

Family-centred practice: collaboration, competency and evidence

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In the 1990s, the developing field of early intervention with young children with disabilities and their families adopted family-centred practice as its philosophical foundation. Family-centred practice includes three key elements: (1) an emphasis on strengths, not deficits; (2) promoting family choice and control over desired resources; and (3) the development of a collaborative relationship between parents and professionals. During the last two decades, the field of early childhood disability has successfully defined the working principles of family-centred practice for practitioners. Although research has acknowledged that the paradigm shift to family-centred practice is neither simple nor easy, a substantive body of evidence demonstrates that (a) family-centred practice can be linked to a wide range of demonstrated benefits for both children and families, and (b) families are more satisfied and find family-centred practice to be more helpful than other models of practice.

Keywords: intervention, collaboration, family-centred practice.

Family-centred practice is a term not unfamiliar to professionals who educate and support children and adults with special educational needs. In essence, family-centred practice is a systematic way of creating a partnership with families that (a) treats them with dignity and respect, (b) honors their values and choices, and (c) provides supports that strengthen and enhance their functioning as a family (Dunst, Trivette and Hamby, 2007a). At this point in time, we know a great deal about family-centred practice: its history, its principles and its impacts, all of which will be discussed in this article. By its very definition, however, any overview of family-centred practice is incomplete without the voice of families guiding our way:

When my son was born in 2004, I was thrilled beyond belief as I finally had my little boy. Someone I could teach to play,

if he wanted to, the sports I so loved as a child: baseball, football, basketball and hockey. I had my little buddy.

All along he wasn't a happy little boy. It started right away: when we'd take him for a ride in his car seat, he would just scream. It got so that we started feeling a lot of anxiety when we thought about having to go someplace as a family. This was the start of our family life taking a turn we hadn't expected it would. Then he actually turned over onto his tummy, and he seemed to sleep better. Finally we were turning the corner. Yes, we were – just not the way we had hoped.

Our son wasn't pointing, nor did he have any vocabulary. When his typical peers were babbling, we got none of that from him. Nothing like his big sister, but boys are different than girls, we were told. We called his name, and he acted as if he didn't hear us. We had hearing tests and initially he failed. However, when we did a more comprehensive one he passed.

Finally, our pediatrician told us that he thought he might have autism. We scheduled an appointment for a developmental pediatrician in the summer of 2006. It was the day the world became a very sad place for me and my family. It was the day our son was formally diagnosed with autism. Things that were important to me before, no longer seemed to be very important. Gardening, which I really loved, no longer meant anything to me. Our beds, flowers, roses became overgrown, and honestly I didn't care.

We struggled to find meaning to this: why us, why our son? There were no answers. The treatment options were even less optimistic. We could do a program at a well known nearby hospital for \$70,000 per year and go bankrupt in the process. We could also do some early intervention through our county, although there were waiting lists, which seemed to be the case everywhere we went. When our son turned two, we finally got into our local early intervention program. They did the best they could under the circumstances; they were understaffed, under-funded and not really fully prepared to deal with kids on the spectrum.

Yet we struggled in trying to find the best treatment for our son. It just so happened that our service coordinator knew of this facility that worked with a lot of kids on the spectrum. They had an early intervention program but of course it had . . . you guessed it . . . a waiting list. Finally we got in and met with them on what was the snowiest day of the season; we had over 12 inches of snow that day. And when we left our house, I thought, "Tell me again why we are going all the way to this place?" It's over 22 miles one way, and took us over an hour to get to.

When we got there, I realized why. It truly was a center not only for the child but also a center that worked to develop a partnership and strategy to help heal the whole family. We felt like we had just been rescued by the Coast Guard, after being left out adrift for almost a year, by someone who understood and who could provide us the much needed assistance to make our lives and my son's life infinitely better.

