“More than my child’s disability…”

A study of family experiences and family-centred practices of Scope early childhood intervention services and supports

*A research project undertaken by the Specialist Services division of Scope with the support of the RE Ross Trust.*

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SUMMARY

A family-centred approach is recognised both in Australia and internationally, as one of the most important principles for the provision of early childhood intervention services. The role of families in determining the shape and extent of the services, supports and resources that they receive is therefore, an important aspect of service planning and provision. Given this, how can services measure how family-centred they are and do families and service providers have similar perceptions as to the extent of family-centred practice? What are the experiences of families who receive early childhood intervention services? This study addressed these and other issues. Specifically the aims of the study were to:

- Undertake an extensive review of the literature in the field of family-centred practice;
- Identify and describe the experiences of families who access Scope services;
- Identify the most important aspects of family-centred practice from the perspective of families and Scope staff;
- Compare and contrast these two views;
- Measure the current level of family-centred practice from the perspective of families and Scope staff;
- Compare and contrast these two views; and,
- Establish base line measures in relation to family-centred practice for future re-evaluation purposes and for benchmarking with other organisations.

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.

A total of 52 people from across Victoria participated in the focus groups and telephone interviews. Of those who participated, most (91%) were mothers. A total of 65 families and 57 Scope staff completed questionnaires. The typical primary disabilities of the children of those families who participated were developmental delay and physical disability, which accounted for 68% of the children. Almost 40% of children receiving
services and supports had three or more secondary disabilities with the most common secondary disability being communication impairment. Families reported that services were most commonly received at home (39%) or at a Scope site (39%) with another 17% of services being delivered at a community facility. During the focus groups and telephone interviews, families shared their experiences of, and feelings about, Scope services and early childhood services in general. The voices of participants are heard through the extensive use of quotations throughout this report.

As measured by the MPOC questionnaire, the extent of family-centred practice was examined. This component of the study revealed that families rated similarly regardless of where they lived, the gender, age or disability of their child or the length of time that they had been receiving services. Scope staff were more critical of the service they provided than families were, and had higher expectations of the services they believed they should provide. Families believed that services had a high level of family-centred practice as measured by the MPOC with the exception of Provision of General Information. Clearly families want an increased emphasis on the variety and extent of information that they can access regarding general, social and community supports and services. A number of common themes emerged from the study findings. These are:

- **A context for family-centred practice:** The need to put the philosophies, principles and practices of family-centred practice within a context of overall service provision;
- **First messages and other information:** The need of families to have a range of information and the way this information is communicated;
- **Finding the balance:** The importance of families having a balance in their lives and having access to services that can support this balance;
- **Inclusive practices and natural environments:** Recognising the importance of delivering services and supports in the child’s natural environments; and,
- **Challenges for future evaluation and research:** What has been learnt about the issues associated with future evaluation and research in early childhood intervention?

These themes and the implications for practice are discussed in Chapter 6. Finally, recommendations are presented that will guide Scope in future service development activities but are also designed to support the sector generally regarding gaps and areas of need. 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 mission to embed a family-centred, strengths-based approach into the delivery of services to children and families.
CHAPTER 1
BACKGROUND

1.1 INTRODUCTION

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 & Gilkerson, 1999, p.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 study addresses these and other issues.

1.2 SCOPE: PROVIDER OF EARLY CHILDHOOD INTERVENTION SERVICES

Scope provides early childhood intervention services and supports 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 coordinators, early intervention educators and others.

1.3 RESEARCH AIMS AND METHODOLOGY

This study explored the experiences of families who use Scope services and measured the level of family-centred practice. Specifically the aims of the study were to:

- Undertake an extensive review of the literature in the field of family-centred practice;
- Identify and describe the experiences of families who access Scope services;
  Identify the most important aspects of family-centred practice from the perspectives of families and Scope staff;
- Compare and contrast these two views;
- Measure the current level of family-centred practice from the perspectives of families and Scope staff;
- Compare and contrast these two views; and,
- Establish base line measures in relation to family-centred practice for future re-evaluation purposes and for benchmarking with other organisations.

This literature review explored the relevant research regarding the principles and philosophy of family-centred practice, the experiences of families and the way in which family-centred practice has been measured in previous research. The review is extensive in nature and reflects the diversity and amount of literature that is available. It provides a summation of the literature and research in the field and presents information in a way that is useful to practitioners and families.

This study consisted of two parts. The first part explored the experiences of families who use Scope early childhood intervention services. The second part examined the degree of family-centred practice from the perspectives of families and Scope staff as well as the views of families and staff members in relation to their perceptions of ideal services.

The findings of the literature review are contained in Chapter 2. Chapter 3 describes the methodology used in both parts of the study. Chapters 4 and 5 describe the results of
each of these two components while Chapter 6 provides a discussion of the overall findings, including recommendations arising out of the research.
CHAPTER 2
WHAT DOES THE LITERATURE SAY?

2.1 AIMS AND OUTLINE OF LITERATURE REVIEW

The aims of the literature review were to:

- Provide an overview of the principles and philosophy of family-centred practice;
- Review the literature that has specifically explored the direct experiences of families using early childhood intervention services and their perspectives of family-centred practice;
- Identify what is most important to families when accessing these services;
- Explore the responses of service providers as to how well they believe they have undertaken family-centred practice and what they believe are the most important aspects for families; and,
- Review studies that have measured the level of family-centred practice (and associated importance) from the perspectives of families and service providers.

This literature review is divided into four sections. The first section (2.2) looks at definitions of family-centred practice and summarises key statements of the underlying principles and practices. The second section (2.3) reviews the literature regarding the evidence for the effectiveness of family-centred practice, while the third (2.5) explores what is known about the experiences of families. The final section (2.6) reviews studies using the particular measure of family-centred practice used in this study, namely the Measure of Processes of Care (MPOC).

2.2 PRINCIPLES AND PRACTICES RELATED TO FAMILY-CENTRED PRACTICE

2.2.1 Definitions

There is no single, accepted definition of family-centred practice. Indeed, there is not even an accepted term. Family-centred practice is also referred to as family-centred service and family-centred care. On the basis of discussions with fellow parents of young children with developmental disabilities, Viscardis (1998) defined the family-centred approach as one that:
… begins with the child’s and family’s strengths, needs and hopes, and results in a service plan which responds to the needs of the whole family. It involves education, support, direct services and self-help approaches. The role of the service provider is to support, encourage, and enhance the competence of parents in their role as caregivers. (p. 44)

Allen and Petr (1996) further defined family-centredness as:

*Family-centred service delivery, across disciplines and settings, recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses upon the strengths and capabilities of these families.* (p.68)

Law, Rosenbaum, King, King, Burke-Gaffney, Moning, Szkut, Kertoy, Pollock, Viscardis, and Teplicky (2003) offered this definition:

*Family-centred service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred service recognises that each family is unique: that the family is the constant in the child’s life; and that they are the experts on the child’s abilities and needs. The family works with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service, the strengths and needs of all family members are considered.* (p.2)

Inevitably, these and other definitions tend to consist of lists of practices and principles, indicating that family-centred practice is actually, as Rosenbaum King, Law, King and Evans (1998) stated, an umbrella term for both a philosophy and a method of service delivery. The important issue is not whether a definition can be agreed upon, but whether agreement can be reached regarding the underlying principles and consequent practices.

### 2.2.2 Principles and practices

Reaching agreement on underlying principles and practices is complicated by the fact that work on family-centred practice has been done by several groups more or less independently of each other over many years. Cross-fertilisation of ideas between groups is sometimes limited because their work is published in different types of journals, for example, medical/therapy journals rather than early childhood/early childhood intervention journals, or in different countries. Although the principles and practices identified by these groups have much in common, each tends to emphasise different principles and practices over others. Sometimes these emphases reflect the
particular settings in which the ideas are being developed, while in other cases they reflect personal experiences.

Key bodies of work on family-centred practice include the following:

- The work of Carl Dunst and colleagues, from the publication of their seminal book *Enabling and Empowering Families* (Dunst, Trivette & Deal, 1988) to a recent review of their work (Dunst, 2000). Their recent work has emphasised the use of natural learning environments and the mobilisation of family and community resources.

- The work of Don Bailey and colleagues at the Frank Porter Graham Centre at the University of North Carolina (Bailey, McWilliam, Winton & Simeonsson, 1992; McWilliam, 1992; McWilliam & Bailey, 1993; McWilliam, Winton & Crais, 1996; Winton, 1992). They have been particularly active in developing approaches to training professionals in family-centred practice.

- The work of Ann and Rud Turnbull and colleagues at the Beach Centre in Kansas (Allen & Petr, 1996; Turnbull, Turbiville & Turnbull, 2000; Turnbull & Turnbull, 2000). As parents of a child with a disability, their particular interest has been on parent/professional partnerships.

- The work of Mary Law and Peter Rosenbaum’s team at the CanChild Centre for Childhood Disability Research at McMaster University in Canada (Rosenbaum et al., 1998). Working primarily with rehabilitation services settings initially, they have emphasised the importance of information provision.

- The work of the Family Resource Coalition (now Family Support America) (Family Resource Coalition, 1987, 1996, 1997; Dunst, 1995). Working with families in need of support, their emphasis has been on a strengths-based approach.

As family-centred practice has become the accepted service philosophy in a number of related fields, numerous other authors have contributed to the furthering of theory and practice in early childhood intervention (Baird & Peterson, 1997; Beckman, 2002; Beckman, Robinson, Rosenberg & Filer, 1994; Epps & Jackson, 2000; McBride, 1999; Powell, 1996).

What follows is a series of representative statements of family-centred principles and practices that have been developed by the groups mentioned above.
The Dunst Model

On the basis of a thorough review of the literature and his own group’s work, Dunst (1997) identified the following core practices of a family-centred approach to intervention as:

- Families and family members are treated with dignity and respect at all times;
- Practitioners are sensitive and responsive to family cultural, ethnic and socio-economic diversity;
- Family choice and decision-making occurs at all levels of family involvement in the intervention process;
- Information necessary for families to make informed choices is shared in a complete and unbiased manner;
- The focus of intervention practices is based on family-identified desires, priorities, and needs;
- Support, resources and services are provided in a flexible, responsive, and individualised manner;
- A broad range of informal, community, and formal supports and resources are used for achieving family-identified outcomes;
- The strengths and capabilities of families and individual family members are used as resources for meeting family-identified needs and as competencies for procuring extra-family resources;
- Practitioner-family relationships are characterised by partnerships and collaboration based on mutual trust and respect; and,
- Practitioners employ competency-enhancing and empowering help-giving styles that promote and enhance family functioning and have family strengthening influences.

Many of these principles appear in other statements of family-centred practice. However, what distinguishes Dunst’s approach is the emphasis on using a broad range of informal, community, and formal supports and resources to enable families to meet their child’s and family’s needs. Dunst and colleagues also stressed that effective family-centred practice depends upon professionals using particular help-giving styles. These styles are described later in Section 2.3.5.
The Frank Porter Graham Model

The Frank Porter Graham team has worked on a number of aspects of family-centred practice. These include the assessment of family-needs (Bailey, 1995), training professionals in family-centred practices (Bailey et al., 1992; McWilliam & Bailey, 1993), and embedding interventions in family routines (McWilliam, 1992). In their book *Practical Strategies for Family-Centered Intervention* (a book that encompasses a strong practitioner focus), McWilliam, Winton and Crais in 1996, identified the following key principles of family-centred practice:

- Viewing the family as the unit of service delivery;
- Recognising child and family strengths;
- Responding to family-identified priorities;
- Individualising service delivery;
- Responding to the changing priorities of families; and,
- Supporting family values and lifestyles.

The Turnbull Model

The principles of family-centred practice highlighted by the Turnbulls and colleagues at the Beach Centre at the University of Kansas are a family choice, strengths-based approach, and parent/professional partnerships. Allen and Petr (1996) argued that family-centred service delivery is based on two key elements: *family choice*, and the adoption of a *strengths perspective*.

*Family choice:* Here the family is both the director and consumer of the service delivery process and has the ultimate decision-making authority. Family-centred services should seek to maximise family choice as to:

- Who is included in the family (e.g., nuclear family only or extended family);
- Which family members make the decisions;
- What the service will focus on (e.g., child or child/care-giver relationship or parent needs);
- What the nature of the family-professional relationship will be (e.g., parent-directed, professional-controlled or transitional);
- How information is shared (both information given and received);
- What the family needs are and what goals services will work towards; and,
What the family’s level of involvement in treatment will be.

Strengths and capabilities: Family-centred practice requires a strong belief in the importance of the family and a respect for the inherent strength and capabilities of family members. This also applies to identifying, using and building on strengths among family support networks and broader community resources.

The Turnbulls, as parents of a (now) young man with disabilities, have been much more interested in the nature of the relationship between parents and professionals (Turnbull, Turbiville & Turnbull, 2000; Turnbull & Turnbull, 2000). They suggested that this relationship is continuing to evolve, and that this process can be described as an evolution along a power continuum from ‘power-over’ relationships to ‘power-through’ relationships (Turnbull et al., 2000). These are described below:

- **Power-over relationships** are characterised by professionals exerting decision-making control over parents through perceived higher competence, professionalised communication, and control over environmental resources. Parent-professional partnerships have traditionally taken this form.

- **Power-with relationships** arise when collaborative decision-making is used among parents and professionals through perceived equal competence, contextual communication, and sharing of environmental resources. Family-centred partnerships are based on this form of power sharing.

- **Power-through relationships** incorporate synergistic decision-making among family members, professionals, friends, and community citizens through perceived group competence, ‘mind and heart’ communication, and the creation of new and preferred environmental resources. Synergistic decision-making results in decisions and effects that are greater than the sum of the parts.

Whereas empowerment was originally conceptualised in terms of empowering families, there is an increasing focus on collective empowerment. This is a process through which “…all participants (i.e., professionals and families) increase their capacity and mastery over the resources needed to achieve mutually desired outcomes” (Turnbull et al., 2000, p. 641). Thus, power is no longer simply about controlling events and processes, but it is also about capacity building. All participants gain in competence,
abilities, resource acquisition, and capabilities without taking power from others. This results in increased satisfaction by all participants, parents and professionals alike.

**The CanChild Model**

The CanChild Centre for Childhood Disability Research has developed a three-level model of family-centred practice (Rosenbaum, et al., 1998). This comprises three basic premises or assumptions, guiding principles deriving from each of these, and key service provider behaviours that follow from each set of assumptions and guiding principles. These are shown in Box 1.

**The Family Resource Coalition Model**

Unlike the other models so far outlined, the focus of the Family Resource Coalition (now Family Support America) has not been families of children with developmental disabilities, but families who were experiencing difficulties in raising their children and were in need of family support services. In the early 1990s, the Coalition set out to identify best practices and principles for family support services, beginning with a synthesis of the research literature of the key features of community-based family support services (Dunst, 1995), and culminating in a set of key statements of best practices (Family Resource Coalition, 1996, 1997).
Box 1

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<tr>
<th>Premise 1: Parents know their children best and want the best for their children.</th>
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<td><strong>Guiding principles:</strong></td>
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<td>• Each family should have the opportunity to decide the level of involvement they wish in decision-making for their child.</td>
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<td>• Parents should have the ultimate responsibility for the care of their children.</td>
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<td><strong>Service provider behaviours:</strong></td>
</tr>
<tr>
<td>• Encourage parent decision-making</td>
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<tr>
<td>• Assist in identifying strengths</td>
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<tr>
<td>• Provide information</td>
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<tr>
<td>• Assist in identifying needs</td>
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<td>• Collaborate with parents</td>
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<tr>
<td>• Provide accessible services</td>
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<td>• Share information about the child</td>
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<td><strong>Guiding principle:</strong></td>
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<td>• Each family and each family member should be treated with respect (as individuals).</td>
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<tr>
<td><strong>Service provider behaviours:</strong></td>
</tr>
<tr>
<td>• Respect families</td>
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<td>• Support families</td>
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<tr>
<td>• Listen.</td>
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<tr>
<td>• Provide individualised services</td>
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<td>• Accept diversity</td>
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<tr>
<td>• Believe and trust parents</td>
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<td>• Communicate clearly</td>
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<tr>
<th>Premise 3: Optimal child functioning occurs within a supportive family framework and community context. The child is affected by the stress and coping of other family members.</th>
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<tr>
<td><strong>Guiding principles:</strong></td>
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<tr>
<td>• The needs of all family members should be considered</td>
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<td>• The involvement of all family members should be supported and encouraged</td>
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<td><strong>Service provider behaviours:</strong></td>
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<td>• Consider the psychosocial needs of all family members</td>
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<td>• Encourage the participation of all family members</td>
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<tr>
<td>• Respect coping styles</td>
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<tr>
<td>• Encourage the use of community supports</td>
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<tr>
<td>• Build on strengths</td>
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</table>
The principles of family support practice that the Family Resource Coalition identified are as follows (Family Resource Coalition, 1996):

- Staff and families work together in relationships based on equality and respect;
- Staff enhance families’ capacities to support the growth and development of family members – adults, youth, and children;
- Families are resources to their own members, to programs, and to communities;
- Programs affirm and strengthen families’ cultural, racial, and linguistic identities and enhance their abilities to function in a multicultural society;
- Programs are embedded in their communities and contribute to the community-building process;
- Programs advocate with families for services and systems that are fair, responsive and accountable to the families served;
- Practitioners work with families to mobilise formal and informal resources to support family development;
- Programs are flexible and continually responsive to emerging family and community issues; and,
- Principles of family support are modeled in all program activities, including planning, governance and administration.

