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Abstract

The central role of family support in programs serving young children with disabilities was emphasized in Public Law 99-457. In the ensuing 25 years, much work has been done to describe the principles and practices that characterize effective family support. Less clear is whether and how programs serving infants, toddlers, and preschoolers promote family outcomes. This article describes the components of family-centered practice and summarizes the data in support of the use of such practices. The authors show that early intervention and preschool programs are not held accountable for family outcomes; instead, they are limited only to showing that families are satisfied with services. The authors predict that family outcomes will not be part of any national accountability effort in the near future until research clearly shows that such outcomes ultimately will benefit children, and they suggest several lines of work needed to advance the field toward making an informed policy decision about documenting family benefit.

Keywords

accountability, families, outcomes

When Public Law 99-457 was passed 25 years ago, it recognized the unique role of families in the development of young children with disabilities. Evidence of this is most salient in the requirement that infant and toddler programs must create an Individualized Family Service Plan (IFSP) for all children served and their families. The IFSP should be developed in concert with the family and can contain both family- and child-directed services. Section 619 of the law also mandated the provision of services for children of 3 to 5 years, although the focus on families is geared toward participation in the assessment and decision-making process. The passage of the law, now known as the Individuals With Disabilities Education Act, prompted substantial research on families in early intervention and preschool programs (e.g., Bailey et al., 1986; Brooks-Gunn, Berlin, & Fuligni, 2000; Dunst, Trivette, & Deal, 1988).

In recent years, there has been a growing priority to measure the efficacy of programs that serve young children with disabilities and their families. Accountability has traditionally focused on whether children and families have received the services to which they are entitled, the quality of those services, family satisfaction, and the attainment of goals and objectives as specified in the annual individualized plans required for each eligible student (Bailey, 2001). But in response to increasing demands for accountability and demonstration of results, in 2005 the Office of Special Education Programs (OSEP) in the U.S. Department of Education began requiring state early intervention and preschool

special education programs to report the percentage of infants and toddlers with IFSPs or preschool children with Individualized Education Plans who demonstrate improvements in (a) positive social-emotional skills (including social relationships), (b) acquisition and use of knowledge and skills (including early language/communication and early literacy), and (c) use of appropriate behaviors to meet their needs (Hebbeler & Barton, 2007; Hebbeler, Barton, & Mallik, 2008).

Historically, evidence of school success has rested entirely on child outcomes such as these, either in school or following school completion. We agree that the assessment of child outcomes is a *necessary* aspect of any effort to determine whether education has attained its stated goals. If students do not show clear benefits, schools will have failed in achieving this fundamental mission. But in the case of early intervention and preschool special education, is a singular focus on child outcomes *sufficient* evidence of benefit? For nearly 30 years, we and others have argued that a family-centered approach must be a central component of any program serving young children with or at risk for

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disability, and that as a result, family benefit is a reasonable and desirable expectation. But early intervention and preschool programs are not currently held accountable for family outcomes other than satisfaction with services, suggesting that family benefits are neither necessary nor sufficient indicators of program efficacy.

In this article, we briefly review the nature and status of family-centered services and family outcomes in the early childhood years. We predict that until tangible family benefit can be convincingly shown to be either cost-effective or of direct measurable benefit to the child, outcomes for children will remain at the center of program accountability. Based on this assumption, we discuss five initiatives now needed to provide a sufficient evidence base to determine whether family outcomes should be included in efforts to establish program efficacy.

Family-Centered Practices

The essential components of a family-centered approach in early intervention, early childhood special education, and medical settings such as pediatric hospitals or primary care have been well documented in other literature. Here, we provide only a brief summary to set the stage for a discussion of family outcomes. The essential assumption of a family-centered approach is that young children cannot be viewed apart from their families, nor can services be provided without a consideration of the family context. In fact, families are seen not as clients receiving services but as partners in making decisions about goals and activities. Core principles of a family-centered approach include focusing on family strengths, respecting family diversity and values, encouraging family decision making and empowerment, communicating with families in an open and collaborative fashion, adopting a flexible approach to service provision, and recognizing the value of informal support systems (Bailey, Raspa, Humphreys, & Sam, 2011; Brewer, McPherson, Magrab, & Hutchins, 1989; Dunst, 2000; McWilliam, Tocci, & Harbin, 1995; Perrin et al., 2007).