Recognising family-centred practice

References to family-centred practice can be found as early as the 1950s; in the mid-1970s, Bronfenbrenner (1975) described the impact of family involvement on the developmental and educational outcomes of children. However, the concept did not become part of widespread conversations about practice with children with disabilities and their families until the late 1980s, when the Association for the Care of Children's Health (ACCH) published the core elements of family-centred practice in the care of children with special health care needs (Shelton, Jeppson and Johnson, 1987). These core elements included the following:

- recognising that the family is the constant in the child's life;
- facilitating parent-professional collaboration at all levels, from individual care to programme development/implementation/evaluation to policy formation;
- honouring the racial, ethnic, cultural and socio-economic diversity of families;
- recognising family strengths, individuality and different methods of coping;
- continually sharing complete and unbiased information with parents in supportive ways;
- encouraging family-to-family support and networking;
- creating systems that incorporate the developmental needs of children and their families;
- implementing comprehensive policies and programmes that provide emotional and financial support to meet the needs of families;
- designing accessible service systems that are flexible, culturally competent, and responsive to family-identified needs.

In essence, family-centred care was defined as:

a philosophy of care in which the pivotal role of the family is recognized and respected . . . [in which] fami-

lies should be supported in their natural caregiving and decision-making roles . . . [in which] parents and professionals are seen as equals.

(Brewer, McPherson, Magrab and Hutchin, 1989, p. 1056).

In the 1990s, the developing field of early intervention with young children with disabilities and their families adopted family-centred practice as its philosophical foundation. Family-centred practice was (and continues to be) defined as:

a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing.

(Dunst, Johanson, Trivette and Hamby, 1991, p. 115).

Family-centred practice recognises that, if working with families is to have positive effects, then *how* intervention is provided is as important as *what* is provided (Henneman and Cardin, 2002; Trivette and Dunst, 2000). Family-centred practice includes three key elements: (1) an emphasis on strengths, not deficits; (2) promoting family choice and control over desired resources; and (3) the development of a collaborative relationship between parents and professionals (Dunst, Trivette and Deal, 1994).

What does this model look like in day-to-day practice? How can family-centred practice be distinguished from other models? Professional practices have been described as falling along a continuum, from a professionally-centred model at one end to a family-centred model at the other; the models on the continuum are distinguished by the roles, use of expertise, and decision-making power of families (Dunst, Johanson, Trivette and Hamby, 1991):

- *Professionally-centred model*: Professionals are the experts who determine what the child and family needs and how to meet those needs. Families are expected to rely and depend upon the professional, who is the primary decision-maker.
- *Family-allied model*: Professionals view families as being able to implement intervention, but the needs of the child and family and intervention continue to be identified by the professionals.
- *Family-focused model*: Professionals view families as consumers who, with assistance, can choose among the various options identified and presented to the family by the professionals.
- *Family-centred model*: Professionals view families as equal partners. Intervention is individualised, flexible and responsive to the family-identified needs of each child and family. Intervention focuses on strengthening and supporting family functioning. Families are the ultimate decision-makers.

Multiple studies have demonstrated that these categories of models can successfully be used by raters to distinguish the variations in help-giving practices among individual

professionals (Dunst, 2002; O'Neil, Palisano and Westcott, 2001), programme models and practices (Dunst, Boyd, Trivette and Hamby, 2002; Trivette, Dunst and Hamby, 1996), and government agency policies and procedures (Dunst, Johanson, Trivette and Hamby, 1991). Families who are receiving services can recognise the differences among the models as well; the differences identified appear to be the result of the differing practices associated with the programme models, and not the result of characteristics of the families receiving services (Dunst, Boyd, Trivette and Hamby, 2002; Trivette, Dunst, Boyd and Hamby, 1995; Trivette, Dunst and Hamby, 1996) or the severity of their child's disability (O'Neil, Palisano and Westcott, 2001; Trivette, Dunst, Boyd and Hamby, 1995). Families are more satisfied and find family-centred practice to be more helpful than other models of practice (Judge, 1997; King, King, Rosenbaum and Goffin, 1999; Law *et al.*, 2003; Neff *et al.*, 2003; Trivette, Dunst and Hamby, 1996; Wade, Mildon and Matthews, 2007).

The program models either implicitly or explicitly adopted by helping organizations and agencies mattered a great deal in terms of how professionals were judged by people they were attempting to help.