Despite the different clientele and focus of family support services, these principles demonstrate a striking similarity to those articulated by the early childhood intervention services working with families of young children with developmental disabilities.

**Other models**

Other statements of family-centred practice principles have been developed in the USA by Susan McBride and colleagues (McBride, 1999; McBride, Brotherson, Joanning, Whiddon and Demmitt, 1993) and Paula Beckman and colleagues (Beckman, 2002; Beckman et al., 1994), in Germany by Franz Peterander (2000), and in Australia by the NSW Ageing and Disability Department and Early Childhood Intervention Australia (1998).
McBride et al. suggested three over-arching principles that drive family-centered practice and appear to be equally applicable across various medical, social and educational settings. These are:

- Establishing the family as the focus of services;
- Supporting and respecting family decision-making; and,
- Providing flexible, responsive, and comprehensive services designed to strengthen child and family functioning.

Thus, family-centered practice is not defined by a particular set of forms and procedures. Instead, it requires a willingness to embrace values that are respectful of, and collaborative with, families (McBride, 1999).

Beckman (2002) identified five key elements of working in a family-centred way, two of which have to do with effective communication and the skills that practitioners need to work effectively with families:

- Empowering families;
- Providing social supports;
- Building relationships with families as the basis for intervention;
- Building communication skills; and,
- Maintaining effective communication.

All of the above models have been developed in the North American context, and therefore could be considered as specific to the cultures and service settings in the USA and Canada. However, the same themes and principles are evident in the work being done in Europe and Australia. For instance, in Germany, Peterander (2000) noted that the process of early intervention, both for children with delayed development and for those with disabilities, depends to a great extent on ‘parent-expert’ cooperation. He identified the following aims and tasks of cooperative partnerships between parents and professionals:

- *Strengthening parental competence*: strengthening parents’ ability to create a family environment that meets the needs of the whole family;
- *The creation of a family environment that is conducive to the child’s development*: helping families accommodate the individual needs of the child with disabilities;
• Fostering positive interaction and communication between parents and children: helping parents interact effectively with their children;

• Parental counseling on the prospects of a child’s development: providing parents with knowledge and skills to promote their child’s development;

• Establishing a dialogue between parents and experts about early intervention treatment: actively involving parents in the child’s intervention; and,

• Building up social relationships: ensuring that the family has adequate social supports.

In Australia, the NSW Ageing and Disability Department, together with the Australian Early Intervention Association (New South Wales), produced a comprehensive training package in family-centred practice for early childhood intervention workers: Partners: Recommended Practices in Family-Centred Early Childhood Intervention (1998). This identified six key characteristics of family-centred practice that distinguish it from traditional ways of working with children and families:

• Following a family systems perspective;

• Treating adults as capable and competent individuals having different needs at different times;

• Building on family strengths rather than focusing on deficits and weaknesses;

• Working in partnership with families;

• Acknowledging and responding to the diverse needs of families; and,

• Working with families in ways that are enabling and empowering.

As noted already, there are various recurring themes in these statements of family-centred practice principles, with each emphasising different principles and practices. Before this report attempts to synthesise these principles, it will consider wider applications of family-centred principles along with evidence for the effectiveness of this approach.

2.2.3 Wider applications of family-centred principles

Family-centred principles are now being applied in an increasingly diverse range of settings including:

• Early care and education settings (Hamilton, Roach & Riley, 2003);
Child protection programs (Berg, 1994; McCroskey & Meezan, 1998; Scott & O’Neill, 1998; Turnell & Edwards, 1999);

Intervention and prevention programs for at-risk adolescents and their families (Dishion & Kavanagh, 2003);

Families with particular structures or special needs: e.g., single-parent families (Jung, 1996), racially and ethnically mixed families (Oriti, Bibb & Mahboubi (1996), lesbian and gay families (Laird, 1996), foster parent families (McFadden, 1996), stepfamilies (Kelley, 1996), and adoptive families (Watson, 1996);

Hospital and health care settings (Newton, 2000; Shelton & Stepenek, 1994); and,


The last two of these applications deserve particular mention.

Shelton and Stepenek (1994) identified a number of key elements in hospital and health care settings that are frequently cited by others as key principles of family-centred practice. This is curious given the somewhat medical model that is often experienced in these settings. Shelton and Stepenek identified the following elements:

- Recognising that the family is the constant in a child’s life, while the service systems and personnel within those systems fluctuate;
- Facilitating parent/professional collaboration at all levels of health care: care of an individual child; program development; implementation and evaluation; and, policy formation;
- Honouring the racial, ethnic, cultural and socioeconomic diversity of families;
- Recognizing family strengths and individuality and respecting different methods of coping;
- Sharing with parents complete and unbiased information on a continuing basis and in a supportive manner;
- Encouraging and facilitating family-to-family support and networking;
- Understanding and incorporating the developmental needs of infants, children, adolescents, and their families into the health care systems;
- Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families; and,
• Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs.

Much of the work done on family-centred practice is based on work with children who have additional needs, and their families. However, more recently work has been done in the area of international family policy and practice. Briar-Lawson and Lawson (2001), however, have adopted a much broader perspective and sought to identify a set of family-centred policies and practices that would be applicable to any family anywhere in the world. They proposed that such policies and practices would share the same essential features:

• Families are considered experts in what helps them and hurts them;
• Families are indispensable, invaluable partners for policy-makers, helping professionals, and advocates;
• Families are not called, or treated as, dependent clients. Helping professionals and policy makers view families as equals, as citizens, with whom they collaborate and whom they empower;
• Family-centred policies are strengths-based and asset-based, and promote family-to-family and community-based systems of care and mutual support; and,
• Family-centred policies and practices promote democratisation and gender equity.

The first four of these features are strikingly similar to the principles of family-centred practice that appear repeatedly throughout the early childhood intervention literature, and only the last feature reflects a new and wider social agenda.

As noted earlier, all of the various statements of family-centred principles have certain key features in common, although each tends to emphasise a different aspect. As these common features have been identified, each has been the focus of closer study and analysis, resulting in an enriched understanding of the underlying principles and their application. Examples of this work include:


• **Family empowerment**: Cunningham, Henggeler, Brondino and Pickrel (1999), Dunst, Trivette and LaPointe (1992), Pease (2002), Thompson, Lobb, Elling, Herman, Jurkiewicz and Hulleza (1997), Turnbull, Turbiville and Turnbull (2000);

• **Help-giving**: Dunst, Boyd, Trivette and Hamby (2002), Dunst and Trivette (1996), Judge (1997), King, King and Rosenbaum (1996);

• **Assessment of family needs**: Bailey (1995), Krauss (2000);

• **Interdisciplinary teamwork**: Lubetsky, Mueller, Madden, Walker and Len (1995), McGonigel, Woodruff and Roszmann-Millican (1994); and,

• **Service coordination**: Walter and Petr (2000).

### 2.2.4 Best practice principles of family-centred practice

On the basis of this accumulated work, it is now possible to identify best practice principles for family-centred practice. In the USA, a statement of best practice principles has been developed by the Council for Exceptional Children’s Division of Early Childhood (Trivette & Dunst, 2000), together with a program assessment tool (Hemmeter, Joseph, Smith & Sandall, 2001).
Box 2

**US Council for Exceptional Children: Division of Early Childhood**

**Recommended Family-Based Practices**

**Families and professionals share responsibility and work collaboratively**

- Family members and professionals jointly develop appropriate family-identified outcomes.
- Family members and professionals work together and share information routinely and collaboratively to achieve family-identified outcomes.
- Professionals fully and appropriately provide relevant information so parents can make informed choices and decisions.
- Professionals use helping styles that promote shared family/professional responsibility in achieving family-identified outcomes.
- Family/professionals’ relationship building is accomplished in ways that are responsive to cultural, language, and other family characteristics.

**Practices strengthen family functioning**

- Practices, supports, and resources provide families with participatory experiences and opportunities promoting choice and decision making.
- Practices, supports, and resources support family participation in obtaining desired resources and supports to strengthen parenting competence and confidence.
- Intra-family, informal, community, and formal supports and resources (e.g., respite care) are used to achieve desired outcomes.
- Supports and resources provide families with information, competency-enhancing experiences, and participatory opportunities to strengthen family functioning and promote parenting knowledge and skills.
- Supports and resources are mobilized in ways that are supportive and do not disrupt family and community life.

**Practices are individualized and flexible.**

- Resources and supports are provided in ways that are flexible, individualized, and tailored to the child’s and family’s preferences and styles, and promote well-being.
- Resources and supports match each family member’s identified priorities and preferences (e.g., mothers and fathers may be different).
- Practices, supports and resources are responsive to the cultural, ethnic, racial, language, and socio-economic characteristics and preferences of families and their communities.
- Practices, supports, and resources incorporate family beliefs and values into decisions, intervention plans, and resources and support mobilization.

© Scope (2004)
Practices are strengths and assets-based.

- Family and child strengths and assets are used as a basis for engaging families in participatory experiences supporting parenting competence and confidence.
- Practices, supports and resources build on existing parenting competence and confidence.
- Practices, supports and resources promote the family’s and professionals’ acquisition of new knowledge and skills to strengthen competence and confidence.

McBride (1999) compiled a list of behaviour-based practice indicators of family-centred practice that apply to work with all families, not just those with children with special needs. As guidelines, they need to be adapted for each setting and each situation.
Box 3

**Practice Indicators for Family-Centred Partnerships in Early Childhood Education and Care Settings (McBride, 1999)**

*Use positive communication skills.*

- Spend more time listening to parents than asking questions or providing advice.
- Provide parents with frequent verbal and written feedback about their child's learning and education.
- Individualize methods to send information to families and for families to send information to the school.
- Schedule meetings with parents at times and places convenient to the family.
- Ask questions and provide information using language understood by the family.
- Convey to parents that you are willing to talk about a broad range of topics that affect them and their family.
- Ask parents what they want before telling them what the program does.
- Respond positively and in a timely manner to suggestions, ideas and special requests made by parents.
- Use problem-solving skills for making decisions with families about their children and themselves.

*Promote family choices and decision-making.*

- Assist families in summarizing what they want for their children and themselves, and work together to come up with a list of goals written in the parents' own words.
- Treat families as the true experts about their children when planning and providing services.
- Work together with parents to generate options for intervention strategies and let parents decide which options best suit their needs and resources.
- Seek parents' opinions about changes in school or classroom practices.
- Provide parents with choices about when and where they will be involved in their child's education.
- Include family members on committees and advisory boards that make decisions regarding the program or school.
- Ask all parents regularly about how well the program is doing and what changes they might like to see.

*Affirm and build on the positive aspects and strengths of the child and family*

- Comment to parents about the strengths, accomplishments, and positive aspects of the child through conversation, notes home, phone calls etc.
- Obtain information from parents about long-range goals, hopes, and aspirations for the future for their child and family.
• Acknowledge and compliment parents on the unique contributions they make to their child's progress.
• Ask parents to formulate goals and interventions for their child's areas of strength, and include these on the intervention plan.
• Help parents see they can make a positive difference in their child's life.

Honour and respect the diversity and uniqueness of families.

• Ask questions and provide information using language that is readily understood by the family.
• Develop publications that are easily understood by a large audience.
• Convey a sense of respect for and acceptance of parents’ opinions and feelings, even when they are in conflict with your own.
• Develop an understanding of the cultures and value systems of the families you serve. Can you accept their values even when they are in conflict with your own?
• Provide written information in each family’s primary language.
• Use translators and interpreters as needed to promote family participation in their child's education.

Provide a welcoming school-home partnership

• Provide opportunities for all members of the family to actively participate in classroom activities, and make parents feel comfortable being there.
• Give parents opportunities to be involved in decisions regarding the activities and scheduling of the classroom/school activities.
• Involve families in their children's education in ways that make them feel comfortable and at ease.
• Work together with families to improve school policies and practices.
• Welcome parents in the school and classroom at any time during the school day.
• Assist families in finding other community services that they need.

The principles described in this section, along with the practice indicators, provide practical guidance to agencies about the way in which they can work towards services that are truly family-centred.
2.3 EVIDENCE FOR THE EFFECTIVENESS OF FAMILY-CENTRED PRACTICE

Considerable work has now been done in articulating family-centred principles and practices, but what is the evidence for the effectiveness of this approach? Specific questions that need to be addressed are:

- Can services providing different levels of family-centred services be discriminated from one another?
- Are services that are more family-centred preferred by parents?
- What effects do family-centred services have on parents and families?
- What effects do family-centred services have on children?
- What aspects of help-giving or care-giving are associated with better outcomes for clients?

The evidence for each of these questions will now be considered.

2.3.1 Can services providing different levels of family-centred services be discriminated from one another?

One of the ways of testing the effectiveness of family-centred practice is to see if families receiving different types of services experience them differently and view those services that are family-centred more positively than they do those that are less so. Dunst and colleagues developed a typology of human services programs for this purpose and identified four program models that fall along a continuum (Dunst, Johanson, Trivette & Hamby, 1991; Dunst et al., 2002). These models, described in Table 1, are each characterised by different assumptions and beliefs about the capabilities of family members, and the roles that ‘help-giving’ professionals and families play in promoting changes in family development and functioning.
Table 1
Typology of Human Services Programs

<table>
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<th>Model</th>
<th>Characteristics</th>
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| Professionally-centred | • Families are seen mostly as deficient and incapable of healthy functioning without professional interventions.  
                          • Professionals see themselves as experts who determine family needs.  
                          • Families' views and opinions are given little or no credence.  
                          • Interventions are implemented by professionals with families being passive participants in the intervention process. |
| Family-allied      | • Families are seen as minimally capable of independently affecting changes in their lives.  
                          • Families are viewed as agents of professionals for carrying out professionally prescribed recommendations and courses of action.  
                          • Professionals enlist families to implement intervention under the guidance and tutelage of the professionals. |
| Family-focussed    | • Families are seen as capable of making choices among options professionals deem important for healthy functioning.  
                          • Professionals provide advice and encouragement to families on the basis of their choices and decisions.  
                          • Interventions focus on monitoring family use of professionally valued services. |
| Family-centred     | • Families are viewed as fully capable of making informed choices and acting on their choices.  
                          • Professionals view themselves as agents of families who strengthen existing skills and the promote acquisition of new skills.  
                          • Interventions emphasize capacity-building, resources and support. |

There is evidence that human services programs can be reliably classified into these four models (Dunst et al., 2002; Dunst, Trivette, Starnes, Hamby & Gordon, 1993; McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993). There is also evidence that staff in programs with different family-oriented philosophies, use different help-giving styles reflecting the programs’ underlying assumptions about the capabilities of family members and the roles that staff should play in helping them (Dunst et al., 2002; Dunst
& Trivette, 1996; Trivette, Dunst & Hamby, 1996a). Confirmation of these findings comes from a Canadian survey that found when service providers report they are providing better family-centred service, parents from the same centre or organisation report receiving better family-centred service (King, Kertoy, King, Hurley, Rosenbaum & Law, 2000).

These studies show that families are well aware of the differences between services with different orientations and different parent/professional power relationships. The next question to be addressed is which services do they prefer?

2.3.2 Do families prefer services that are more family-centred?

Studies that address this question have been conducted by King, King and Rosenbaum (1996), King, King, Rosenbaum and Goffin (1999), King, Rosenbaum and King (1996), and Trivette et al., (1996a). Trivette et al. examined the experiences of mothers involved in three contrasting types of human services programs. These were:

- Social services programs (which were generally professionally-centred in their approach);
- Public health programs (which were family-allied); and,
- Family support or early intervention programs (which were family-centred).