From a philosophical perspective, family-centered principles and practices enjoy wide support and have been adopted as recommended practice by various professional and scientific groups and in a variety of settings, including the Institute of Medicine (2001), pediatrics (American Academy of Pediatrics, 2003), hospitals (American Hospital Association, 2009; Muething et al., 2007; O'Malley, Brown, & Krug, 2008), early intervention and early childhood special education (Sandall, Hemmeter, Smith, & McLean, 2005), and allied health professions (e.g., American Speech-Language-Hearing Association, 2008). Most reviews, however, suggest that, despite the almost universal recommendation for a family-centered approach, implementation has been a challenge due to factors such as leadership, training, attitudes, and lack of resources (Gooding et al., 2011; Kuo, Houtrow, et al., 2011;

Perrin et al., 2007; Piper, 2011). For example, recent large-scale studies based on the Medical Expenditure Panel Survey (Raphael, Mei, Brousseau, & Giordano, 2011) and the National Survey of Children With Special Health Care Needs (Coker, Rodriguez, & Flores, 2010; Kuo, Bird, & Tilford, 2011) found that only about two thirds of families of children with special health care needs reported experiencing family-centered care. A survey of hospitals found that only about half reported that they were using family-centered rounds in pediatric inpatient settings (Mittal et al., 2010). Minority families generally report fewer family-centered services and less satisfaction with services (Bailey, Nelson, Hebbeler, & Spiker, 2007; Coker et al., 2010).

Family Outcomes

A family-centered approach is a philosophy and a set of practices that characterize service delivery. In contrast, a family *outcome* is a benefit that families receive as a result of services. For the most part, family outcomes in early intervention and early childhood special education have been limited to those specified as part of a particular model, curriculum approach, or research study. For example, Dunst's (1985) early writing argued that parent empowerment ought to be the primary indicator of the success of early intervention, more recently broadened to consider six domains: parenting, well-being, child behavior, social support, self-efficacy, and satisfaction (Dunst, Trivette, & Hamby, 2007). Turnbull and colleagues (e.g., Turnbull, Summers, Lee, & Kyzar, 2007) emphasize family quality of life. Recent literature reviews and meta-analyses of research across a wide range of medical and early intervention service sectors have examined the extent to which family-centered practices are related to wide variety of outcomes, such as more efficient use of services, family satisfaction with services, family well-being, parenting practices, and improved health or developmental outcomes for children (Bailey et al., 2007; Dunst et al., 2007; Dunst & Trivette, 2009; Gooding et al., 2011; Kuhlthau et al., 2011; McBroom & Enriquez, 2009; Piotrowski, Talavera, & Mayer, 2009; Raspa et al., 2010). These studies consistently show that family-centered practices have positive effects in a diverse array of child and family domains.

Our own thinking about family outcomes has evolved over the years. In 1986, we (Bailey et al., 1986) proposed a model of "family-focused intervention," with four primary goals: (a) helping families cope with the unique needs of caring for and raising a child with a disability, (b) helping families understand their child's development and needs, (c) promoting high-quality parent-child interactions, and (d) preserving and reinforcing family dignity and independent decision making. Later, we proposed eight family outcomes to be assessed as part of the National Early Intervention Longitudinal Study (Bailey et al., 1998): (a)