(Dunst, Boyd, Trivette and Hamby, 2002, p. 227).

During the last two decades, the field of early childhood disability has worked hard to define the working principles of family-centred practice for practitioners. In the recommended practices publication of the Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) (Sandall, McLean and Smith, 2000), family-based practices are defined in the following way:

Family-based practices provide or mediate the provision of resources and supports necessary for families to have the time, energy, knowledge and skills to provide their children with learning opportunities and experiences that promote child development. Resources and supports provided . . . are done in a family-centered manner so family-based practices will have child, parent and family strengthening and competency-enhancing consequences.

(Trivette and Dunst, 2000, p. 39)

Seventeen evidence-based, family-centred practices are identified and grouped into four categories (Trivette and Dunst, 2000):

1. *Families and professionals share responsibility and work collaboratively*: This group of practices focuses on the development of relationships, shared power and control, and professionals' complete sharing of information so that families can make informed decisions.
2. *Practices strengthen family functioning*: This group of practices emphasises providing supports and resources in ways that build parents' sense of confidence and competence, using not only formal but informal supports and resources, and enhancing families' abilities to have what Carpenter (2007) describes as 'a normal life'.

3. *Practices are individualised and flexible*: This group of practices underscores the importance of shaping intervention to fit the needs, priorities and values of each child and family; of not making assumptions about the family's beliefs and values; and of providing supports and resources in ways that do not add stress.
4. *Practices are strengths-based and assets-based*: This group of practices stresses not only identifying the strengths of each child and family, but *using* those strengths as the building blocks for intervention.

Does family-centred practice make a difference?

In addition to there being a strong rationale for family-centred practice, a growing body of research has tied the use of family-centred practice to positive child and family outcomes (Dunst and Trivette, 2005; King, King, Rosenbaum and Goffin, 1999; Trivette, Dunst, Boyd and Hamby, 1995; Trivette, Dunst and Hamby, 1996; Wilson, 2005). Results of a meta-analysis of 18 studies indicate that the use of family-centred practice was strongly related to self-efficacy beliefs, programme satisfaction, parent perceptions of child behaviour and functioning, and parenting behaviour (Dunst, Trivette and Hamby, 2006). A subsequent meta-analysis of 47 different studies from seven different countries links family-centred practice to greater family satisfaction, stronger family beliefs of self-efficacy and sense of control, and greater family perceptions of helpfulness of programme supports and services (Dunst, Trivette and Hamby, 2007a). Family-centred practice also is related to parent perceptions of their child's behaviour (more positive, less negative), perceptions of their family's well-being, and feelings of parenting competence and confidence (both of which in turn significantly impact on child development). The efficacy of family-centred practice has been shown across types of programmes (hospitals, mental health settings, early childhood settings, rehabilitation settings, schools) (Dunst, Trivette and Hamby, 2007a; Reich, Bickman and Heflinger, 2004) as well as across a diversity of families, including those with parents with intellectual disabilities (Wade, Mildon and Matthews, 2007), parents with children at a variety of ages (Dempsey and Dunst, 2004), parents from differing economic backgrounds (Law *et al.*, 2003; Trivette, Dunst, Boyd and Hamby, 1995; Trivette, Dunst and Hamby, 1996), and parents across cultures (Dempsey and Dunst, 2004). When practices are family-centred, outcomes tend to be broader based with regard to child, parent and family benefits (Dunst, 2002; Trivette, Dunst, Boyd and Hamby, 1995).

Which aspects of family-centred practice are likely to make a difference?