The mothers rated the characteristics of the help they received from the different agencies, using the Helpgiving Practices Scale (Dunst, Trivette & Hamby, 1995). Results indicated that the help-giving practices of family-centred programs were rated significantly more positively than those of either of the other two types of programs, and that the help-giving practices of family-allied programs were rated significantly more positively than those of professionally-centred programs.

In a series of studies conducted by the CanChild Centre in Canada, parental perceptions of the family-centredness of the services they received were compared with their satisfaction with services (King, King & Rosenbaum, 1996; King, King, Rosenbaum & Goffin, 1999; King, Rosenbaum & King, 1996). These studies indicated that higher levels of family-centered care-giving were significantly related to greater satisfaction with services.
Generally, parents are more satisfied with, and view more positively, services that are family-centred in their overall orientation and which use empowering help-giving styles. However, the links between family-centred services and parental satisfaction are not strong, indicating that other factors are also involved. To find out what these might be, we need to examine the evidence regarding the effects of family-centred practice on parents and families.

2.3.3 What effects do family-centred services have on parents and families?
Reviews of the effects of family-centred practice have been conducted by Rosenbaum et al. (1998) and Dunst, Brookfield and Epstein (1998). In addition, there have been a number of individual studies (Judge, 1997; King, King, Rosenbaum & Goffin, 1999; Trivette et al., 1996a and b; Van Riper, 1999).

Rosenbaum et al. (1998) conducted a literature review of efficacy studies of family-centred practice with paediatric populations. They classified the available studies according to the type of research design used and found five studies that involved randomised control trials, the most powerful method of evaluating effectiveness. These studies involved a variety of children with additional needs (some with developmental disabilities, some with chronic health needs) and service types. All the studies incorporated some elements of family-centred practice and all demonstrated evidence of the effectiveness of this approach to service delivery in positively influencing both child and family outcomes. Studies using less powerful methodologies also supported the effectiveness of family-centred service delivery.

On the basis of their review of the literature, Dunst et al. (1998) summarised the benefits of family-centred practice as:

The research base indicates that programs and practices that are family-centred, or which show a presumption toward family-centredness, are associated with a number of positive parent, family, and child benefits. Parents of children who experience practices that are family-centred in their orientation are more likely to report and demonstrate positive effects in terms of satisfaction with parenting, parent empowerment, parent and family well-being, personal self-efficacy, family cohesion, parent-child interactions, parent satisfaction with child progress, and other aspects of child, parent and family functioning. (p.4)

However, they also caution against expecting family-centred practice to be a major determinant of program outcomes:
... family-centred practices are but one early intervention program characteristic that would be expected to influence child, parent, and family functioning, and one ecological variable that would be expected to be related to human behaviour and development. Other early intervention variables that have been suggested or found to be related to different outcomes include length of program involvement, service delivery location, frequency of child and parent contact, and type and amount of services provided to a child and his/her family. (p.5)

Individual studies of the effects of family-centred practice have focused on parental outcomes such as increased sense of control and reduced stress. Two studies have shown that parents receiving family-centred services experience a greater sense of control (Judge, 1997; Trivette et al., 1996b). In this study cited earlier, Trivette et al. asked mothers involved in three contrasting types of human services programs to rate the degree of control they experienced in getting the help they needed. Those receiving help from family-centred programs rated themselves as having significantly more control than those receiving help from either family allied or professionally-centred programs. Those receiving help from family-allied programs rated themselves as having significantly more control than those receiving help from professionally-centred programs.

In the second study, Judge (1997) investigated sources of variations in parents' assessments of help-giving practices and their perceptions of the degree of control they had over what happened. The study involved 69 parents of children, from birth to age five with disabilities or at risk of poor developmental outcomes. Results indicated that parent and family characteristics showed no relationship to either help-giving practices or perceptions of personal control and self-efficacy. In contrast, program characteristics and help-giving practices were highly associated with the degree to which parents indicated they had control over needed services, resources and supports.

In a USA study, Van Riper (1999) explored the perceptions of a group of mothers of children with Down Syndrome and their relationships with early childhood intervention service providers, and how these perceptions related to well-being in parents and families. She found that when the mothers believed that their families' relationships with health care providers were positive and family-centered, they felt more satisfied with the care their children were receiving, and were more likely to seek help from health care providers. When a discrepancy existed between what mothers wanted the family-health
care provider relationship to be, and what they believed the relationship was, they felt less satisfied with the care that their children were receiving. Furthermore, those mothers who believed they had positive family-centered relationships with providers, and who felt more satisfied with care received, reported higher levels of individual and family well-being.

King, King, Rosenbaum and Goffin (1999) set out to determine whether (and to what extent) family-centred care-giving helps to lessen the feelings of distress and depression that some parents experience in raising a child with a disability. They also took into account other factors known to affect well-being (child behavior problems, coping strategies of parents, protective factors in the social environment, child factors related to disability, and family factors). The authors asked 164 parents of children (aged 3 to 5.9 years) with neurodevelopmental disorders, to complete a series of instruments measuring the severity of the child’s disability, social-ecological factors (family functioning, and satisfaction with social support), psychosocial life stresses (family stressors, child behavioural problems), parental emotional well-being (depression, and stress), how family-centred the services were, and how satisfied they were with the services they received.

Results showed that a higher level of family-centered care-giving was a significant predictor of three parental outcomes: greater satisfaction with services, less stress, and better parental well-being. However, the most important predictors of parental well-being were child behavior problems and protective factors in the social environment (general social support and having a supportive and well-functioning family). Thus, parents reported less stress and depression when their children had fewer behavioural problems and the parents themselves had strong support networks and supportive families. Thus, family-centred care-giving increased the benefits experienced by parents but were not the most important factors contributing to positive outcomes for parents.

In the light of findings of this kind, Dunst and colleagues (Dunst, 1997; Dunst, Brookfield & Epstein, 1998) have suggested that family-centred practices have value-added benefits; that is, they produce positive parent and family benefits beyond those produced by structural intervention factors (such as the form and frequency of services provided) and non-intervention factors (such as employment, housing, health care and social
support). The implication is that the full benefits of family-centred service may only be experienced when all the other factors are in place; that is, when the families have access to technically competent services and have adequate social and financial support.

Another way of interpreting the findings is that family-centred service delivery has both direct and indirect effects. Thus, Thompson, Lobb, Elling, Herman, Jurkiewicz and Hulleza (1997) found that parents receiving family-centred services were more likely to report feeling more empowered (direct effect) as well as to report that they had more social support and experienced less stress, which, in combination, were associated with a greater sense of empowerment (indirect effect).

Thus, the evidence suggests that family-centred practice does have positive effects on parents, but these may be limited by other factors in families’ lives. Family-centred practice also appears to have indirect benefits for families. Whether these include benefits for children is the next question to be addressed.

### 2.3.4 What effects do family-centred services have on children?

According to a review by McBride (1999), studies have shown that parent/professional partnerships are important components of healthy environments for children and parents. Children respond positively, become more involved in centre activities, make smoother transitions, and enjoy their experiences away from home when they see and sense a trusting relationship between parents and staff.

Such studies suggest that children are likely to be better adjusted in non-home environments when parents and professionals work successfully as partners. However, is there any evidence that children make better progress when the services they receive are more family-centred? Evidence that they can benefit comes from a series of studies by Law, Hanna, King, Hurley, King, Kertoy and Rosenbaum (2001) designed to develop and evaluate the feasibility of a family-centred functional therapy approach to work with young children with cerebral palsy. This involved using family-centred methods of identifying functional goals in the home and other environments. Results indicated that children receiving this approach improved in functional performance over the course of intervention. This suggests that children are most likely to benefit when family-centred practice is integrated with therapeutic interventions, although the research in this area is not extensive.
In considering the effects of family-centred practice on families, the final question to be addressed concerns the impact of different help-giving styles.

2.3.5 What are the effects of different help-giving styles?
As noted above, different help-giving styles have different effects on those being helped. What aspects of help-giving or care-giving are associated with better outcomes for families and children?

King, King and Rosenbaum (1996) identified outcomes of quality care that were repeatedly identified in the medical and rehabilitation literature. They identified three key outcomes: client satisfaction with service; adherence to agreed-upon treatments; and reduction in levels of client stress. King et al. then examined the relationship between these outcomes and the interpersonal aspects of care-giving such as information exchange, respectful and supportive care, partnership and enabling practices. While this review was useful, it is limited by the focus on medical and rehabilitation literature only, and does not link up with similar studies in the psychological, educational and family support literature such as those conducted by Dunst and colleagues.

On the basis of a number of studies they have conducted on the characteristics and effects of help-giving behaviours, Dunst and Trivette (1996) concluded that there are three elements of effective help-giving. These are:

- **Technical knowledge and skills.** This refers to the help-giver’s specialist knowledge and skills. High quality technical knowledge and skills result in the implementation of appropriate educational, therapeutic and medical interventions. Help which is of a high technical quality but which does not incorporate the other two elements can have positive outcomes in one area (e.g., in the child’s health) but negative outcomes in others (e.g., parental resentment and disempowerment as a result of the manner in which the services are delivered).

- **Help-giver behaviours and attributions.** Help-giver behaviours which positively influence psychological well-being include good listening, empathy and warmth. Help-giver attributions that have positive outcomes include beliefs in the person or family’s competence and capabilities. Positive help-giver behaviours and attributions result in: (a) greater parental satisfaction with and acceptance of helping; and (b) greater psychological and emotional well-being. Help-giving behaviours and attributions are a necessary but insufficient condition for strengthening family
competencies and developing new capabilities. To achieve that, the third element of effective help-giving is necessary.

- **Participatory involvement.** This entails the recipients of help being offered information about intervention options, sharing decision-making, and being directly involved in acting on decisions. Effective participatory involvement results in: (a) parents feeling more in control; and (b) the strengthening of parental competencies.

All three elements need to be present for help-giving to be truly effective. The second and third components provide value-added benefits. According to Dunst and Trivette (1996), the help-giving and participatory involvement elements cannot be faked:

> Research indicates that help receivers are especially able to “see through” helpgivers who act as if they care but don’t, and helpgivers that give the impression that help receivers have meaningful choices and decisions when they do not. (p. 337)

What evidence is there that these help-giving styles are associated with better outcomes? A number of studies have found that help-giving that incorporates the above features is associated with greater parental sense of control (Trivette, Dunst, Boyd & Hamby, 1995; Trivette et al., 1996), as well as fostering perceived confidence and competence of family members (Washington & Schwartz, 1996). There is also evidence that family-centred programs models incorporating participatory help-giving practices are more effective in empowering families; that is, in supporting and strengthening family competencies and problem solving abilities (Trivette, Dunst & Hamby, 1996a, 1996b; Judge, 1997; King, King, Rosenbaum & Goffin, 1999; Thompson, Lobb, Elling, Herman, Jurkiewicz & Hulleza, 1997). Participatory practices have therefore been shown to have value-added benefits beyond those attributable to relational help-giving practices (Dunst & Trivette, 1996; Guttierez, GlenMaye & DeLois, 1995).

### 2.3.6 Summary of the effects of family-centred practices

The research that has been conducted to date on family-centred practice is generally supportive of its benefits. Clear benefits for parents and families have been found, with indirect benefits for children. In addition, no studies have identified any negative effects.
However, there are a number of weaknesses in the existing research base that suggest that the full power of family-centred practice has yet to be tested. One weakness lies in the shortage of studies involving randomised control trials, always a difficulty performing research in the human services sector. Another weakness is that many of the studies that have been conducted have involved programs with some features of family-centred practice, but not all the qualities that make up a comprehensive family-centred approach. A third deficiency is that all studies so far have relied upon parent ratings of the family-centredness of services, and there have been no studies that involved objective measures of how the services were actually delivered.

As will be seen when the evidence regarding parents’ experiences of service delivery is examined in Section 2.5, there is sometimes a considerable gap between the rhetoric of family-centred practice and the reality of the services families receive. The true impact of family-centred practice will not be known until we can demonstrate that the families received the services they were meant to receive in the manner that was intended.

2.4 SUMMARY OF FAMILY-CENTRED PRINCIPLES, PRACTICES AND EFFECTIVENESS

The preceding sections of the literature review have examined the key statements of principles of family-centred practice, the application of these principles and practices in wider settings, and the evidence for the effectiveness of this approach. Table 2 summarises the body of knowledge in relation to theory, practice and evidence, divided into principles, practices and skills.
Table 2
Summary of Family-Centred Principles, Practices and Skills

<table>
<thead>
<tr>
<th>PRINCIPLES</th>
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<tbody>
<tr>
<td>• Services recognise that all families are unique, and provide support in</td>
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<td>ways that are respectful and non-judgmental of particular family styles,</td>
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<td>values and abilities.</td>
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<td>• Services are sensitive and responsive to family cultural, ethnic, and</td>
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<td>socio-economic diversity.</td>
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<td>• Services recognise that parents know their children best and want the</td>
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<td>best for them.</td>
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<tr>
<td>• Services accept that parents have the ultimate responsibility for the</td>
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<td>care of their children and for all decisions made about them.</td>
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<td>• Services understand that children’s needs are best met when families</td>
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<td>are supported in making informed decisions about them and their families,</td>
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<tr>
<td>• Services recognise that children, families and service providers all</td>
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<td>benefit most when services are based on true collaborative partnerships</td>
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<tr>
<td>between families and professionals.</td>
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<td>• The way in which services are delivered is as important as what is</td>
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<td>delivered.</td>
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<tr>
<td>• Children’s needs are most likely to be met when the needs of all family</td>
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<td>members and of the family as a whole are also met.</td>
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<th>PRACTICES</th>
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<tr>
<td>• Families and family members are treated with dignity and respect at all</td>
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<td>times.</td>
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<td>• Services are based on the needs and priorities of families.</td>
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<td>• Service providers seek to engage parents in collaborative partnerships</td>
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<td>based on mutual trust and respect.</td>
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<td>• Service providers acknowledge and respect the family’s expert knowledge</td>
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<td>of the child and the family circumstances as complementing their own</td>
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<td>professional expertise.</td>
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<tr>
<td>• Service providers take account of the needs of all individual family</td>
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<td>members as well as the needs of the family as a whole.</td>
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<td>• The information that families need to make informed choices is shared</td>
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<tr>
<td>in a complete and unbiased manner.</td>
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<td>• Service providers offer families choices about the goals and nature of</td>
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<td>the services, and support and respect the choices that families make.</td>
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<tr>
<td>• Services are provided in a flexible fashion according to the evolving</td>
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<td>needs and circumstances of particular families.</td>
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<tr>
<td>• Family needs are met through a broad range of informal, community and</td>
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<td>formal supports and resources, rather than through formal resources</td>
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<td>alone.</td>
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• Where possible, families are helped to find ways of meeting their own needs using the existing strengths and competencies of the family and family members.
• Families are helped to develop new strengths and competencies to meet the needs of their children and the family as a whole.
• Families are helped to identify and mobilise sources of support in their family and social networks and local communities.
• Service providers help families establish and maintain strong social support networks according to need.
• Services form strong links with other mainstream and specialist child and family services to ensure that all family needs are addressed in an integrated fashion.

<table>
<thead>
<tr>
<th>SKILLS</th>
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| • Service providers need well-developed listening and communication skills.  
• Service providers need skills to establish and maintain good collaborative relationships with families.  
• Service providers need skills in helping parents determine their priorities and clarify their goals.  
• Service providers need skills in recognising, acknowledging and helping families build upon their strengths and competencies.  
• Service providers need skills in identifying and mobilising social support networks and community resources.  
• Service providers need skills in establishing and maintaining good collaborative relationships with other mainstream and specialist child and family services. |

In addition, the literature also emphasises the points below:
• Family-centred practice is both a philosophy and a set of practices. Although there is agreement about the core elements involved, different researchers and practitioners emphasise different aspects.
• Family-centred practice has a powerful rationale that is clearly linked to a number of positive benefits for families and children.
• Although family-centred practice was developed in the context of early childhood intervention services for young children with disabilities and their families, it has been increasingly adopted in other service settings.
• Research evidence indicates that parents can clearly discriminate between services that provide different levels of family-centred practice, and that they prefer those that are more family-centred.
• The evidence also indicates that higher levels of family-centred practice are a significant predictor of parental satisfaction with services, reduced stress levels and greater parental well-being.