Does the family see early intervention as appropriate in making a difference in their child's life? (b) Does the family see early intervention as appropriate in making a difference in their family's life? (c) Does the family have a positive view of professionals and the special service system? (d) Did early intervention enable the family to help their child grow, learn, and develop? (e) Did early intervention enhance the family's perceived ability to work with professionals and advocate for services? (f) Did early intervention assist the family in building a strong support system? (g) Did early intervention help enhance an optimistic view of the future? and (h) Did early intervention enhance the family's perceived quality of life? We found that at the conclusion of early intervention, when the child was 36 months of age, most families felt competent in their ability to help their child develop and learn, advocate for services, and build support systems, and families were generally satisfied with services provided and optimistic about the future (Bailey et al., 2005). In a subsequent publication, we showed that parent perceptions of the quality of family services had a direct relationship to their perceptions of program impact on the child and the family (Bailey et al., 2007).

Clearly, family-centered practices, when used in early intervention and early childhood special education programs, can affect a wide range of outcomes. However, there is a difference between the assessment of outcomes for a research study or project evaluation, and the assessment of outcomes as part of a program accountability initiative. From an accountability perspective, the question shifts from "What are the possible benefits of services?" to "What are the outcomes for which programs are accountable?" The latter question adds another layer of complexity and raises the stakes considerably because it sets an expectation for demonstrating certain benefits and naturally evokes fears over what will happen to the program if outcomes are not achieved at expected levels, such as a possible cut in funding. Although program administrators might accept the need to be accountable for child outcomes, demonstrating benefit to families is more controversial, and thus any effort to start such an initiative would require substantial stakeholder involvement to reach a consensus as to the relevant outcomes to measure.

To answer the question, "What family outcomes should be measured as part of an accountability initiative for early intervention and early childhood special education programs?" we engaged in an evidence-based process with substantial stakeholder input as part of the Early Childhood Outcomes (ECO) Center. Five recommended outcomes emerged from this process. Families participating in programs for young children with disabilities should (a) understand their child's strengths, abilities, and special needs; (b) know their rights and advocate effectively for their children; (c) help their child develop and learn; (d) have support systems; and (e) access desired services, programs, and activities in their community (Bailey et al., 2006).

Current Expectations for Reporting Family Benefit

The five family outcomes were generated as part of a project funded by OSEP to help the department determine what indicators states should be asked to report each year (Hebbeler & Barton, 2007; Hebbeler et al., 2008). But for a variety of reasons, OSEP made a decision not to ask states to report the recommended family outcomes. Instead, for programs serving infants and toddlers with disabilities, states are now required to report the percentage of families who report that early intervention has helped them (a) know and understand their rights, (b) communicate their child's needs, and (c) help their child develop and learn. For preschoolers ages 3 to 5 years, states are required to report the same indicator that is used for all children with disabilities ages 3 to 21: the percentage of parents with a child receiving special education services who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities. Thus, for both infant-toddler and preschool programs, the family indicators reflect family's perceptions of perceived helpfulness, essentially an indicator of family satisfaction with services received.

We reviewed the annual data submitted by states for the infant-toddler indicators. The 2005–2006 year was considered baseline, after which states were to begin reporting perceived helpfulness in each of the three indicators and, when appropriate, setting targets for improvement. Across all reporting periods, most (80%–90%) families acknowledged helpfulness in each area, with only slight differences among the indicators—parents were somewhat more likely to say that the program had helped them help their child develop and learn (mean of 88% across the three data years) than it helped with knowing rights (mean of 82%) or communicating their child's needs (mean of 83%). However, there were a few outlier states. Across each of the years, 5 to 10 states consistently reported lower percentages of families (less than 70%) who said that early intervention had helped their family with each of the three indicators. The reasons for lower percentages are unknown; they could be due to variations in program models or practices, different populations served, or methodological differences in data collection such as the instrument used, calculation of cutoff scores, or representativeness of the sample.