Research has identified two related but distinctly different components of family-centred practice: (1) relational and (2) participatory help-giving practices (Dunst, Boyd,

Trivette and Hamby, 2002). Relational practices are made up of those interpersonal behaviours such as warmth, active listening, empathy, authenticity and viewing parents in a positive light. These are the behaviours used by professionals to build effective relationships with families (Dempsey and Dunst, 2004; Dunst, Boyd, Trivette and Hamby, 2002). Such behaviours have been widely studied, particularly in the mental health literature (Trute and Hiebert-Murphy, 2007), and the strength of the 'working alliance' between parents and professionals has been shown to be related to positive outcomes in a recent meta-analysis (Martin, Garske and Davis, 2000). Participatory behaviours, on the other hand, are more action-oriented, and encompass control and ways of sharing: professionals share all information from families, professionals encourage parents to make their own decisions, professionals encourage families to use their existing knowledge and capabilities, and professionals help families learn new skills (Dempsey and Dunst, 2004; Dunst, Boyd, Trivette and Hamby, 2002).

Why is the distinction between relational and participatory behaviours so important? First, it appears to be the use of *participatory* behaviours that are particularly distinctive of family-centred practice when compared to other models along the continuum (Dunst, 2002). For example, when parents receiving services from professionally centred, family-allied or family-centred programmes rated the practices used by professionals, not surprisingly professionals in professionally centred programmes were rated as poor in using relational or participatory practices, professionals in family-allied programmes received higher ratings for relational than participatory behaviours, and professionals in family-centred programmes were highly rated for their use of both relational and participatory behaviours (Dunst, Boyd, Trivette and Hamby, 2002). Even when examining the variations among family-centred programmes themselves, it is the use of participatory practices, not relational practices, that distinguishes between 'low' and 'high' family-centred programmes (Dunst, Boyd, Trivette and Hamby, 2002). Second, relational and participatory practices impact differently upon outcomes (Dunst, Boyd, Trivette and Hamby, 2002; Trute and Hiebert-Murphy, 2007).

There are value-added benefits of participatory practices beyond those attributable to relational practices, at least in terms of certain parent and family outcomes.

(Dunst, Boyd, Trivette and Hamby, 2002, p. 227)

In other words, being warm and caring and using excellent communication skills does not automatically mean that a professional or programme is family-centred; it is not enough to be 'nice'. Professionals and programmes seeking to be family-centred must not only establish a trusting relationship with families; they must also consciously use specific practices that equalise the balance of power such that families become the ultimate decision-makers and agents of change.

Has family-centred practice been widely adopted?

More than 20 years ago, Healy, Keesee and Smith (1989) predicted the challenges to widespread adoption of family-centred practice in early intervention. They suggested that the difficulty would not be in teaching professionals discipline-specific skills to work with children, but rather in teaching professionals the skills required to work with families in a family-centred way (or, in the words of a quoted administrator, in 'a very inconvenient' way). Since that time, studies have consistently shown that professionals are less family-centred than they think, whether they are working with infants and toddlers with disabilities or with school-age children (Dunst, 2002).

Professionals struggle to include families at the most basic levels, let alone to implement not only relational but also participatory family-centred practices (Campbell and Halbert, 2002; Dunst, 2002; Mahoney and Filer, 1996; McBride and Peterson, 1997; McWilliam, Tocci and Harbin, 1998). One recent study surveying 241 early intervention professionals from a variety of disciplines suggested that many practitioners still are unlikely to adopt and implement family-centred practice, despite the evidence supporting its efficacy (Campbell and Halbert, 2002). Simply put: 'family-centred early intervention remains an elusive goal for our field' (Bruder, 2000, p. 105).

Multiple reasons have been proposed to explain the lag in implementation (Bruder, 2000; O'Neil, Palisano and Westcott, 2001). A frequently cited reason has to do with the *gap between research and practice*. On the one hand, researchers often describe variables and results rather than concrete practices that practitioners can put into use; on the other hand, professionals may not have the time for or interest in reading research (Bruder, 2000; McWilliam, 1999). McWilliam (1999) further speculates that professionals who do have the time and inclination to keep up with published research often tend to believe only the research that supports their values. A second reason appears to be a *lack of effective and available training in family-centred practice* at both preservice and inservice levels; training tends to focus on discipline-specific skills and credentials and may include little direct contact with families (Bailey, Aytch, Odom, Symons and Wolery, 1999; Bruce *et al.*, 2002; Bruder, 2000; Gallagher, Malone, Cleghorne and Helms, 1997). Third, *federal and state rules and regulations* have tended to focus time and attention more on billable services for the child than family-centred practice (Bruder, 2000; Shannon, 2004); professionals describe being caught up in paperwork and productivity (O'Neil, Palisano and Westcott, 2001). Fourth, professionals trained in and committed to family-centred practice have encountered obstacles in day-to-day implementation due to *limited understanding and lack of support from colleagues and administrators* (Murray and Mandell, 2006). Finally, *professional attitudes* can make it difficult to view families as 'experts' and 'equal' members of