• However, the most important predictors of stress and parental well-being were child behaviour issues and factors in the social environment such as social support and having a supportive and well-functioning family. Therefore, family-centred care-giving increases the benefits experienced by families but is not the most important aspect contributing to positive outcomes for parents.

• For children, the benefits of family-centred practice are indirect. Children are only most likely to benefit when these practices are integrated with therapeutic interventions.

• For early intervention services to be effective, they need to incorporate the three elements of technical competence in the provision of therapeutic interventions, positive behaviours and interpersonal skills of staff, and a family-centred approach to collaboration with, and empowerment of, families.

• Although the effectiveness of family-centred practice has yet to be fully tested, there is an accumulating body of evidence indicating that family-centred practices have value-added benefits. That is, they produce positive parent and family benefits beyond those produced by structural intervention factors (such as the form and frequency of services provided) and non-intervention factors (such as employment, housing and health care).

Sections 2.2 and 2.3 have explored the literature relevant to the principles, practices and effectiveness of family-centred practice. Section 2.5 will now outline the literature relevant to families' experiences of early childhood intervention services and family-centred practice and studies that have explored the views of service providers.
2.5 FAMILY EXPERIENCES OF EARLY CHILDHOOD INTERVENTION AND FAMILY-CENTRED PRACTICE

This section reviews the literature in relation to:

- Experiences of families who use early childhood intervention services;
- Aspects of service delivery valued by families;
- Aspects of service delivery valued by service providers; and,
- Families’ and service providers’ experiences and perceptions of family-centred practice.

There is a great deal of material dealing with parental reactions and adaptation to having a child with a disability, but very little that simply describes what it is that families receive from early childhood intervention services, and what it feels like to receive such services. There is a major longitudinal study underway in the USA, the National Early Intervention Longitudinal Study, that should provide a comprehensive picture of what families in the USA receive, but this study is not yet reporting findings. There is also one small study (Thompson, 1998) that provides some insights into how Australian mothers of young children with disabilities experience early childhood intervention services. There are a reasonable number of studies that have explored family experiences of early childhood intervention and disability services with specific questions in mind, and these are the focus of what follows.

2.5.1 Experiences of families using early childhood intervention services

In a small study conducted in New South Wales (Thompson, 1998), parents of young children with disabilities and high support needs, completed questionnaires and were interviewed about the early childhood intervention services that they received. The study was particularly interested in the services provided by occupational therapists, but parents did not discriminate between the different members of the early childhood intervention team. Therefore, results reflect parents’ perceptions of early childhood intervention services and providers in general.

The key themes reported by parents in this study were:

“Doing the best for my child.”

- Mothers evaluated their own efforts in terms of their child's progress. When the child was doing well, the mothers felt that their efforts to participate in the early childhood intervention service were worthwhile.
• Mothers felt they were involved in ‘an ongoing cyclical process of seeking, waiting, participating in, adjusting to and analysing the early intervention services their child received’. (pp. 13-14)
• Mothers made considerable efforts to develop and adapt family routines to incorporate direct contact time with therapists and the home programs that were recommended. When these demands proved too great, they selectively adapted home therapy routines to their routines.
• All the mothers reported forgoing employment or other opportunities to be involved in early childhood intervention services for their children.

“Helping the child to develop skills.”
• Mothers measured their children’s development in terms of functional goals such as ‘communication’ and ‘walking’, but felt that therapists measured a child’s progress in terms of component skills such as ‘muscle strength’.
• Mothers believed that the more time they spent repeating and reinforcing therapy sessions at home, the more likely their child would make progress.

“I have to think of my whole family.”
• Mothers continuously balanced the demands placed on them by their home, their family, and the early childhood intervention services they received. As one mother said, ‘It’s just a matter of trying to cut yourself in half really, trying to spend that therapy time with her and then trying to give them [the family] some attention at the same time’ (p. 214)
• Attempts by mothers to incorporate early childhood intervention services into daily family routines were often thwarted by the incompatibility of family and therapist routines; that is, appointments provided at times that took no account of family demands and schedules.

“What does that do?” – the place of services.
• Mothers saw therapists as ‘teachers’ of therapy techniques to both the children and their caregivers.
• They also saw them as important providers of information about other services.

A recurrent theme in these comments is the difficulties parents experience in balancing the demands of early childhood intervention programs and home life. This group of parents
may have been receiving services that were not truly family-centred. It appears that the therapists determined the strategies needed and the parents were expected to carry these out at home and to make the necessary adjustments to their lives. Inevitably, parents sometimes found this difficult to do, and felt guilty as a consequence.

2.5.2  Aspects of service delivery valued by families

A number of studies have investigated what aspects of service delivery are most important for families of young children with disabilities (Able-Boone, Sandall, Loughry & Frederick, 1990; Peterander, 2000; Rosenbaum, King & Cadman, 1992; Roush, 1994; Thompson, 1998; Wehman & Gilkerson, 1999). These studies, from different countries (USA, Canada, Germany and Australia) involve different models of service delivery, and use different research methods. Although some common themes emerge, there are substantial differences that presumably reflect the nature of the services that the parents were receiving at the time.

In the Australian study by Thompson, parents described a number of needs and desires that they were looking to have met by service providers. These include:

- A need for constant reassurance and feedback from the service providers;
- Therapists helping families determine their own comfortable level of involvement in therapy services;
- Assisting families help their child to develop further;
- Interventions that encouraged sibling participation to reduce the impact that having a child with high support needs may have on other family members; and,
- Early childhood intervention services that used a family-oriented approach and assisted in bringing the family closer together and strengthening family relationships.

On the basis of an analysis of the experiences of parents of young, deaf children, Roush (1994) identified certain recurring themes in the shared experiences of parents. Parents wanted professionals to provide facts and information, particularly in the early stages of diagnosis, which is one of the most stressful periods that parents will experience in their entire lives. Parents also reported that a sincere, caring attitude from professionals, even if they do not know all the answers, was noticed and appreciated. Parents also commented that in the early stages they wanted the 'right choices' presented to them but that in the end most wanted to make their own decisions. They depended on
professionals, however, to provide honest, unbiased information, delivered at a level appropriate to parents' knowledge and experience. Most families sought professionals who would support and encourage them along the path of their own choosing.

Roush also found that families wanted flexibility in intervention and placement decisions. What may be the 'right decision' at a given point in time may change later on. Families wanted to be supported in the options they choose, and not made to feel 'locked in' to these important decisions. It was also important to families to be praised and supported for what they were able to do, and not 'judged' for what they were unable to do. Parents were also seeking and needing the support of other parents. Many families reported an emotional 'turning point' when they connected with a supportive group of other parents.

Parents were particularly appreciative when professionals sought creative ways to encourage the participation of all family members rather than designating a given individual, usually the mother, as the family expert and decision-maker. Finally, parents valued the notion that regardless of the options or pathway they chose, they wanted professionals to impart a sense of hope for the future, with an emphasis on ability rather than disability.

Wehman and Gilkerson (1999) surveyed American parents who used early childhood intervention services. Parents were asked open-ended questions about the most helpful aspects of the services they received and the biggest barriers to family involvement. The most common factors mentioned were:

**Most helpful/beneficial aspects of early intervention experiences**

- Technical knowledge and skills of professionals (reported by 40% of parents);
- Direct child-focused therapy services (34%);
- Parent education (32%);
- Diagnostic evaluation/assessment of the child (28%); and,
- Parent-to-parent social support (24%).

**Biggest barriers to achieving desired levels of family involvement**

- Providing service at times that were incompatible with family commitments (40%);
- Poor parent-professional communication (30%);
- Insufficient level of service provision (28%); and,
• Difficulties in finding child-care for siblings (22%).

Able-Boone et al. (1990) interviewed parents of young children with special needs about the early intervention services they were receiving and what changes were needed to make services more family-centred. Two major themes emerged from the interviews. First, parents wanted information regarding their child’s special needs and about available community resources. Second, they wanted professionals to relay this information and empower families to become their own decision-makers. Thus, parents wanted to know their own options so they could make informed choices. Other points made by parents were:

• Parents are more able to make decisions over time;
• Multiple service options need to be available and communicated to parents;
• Service plans need to be working plans that can be changed according to need;
• Family assessments need to be conducted over time so that early intervention practitioners can establish a relationship with the family; and,
• The process of accessing early intervention services for infants must become easier and friendlier.

In a further study out of the USA, Summers, Dell’Oliver, Turnbull, Benson, Santelli, Campbell and Siegel-Causey (1990) explored families’ and practitioners’ opinions about the expected outcomes for families of early intervention, and their preferences for the methods used to gather information about family strengths and needs. Focus groups involving a mix of practitioners and family members were conducted. Statements generated by the focus groups were divided into three main categories: (1) early intervention program principles; (2) identification of family needs and strengths; and, (3) expected outcomes of early intervention for families. The main issues identified in this study were:
Early intervention program principles
The most commonly mentioned theme was sensitivity to families. Respondents wanted service providers to be supportive of families experiencing a wide range of emotions, to be accepting and non-judgmental and to consider the possible unintended consequences of casual comments or program expectations. Other principles reported as important include:

- Acknowledging the family as the ultimate decision-maker;
- Acknowledging diversity and meeting family preferences;
- Communicating clearly;
- Considering the whole family; and,
- Enhancing social support for families.

Identification of family strengths and needs
There was a strong preference for informal methods of gathering information. Some parents even found that open-ended interviews were too structured, and preferred conversations that created a friendly and relaxed atmosphere in which parents could tell their stories. Equally important was the willingness of practitioners to invest time and energy in developing rapport and friendship with families.

Expected outcomes of early intervention for families
The most commonly identified topic was families’ needs for information of all kinds. This was particularly important for families of very young children. The information they wanted concerned normal child development, their children’s special needs, and available services. This information should be available in several different formats and repeated at different points in time, as families’ changing emotional states allow them to attend to the information.

In a Canadian study, Rosenbaum et al. (1992) set out to determine the relative importance of components of care-giving for the promotion and maintenance of mental health and well-being of parents of children with long-term disabilities. Through a search of the literature, 22 components of effective care-giving were identified. Health care professionals and parents were then asked to rate the importance and relative priority of these aspects of caregiving. Among the seven highest-ranked aspects of care, both parents and professionals identified the following:
• **Parent involvement**: Recognising the role that parents have in decision-making.

• **Education and information to child and family about the child’s condition**: Provide initial and continuous explanations about the child’s condition, its causes, course and prognosis. Suggest reading materials and parent groups as sources of information and act as a resource for questions about the condition and relevant interventions.

• **Treatment of disability**: Provide continuous evaluation of the child’s progress, necessary treatment and therapies, including the provision of equipment.

• **Accessible and available care**: Provide prompt response to referral; a convenient location, parking and office hours; and a reasonable waiting time.

• **Co-ordination of care**: Recognise the need for services from other sources and make appropriate referral. Ensure information is shared among others involved. Act as liaison with school, specialists, agencies and others involved in caregiving by providing a necessary link to or follow-up of required services.

• **Continuity and consistency of care**: Provide continuity over time so that the same professionals act as regular providers of care. Link information from one visit to another and one professional/caregiver to another.

• **Family-centred approach to care**: Recognise the potential social and emotional impact of the child’s disability on all family members, and demonstrate a willingness to anticipate and respond to each member’s problems and needs.

These North American studies revealed that parents want services that are sensitive to their needs and provide them with the skills and knowledge to meet their children’s needs more effectively. However, a rather different picture emerged from a German study (Peterander, 2000) which involved a large survey of mothers and investigated the nature of their relationships with professionals, what they expect from cooperation with professionals, and what factors influence cooperation. Among the results reported were:

*Aims of early childhood intervention reported by mothers:*

• Child’s well-being (98%);

• Recognition of even slight progress in their child (95%);

• Continuation of intervention by parents in everyday life (91%);

• ‘Acceptance’ of the child’s disabilities by the parents (88%);

• Intervention by the specialists so the child can overcome its disabilities as far as possible (82%); and,

• Substantial progress by the child (70%).
Helpful ways of cooperating in early intervention:

- Families to work with one expert over longer periods of time (88%);
- The course of intervention includes many elements based on play and games (88%);
- Experts to do home visits (72%);
- Intervention does not emphasise a child’s achievements as much as its well-being (67%);
- Specialists systematically train children in individual skills (60%);

However, in this German study, mothers were less likely to find it helpful if:

- Early intervention relieves them of some responsibilities (34%); and,
- Specialists also dealt with general family problems (25%).

Mothers wanted to be actively involved in early intervention and believed that:

- Long-term success can only be achieved if the parents are proactive (91%);
- Specialists should make home visits (72%); and,
- Intervention cannot be successful unless the whole family is involved (68%).

Most mothers were very satisfied with the:

- Early intervention services received by their child (90%);
- General work of the early intervention centre (90%);
- Professional knowledge of the therapists (88%); and,
- Ability of the specialists to consider the individual needs of their child (87%).

However, not as many mothers were happy about the:

- Child being referred to another service (56%);
- Medical care given to their child (47%);
- Information made available by the early intervention centre (40%); and,
- Help offered by support groups for parents (33%).

Maternal assessment of the professionalism of the specialists was that they:

- Enjoyed working together with the specialists (96%);
- Were confident and relaxed when their child goes for intervention sessions (95%);
- Have confidence in the early intervention work (94%);
- Accepted the treatment given by the experts (93%);
- Thought the experts were professionally very competent (93%); and,
- Found talking to them helpful (87%).
This pattern of responses suggests that the German mothers were much more accepting than USA parents of a traditional service model in which the professionals were clearly the experts and there was little emphasis building parental competencies. While this may reflect cultural differences between Germany and the USA, it also suggests that what parents value about services is shaped by what they are offered. If the only model of service available is professionally-centred, then what parents are likely to value most is professional competence, whereas if services are family-centred they are likely to regard the development of their own competencies and decision-making as important as the competence of the professionals.

Finally, in a comprehensive review of the research evidence out of the UK, Sloper (1999) identified the following key features of service models that are effective in meeting the needs of parents of children with disabilities. He identified that services need to:

- Take a holistic approach to assessing and meeting family needs;
- Recognise the importance of relationship building between parents and professionals;
- Provide a consistent, single point of contact for the family;
- Have a flexible, individualised, needs-led approach;
- Focus on parents’ own concerns and recognise the importance of understanding parents’ own perceptions of the hierarchy of their needs;
- Provide support in ways that empower parents rather than take control away from them; and,
- Recognise and acknowledge parents’ own expertise with regard to their child and family.

What is striking about these findings is that nearly all these features are recognisable as consistent with family-centred practice, although this is not a term much used in the UK context. Sloper continued on to suggest that services could support families more effectively by providing them with a key worker, training workers in basic counselling skills and using parent/partnership service delivery models.

Despite the differences, certain common themes emerged from all of the studies described in this section. The features of early childhood intervention services that were most important for families in all the studies were:
• Being able to balance the demands of the intervention program and home life;
• Having services that consider the needs of the whole family; and,
• Professional competence.

The issues that were important for USA, Canadian and UK families but not as valued apparently by the German families were:
• Being provided with information about child needs and community resources;
• Having services that are flexible and able to change as family needs changed;
• Professionals who use empowerment approaches that build on family strengths; and,
• Professionals who are sensitive to family issues and communicate effectively.

2.5.3 Satisfaction as a dimension of service delivery

An often-used method of service evaluation is to look at the level of family satisfaction. A number of studies have been undertaken that tell us what can be learnt from this sort of activity. These include King, Cathers, King and Rosenbaum, 2001; McNaughton, 1994; Stallard and Hutchison, 1995; McWilliam, Lang, Vandivere, Angell, Collins and Underdown, 1995; Viscardis, 1998.

A common finding in studies of parental experiences of early childhood intervention services is that parents report high levels of satisfaction with the services they receive. McNaughton (1994) reviewed the relevant research literature and found 14 studies using a variety of procedures to measure parental satisfaction, including questionnaires, personal interviews, and telephone surveys. All of the studies reported high levels of parent satisfaction. McNaughton speculated that this might have been because most of the programs described in the research were model programs that employed the best practices in early childhood intervention. However, there are several other factors that are likely to have contributed to the high ratings. First, most parents have usually only had experience with the particular service that they are rating, and therefore cannot compare it with others. Second, parents are genuinely grateful for any help they get and their high satisfaction levels may be more a reflection of their gratitude rather than an indication that they have no complaints about the service they are receiving. Finally, there is the possibility that satisfaction and dissatisfaction are not simply opposite ends of the same continuum.
The third possibility was explored by King, Cathers, King and Rosenbaum (2001) where they treated satisfaction as a global concept, and explored the major features of care associated with both satisfaction and dissatisfaction. Donabedian (1988) also regarded satisfaction as a consequence of the whole experience of care with three main elements: structure, process and outcomes.