With regard to data from preschool programs, the Technical Assistance ALLIANCE for Parent Centers has been preparing annual reports summarizing state data on the age 3-to-21 family indicator. Most states do not break out the data for the 3-to-5 programs, and so we have little knowledge of parent perceptions of helpfulness in preschool. For total state data across the last three reporting periods, the mean percentage of parents reporting that schools facilitated parent involvement was 64 (2006–2007), 63 (2007–2008), and 66 (2008–2009). For the states that did report preschool

separately, the percentages for the 3-to-5 age group were 68 (2006–2007, $n = 5$ states), 69 (2007–2008, $n = 6$ states), and 69 ($n = 9$ states), respectively. These figures are lower than the percentages for the infant–toddler programs, but of course this is a different item and different measures were used across states, making it virtually impossible to compare. However, the range was greater than that seen in infant–toddler programs, and 22 states reported that fewer than 50% of parents report that schools have been helpful.

Future Directions

To summarize, a family-centered approach is now recommended as an important component of early intervention and preschool programs, as well as in pediatric practice. Research provides strong evidence that this approach has many benefits for children and families, but most of this research has been conducted in medical settings, not early intervention and preschool settings. Concerns remain about the extent to which family-centered practices are actually used in practice. A majority of families in infant–toddler and preschool programs report that programs have been helpful to them, though less so in preschool programs. And although a set of family outcomes has been recommended for early intervention and preschool programs, states are not expected to report on such outcomes, and we have no way of knowing, at a national level, the extent to which family outcomes have been achieved.

Although we have long argued that families ought to benefit from early intervention and preschool programs and that such benefits should be documented, it is unlikely that family outcomes will become part of any state or national accountability efforts in the near future. Competing needs for scarce resources means that most advocacy efforts will continue to focus on enhancing the amount and quality of services for children; this will especially be true in the current economic climate, when many states are looking for ways to reduce investments in state-funded programs. Federal officials are reluctant to ask states to collect more data when states already complain about the administrative burden of multiple reporting requirements. And despite compelling research indicating the real potential for showing family benefit, local programs are concerned that being expected to implement a family-centered approach to services and to demonstrate family outcomes as a result of those services goes beyond the capability, training, and comfort level of program staff and services.

We predict that child services and child outcomes will remain at the center of program accountability in the foreseeable future for early intervention and preschool programs until it can be demonstrated in a convincing and compelling fashion that (a) family-centered practices lead to measurable family outcomes *and* (b) the resultant family outcomes lead to direct and measurable benefit to the child. If family

outcomes cannot be demonstrated to result in benefits for children, then a different type of cost-benefit analysis will be needed to show that the attainment of family outcomes in and of themselves results in demonstrable cost savings for society.

If these assumptions are accurate, an integrated program of research tightly organized around a strategic agenda designed to provide policy-relevant information will be needed. We suggest five considerations in developing such an agenda.

First, the extent to which early intervention and preschool programs use family-centered practices needs further documentation, and the factors associated with variation in the use of family-centered practices need to be identified. Maximum benefit to families assumes that programs and services are intentionally organized and use the practices known to achieve such benefit. Multiple recent large-scale studies in the medical sector, however, show that the widespread push for family-centered care has not resulted in full adoption of family-centered practices (Coker et al., 2010; Kuo, Bird, et al., 2011, Mittal et al., 2010; Raphael et al., 2011). Some evidence suggests that the same is likely true in early intervention programs (Bailey, Buysse, Edmondson, & Smith, 1992; McWilliam et al., 1998; Zhang, Bennett, & Dahl, 1999), but these data are relatively old, the studies use small samples of convenience, and nothing is known about family-centered practices in preschool (ages 3–5 programs). Needed are large studies of representative samples of early intervention and preschool programs, comparable with studies now available in the medical community. Such studies should use multiple sources of information (parent ratings, practitioner reports, direct observation) to document the extent to which typical professional interactions and program practices build on family-centered principles and embed across all program activities (e.g., assessment, program planning, service delivery, service coordination), the practices known to promote family outcomes (Bailey et al., 2011; Turnbull, Summers, Turnbull, et al., 2007). Factors associated with cross-program variability (e.g., local leadership, state guidelines, professional training, nature of the families served) need to be identified. This line of work should result in a comprehensive description of the status of family-centered practices in early intervention and preschool programs and a clear understanding of the major factors that explain why some programs are more family centered than others. This information is needed to determine whether there is need for new initiatives to promote family-centered practices and the targets most likely to result in improvement in factors known to be effective in supporting and engaging families.

