

The content required of the family service plan was specific, family- and strengths-focused, completely individualized, and outcome-oriented. It required objective demonstration of the child's progress and benefit. It required specification of the nature, frequency, and method of each type of intervention provided. Finally, it required that parents receive the help and information needed to participate in the educational decision-making processes, including the development of the child's individualized educational program, as well as the right to obtain information about what programs, services, and resources were available to children with disabilities and the degree to which the programs, services, and resources were appropriate for their child.

This family-centered orientation was a drastic change from the medical model of therapy delivery for infants and toddlers that prevailed at the time. Parents were required to be at the table, fully informed on all available services and members of the decision-making group establishing a service plan for their child—and for themselves. This focus on supporting the family set in place the idea of parents and professionals as partners in all aspects of infant–toddler identification assessment and intervention. It also reflected the importance of professionals learning about the challenges to families created by a young child's delays or disabilities, and of supporting families and parenting in order to support children's development. The focus on services at home and in typical community settings further emphasized the socioecological Bronfenbrenner model of child development (1986) and its grounding in the family, home, neighborhood, and community for supports. Working at home with parents to help them incorporate children's intervention needs into everyday life developed during these years as a primary delivery model for children from birth to age 3 (Brown & Moersch, 1978).

It is interesting that in 2021 these principles are often set aside for young children with ASD in favor of an intensive one-on-one therapy model, likely due to the downward extension of what some consider a "best practices" model of service delivery for older children with ASD. One wonders what has been gained and what has been lost by replacing the family-centered model of infant–toddler intervention described in Public Law 94-457 with a direct intensive service model.

Key Practice: Parent Coaching and Family-Centered Care

Coaching approaches can be found within sports, business, education, humanistic psychology, behavioral and cognitive psychology (Allcorn, 2006). Grant (2006) suggests several common themes that unify the widely different contexts and practices in which coaching occurs:

1. Relationships are egalitarian and collaborative, rather than authoritarian.
2. The process begins with defining goals, constructing plans, and working systematically toward goal attainment.
3. Goals involve personal growth or self-directed learning rather than treatment, recovery, or diminished symptoms.
4. Goal setting is a collaborative process.
5. Coaches are not necessarily content experts, but they are process experts.

These themes and values resonate with the kinds of relationships that we authors have maintained in parent coaching relationships with families and with the values that we hold as clinicians. The development of our parent coaching approach has been powerfully influenced by many voices. Two, in particular, require mention. Carl Dunst has provided an unwavering voice and key research in support of family-centered care (Dunst & Trivette, 2009a, 2009b; Dunst, Trivette, & Hamby, 2007). His research findings and values have influenced an entire generation of early intervention practices. Ann Turnbull, a professor of special education and the parent of a child with disabilities, has powerfully voiced the necessity of parental advocacy and parent–professional partnerships in order to create a world of inclusive education, work, and supports for persons with developmental disabilities (Turnbull & Turnbull, 2015). Dunst's and Turnbull's visions, advocacy, and science have had major impacts on special education and early interventions' transition to a more family-centered focus on parent coaching and parent–professional partnerships.

In 2004, a landmark publication by Hanft, Rush, and Shelden (2004) brought the practice of coaching into early childhood intervention front and center. It clearly articulated a radically different way of working with parents from that to be found in parent training models, like TEACCH and DTT, or the "show-and-tell" or "magic hands" models that came from the health sciences and emphasized hands-on therapy practices. Deeply informed by research in infant–toddler development, infant mental health, the science of adult learning, and communication science, these authors stressed the parent–child dyad as the necessary focus of attention for early intervention, and children's interactions with caregivers within activities of daily life as the necessary source of learning opportunities supported by early intervention. Their work continues at this time with their collaboration in the Family, Infant and Preschool Program (FIPP) and a second coaching handbook (Rush & Shelden, 2011). Starting from the Hanft et al. (2004) text, the Rush and Shelden (2011) text, and the FIPP website materials (*www.fipp.org*), and also deeply influenced by the knowledge and practice base of infant mental health (Fraiberg, Adelson, & Shapiro, 1975; Stern, 1985; Zeanah, Berlin, & Boris, 2011), we constructed and tested a parent-implemented ESDM model (P-ESDM) based on parent coaching practices. The framework, materials, and measurement tools that we developed and tested in our multiple P-ESDM studies and our clinical P-ESDM practices are all available in this text.

