

# Family-centred practice: An evaluation of an early childhood intervention service

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“Although family participation/involvement has been promoted as an important component in early intervention service delivery, there remain discrepancies in how families are allowed to and elect to participate in actual program practice ... it is imperative that parent perceptions of early intervention services be more clearly examined.” (Wehman and Gilkerson 1999: 138)

With the move in recent years from a medical model, to a social model of disability (World Health Organization, 2001), there has been a growing recognition of the need for families who have a child with a disability or developmental impairment, to be considered as families first, and for services to reflect the strengths, needs and desires of the whole family. Thus, the role of families in determining the shape and extent of the services, supports and resources they receive is an important aspect of service planning and provision in early childhood intervention.

There is a great deal of literature that indicates the importance of a family-centred approach and it is recognised as one of the most important principles for the provision of services to children and their families. Given this, how can services measure the degree of family-centred practice? Do families and service providers have similar perceptions of how family-centred those services are? What are the experiences of families who receive early childhood intervention services?

This article is an extract from a study into family experiences and family-centred practice undertaken by Scope. Scope provides early childhood intervention services and support to over 200 families throughout Victoria (at the time the study was undertaken). These services are provided through six regional teams, two of which operate in metropolitan Melbourne and the others in regional and rural Victoria. Scope early childhood intervention services employs over 60 staff who come from a variety of backgrounds including, but not limited to, occupational therapists, physiotherapists, speech pathologists, psychologists, family service co-ordinators, early intervention educators and others. The study explored the experiences of families who use Scope services and measured the level of family-centred practice.

### Methodology

The study included an extensive review of the literature, and focus groups and telephone interviews were used to explore the experiences of families who use Scope early childhood intervention services. The third component of the research used the Measure of Processes of Care (MPOC) questionnaire (King, Rosenbaum and King 1995) to measure the extent of family-centred practice within Scope early childhood intervention services.



### Findings and discussion from Scope's research

A number of themes emerged from the literature review and Scope's primary research: a context for family-centred practice; first messages and other information; finding the balance; inclusive practices and natural environments and finally the challenges for future evaluation and research.

#### *A context for family-centred practice*

There is a need to put the philosophies, principles and practices of family-centred practice within a context of overall service provision. There is a large body of knowledge in relation to family-centred practices and principles. These are not only relevant to the early childhood intervention sector but also to a much broader range of community services and supports.

Families prefer family-centred services and supports over professionally-centred services, and there are clear benefits for parents in terms of satisfaction with parenting, empowerment and parental and family wellbeing. However, there are other program characteristics that influence child/parent and family functioning. The

most important predictors of parental well-being are behaviour problems in children and the evidence of the general social support networks that all families need. Family-centred practice is therefore a value-added benefit for families and the full benefits are only felt when other supports are in place. This has implications for the partnerships and links that specialist services need to establish with generic and community agencies. Also, if practitioners are to be truly family-centred, they need to be aware that all families will differ depending on where they are in their lives at any point in time. It is possible to be family-centred yet be primarily child-focused for a particular family, if that is the priority of the family. However, this only applies if the family has an understanding of what else is possible, have a sense of what that might be like, and have been offered other options.

It is important to honour the racial, cultural, ethnic and socio-economic diversity of families. This diversity is often reflected by values, attitudes and lifestyles that may be in conflict with those of the practitioner. These pathways are not always easy to negotiate. Services and staff need to be flexible and responsive. The message for practitioners is clear. Listen more than you talk, and focus on the strengths and capabilities of families. So often therapists and others believe that it is their role to present solutions to the problems identified by families and others. Instead, it is their role to support families to develop their own solutions over time that build on the strengths and capabilities of children and families.

#### *First messages and other information*

Families have a substantial need for all types of information. There is often a gap between the information they need and the information they are given. This raises many questions about the type of information in question, the manner in which it is shared, by whom and to whom it is provided, in what sort of format, and when is it provided?

The research demonstrated that Scope performs reasonably well in providing information to families regarding their own child. However, of all of the domains of care, the biggest service delivery gap was in the provision of general information to families. The literature would suggest that Scope is not on its own in this respect.

The first messages provided to families by primary health care providers were shown to be powerful influences and memories in the lives of families. All too often families are given information that is without hope, or is misinformed. The literature and the studies found that families want accurate information that is shared in a complete and unbiased manner but leaves them with some sense of hope for the future. How can the sector work towards ensuring families receive such positive first messages in the early stages?

Having established that providing information to families is a priority, the next question is how to deliver it in a variety of formats and methods that will match the diversity of family needs? Can information be provided formally and informally? Should it be via traditional methods or delivered electronically? What is the role of web-based services and how can Scope provide information that is jargon-free and in a language that is easily understood by families taking account of social, cultural and language considerations? Families also want research-based information that further allows them to make choices in their selection of services and supports.

Families are an under-utilised resource when it comes to the giving and sharing of information. They are looking for support and information from other parents and are willing to share with them the knowledge they have gained. This reflects a need for a greater emphasis on the centrality of families to policy and practice.

Families are the experts with respect to their child and they can bring a great deal of information to a collaborative relationship with practitioners. It is important for practitioners to recognise this and ensure families have opportunities to share their expertise. To do this, (families need to feel comfortable in sharing the information and practitioners need to use strategies and provide environments where families will comfortably share this information and tell their stories.