Second, the mechanisms or pathways by which family-centered practices lead to improved child and family outcomes need to be modeled and understood. Data in support of the argument that families exert tremendous influence on

their child's development have been evident in hundreds of studies ranging from small and focused research projects to meta-analyses of multiple large data sets, and it is now generally well accepted that the nature and quality of parent-child interactions and family-orchestrated child experiences are powerful determinants of child development (see Guralnick, 2005; Head & Abbeduto, 2007; Warren & Brady, 2007). A logical extension of these data is that anything that programs can do to enable and support families ought to have direct benefit for children. Some family characteristics such as maternal responsivity are likely to exert wide-ranging influence on children's development (Warren & Brady, 2007), but others might be more focused.

Many studies in pediatric practice have shown that family-centered practices can improve physical, psychological, developmental, and health outcomes for children (e.g., Gooding et al., 2011; McBroom & Enriquez, 2009), and some evidence of this is available in early intervention programs for children with disabilities (Dunst & Trivette, 2009; Raspa et al., 2010). But research is needed to determine how family-centered practices are related to child and family outcomes. For example, is there a direct relationship between what professionals do with children and the outcomes they achieve, or is this path mediated by family outcomes? Which family outcomes are directly related to child outcomes? Is there a one-to-one correspondence between helping a family know how to help their child develop and learn (family outcome) and a child acquiring and using new skills (child outcome)? Or, rather is it that multiple family outcomes are linked with individual child outcomes? Which practices need to be individualized and which ones are appropriate for all families?

Questions such as these need to be further explored using existing theories and methods such as structural equation modeling (Dunst et al., 2007). For example, one structural equation modeling meta-analysis suggested that the effects of family-centered care on child and family well-being were indirect, and mediated by parental self-efficacy beliefs (Dunst & Trivette, 2009), but another study using structural equation modeling showed that informal support provided to families was strongly related to confidence in parenting and optimism, but that neither optimism nor confidence in parenting mediated the relationship between quality of services received by children and families and perceived impact (Bailey et al., 2007).

At a practical level, using state data from early intervention and preschool programs to study the link between program practices and child and family outcomes will be challenging. For example, many states do not coordinate the collection of child and family data. Both child- and family-level assessments would need to be conducted and coordinated with each family to examine whether programs that have used more family-centered practices have children and families who have better outcomes. In addition, most states

collect de-identified family information to ensure confidentiality. Linking family and child data would be difficult unless a common variable was created. Some states are in the early stages of being able to link their data, so it will be possible to begin exploring the relationship between child and family outcomes in the near future.

Third, the opinions of stakeholders regarding the desirability and utility of family outcomes assessment within preschool programs need to be studied in a more comprehensive fashion. The ECO Center developed the five family outcomes with the input of a variety of stakeholder groups. Although the goal was for these outcomes to be adopted by both infant-toddler and preschool programs, neither group is required by the federal government to collect these data. A more in-depth analysis of the utility of family outcomes needs to be conducted with an extensive network of special education professionals (e.g., teachers, therapists), local educational agencies, state program officials, federal staff, and families. Gathering input from multiple stakeholders will ensure that all those involved in program accountability will be invested in measuring family outcomes across the early childhood years.