- **Structure** of care refers to attributes of the setting in which care occurs and the actual service provided.
- **Process** of care refers to what is actually done in giving and receiving care; that is, the manner in which services are delivered and the interpersonal processes involved.
- **Outcomes** refer to the effects of care on the recipient.

Of these Donabedian found that the manner in which services are delivered and the interpersonal processes involved, were the most important contributors to reported satisfaction.

King et al. used these three elements in a study involving 645 parents of children with special needs that explored issues related to family satisfaction. They compared the responses between families who were previously assessed as highly satisfied or relatively dissatisfied. Their main findings were:

- Parents made considerably more comments about the process of service delivery than about the structure, indicating that how services are delivered was more important to them than what was delivered.
- Satisfied parents made more comments about what they liked than about what they disliked, whereas the opposite was true of dissatisfied parents.
- Overall, however, parents made more comments about what they liked than about what they disliked; this suggests that even relatively dissatisfied parents were able to see the positives in the services they were receiving.
- Relatively dissatisfied parents made more comments about structural aspects of service than did satisfied parents, whereas the two groups did not differ in the references to process elements. This means that, even when dissatisfied with what they were receiving, dissatisfied parents did not necessarily have any complaints about the manner in which the service was delivered.
Parents made very few references to the actual outcomes of care for their child or family. The reasons for this are unclear, as there are grounds for believing that actual outcomes are important for client satisfaction.

The most common feature of service mentioned by both satisfied and dissatisfied parents was respectful and supportive care (i.e., feeling listened to and having a sense of rapport with service providers).

Highly satisfied parents most often mentioned respectful and supportive care, staff competence, availability of services, and being provided with general information (about their child’s disability or available services).

Relatively dissatisfied parents most often mentioned lack of respectful and supportive care, lack of continuity in service provision, lack of coordinated service provision, and difficulties in accessing services easily.

Another version of those features of service that lead to parental satisfaction is provided by Viscardis (1998), herself the parent of child with a disability. In her view, families tend to approach issues related to service delivery in a very straightforward way. They know what they want because they know what will work for them and for their child. Thus, they tend to focus on what works for them, rather than on the barriers that prevent them from being satisfied with a service. She observed that families are likely to be highly satisfied with the services they receive when:

- Service providers respect differences among children, families and families’ ways of life;
- Service providers acknowledge that they do not know what it is like to be in the family’s situation;
- Parents are acknowledged as the constant in the child’s life and as such are recognised as knowing their child best;
- Parents are considered equal members of the child’s team when the service is being developed, reviewed or changed;
- Family’s choices and decisions are respected;
- Services are planned with families’ scheduling needs in mind;
- Service providers acknowledge that they may provide only a portion of the service to a family and that in many cases there are other priorities in the families’ lives;
Service providers have found a way to balance the families’ need for information with the need for support;
Informal supports are offered, for example, information about peer support; and,
Services can change quickly when families’ or children’s needs change.

These studies of parental satisfaction and dissatisfaction show that, although parents usually rate early childhood intervention services very highly, this does not mean that they are satisfied with all aspects of service. As satisfaction and dissatisfaction are not bipolar, it is possible for parents to report that they are very satisfied with services overall while identifying some quite unsatisfactory aspects of service. How services are delivered appears to be more important to parents than what is delivered. Parents particularly value respectful and supportive care from professionals, and being treated as equals. When they are dissatisfied with aspects of service, it is most often because the professionals do not respect or understand their views, or fully inform or involve them in decisions. Parents are also dissatisfied when services are intermittent, poorly coordinated or hard to access.

This approach to satisfaction is not limited to the early childhood intervention sector. In a study based around the delivery of school-based therapy service, King, McDougall, Tucker, Gritzon, Malloy-Miller, Alambets, Cunning, Thomas and Gregory (1999) found that:

...satisfaction was not related to the amount of improvement made by the children or their goals. The low correlation indicates that parent-teacher satisfaction may be based on aspects of service other than the children’s functional outcomes. (p. 23)

2.5.4 A comparison of parents’ and practitioners’ views of early childhood intervention services and family-centred practice

A number of studies have directly explored parental and professional views of the extent to which services are delivered in a family-centred way (Brotherson & Goldstein, 1992; King, Law, King & Rosenbaum, 1998; McWilliam, Snyder, Harbin, Porter & Munn, 2000; Rosenbaum et al., 1992; Wesley, Buysse & Tyndall, 1997).

In 1998, King et al. conducted a province-wide survey of 436 parents of children with disabilities in Ontario, Canada. Parents completed the Measure of Process of Care (MPOC), a measure with five sub-scales, of parents’ perceptions of the behaviours of service providers. Parents scored moderately high on three of the sub-scales: Respectful and Supportive Care, Enabling and Partnership, and Coordinated and Comprehensive
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Care; but lower ratings on the remaining two: Providing General Information and Providing Specific Information about the Child.

In the same study, King et al. reported the results of a survey of 309 early childhood intervention service providers using the Family-Centred Program Rating Scale (FamPRS) (Murphy, Lee, Turnbull & Turbiville, 1995) to measure service providers' perceptions of the importance and occurrence of family-centred practice in children's rehabilitation centres. Service providers reported that they felt they were doing well at:

- Communicating with parents in a timely, complete, friendly and honest manner;
- Treating parents as experts with their children;
- Considering the strengths of families; and,
- Providing families with a positive view of the future and how they can help their child.

However, service providers said they fell short of the ideal on four of the features of family-centred practice. These were:

- Providing information in a variety of ways to families;
- Involving family members in making plans and decisions about services;
- Assisting families in making decisions and obtaining services quickly and easily; and,
- Considering families' practical constraints and making them feel comfortable about asking questions and raising concerns.
King et al. suggested that:

...these four aspects of service delivery may be the most difficult for service providers to implement because they involve close collaboration with others (including the family), or networking with other agencies, and may be seen by management as less efficient ways of delivering services.  (p. 36)

In an earlier study by the same research team, Rosenbaum, King and Cadman (1992) asked service providers and parents to rate the importance and relative priority of various aspects of care-giving. They identified seven aspects of care that were highly rated by parents and professionals alike, and two further aspects of care that were important to the parents but less so to the professionals. They then asked the professionals to say which of these were ‘routinely’ offered at their centre. Several of the care-giving elements most highly rated by parents (Accessible and available care, Continuity and consistency of care, and Family-centred approach to care) were relatively less frequently and variably available through Ontario’s children’s treatment centres. Instead, services that were less highly valued by parents (such as Evaluation of disability, Advice on present concerns about development, and Team approach) were more likely to be offered.

Brotherson and Goldstein’s study in 1992 of the experiences of American parents and professionals of parent/professional partnerships in early intervention programs found that both groups reported that time was critical to parents and professionals, both as a resource and a constraint. Parents reported that professionals could make the best use of the parents’ time by fitting therapy and education into their family’s daily routine and environment, and by listening to what they know about their child and family. Factors that contributed to an inefficient use of parents’ time included lack of coordination between professionals and lack of services for families and children in the community. Parents and professionals often agreed about what was essential for efficient and effective time use for families, but they described early intervention services and time usage differently.

In another USA study, McWilliam, Snyder, Harbin, Porter and Munn (2000) asked professionals and families to rate the family-centredness of the services they were actually providing or receiving, as well as what they would ideally like to provide or receive. They found that professionals tended to rate the services as more family-centered than did the parents, but the two groups did not differ in their views of what the services should ideally be. The most significant factor in determining whether services were family-centred or not
was the level of experience of both the professionals and the families; the more experienced the professionals were, the more likely they were to report delivering services in a family-centred way; and the longer families had been receiving services, the more frequently they reported receiving family-centred services. This suggests that it may be more difficult for relatively inexperienced professionals to work in a family-centred way. It also suggests that relatively inexperienced families are less likely to be provided with family-centred services, perhaps because they find it hard to work as partners with professionals until they gain experience and confidence. If this is the case, it indicates the two-way nature of family-centred practice. It requires both parties to understand and engage in true partnerships, and is not a way of working that can be adopted either by parents or professionals unilaterally.

In yet another USA study, Wesley, Buysse and Tyndall (1997) explored the differing experiences and perspectives of parents and professional regarding inclusion and early intervention. They conducted a series of focus groups involving parents of young children with disabilities, and professionals representing service providers and administrators from an array of human services programs and agencies such as child-care, early intervention, social services, public health, mental health, and public schools.

An analysis of participant responses revealed important similarities and differences between families and professionals in how they perceived the early intervention system. These similarities and differences represent four overarching themes:

1. When compared to parents, professionals were better able to articulate and describe the existing system of early intervention services. Parents in the focus groups did not see the services they received as a part of a coordinated system.

2. Parents needed information of all sorts and clearer communication about the complex interrelationships of programs and agencies. Parents identified a need for additional information about early intervention services, early childhood services, and family support services. Parents also asked to be provided with research findings related to these issues in a form that they could understand and use.

3. Although parents and professionals appeared to agree on many obstacles that exist to prevent full access to inclusive early childhood settings, professionals identified more barriers than did parents. This is not surprising given that professionals were better able to describe comprehensively the early intervention system and had a broader base
of experience within the system. Whereas both parents and professionals described aspects of the classroom that served to inhibit the inclusion of children with special needs (class size, teacher-child ratio, staff qualifications), professionals also cited limitations in community resources, including lack of transportation and limited availability of high-quality childcare options. They also recognised that their own lack of knowledge about community resources was a barrier to effective service delivery.

4. Finally, compared to professionals, parents offered numerous clearly articulated ideas for an ideal system of early intervention services. Most notably, parents mentioned competent and caring human services professionals as essential in the ideal system, confirming the findings of other studies that families look to the early intervention practitioner as an important source of emotional sensitivity and support.

Wesley et al. believed that these findings emphasised the value of parental participation in long-term strategic planning. They questioned whether services could be truly family-friendly without building upon families' ideas to design a service system from the ground up. Rather than waiting until the program is under way to ask families what they think of the services, agencies would benefit from their ideas and vision from the beginning. They suggested the following ways of involving parents:

- Designers of early education and intervention programs should consider gathering information from families and professionals through focus groups or other methods before the onset of child and family services to ensure that all stakeholders are given a voice in designing these services.

- Those delivering these programs should strive to create opportunities for dialogue with parents as a means of enriching collaborative partnerships and promoting shared decision-making in these settings.

- Evaluators should seek family and professional input throughout the process of designing and implementing an evaluation plan to ensure that evaluation outcomes and methods are acceptable, relevant and meaningful for consumers.

- Parents should be viewed as partners in personnel preparation and invited to share their experiences and perspectives as part of both induction and in-service education for professionals.

- Finally, ways of involving parents in research should be explored in order to increase its relevance to, and utilisation by, families.
These studies comparing parental and professional views of early childhood intervention services reveal some commonalities as well as some important differences between the two groups. In terms of their judgments of how family-centred services are, both parents and professionals felt that services were generally good at treating the families in a supportive and caring way, but relatively poor at providing parents with information about the child and about relevant services. There were also indications that the forms of service that parents most valued and wanted were not necessarily those that the professionals judged to be most important and therefore offered to a greater extent.

These studies also provided other valuable insights into the different experiences of parents and professionals. They show that professionals know the existing service system best but may be limited in their ability to think of alternative ways of delivering services. Parents, on the other hand, are well able to conceptualise a more effective system, and professionals should be seeking to engage parents in the planning and evaluation of services much more than currently occurs. The other insight from these studies concerns the important contribution of experience. The more experienced the professionals and the parents are the more likely it is that they will be able to establish true collaborative partnerships.

2.5.5 Service delivery issues in family-centred practice: The Family Service Plan and other processes

It is worthwhile spending some time examining family experiences of the processes of care or service delivery issues (see Section 2.5.3). An important vehicle through which families can experience the degree of family-centred service, is through Family Service Plans.

Individualised family service plans are one of the key features of family-centred practice. They are used to formalise agreements reached between service providers and parents about the outcomes to be sought, the actions to be taken, and who is to be responsible for each action. For a family service plan to be truly family-centred, what qualities should it have? McWilliam, Ferguson, Harbin, Porter, Munn and Vandiviere (1998) describe an ideal plan as having the following features:

A family-centered document is positive, written with understandable language, and has the right balance of precision and scope. A document that reflects what the family wants should have no more equivocation than the family feels. Neither the ambiguity of professional jargon nor the double talk of bureaucratic evasion should appear. A document with recommended practices should emphasize
developmentally appropriate activities, individualized interventions, and integrated services and should de-emphasize therapy-oriented activities, indeterminate interventions, and segregated services. Finally, a functional document should be written in a way that enables it to be used as both a service plan and an intervention curriculum. Plans with distant outcomes (i.e., not to be accomplished for 1 year or more), unintelligible interventions, and meaningless tasks are not very likely to be used. (p. 69)

What evidence is there about the extent to which family service plans possess these features? The evidence concerning the following questions will now be summarised:

- Are families involved in the development of family service plans?
- Do families receive all the services identified in family service plans?
- Are the goals in family service plans written in easily understandable language?
- Are the goals in family service plans appropriately pitched and achievable?
- Do the outcomes identified in family service plans match the concerns raised by parents?
- Are the services provided family-focused or child-focused?
- What is the nature of parental involvement in implementing service plans?
- What actually happens on home visits?
- Does true parent-professional collaboration occur?

**Are families involved in the development of family service plans?**

Although family service plans are clearly designed to be drawn up with full parental participation, this is not necessarily a role that all parents find easy. Two studies have explored ways of supporting parents in being more involved in planning and decision-making (Campbell, Strickland & la Forme, 1992; Stallard & Hutchinson, 1995).

In a UK study, Stallard and Hutchison (1995) surveyed parents whose children had disabilities and were involved in a preschool disability service. Although the parents reported high overall rates of satisfaction with the services they were receiving, 37% did not feel involved in the decisions made about their child, and 21% were not in agreement with the decisions made. In an effort to rectify this situation, a system of individual program planning involving parents and professionals was introduced. Evaluations showed that this process was well received, with 92% of the parents and 96% of the professionals reporting high levels of satisfaction. Parents now felt fully involved in decision-making, with 80% of them feeling their views were understood and 100% agreeing with treatment goals.
Another strategy for improving parental involvement in decision making is described by Campbell, Strickland and la Forme (1992). They recognised that, despite the faith in parents’ capacities embodied in family-centred practice, it is by no means easy for parents to become equal partners with professionals, especially in the early stages. To speed up the process of parent participation, they developed a short training and education program in individualised family service planning for parents. They found that parents who did this training became more able to participate meaningfully.

*Do families receive and use all the services agreed in the family service plans?*

One fundamental question that needs to be asked about family service plans is whether families actually receive all the services agreed in plans. This is not as simple a question as it might seem, since there is more than one explanation as to why there might be a shortfall in service delivery. Relevant studies have been conducted in the USA by Kochanek and Buka (1998) and Perry, Greer, Goldhammer and Mackey-Andrews (2001).

Perry, Greer, Goldhammer and Mackey-Andrews (2001) examined the extent to which families received all the services specified in their Individualised Family Service Plans. Analyses of data from more than 6,000 plans in Indiana revealed that on average only half of the service hours on the plans were actually delivered to children and families. Four types of early intervention services were most commonly delivered to enrolled children. These were occupational, physical and speech therapy, and special instruction.

Kochanek and Buka (1998) looked at families using services in three contrasting USA states. The children were selected on the basis of four characteristics which were hypothesised to influence service utilisation: age, race, primary diagnosis (whether having an established condition, developmental delay, or being substantially at risk), or level of need complexity. Data was gathered on the degree of service utilisation and the family-centred practice beliefs of parents and service providers. The results indicated that:

- Service usage was generally high (79%), with nearly half of the families using over 90% of their scheduled services, and only 18% of families using less than 50% of services.
- The extent to which parents used the services offered was not related to any measured characteristics of either the child (age, need complexity, length of program involvement) or mother (education, employment status, race, family structure).
The extent to which parents used the services offered was related to particular characteristics of their service providers. Those who were younger and who were teachers (rather than therapists) produced higher utilisation rates.