Parent coaching (as contrasted to parent training or parent education) nests within the larger framework of family-centered care. While the term *family-centered care* is used throughout service delivery systems, not all systems of care that describe themselves as family-centered actually provide care that is centered on family needs, family strengths, family beliefs, family values, and family routines and practices. Two main factors in family-centered care have to do with shared decision-making and parent–professional communication styles. The concept of family-centered care gained much of its momentum from the advocacy of parents of children with developmental and chronic health needs in the 1980s:

> In a system-centered model, care processes are structured to facilitate the function of health care professionals to serve patients; patients must adapt to the constraints of the system. When a patient-centered model is used, the opposite is true: The system accommodates the individual. In pediatrics, patient-centered care is typically referred to as *family-centered care* to acknowledge that children's well-being is inextricably linked to that of their families. A family-centered approach requires recognition that families have the most expertise about their child and, therefore, that they have the right and the responsibility to collaborate in medical decision making in behalf of their child. (McGuinn & Worley, 2008, p. 215)

Dunst and Trivette (2009a) proposed a framework for help-giving relationships that empowers families by promoting family competency as it pertains to identifying and managing their child's needs. Their model of empowerment requires specific conditions for both families and professionals: that families acquire (1) an increased understanding of their child's needs, (2) the ability to deploy competencies to meet those needs, and (3) self-efficacy (a belief that they are capable) to do so. Among the desired qualities of help-givers (professionals) in this model are:

(1) that professionals have a proactive stance marked by a belief that help-seekers are already competent or have the capacity to become competent; (2) that professionals create opportunities for competence to be displayed by providing enabling experiences to help-seekers; and (3) that they allow help-seekers to use their competencies to access resources and attribute success to their own actions, not the professional's. In essence, Dunst and Trivette (2009a) suggested that viewing the relationship with help-seekers from a strengths-based perspective rather than one of deficits is a more effective way to achieve desired outcomes for children with special needs and their families. Dunst and his colleagues have been leaders in advocating, defining, demonstrating, and examining family-centered care for decades. Their work to transform early intervention practices from "a deficit-based, child-focused early intervention to a strengths-based, family-focused early childhood and family support program" (Dunst & Trivette, 2009a, p. 120) began in 1975 and continues to the present, influenced strongly by advanced in-family systems theories, by the development of ecologically based frameworks for looking at child development (e.g., Bronfenbrenner, 1986), and by a productive program of research (Dunst & Trivette, 2009b) into every aspect of the model that has generated considerable support. Table 2.1 condenses descriptors of family-centered care from McGuinn and Worley (2008) and coaching practices from Hanft, Rush, and Shelden (2004).

Conclusion

The importance of family interactions and routines as the context for children's early learning was a compelling concept behind the 1975 creation of the Education for All Handicapped Children Act (Public Law 94-142). The concepts and law were extended to infants and toddlers with risks and disabilities (Part C of IDEA) to enhance infant–toddler development and to provide support for families to meet the special needs of their young child, as well as to reduce the downstream governmental costs of treatment and education by intervening as soon as intervention needs were recognized and by emphasizing least-restrictive environments. Both the law and findings from decades of research on infant–toddler development of both typically and atypically developing young children over the past 4 decades emphasize the necessity of (1) supporting positive parent–child relationships fundamental to optimal early development, and (2) supporting caregivers in each child's natural environments and activities, to understand and support the young child's development—in order to optimize child and family outcomes.

Table 2.1. **Similarities and Differences in Family-Centered Care and Parent Coaching Concepts**

Family-centered models of care	Coaching in early childhood intervention
Parents are experts on their children.	Coach and parents pool their expertise.
Parents need to be part of the decision-making process.	Parents and coach make decisions together.
Identifying family strengths and needs.	Emphasis on assessment of family strengths and needs for support; parents' goals, values, practices.
Relationship between medical personnel and parents should be collaborative.	Collaborative, partnership relations.
Importance of culturally sensitive care.	Importance of cultural sensitivity and learning from family.
Importance of community ties and community-based supports.	Community-based activities and supports.
Treat families with respect and support.	Mutually respectful partnership.
Optimal child functioning reflects supportive family and community.	Intervention focused on child participation in the family and community.
Needs of all family members must be considered.	Supporting family means supporting all its members.
Services need to be easy for parents to use.	Skills being coached need to be easy to learn and easy to implement in everyday contexts.
Providing honest, unbiased information to families.	Having honest reciprocal exchanges and sharing reflections and evaluations.
Honoring diversity in all its aspects within families.	Having honest reciprocal exchanges and sharing reflections and evaluations.
Respecting different methods of coping and use of supports.	Acknowledging and building on parents' ways of coping and their use of their own supports.
Importance of parent–parent support and social support systems for the child and family well-being.	Attention to social network that supports parents and family, focus on community relations more than professional relations.
Services organized and designed based on child–family needs, not agency needs.	Coaching services designed based on family needs and preferences.
Interdisciplinary care and comprehensive services.	Coach functions in an interdisciplinary way—addresses all child's treatment goals.

Note. Data from McGuinn and Worley (2008) and Hanft, Rush, and Shelden (2004).

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New York, NY 10001
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