Many professional organizations espouse family-centered care; however, there are few established guidelines or recommendations about adopting family outcomes in program efficacy or accountability evaluations beyond those proposed by the ECO Center. For example, the National Goals Conference convened more than 200 experts to recommend research goals and activities for individuals with intellectual and developmental disabilities (Lakin & Turnbull, 2005), including ones related to supporting families. Another consortium of professionals, which was part of the Federal Interagency Coordinating Council's Subcommittee on Service Integration and Continuity of Services recommended different levels of program evaluation, such as outcomes related to children and families (Roberts, Innocenti, & Goetze, 1999). Finally, the Council on Quality Leadership (2004), in collaboration with their member organizations, developed a set of principles for programs that work with families of young children with disabilities. Following similar processes for the development of family outcomes for preschool programs would ensure that different opinions and perspectives would be reviewed and evaluated to determine the best set of recommendations that all groups would agree on.

Fourth, the issue of whether family outcomes and outcomes assessment for infants and toddlers differ from family outcomes and assessment for preschoolers needs consideration. Families are at the core of a child's development from birth and into adulthood. The nature and complexity of a family's involvement in their children's lives change over time and there are natural transition periods, such as when a child begins formal schooling. Should family outcomes change depending on the age of the child or the type of

program from which the child is receiving services, or should there be a core set of outcomes that are examined and measured for all families? Furthermore, OSEP currently does not separate preschool family outcomes from those for older children, but it is likely that family experiences for young children differ substantially from those of other children.

There is limited research that has examined how programs work with families across the early childhood years. Some recent work has advanced the theory that researchers and practitioners should take a broad perspective of early childhood development, from birth through 8 years of age (National Association for the Education of Young Children, 2009; Ritchie, Maxwell, & Bredekamp, 2009). Another study by Dunst (2002) explored family-centered practices from birth through high school. Results indicated that early childhood programs (i.e., early intervention and preschool programs) were more family centered than elementary and secondary schools, although there were fewer studies in each successive level of schooling. The author concludes that there is “a tremendous need for additional information to inform policy and practice . . . [such as using] similar conceptual frameworks, constructs, and measurement procedures in studies at all school levels” (p. 145). Although there are challenges to having a coordinated approach to assessing family outcomes across the early childhood years, the issue deserves consideration, and once a decision is made there should be a sound rationale to support it.

Finally, the argument that family benefit is a worthwhile outcome, even in the absence of direct impact on child development, needs to be substantiated. Ultimately, the field needs to determine whether helping families is a necessary and sufficient indicator of program efficacy. Our belief is that families are central to the lives of their children, and measuring the benefits families receive as a result of receiving services is important in its own right. Although we have argued earlier that all early childhood programs be held accountable for family outcomes (Bailey et al., 2006), the field has not advanced significantly in the past 5 years. Much remains to be done to substantiate the need for family outcomes.

Research continues to document that family adaptation is critical to having a child with a disability (Bailey, Sideris, Roberts, & Hatton, 2008; Wheeler, Sideris, & Bailey, under review) and that family and environmental factors are strong influences on a child’s development (Guralnick, 2011). Work in the area of child mental health also shows evidence that working directly with families is ultimately beneficial to the child (Cook & Khmer, 2004; Hoagwood et al., 2010; Romanelli et al., 2009). The fields of early intervention and childhood special education need to build additional consensus that working with families is a vital step in helping children with disabilities succeed. Demonstrating this belief will be central if states are asked to document family outcomes in the future.

Conclusion

The central role of family support in early intervention programs serving infants and toddlers with disabilities was established in Public Law 99-457, and a family-centered approach enjoys widespread and almost universal endorsement in literature and policy statements of a variety of professional societies. Data suggest, however, that despite research documenting the potential benefits of family-centered services, full implementation in practice is difficult to achieve. And although logic would dictate that family-centered services should result in positive outcomes for families and children, programs serving young children with disabilities are not expected to demonstrate such benefit. Understanding, promoting, and measuring outcomes for families of young children with disabilities have been relatively ignored. Whether and how programs should be held accountable for family benefit stands as a formidable challenge for our field, but one that must be addressed if we are to fulfill the implicit and explicit expectations of services provided prior to kindergarten.

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