Service providers were more committed than parents to family-centred practice: Parents believed (a) that services should focus more on the child and that (b) professionals should primarily determine the service goals and methods.

Neither of the studies was able to establish why services were not delivered as planned. The features that were hypothesised to affect service utilisation turned out not to be relevant. There are several other possible explanations for the shortfall in service provision: The original plans may have been unrealistic in what was promised; the early childhood intervention services may have been inefficient or under-funded; or the families may have had other priorities and were not sufficiently committed to the chosen goals or action plans. In both studies, there was an assumption on the part of the families that the professionals should be the primary providers of service, suggesting that the families had not been introduced to more family centred ways of working in which they played a more active role and action plans focused on natural learning opportunities in everyday environments. If this is the case, it is quite possible that part of the reason why parents did not make full use of services is that they were based on goals that were not truly salient for them and used methods that did not involve them developing new skills and competencies.
Are the goals in family service plans written in easily understandable language?

Boone, McBride, Swann, Moore and Drew (1998) compared family service plans collected in two USA states to see to what extent they were written in professional versus family-friendly (lay) language. They found that the majority of plans used professional language and discipline-specific jargon in their descriptions of children's current functioning levels. Similarly, the outcomes were often written in behavioral terms, with specific criteria and timelines, rather than functional terms.

The other relevant study by Pretti-Frontczak and Bricker (2000) took the form of an intervention designed to improve the clarity of family service plans. This study demonstrated that it was possible to train professionals to write better quality goals for such plans.

Are the goals in family service plans appropriately pitched and achievable?

Another question to be asked of family support plans is whether the goals are appropriately pitched for the child and family abilities and are they achievable in a reasonable time. There is evidence that family support plan goals may not always be appropriate and achievable. Based on a study of support plans from 15 early childhood intervention programs in the USA, Goodman, (1992) and Goodman and Lloyds (1993) found a clear tendency for goals to be pitched beyond children’s developmental levels. As a result, the same goals tended to be repeated from year to year. This appeared to be more the result of inappropriate expectations rather than the children needing to practice the relevant skills extensively in order to learn them.

Do the outcomes identified in family service plans match the concern raised by parents?

One of the key tenets of family-centred practice is that services should be based upon the needs and priorities of families. Thus, the goals or outcomes identified in family support plans should reflect the principal concerns of families. There is only one study that has looked at the extent to which this happens (Boone, McBride, Swann, Moore & Drew, 1998), although there is another study that looked at the more general question of whether services were responsive to families’ needs (Mahoney & Filer, 1996).
In an analysis of family service plans from two USA states, Boone et al. asked whether there was a match between the expressed concerns noted on the service plan and the outcomes identified. They found that the extent to which parental concerns were actually addressed in outcome statements was modest at best: 50% in one state and 46% in the other. Findings suggested that professionals felt confident in their abilities to help facilitate children’s developmental needs but less confident in their abilities to assist families with other identified concerns of a more general nature.

A study by Mahoney and Filer (1996) explored the responsiveness of services by examining the type and scope of services provided to families in early intervention programs to see if they were responsive to families’ needs and priorities. Results indicated that there was a significant correlation between the parents’ ratings of the importance of various forms of service and the actual services they received. However, there was a significant gap between the level of services that parents reported receiving and the level they felt they needed.

Mahoney and Filer interpreted these results as indicating that the early childhood intervention programs were responding to parental needs. This appears to contradict the results of the Boone et al. study, but the differences may be more apparent than real. The two studies were actually asking different questions as well as using different methodologies. Mahoney and Filer were interested in the general question of whether parents felt that services were responsive to their needs, whereas the study by Boone and colleagues looked at what actually happened in practice. It is perfectly possible that, although the parents in the Mahoney and Filer study felt that services did respond to their concerns, an analysis of their family service plans might have revealed the same picture found in the Boone et al. study; namely, that service plans may imperfectly reflect parental concerns.

**Are services provided family-focused or child-focused?**

Many studies show that family support plans in the USA still tend to stress child outcomes to the exclusion of more broad-based family mediated outcomes and support strategies (Boone, McBride, Swann, Moore & Drew, 1998; Bruder, 2000; Bruder, Staff & McMurrer-Kaminer, 1997; Farel, Shackelford & Hurth, 1997; Mahoney & Filer, 1996; McWilliam,
Ferguson, Harbin, Porter, Munn & Vandiviere, 1998; Summers, Dell’Oliver, Turnbull, Benson, Santelli, Campbell & Siegel-Causey, 1990).

These findings pose a considerable challenge to the early childhood intervention field. If family-centred practice has long been accepted as the model for service delivery, why are services still focused on child outcomes at the expense of family outcomes? Insights into this dilemma have been provided by a series of studies by McWilliam and colleagues (McWilliam, Lang, Vandivere, Angell, Collins & Underdown, 1995; McWilliam, Tocci & Harbin, 1995, 1998; McWilliam, Young & Harville, 1996). Some of the key findings of these studies are summarised below:

- Solely responding to what families want implies a unidimensional understanding of family-centredness: that the aim is to make families happy. Family-centredness has at least four dimensions including: responding to family priorities, empowering family members, taking a holistic approach to the family, and being insightful and sensitive to families.

- A child-focused service can be family-centred if the family has deemed that such a focus is their main priority. However, this only applies if they are aware that a family focus is also possible; that is, they have been offered options.

- There are unquestioned assumptions shared by professionals and parents alike that children needed therapy and that the more they got the better, and the best form of therapy was individual hands-on therapy. The researchers argued that therapy is a means to an end, not an end in itself. It is the role of professionals to help families identify what ends or outcomes are most desirable and by what means they can be best achieved. When professionals fail to do this, the choices of families make about what they and their children need are not based on a full understanding of how to get the best results.

What this highlights is that what parents come to identify as priorities are shaped by what has been provided and what they understand to be possible. If professionals explicitly or implicitly present hands-on therapy as the most effective way to help their child, parents will tend to perceive this as what their child needs. If professionals present them with viable alternative ways of achieving their goals (e.g., making use of the natural learning environments rather than clinical settings), parents can make an informed choice about what they want. The studies by McWilliam and colleagues suggest that professionals do
not always make these options available to parents and that parents therefore opt for traditional child-focused professional-delivered forms of service.

Again, this will be a developmental process for parents. Whereas they are more likely in the early stages to see individual therapy as what the child most needs, in time they may come to recognise the value of other approaches (e.g., natural learning approaches). This will only happen, however, if they are fully informed about different options and offered choices. McWilliam, Young and Harville (1996) note that, although there is no evidence that more intensive therapy leads to better outcomes, parents are unlikely to believe this unless they can experience the benefits of alternative approaches.

In conclusion, what these studies by McWilliam and colleagues show is that the kind of involvement parents have in meeting their child’s needs develops in the context of the relationship with service providers. When parents first enter the world of early childhood intervention, they do not know what role they are expected to play or can play. Through their interactions with service providers, their respective roles are negotiated or constructed. How active a role parents play will depend upon a number of factors, including what preconceptions the parents might have about parent/professional relationships, what the service providers say their role is, and what the service providers actually do (which may or may not be the same as what they say they are doing). Thus, parents construct a working model (Van Riper, 1999) of their relationships with professionals which may or may not be consistent with family-centred practice.

What these studies also suggest is that learning to partner in a family-centred collaboration with professionals is a developmental process for parents. The more experience they have with truly family-centred services, the more they will understand how they can become involved, and can make fully informed choices regarding their role as well as their priorities.

**What is the nature of parental involvement in intervention programs?**

Boone et al. (1998) highlighted that parental involvement can have two meanings. On the one hand, it can mean that parents are involved in the direct treatment of their children, implementing therapy programs at home and thereby acting as aides to the professionals. On the other hand, parental involvement can mean parents being involved in the decisions
about the goals and forms of intervention, thereby acting as partners with the professionals. In family-centred practice, this is the true meaning of parental involvement.

The issue of parental involvement in the intervention program or therapy can be a source of confusion for professionals as well as a source of tension for parents. Jansen, Ketelaar and Vermeer (2003) and Ketelaar, Vermeer, Helders and Hart (1998) investigated the effects on parents by these two vastly different forms of parental involvement. They found clear evidence of the positive effect of parental involvement on child-related outcomes, but inconsistent outcomes for the parents themselves, with both positive and negative effects being reported.

In a subsequent research review by the same team, Jansen, Ketelaar and Vermeer (2003) examined studies of the effects on parents themselves of participation in physical therapy for their children with physical disabilities. They suggested that there are two main arguments for involving parents in the physical therapy of their children:

- There are direct benefits for children. In order to ensure generalisation of learning from therapy sessions to functional daily activities, it is important to incorporate therapy activities into daily routines, and parents need to be involved in the therapy sessions if they are to do this; and,

- There are also direct benefits for the parents themselves. They are likely to develop more insight into the impairments and disabilities of their children, and become more proficient at meeting their needs.

Jansen et al. found that parental involvement has positive effects on the children but that parental participation may be beneficial for some parents, but not for all of them. The effects of parental participation on parents seems to depend on three factors:

- **The nature of the relationships between the parents and therapists is important.** Parents can find their dealings with professionals stressful. This does not happen when information is exchanged freely, and parents are fully involved, not just in implementing therapy devised by therapists, but in setting and evaluating therapy goals and determining what form the home program will take. When this occurs, parents are better able to carry out the home program and feel more competent as parents.

- **It is important for therapists to focus on family functioning and the functioning of the child within the family.** Parents only implement home programs if they are easy to
integrate into daily family routines. However, greater parental involvement is not beneficial for all parents; some parents find any additional demands to be stressful.

- **Contact with other parents during therapy can be valuable.** Parents who are attempting to implement therapy in the home find informal contact with others in the same situation helpful.

These reviews indicate that parental involvement in their children’s intervention programs is usually of direct benefit for the children but can have a positive or negative effect on the parents, depending upon the nature of their involvement. Parents only benefit if:

- They are involved in setting and evaluating goals;
- They help determine what form the home program will take;
- They are helped to develop skills in meeting their child’s needs; and,
- The home programs are easy to integrate into daily family routines.

**What actually happens on home visits?**

Another way of establishing whether services are truly family centred is to analyse what happens on home visits. Family-centred home visits will focus on family needs as well as child needs, will involve listening to family concerns as well as sharing information, and will seek to build parent competencies rather than simply doing the work for them.

In a unique study, McBride and Peterson (1997) analysed observations of 160 home visits conducted by 15 professionals with 28 families of young children with disabilities. The study found that the major focus of interactions during these home visits was on the child’s development or care-giving (89%), with very little time spent on family issues (3.5%). Practitioners spent half of their time in direct teaching activities with the child, a quarter of their time giving or asking for information from the parents or others, and relatively little time listening (7%), observing (7%), facilitating the child’s play (3%), or modeling (0.5%).

Evidence in this study also indicated that the practitioners were operating in a child-focused way with the interventionist as the major agent of change, rather than dividing their time equally between child and family issues, and seeking to make the parents the major agents of change. When these results were taken up with the practitioners involved, they perceived themselves as doing much more modeling than was recorded during observations. Since some of the interactions observed also involved parents, it is possible
to interpret these as modeling, but the parents’ role during such interactions was typically passive, and the argument therefore not convincing. The practitioners were clearly aware of the importance of paying attention to family needs, but their actual practices did not reflect this emphasis.

This study suggests a significant gap between the rhetoric and the reality of family-centred practice when it comes to home-visiting. Blue-Banning, Summers, Frankland, Nelson and Beegle (2004) suggested that part of the problem may be because we have never operationally defined the indicators (as distinct from the principles) of family-centred practice and collaborative partnerships so that practitioners could be clear about what was involved. To address this, Blue-Banning et al. conducted focus groups and interviews with family members of children with and without disabilities and with service providers and administrators about the professional behaviours that facilitated collaborative partnerships with parents. They identified six key themes or qualities: communication; commitment; equality; skills; trust; and, respect, and described the specific meaning of each. It remains to be seen whether these definitions can be used to help professionals to become more truly collaborative and family-centred in their work.

**Does true parent-professional collaboration occur?**

There have been no studies that have explored the extent to which parent-professional collaboration actually occurs although several studies have specifically investigated the factors that help or hinder parent-professional collaboration (Dinnebeil, Hale & Rule, 1996; McWilliam, Tocci & Harbin, 1998; and Peterander, 2000).

In a USA study, Dinnebeil et al. analysed parents’ and service coordinators’ responses to two open-ended questions in a survey to study the variables that enhance or detract from collaboration between the two groups. Respondents were asked to describe the variables that the other person in the partnership brings to the relationship that either enhance or interfere with collaboration.

The factors most commonly identified were:

- **Personal characteristics** – friendliness, optimism, patience, sincerity, and open-mindedness;
• **Beliefs, values and attitudes** – family-centred beliefs (empowerment of family, recognising the needs of the family as a whole) and attitudes (being non-judgmental, accepting differences, mutual trust);

• **Ways of working together** – open communication, good listening skills, honesty and tact;

• **Beliefs into practice** – the congruence between what professionals said or believed they were doing and what they actually did (i.e., the gap between the rhetoric of family-centred practice and the reality);

• **Knowledge base** – when both parties have meaningful knowledge and experience to share;

• **Outside influences** – factors beyond the direct control of the professional and family (e.g., illness, logistical constraints, staff turnover).

Dinnebeil et al. discussed the extent to which these various characteristics can be modified or trained. While personal characteristics are not readily modifiable, beliefs and attitudes are, and communication skills can also be improved through training. Closing the gap between rhetoric and practice can also be achieved through appropriate reflection, supervision and parental feedback. Knowledge can also be gained through experience and professional development.

**Conclusions regarding service delivery issues**

Section 2.5.5 has reviewed the evidence regarding the extent to which various features of family-centred practice are reflected in family service plans and other aspects of service delivery. The main conclusions are:

• Families are not always involved in the development of family service plans, but their participation can be improved if they are provided with training and support.

• Families do not necessarily receive all the services identified in family service plans. It is not clear from the evidence why this is so, but there are likely to be several reasons. One reason why parents do not make full use of services is that they are based on goals that were not truly important for them and which use methods that did not involve them developing new skills and competencies.

• Family service plans are often written in a formal or technical style that is not easily understood by parents. It is, however, possible to train professionals to write more plainly.
The goals in family service plans are not always appropriately pitched or achievable within reasonable time spans.

Although parents may feel that services are generally responsive to their needs, this is not necessarily reflected in the range of goals identified in family service plans. These tend to be biased towards what the professionals rather than the parents regard as important.

Services tend to be predominantly child-focused rather than reflecting a balance between the child’s needs and those of the family. The tendency to focus mainly on the child appears to be the result of a complex interaction between what professionals are most comfortable with and what parents initially expect. Until parents know the potential benefits of a family-centred approach, they are likely to prefer a professionally-directed and child-focused approach.

Parental involvement in implementing their children’s intervention programs is usually of direct benefit to the children but can have a positive or negative effect on the parents, depending upon the nature of their involvement. Parents only benefit if they help set the goals and determine what form the home program will take, increase their ability to meet their child’s needs themselves, and find the interventions easy to integrate into daily family routines.

On home visits, professionals tend to operate in a child-focused way and act as the major agent of change, rather than dividing their time equally between child and family issues, and seeking to make the parents the major agents of change.

The key qualities that professionals need to promote collaboration with parents include their personal characteristics; their beliefs, values and attitudes; their people skills; their professional/technical competence; and, their actual practices.

The extent to which family service plans encourage the use of informal rather than formal supports varies according to the formality of the procedures used to develop family service plans.

Overall, the evidence indicates that there is a gap between the rhetoric and the practice in most aspects of service delivery.

How can family service plans be made more truly family-centred? Several studies have shown that it is possible to do this by providing specific training in their use either for professionals (Pretti-Frontczak & Bricker, 2000), for parents (Campbell, Strickland & la Forme, 1992) or for both (Stallard & Hutchison, 1995). Another approach is to use scales
that are specifically designed to measure the family-centredness of service plans as described in Appendix 1. These scales can be used to provide professionals with feedback about the extent to which family service plans reflect family-centred principles.

2.5.6 Summary and conclusions

Overall, Section 2.5 has reviewed the research literature on the experiences of families receiving support from early childhood intervention services, particularly their experiences of family-centred services. Because of the fragmentary nature of the available research, it has been necessary to approach this from a number of different angles, looking both at parents’ subjective experiences and views of service as well as objective indicators of the extent to which services are delivered in family-centred ways.

What follows is a synthesis of the key findings that emerge from these studies.