Information may need to be repeated over the course of the journey as the changing emotional and life stages of families allows them to attend to different information and messages at different times. Practitioners need to be flexible and responsive to these needs.

#### *Finding the balance*

Families want balance in their life. They want their lives to be more than just about their child's disability. They want to be respected, valued and confirmed for the choices they make. They want practitioners to impart a sense of balance in the information they provide that leaves them with feelings of hope and choice. Families want services and supports that are responsive and flexible. Practitioners need to be sensitive to the realities of everyday life for families and the many competing demands that they manage. Family life is not just about disability. Therapy is not the most important thing in their life, nor should it be.

From the perspective of practitioners, it is important to balance the three elements of effective caregiving as outlined by Dunst and Trivette (1996). First, there is a need for technical knowledge and expertise. High quality specialist skills have positive effects on a child's health and development but may have negative effects on the family if they are not delivered appropriately, for example, increased family stress and disempowerment. Good interpersonal and basic counselling skills (such as listening skills and showing empathy and warmth) are not sufficient on their own to strengthen family competence but are fundamental to the development of collaborative relationships with families. Finally, it is collaborative and participatory practices that result in families feeling more in control and which strengthen parental competencies.

#### *Inclusive practices and natural environments*

The research finds that recognising the importance of delivering services and supports in the child's natural environment is critical. Evidence in the literature suggests that children do better where goal setting is collaborative between practitioners and families, and where goals reflect needs and priorities in the context of the child's natural environments. What are the implications of this for service providers?

Providing services within natural environments can become confused with home programs and families feeling pressure to act as proxy therapists "doing therapy" at home. Some studies have shown the difficulties that families identify in trying to balance the demands of home life with the additional demands of



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“home programs.” It should not be an either/or situation. Participants in this research described that what works best for them is the incorporation of intervention goals into every-day tasks, play and family routines. In this way, working on goals becomes second nature and makes for more effective intervention outcomes, developing the competence of family members to feel that they can meet the needs of their child.

It is important that practitioners have the appropriate skills and instruments to support families in the processes of identifying the outcomes that are the most desirable for them, and the means by which they can best be achieved. What parents identify as priorities is shaped by what they have often been told by the referring paediatrician (for example, “your child needs occupational therapy”) and what they understand to be possible. If practitioners explicitly or implicitly present parents with hands-on therapy in isolation, as the most effective way to help their child, they will tend to perceive this as what their child needs. If service providers present them with viable alternatives of achieving their goals (for example, making use of natural learning environments rather than clinical settings), parents can make an informed choice about what they want.

#### **Challenges for future evaluation and research**

This research has indicated some of the issues that need to be taken into account when services in the early childhood intervention sector are evaluated. Measuring processes and outcomes is never an easy issue in the human services sector. This is certainly true for early childhood intervention where it is difficult to determine what outcomes are to be measured. For example, one could look at the impairment, activity or participation aspects of a child’s function, parental function and finally focus on the community and the impact on the capacity of community

services to be more welcoming and inclusive of children with disabilities and their families. Much work is still to be done by the sector generally, to describe how some of these outcomes may be measured.

The literature tells us that measures of parental satisfaction including questionnaires, interviews and telephone surveys generally show high satisfaction levels. There are several factors associated with this. First, parents only have experience with the services they receive and are unable to compare this experience with anything else. Because of the difficulty parents sometimes experience when attempting to access services, they are at risk of being impelled to feel “grateful” for any services they receive. Thus, high satisfaction levels may be more a reflection of this attitude than a true indication of service quality or orientation. Finally, satisfaction generally only relates to the processes of services that have been delivered rather than what is delivered or the actual outcomes that arise.

For anyone who wishes to seek a true picture of what is happening for children and families in early childhood intervention services, no one answer or instrument will be sufficient. A variety of methods will continue to be necessary. The challenge for future research is to develop a measure that can investigate the impact of natural environments on the child and family. Also needed is a way to measure the influence and impact of early childhood services on the community more broadly.

#### **Conclusion**

This study has explored the experiences and expectations of families who use Scope early childhood intervention services and has enabled the voices of families to be heard. It has also measured the extent of family-centred practice from the perspectives of both families and staff.

This research has highlighted the centrality of families in the delivery of early

childhood intervention services and the need for the focus of services to be on developing family and parental competencies so that they can become powerful agents of change. In this way, they can make a difference for their child into the future beyond the time when therapists and other practitioners have a prominent role. Early childhood intervention practitioners need to find a way that they can walk with families on the journey that is theirs.

This study has demonstrated that Scope early childhood intervention teams set high standards of practice, and in many areas are achieving higher standards of practice than those considered by families to be ideal. It is important to acknowledge and celebrate these findings but also to hear the other important messages from families as to areas of improvement that are necessary. Scope needs to continue its endeavours to embed a family-centred, strengths-based approach to the delivery of services to children and families and to also identify those principles that can be generalised into other areas of practice.

For more about family-centred practice and the particular recommendations from this research see: Scope (2004), “More Than My Child’s Disability: A Study of Family-Centred Practices and Family Experiences of Scope Early Childhood Intervention Services and Supports”, Scope, Glenroy, Victoria.

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This article is taken from the Scope’s 2004 “More Than My Child’s Disability” report.