the team. Unfortunately, attitudes not only impact child and family outcomes, but are at times almost impossible to change (Affleck *et al.*, 1989; Trivette, Dunst, Boyd and Hamby, 1995).

Although the concept of family-centred practice continues to accumulate evidence supporting its impact on child and family outcomes, the sad reality is that family-centred practice can be characterised as having a 'slow rate of adoption'. Despite the emphasis on and efforts to define and operationalise family-centred practice, certain aspects continue to be used infrequently by professionals (Crais, Roy and Free, 2006).

Family-centred practice as 'flawless consulting'

Every professional reading these words can identify with the temptation to adopt the role of the knowledgeable decision-maker and to encourage the parent to adopt the role of the passive recipient. Studies repeatedly have demonstrated that professionals appear to be far better at utilising relational skills than participatory skills (Dunst, 2002; McBride, Brotherson, Joanning, Whiddon and Demmitt, 1993; Wade, Mildon and Matthews, 2007).

Why are participatory skills so challenging? Professionals adopting a family-centred model are asked to replace the role of decision-maker, agenda-setter, advice-prescriber and expert with the more challenging role of partner, listener, facilitator and *consultant* (Mikus, Benn and Weatherston, 1994). Even professionals highly motivated to engage in family-centred practice can find this paradigm shift to be a challenge. We hear the voices of families describing how they are 'adrift', and we want to be of assistance to them; nevertheless, being a help-giver comes with its own set of challenges:

- The tendency to be too 'impatient'. The more eager we are to assess and intervene, the less helpful we become. 'Curing' others should not be our intent (Maslow, 1962).
- The tendency to focus on being too 'clever'. We tend to use words as techniques to move others in the direction we have chosen, to convince families that our perspective is right (Block, 1981).
- The tendency to be too 'helpful'. We tend to believe that we know and the other does not. As Henning (2001) points out, 'It is our instinct to control that actually interferes with change.'
- The tendency to promote 'codependence'. When we see others as needing our expert help, we can make the mistake of *creating* needs in order to justify our role in their lives (Markowitz, 2001a).
- The tendency to be too 'invested'. Help-givers often feel responsible for the other's 'progress'. However, we cannot assume that our advice will lead to change. 'We

are no more responsible for . . . improvements than for . . . setbacks' (Markowitz, 2001a).

Family-centred practice focuses on the interpersonal relationship between the family and the professional (O'Neil, Palisano and Westcott, 2001). A model of 'flawless consulting' that focuses on a similar relationship between the consultant and the client has been proposed by Peter Block (1981), a well-known consultant and author in the business field. Block makes a key distinction between being a 'consultant' and being a 'manager':

Every time you give advice to someone who is faced with a choice, you are consulting. When you don't have direct control over people and yet want them to listen to you and heed your advice, you are face-to-face with the consultant's dilemma . . . A consultant is a person in a position to have some influence over an individual, a group, or an organization, but who has no direct power to make changes or implement programs. A manager is someone who has direct control over the action. The moment you take direct control, you are acting as a manager. This distinction is important.

(Block, 1981, pp. 1–2).

When professionals ask questions such as 'How can I get the family to see this?' or 'Why won't the family follow through?' they are really asking questions about power and control. The underlying questions ('How can I have power over the family?' or 'How can I get the family to do what I think they should do?') are questions related to participatory practices and the paradigm shift from manager to consultant.