- A recurrent theme is the difficulty parents experience in balancing the demands of early intervention programs and home life. When providers are not sensitive to the realities of daily family life, parents are more stressed and less likely to carry through the program or make use of services in general. In practice, the evidence suggests that services do not always consider these factors and instead recommend intervention strategies that are not easily integrated into family life.

- Another key theme concerned the nature of parental involvement in implementing their children’s intervention programs. While greater parental involvement is usually beneficial for the children, parents only benefit if they help set the goals and determine what form the home program will take, develop new skills in meeting their child’s needs themselves, and find the interventions easy to integrate into daily family routines.

- Parents want services to consider the needs of the whole family and not just those of the child with a disability. In practice, the evidence indicates that services often focus predominantly on the needs of the child and do not provide a balance of child-focused and family-focused goals and activities.

- How services are delivered appears to be more important to parents than what is delivered. Parents particularly value respectful and supportive care from professionals, and being treated as equals. In practice, the evidence suggests that professionals generally do provide services that are respectful and supportive, but are less consistent in treating parents as equals and involving them in all decisions.
Parents want professionals who use empowerment approaches that build on family strengths. In practice, the evidence suggests that professionals tend to see themselves as the major agents of change, rather than helping parents develop the skills to become the major change agents.

The key qualities that professionals need to promote collaboration with parents include personal characteristics (such as friendliness, optimism and genuineness), their beliefs, values and attitudes (such as being non-judgmental, and accepting differences), and their people skills (ability to listen and to communicate effectively).

The degree to which parents value working collaboratively with professionals depends upon how fully professionals have informed them about this approach and how well they have supported them in making decisions and developing new competencies. Until parents have experienced the benefits of a family-centred approach directly, they are likely to prefer a more traditional professionally-directed and child-focused approach.

The degree to which parents and professionals can work together according to family-centred principles partly depends upon their level of experience: the more experienced the professionals and the parents are, the more likely it is that they will be able to establish true collaborative partnerships.

Parents place a high value on being provided with information about child needs and community resources, and are dissatisfied and disempowered when this is not done well. Both parents and professionals report that keeping parents fully informed is an aspect of service that is often not done particularly well.

Family service plans do not always reflect family-centred principles. They may be written in a formal or technical style that is not easily understood by parents, focus on child-related goals more than family-related goals, and fail to encourage the use of informal rather than formal services.

Parents want professionals to be technically competent, both in terms of knowing how to work effectively with young children who have developmental disabilities, as well as how to help families access other relevant services. By and large, parents feel that early childhood intervention professionals do possess these skills.

Parents want services that are easy to access, reliable, well coordinated, and flexible. When parents are dissatisfied with services, it is often because they lack these features.
Although parents usually rate early childhood intervention services very highly, this does not mean that they are satisfied with all aspects of service; it is possible for parents to report that they are very satisfied with services overall while identifying some quite unsatisfactory aspects of service.

Professionals know the existing service system best but may be limited in their ability to think of alternative ways of delivering services. Parents on the other hand are well able to conceptualise a more effective system, and professionals should be seeking to engage parents in the planning and evaluation of services much more than they currently do.

Overall, these results indicate that endorsing a family-centred philosophy is not the same as delivering a truly family-centred service. Although family-centred practice has been the accepted service philosophy in the early childhood intervention field for a decade or more, translating the principles into practice has proven elusive. Bruder (2000) suggested that the early childhood intervention field’s difficulties in applying family-centred practices stem from several factors, including the gap between research and practice, inadequate systems for training professionals in family-centred practice, and, most important, the attitudes of service providers:

- **The research-to-practice gap.** One reason why practitioners do not use research findings on family-centred practices or value a family-centred philosophy is that research studies often do not provide operationalised descriptions of the factors that make family-centred practice effective. In addition, researchers pay too little attention to the needs and objectives of different audiences in the development and implementation of both their research and dissemination activities.

- **The current status of training in early intervention.** Another barrier to the adoption of family-centred early intervention is the lack of effective training models for practitioners responsible for the delivery of services.

- **The attitudes of service providers.** Service providers are inclined to see themselves as experts and the families as clients. Such attitudes are the hardest things to change, yet they are powerful determinants of both child and family outcomes.

Bruder believes that the way forward is for workers in the early childhood intervention field to clarify their values both individually and collectively, about why and how we implement early intervention. If the aim is to help children succeed, “we need to renew our
commitment to helping families (however they define themselves) help their children become competent within a reciprocal learning relationship built on respect” (p. 110).

Bruder also believes that early childhood intervention professionals should place a higher value on evidenced-based practices, as opposed to interventions based on “habit, ungrounded philosophy, or ignorance” (p. 111). There is empirical evidence supporting certain practices that facilitate family and child competence:

*These practices include treating families with dignity and respect; being culturally and socioeconomically sensitive to family diversity; providing choices to families in relation to their priorities and concerns; fully disclosing information to families so they can make decisions; focusing on a range of informal, community resources as sources of parenting and family supports; and employing helpgiving practices that are empowering and competency-enhancing.* (p. 111)

These are the essential features of family-centred practice. The challenge is how to ensure that service providers not only endorse these principles, but also know how to apply them in their everyday work with families of children with disabilities.

### 2.6 Measuring Family-Centred Practice

Several measures of family-centred practice are available for use in the early childhood intervention sector. This section, however, focuses predominantly on the Measure of Processes of Care (MPOC) scales as it is this instrument that has been used in the research project described in this report. Appendix 1 provides information about other measures that are described in the research literature.

#### 2.6.1 The Measure of Processes of Care (MPOC)

King, Rosenbaum and King (1995) observed that there had been little research into the effect upon parental health on the manner in which services are delivered. To address this gap, staff at the CanChild Centre for Childhood Disability Research at McMaster University in Ontario, Canada, developed the *Measure of Processes of Care* (MPOC) (King, Rosenbaum & King, 1995). The MPOC is a questionnaire designed to find out what parents of a child with a disability think of the services they and their child receive, and of how these experiences affect parents’ psychosocial outcomes. The researchers focused on the experiences of parents on the assumption that … “parental perspectives mediate between the provision of care and the outcomes of that care” (p. 758). A measure of the
processes of care-giving might therefore be a way of measuring the family-centredness of services.

Another reason behind the development of the scale was, that although there were scales for use with families of preschool age-children, there were none that could be used with families of children of any age. Since the McMaster team was interested in evaluating the services provided through Ontario’s network of rehabilitation centres (which cater for school-age as well as preschool age children), they developed the MPOC for broader use.

The development of the MPOC items was based on earlier work by Rosenbaum, King and Cadman (1992) that identified the elements of care-giving that parents and professionals in Ontario most valued (see Section 2.5.2 for a summary of the findings). At every stage in the development and testing of the MPOC, parents' views were actively sought and used to ensure that the concepts, content, format and language of the measure were relevant, applicable, and accessible to potential users. Close to 2,000 parents across Ontario participated in developing the MPOC.

In its final version, the MPOC is a 56-item questionnaire for use with parents of children with neurodevelopmental disorders. It has been shown to be psychometrically strong, with good internal consistency for each of the five sub-scales (indicating that items in each sub-scale measure a unique underlying theme), good test-retest reliability, and a sound factor structure. A factor analysis of the 56 items identified five factors accounting for nearly 50% of the variance.

These were:

- **Enabling and partnership:** Parents are made to feel as partners; they are given opportunities to make decisions and are treated as the ‘experts’ on their child.
- **Providing general information:** Parents given advice on how to get information or contact other parents and given information about available specialist and general services.
- **Providing specific information about the child:** Parents given written information about child’s progress and reasons for therapy approaches are explained.
- **Co-ordinated and comprehensive care for child and family:** Parents and professionals plan programs together; the needs of the ‘whole’ child are considered; and sensitivity to family demands in caring for a child with special needs is exercised.
• **Respectful and supportive care:** Parents are treated as individuals, not just as ‘typical’ parents of children with a disability. Professionals provide a caring atmosphere, are non-judgmental, help parents feel competent, and provide plenty of time for parents to talk.

To test the construct validity of the MPOC (hereafter referred to as the MPOC-56), scores were compared with responses to a standardised measure of parental satisfaction: the *Client Satisfaction Questionnaire* (Larsen, Attkisson, Hargreaves & Nguyen, 1979), and parents’ ratings of the stress involved in receiving service. As predicted, all five of the MPOC-56 scales were positively (albeit modestly) correlated with parental satisfaction with service, and negatively correlated (again, only modestly) with parents’ ratings of stress in relation to services received. Accordingly, King, Rosenbaum and King (1996) proposed that the MPOC-56 is a generic measure that can be used for clinical, quality assurance and research purposes. Since then it has been used in a number of international studies and has attracted a considerable degree of interest in the early childhood intervention sector in Australia.

### 2.6.2 Modifications to the MPOC

Since the development of the original MPOC-56, the developers of this instrument, and others, have produced modified versions for a variety of purposes and environments. The MPOC-20 has recently been reported by the CanChild Centre through a recent study reported on their website (King, Law, King, Kertoy, Hurley & Rosenbaum, 2000; King, Kertoy, King, Hurley, Rosenbaum & Law, 2000; Law, Hanna, King, Hurley, King, Kertoy, & Rosenbaum (2001). The MPOC-20 is a twenty-item version of the questionnaire that has the same five sub-scales. The website report claims that the MPOC-20 … “works as well as the 56-item form and is easier for parents to complete” although no details to back up this claim are provided.

Woodside, Rosenbaum, King and King (2001) described the development of the MPOC-SP, a 27-item self-assessment questionnaire designed for service providers to measure the reported implementation of family-centred service. It was developed to fulfill a perceived need for a broadly focused, valid and reliable self-assessment measure of care-giving for use with paediatric service providers. Adapted from the MPOC-56 through a systematic process of field-testing, the original 56 items were reduced to 27 and the sub-scales
reduced from five to four. The items eliminated were those relating to professional beliefs and attitudes, rather than actual behaviours. This was done in response to the views of service providers involved in the development of the instrument, that such items were inappropriate in an instrument designed to quantify behaviours. The four scales are:

- Showing interpersonal sensitivity (10 items);
- Providing general information (5 items);
- Communicating specific information about the child (3 items); and,
- Treating people respectfully (9 items).

Woodside et al. noted two limitations of the MPOC-SP. First, it is a self-assessment tool and therefore a measure of self-perceived rather than actual behaviour. Second, the scores reflect the extent to which service providers believe they are delivering services in a family-centred way, but not the factors that influence them in doing so. In other words, there is no contextual information about other contributing factors such as administrative barriers or contradictory values or beliefs. Other studies (O'Neill & Palisano, 2000; O'Neill, Palisano & Westcott, 2001) have also used the MPOC-SP to examine the attitudes of therapists in relation to family-centred practice.

McConachie and Logan (2003) explored the usefulness of the MPOC-56 for the evaluation of services in the UK. They were interested in whether the MPOC could be used as a postal questionnaire, whether it could be used in a different service context and whether it could detect predicted differences in quality of service. They revised the scale minimally to take account of British idiom, for example, taking out explicit references to a ‘centre’. The authors sent the revised MPOC-56 to families in three rural and two urban communities with a total sample of over 500 parents.

The response rates for this study varied from 49% to 67%. Although McConachie and Logan argued that this was less than ideal, they also acknowledged that postal survey was a realistic and cost-effective method of service evaluation. The second question in relation to factor structure was whether or not the questionnaire could be applied in a different service context where there are no rehabilitation centres as in the original Canadian sample. They concluded that the MPOC-56 may need further statistical development if it is to be used in new intervention environments and contexts.
To test whether or not the MPOC-56 could detect predicted differences in the quality of services, McConachie and Logan compared the responses of parents receiving different forms of service known to be associated with different levels of parental satisfaction. Two such comparisons were made, one involving the presence or absence of case coordination, and the other a comparison between home-based and community-based services. Previous studies had shown that parents were more satisfied with services that included case coordination and preferred home-based services to community-based services. As predicted, having a case coordinator and receiving a home-based service were both associated with more favourable perceptions of services being received, demonstrating that the MPOC-56 can discriminate between services on the basis of type and quality.

Granat, Lagander and Börjesson (2002) developed a Swedish instrument for the evaluation of parental participation from a family perspective. They modified the MPOC-20 to become the MPOC-28 by adding five questions from the MPOC-56 and three new items. The questionnaire was designed for families with children up to 18 years of age who had been in contact with a habilitation service for at least a year. A total of 2,458 families completed the questionnaire in 11 out of 26 Swedish counties.

In the study by Granat et al., the responses of parents of children of different ages, different disabilities, and different locations were compared. In all five scales, there were significant differences between the youngest and the older groups, with the parents of younger children having higher (i.e., more positive) scores. There were also significant differences between disability groups in all scales and in 21 out of 28 questions. Compared with other disability groups, those with a child with multiple disabilities registered lower values in all factors, and the same tendency was evident in the group of children with an intellectual disability. There were also significant differences between counties in all of the scales apart from Providing General Information. There was a tendency for rural counties to have more satisfied parents than counties with a more urban structure. The authors concluded that the MPOC-28 can be a useful analytical tool for comparisons over time. However, the authors further concluded that there are areas other than those specified in the MPOC-28 that have a bearing on families’ levels of general satisfaction with services. They commented that good evaluation should be supplemented with other follow-up tools and
measures, such as achievement of objectives set in individual program plans, the number of services provided or other measures of service provision.

In another Canadian study by Swaine, Pless, Friedman and Montes (1999) used the MPOC to document the perceptions of care of parents whose children were hospitalised with a head injury, but more important, to compare parental perceptions of care to those of the service providers. The MPOC-56 was completed by 16 service providers of various disciplines. The MPOC-56 was not designed for use with service providers and has not been validated with this group. Presumably they were asked to complete the scale on the basis of how they thought they were providing services to families, but the published report does not contain details of the instructions given. The authors concluded that the MPOC-56 was an inappropriate tool to use with parents of children with a mild head injury in the acute care setting. However, it proved to be useful for parents of children who are more severely injured. It was also found to give useful feedback to the service providers about the service they were providing.

2.6.3 Related MPOC studies
To test their claim that the MPOC-56 was a generic measure that can be used for clinical, quality assurance and research purposes, King, Rosenbaum and King (1997) evaluated the use of the MPOC-56 to assess the family-centeredness of children's rehabilitation services in Canada. Three groups of parents receiving different types of services were given the questionnaire: 436 parents receiving most of their child's services from Ontario Association of Children's Rehabilitation Services (OACRS) rehabilitation facilities; 213 parents receiving most of their child's services from non-OACRS facilities; and, 104 parents of children receiving services from a regional hospital-based cleft-lip and palate program. The authors had no prior hypotheses about the differences they would find between these sets of services, although they did expect differences in the services provided by individual centres.

The researchers found that parents receiving services from the cleft-lip and palate program reported significantly higher scores on two of the MPOC-56 sub-scales (Enabling and Partnership and Coordinated and Comprehensive Care) than did families receiving services from either the OACRS or non-OACRS services. These same parents also reported higher scores on the Respectful and Supportive Care sub-scale than did families
receiving non-OACRS services. No significant difference was found between the OACRS and non-OACRS services. When the services provided by the OACRS services were analysed on a centre-by-centre basis, significant differences were found in the ratings on the two information sub-scales (Providing General Information and Providing Specific Information about the Child). Findings indicated that the centres provided the same level of interpersonal rapport and support to parents, but differed in the extent to which they met parental needs for information.

This study demonstrated that, in the Canadian context at least, the MPOC-56 can detect differences between parents in their experiences of care-giving. However, while the authors concluded that the MPOC-56 can be used with validity as a tool to evaluate service delivery by individual programs, they advised that:

- The sub-scales cannot be used separately because the scale’s validity was established on the basis of administration of the whole set of 56 items. However, the information given by each sub-scale can provide useful information to service providers.
- The MPOC-56 was developed and validated almost entirely with parents of children with long-term and mainly stable neurodevelopmental disabilities.
- The MPOC-56 was developed as a discriminative measure rather than an evaluative one, and its ability to register changes in program delivery over time has yet to be proven.
- The MPOC-56 is oriented towards therapy services, and may not be as sensitive in discriminating between services provided by other professionals such as teachers or psychologists.