From the perspective of 'flawless' consulting, a relationship characterised by control of the other must be replaced with a relationship characterised by 'engagement'. The question is no longer 'How do I get my own way?' but instead 'How do we commit to working together?' and 'How can we have faith in each other's capacity to contribute to change?' (Henning, 2001). In this kind of relationship, although we care about the other person, we are not responsible for what the other does with our expertise and information; *the other has a right to fail. We are* responsible, however, for how *we* act in the relationship: our behaviour, our way of working, to what degree we are being authentic (Block, 1981).

The pursuit of flawless consulting, like family-centred practice, is more than a simple technique. It requires the systematic use of specific ways of being with others in a relationship (Block, 2001):

- recognising the others as individuals capable of defining meaning and making choices;
- focusing on commitment and shared purpose rather than compliance;
- resisting taking over, giving prescriptive advice, threats and promising more than we can deliver;

- choosing to tell the truth, confess doubts, and forgive;
- not giving up when faced with hostility, indifference or rejection;
- accepting shades of grey;
- paying attention to our own behaviours in the relationship (i.e. the only behaviours that we can control).

Flawless consulting and family-centred practice both comprise relational and participatory components. Flawless consulting and family-centred practice both recognize that trust and confidence in the capacity of the other are critical, since trying to change others means that we have lost faith in them. Flawless consulting and family-centred practice both recognize (a) that there is a significant difference between *making* something happen and *letting* it happen, and (b) that we need to abandon control and judgment (Markowitz, 2001b). Flawless consulting and family-centred practice both require ‘a capacity to care deeply from an objective place’ (Arrien, 1993, quoted in Barbeau, 2001, p. 181). When we apply flawless consulting to family-centred practice, the key questions now become (Barbeau, 2001):

- How can I stand beside the [family] with whom I am working?
- How can I care about the [family] without forgetting whose work this really is?
- How can I support the [family] during the painful and messy times without trying to make everything clean, neat and free of stress?

Some final thoughts

Family-centered care is neither a destination nor something that one instantly becomes. It is a continual pursuit of being responsive to the priorities and choices of families.

(Bissell, n.d.)

We also know that professionals and programmes engaged in this pursuit may not be as family-centred as they believe themselves to be (Dunst, 2002). If one of the principles of family-centred practice is to involve families at all levels, including programme development/implementation/evaluation, then we should be asking families to help us determine the extent to which we are using family-centred practice. Crais, Roy and Free (2006) point out that we should be using not only satisfaction surveys, but also tools that parents can use to rate specific family-centred practices. Dunst, Trivette and Hamby (2007b) have published several scales that can be used by families to rate the extent to which specific family-centred practices are used by the professionals with whom they work.

Family-centred practice is neither simple nor easy (Henne-man and Cardin, 2002); the shift from ‘expert manager’ to ‘flawless consultant’ is a significant shift indeed. Even professionals who are committed to family-centred philosophy and skilled in its relational and participatory components

have identified barriers to its adoption and implementation. We should be neither surprised nor discouraged by the fact that progress is not as rapid as we would like.

Getting a new idea adopted, even when it has obvious advantages, is difficult. Many innovations require a lengthy period of many years from the time when they become available to the time when they are widely adopted.

(Rogers, 2003, p. 1)

Family-centred practice is a specific and systematic way of working with families that has a thorough rationale, obvious advantages and a wide range of demonstrated benefits (Centre for Community Child Health, 2003). At its heart is the aim ‘not to identify the perfect set of practices but to recognize the family’s role in helping decide on those practices’ (Crais, Roy and Free, 2006). The model of ‘flawless consulting’ reminds us that we when we join families, we are joining ‘a drama already in progress’ (Markowitz, 2001b, p. 105). In our desire to help others, we must remember the fine line between managing and consulting, between controlling and having confidence in the capacity of the other.

Carpenter (2007, p. 667) poses the following questions:

How can we help families to rebuild expectations, give them back hope, and create dreams (that may be realized differently)? How can we help families (including the child with a learning disability) reclaim their ordinary life in the long term as well as in the short term?

Or, in the words of the father who introduced this article, how can we help heal the family who has been left adrift? More than 20 years of implementation and research suggest that the model of family-centred practice contains the answers.

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