In another study by the McMaster team, King, Law, King and Rosenbaum (1998) conducted two province-wide surveys of the level of family-centred service in children’s rehabilitation centres in Ontario, Canada. In one survey, 436 parents completed the MPOC-56, while in the second survey, 309 service providers completed the Family-Centred Program Rating Scale (FamPRS), (Murphy & Lee, 1991) a measure of service providers' perceptions of the importance and occurrence of family-centred service. The FamPRS measures service providers' views as to the importance of various features of service delivery, as well as the extent to which they believe they are delivering services in the desired manner. These two scales measure conceptually similar aspects of family-centred services but only have about 30% of their actual content in common.
The results of the two surveys were very similar. The responses of both parents and service providers indicated that the centres were doing well with respect to the interpersonal aspects of service delivery, but that the provision of information was a relatively weak area. In the first survey, parents reported moderately high levels of satisfaction on three of the sub-scales of the MPOC-56; Respectful and Supportive Care, Enabling and Partnership, and Coordinated and Comprehensive Care but lower ratings on the other two; Providing General Information and Providing Specific Information about the Child.

In the second survey, the FamPRS, service providers reported that they felt they were doing well in several key aspects of family-centred practice including:
- Communicating with parents in a timely, complete, friendly and honest manner;
- Treating parents as experts with their children;
- Considering the strengths of families; and,
- Providing families with a positive view of the future and how they can help their child.

However, service providers felt they fell short of the ideal on four of the features of family-centred practice these being:
- Providing information in a variety of ways to families;
- Involving family members in making plans and decisions about services;
- Assisting families in making decisions and obtaining services quickly and easily; and,
- Considering families’ practical constraints and making them feel comfortable to ask questions and raise concerns.

As suggested in Section 2.5.3, ... “these four aspects of service delivery may be the most difficult for service providers to implement because they involve close collaboration with others (including the family), or networking with other agencies, and may be seen by management as less efficient ways of delivering services” (p. 36).

In another Canadian study using the MPOC-56, King, King, Rosenbaum and Goffin (1999) explored whether (and to what extent) family-centred care-giving helps to lessen the feelings of distress and depression that some parents experience in raising a child with a disability. They found that more family-centered care-giving (as measured by the MPOC-
was a significant predictor of three parental outcomes: greater satisfaction with services, less stress, and better parental well-being. The strength of the links were relatively small, however, and not as important as other factors. (See Section 2.3.3 for details of this study).

In 1999, the CanChild team conducted a survey of families and service providers in Ontario to examine the implementation of family-centred service in children’s rehabilitation services. This was a follow-up to similar surveys they had conducted in the early 1990’s (Rosenbaum, King, & Cadman, 1992), and was done in the belief that services had changed in the intervening period. The results of this study are reported in a series of reports available through CanChild’s website (www.fhs.mcmaster.ca/canchild): (King, Law, King, Kertoy, Hurley, & Rosenbaum, 2000; King, Kertoy, King, Hurley, Rosenbaum & Law, 2000; and Law, Hanna, King, Hurley, King, Kertoy & Rosenbaum, 2001).

This large-scale survey used MPOC-20, the Client Satisfaction Questionnaire (Larsen et al. 1979) and the Participating in a Family-Centred Approach to Service Questionnaire. The latter questionnaire was designed by the CanChild centre and is reportedly a standardised measure of global satisfaction with care and services. However, no details are given in the report about this scale, although an account of its development has been submitted for publication (King, Law, Kertoy, Rosenbaum & Pollock, submitted for publication. The MPOC-SP was also used.

The responses to the Participating in a Family-centred Approach to Service questionnaire showed that both parents and service providers believed strongly in the utility of the family-centred approach and in the underlying principles. However, they differed in their beliefs about the negative consequences of this approach for service providers, with the latter believing that more negative outcomes were likely.

The responses to the MPOC-20 and MPOC-SP confirmed that family-centred service was highly valued by parents and service providers alike. Both groups reported that the aspects of family-centred service that were done best were Respectful and Supportive Care, Providing Specific Information about the Child, and Enabling and Partnership. The one aspect that was rated as being done relatively poorly was Providing General Information. Since the previous study eight years earlier, parents reported improvements
in two aspects of family-centred service: Enabling and Partnership and Providing Specific Information about the Child.

The responses to the Client Satisfaction Questionnaire showed that parents were generally quite satisfied with services, although some parents were very dissatisfied. Parental satisfaction was slightly higher in services with a more family-centred culture.

In order to elucidate the findings about parental perceptions of the family-centredness of service delivery and their general satisfaction with services, further analyses were conducted. These showed that parents’ satisfaction with services was strongly linked to their perceptions that the services they were receiving were family-centred. Parents were less satisfied with services and perceived them as being less family-centred when they were provided with services from a greater number of locations, which usually occurred with children who had more complex health and developmental problems.

This study is important because it demonstrated (among other things) that the MPOC is able to detect changes in service delivery over time. It also demonstrated the value of using the MPOC in conjunction with other measures.

2.6.4 Conclusions regarding the MPOC scales
What conclusions can be drawn from these studies about the MPOC scales? These are addressed below.

Is the MPOC’s factor structure replicated in all studies?
In the Canadian context, the MPOC-56’s factor structure has proved robust. Only the study by McConachie and Logan has used a large enough sample to test the robustness of its factor structure in another context. That study found that, in a different service context and country (the UK), there were similarities but also significant differences in the factor structure. McConachie and Logan suggested that the MPOC-56’s factor structure may be unstable, and that new factor analyses may be needed whenever the MPOC is used in any different service context. At this stage it is fair to say that further testing of the MPOC’s factor structure with other populations is needed.
Can the MPOC be used to compare different services?
Studies demonstrating the discriminatory power of the MPOC include: a Canadian study comparing a specialist cleft-palate service in comparison with disability services (King et al., 1997); a British study comparing a home-based nursing service with general disability service provision (McConachie & Logan, 2003); and a Swedish study comparing multidisciplinary habilitation teams with individualised teams (Larsson, 2000). Thus, the MPOC can be used as a measure of outcome for child disability services of differing organisational structures.

Can the MPOC be used to measure services provided by any professional group?
As King, Rosenbaum and King (1996) acknowledged, the development of the MPOC-56 was oriented towards therapy services, and it might not be as sensitive in evaluating the quality of services provided by other professionals such as teachers or psychologists. In later studies by the CanChild group, a wider group of professionals and a greater variety of services has been sampled, and the MPOC continued to perform as expected. It therefore appears to be a suitable measure for a range of early childhood intervention services.

Can the MPOC scales be used to measure changes in services over time?
In 1996, King, Rosenbaum and King noted that the MPOC had not yet been used prospectively as a measure of change, and in the future this will be an important test of its usefulness as an outcome measure of key relevance to clinical governance. The only study to compare the family-centredness of services over time was the CanChild 1999 Ontario survey which compared parents’ ratings on the MPOC-20 in 1999 with family-centred ratings gathered eight years earlier. Although the 1999 cohort of parents perceived their service as being more family-centred than did the 1991 parents, it is not clear whether this was the result of the services becoming more family-centred because neither the parents doing the rating nor the services being rated were the same at both points in time. Moreover, the parent ratings done in 1991 were not based on the MPOC-56, which was still in development at that point. Although the use of the MPOC scales to measure changes in services over time remains to be tested, there is no reason why it should not be able to be used in this way.
Can the MPOC be used with parents of children with a wide range of disabilities?

As acknowledged by King, Rosenbaum and King (1996), the MPOC-56 was only developed and validated with parents of children with long-term neurodevelopmental disabilities, and its applicability to other disability groups was unproven. Since then, the MPOC-56 and MPOC-20 have been used with a much wider range of childhood disabilities in Canada and elsewhere, and appears to have performed equally well with these. The only group for whom the MPOC proved unsuitable was parents of children with relatively mild head injuries in an acute setting, in the study by Swaine et al. (1999). Other parents in the same study whose children had more severe and longer-lasting head injuries had no trouble with the MPOC, suggesting that it may be most suitable for use with families of children with relatively severe developmental disabilities of any kind.

Is the MPOC easy for parents to complete?

In the studies reviewed above, response rates for the MPOC-56 have been moderate at best. One possible reason for this is that it may be simply be too long. The one study involving the MPOC-20 reported a higher return rate of 77%, which may have been because of its relative brevity. However, more evidence regarding the MPOC-20 is needed before it can be recommended as the scale of choice.
Does the MPOC-56 measure all aspects of family-centred practice?

This is a crucial question. As has been seen in the review of family-centred principles and features, there is no single universally accepted definition of family-centred practice, with different research traditions emphasising different aspects. For instance, in the study by King et al. (1998) using the FamPRS and the MPOC, it was noted that, while these two scales measure conceptually similar aspects of family-centred service, only 30% of their content was common. If two-thirds of the questions in these scales address different issues, it is not possible to be sure that the scales are measuring the same construct?

Choosing scales for research or program evaluation purposes must be done not only on the basis of their psychometric properties, but also on the basis of whether the content of the scale captures the features of family-centred practice that the services in question espouse. Compared with other measures of family-centred practice, the MPOC places a relatively heavy emphasis on information-giving (two of the five sub-scales); it also places a correspondingly modest emphasis on partnership and participatory involvement; and it does not contain any items relating to the use of natural learning environments or the mobilisation of local and community resources. If these latter features are not central to the approach of the agencies being evaluated, there should be no problems in using the MPOC. If they are important, another way of determining this may be needed. However, it should be noted that there is no existing standardised measure that covers all aspects of family-centred practice, so the MPOC is not alone in this regard.

This highlights a particular issue with regard to the development of the MPOC or of any scale based on parental perceptions of service: services and practices keep evolving. In many ways, the development of the original MPOC-56 was exemplary, especially in its extensive involvement of parents. However, as highlighted in Section 2.5.2, the value of consulting parents is limited by what the parents know and what services they already receive. While consultation will identify which aspects of the service they receive are most valued, it may not identify aspects of service that they have not experienced but which they might value even more highly if they had. If service philosophies and practices continue to evolve, as they inevitably do, it is likely that any measure developed at a particular point in time will eventually no longer truly reflect the services that are being provided. As already indicated, there are aspects of what would now be considered best practice in family-centred service that the MPOC scales do not fully capture. If these are important aspects of what agencies are seeking to provide, other ways of measuring them will be needed in the future.
Is the MPOC-20 to be preferred to the MPOC-56?

As noted previously, no published details of the development of the MPOC-20 are yet available. Its brevity is a recommendation, since this is likely to make it easier for parents to use. Although it is claimed to perform as well as the MPOC-56, something may have been lost in the excising of 36 questions. Do the sub-scales still measure the same constructs as effectively as before? Until further evidence is available, the MPOC-56 should be the instrument of choice.

Is the MPOC-SP a useful measure of service provider perceptions?

Although there are no reported studies of the use of this instrument in settings outside Ontario, it appears to be a promising instrument for use with service providers. It is designed to be used in conjunction with the parent-completed MPOC, but given the differences in the number of items and the factor structure, exact equivalence between the sub-scales of the two questionnaires cannot be assumed.

2.6.5 Summary

Overall, the MPOC-56 has proven to be a robust research instrument, although its factor structure cannot be assumed when used in other cultural and service settings. It has been used successfully with a variety of disability populations and with different forms of service delivery, although its use in measuring change in services over time remains to be tested. However, there is no reason why it should not be used in this way.

The only significant caveat that needs to be noted about the MPOC scales is that there are aspects of what would now be considered best practice in family-centred service that they do not fully capture. If these are important aspects of what agencies are seeking to provide, other ways of measuring them will be needed in the future. Finally, too few details are available as yet regarding the MPOC-20 and the MPOC-SP to be able to judge their worth.
CHAPTER 3
HOW DID WE DO THE RESEARCH?

3.1 INTRODUCTION

This study adopted a multi-method approach using both quantitative and qualitative methods. It collected data from a variety of sources, thus contributing to the robust nature of the methodology and findings. The study consisted of two distinct components: first, an examination of the experiences of families who use Scope early childhood intervention services; and second; the measurement of the degree of family-centred practice in Scope services across the six regional teams. This chapter describes the methodology used in each of these two components. The results of the first part of the study are detailed in Chapter 4, while the results of the second part are provided in Chapter 5.

3.2 PART ONE: THE EXPERIENCES OF FAMILIES

3.2.1 Aim
The aim of this part of the study was to identify and describe the experiences of families who access Scope early childhood intervention services.

3.2.2 Sampling
Focus group discussions were used to explore the experiences of families for the purpose of this study. Participants were drawn from families who were receiving services from any of the six Scope regional early childhood intervention teams at the time the research was undertaken, commencing in September 2002. Some of the larger rural regions have sub-regional teams and in these cases, one sub-region was chosen in each region to host a focus group. This was done to minimise travel for families. All families within the selected area were contacted by mail with a letter that described the research and seeking their participation in the study. A plain English description of the research project was also included. Families were asked to return through a stamped, addressed envelope, an Expression of Interest advising of their wish to participate or not. Follow-up telephone contact was made with those families who did not respond to the initial contact to achieve
an optimal response rate. Those families who expressed interest in participating were contacted and the venue and details for the focus group were confirmed.

In the planning stages of the research, the steering committee believed that six focus groups (i.e., one focus group in each region) would be sufficient to reach the point at which “additional information no longer generates new understanding” (Rice & Ezzy, 1999, p.81). Due to the inherent difficulties of attracting people to attend focus groups, the steering committee also decided to offer telephone interviews to those families who were willing to participate but who were unable to attend the nominated focus group in their region. It was felt that this would gain a broader, more representative sample and may assist with gaining information from both mothers and fathers.

### 3.2.3 Methodology

A facilitator, external and independent to Scope, who had previous extensive experience in the early childhood intervention sector, conducted all focus groups and telephone interviews. As participants arrived at the focus group, the research project was explained and participants completed a consent form. All focus groups were recorded onto audiocassette to ensure accurate recording of the discussion and to assist with analysis of data (Krueger, 1994). At the completion of all focus groups, the consultant contacted those families who had expressed interest in attending but were unable, and those who had not responded to the initial Expression of Interest letter, to request their participation through a telephone interview. The families who agreed, were sent a consent form that was completed and returned prior to the interviews taking place. A mutually convenient time for the telephone interview was then arranged.

All families who participated in either a focus group or telephone interview were asked to complete a brief questionnaire that provided background and demographic information (see Appendix 2).

### 3.2.4 Response rate

Invitations seeking participation in a focus group or telephone interview, were forwarded to 144 families. Of those families, a total of 20 people participated in focus groups and a further 32 people participated in the telephone interviews. These 52 people came from 48 families, representing an overall response rate of 33%. Of these 48 families, 31 (65%) were from rural regions and 17 (35%) lived in metropolitan Melbourne. Although the
response rate to focus groups was lower than anticipated, the overall response rate was considered satisfactory, given the time commitment required of participants for this type of activity.

3.2.5 Data analysis
All focus groups were transcribed verbatim into printed transcripts. The data analysis was carried out manually and was not computer-assisted. Telephone interviews were not audio-recorded, but detailed notes were taken by the interviewer that were combined with the focus group data to provide overall comments from families.

Initially, thematic analysis was used whereby codes were identified from the data obtained from the focus groups and telephone interviews. Data were then analysed using a Miles and Huberman (1984) grid, in the context of the family-centred practice domains as described by King, Rosenbaum and King (1995) in the MPOC and the three elements of effective care-giving described by Dunst and Trivette (1996). See Section 2.3.5 for more details. In transcribing the focus groups, the intent of the study was to provide insights into the typical or common experiences of families who use Scope early childhood intervention services. Hence, quotes were generally chosen to illuminate common experiences. However, examples that represented diversity of experience were also included.

3.3 PART TWO: MEASURING FAMILY-CENTRED PRACTICE

3.3.1 Aims
The aims of this part of the study were to:

- Identify the most important aspects of family-centred practice from the perspectives of families and Scope staff, that is, ideal service;
- Compare and contrast these two views;
- Measure the current level of family-centred practice from the perspectives of families and Scope staff, that is, actual, service;
- Compare and contrast the two views, and,
- Establish base line measures in relation to family-centred practice for future re-evaluation purposes and for benchmarking with other organisations.
3.3.2 Sampling
All families who accessed Scope early childhood intervention services as at 1st January 2003 were included in the sample of families who were asked to participate in this part of the study. This included families who had also participated in a focus group or telephone interview. The sample included all regions and sub-regions of Scope and constituted 203 families. All regional Scope specialist services team members who worked in the early childhood intervention area as at March 2003 were asked to participate in the study. At that time, the total sample of staff was 61, including service managers.

3.3.3 Methodology
This study used the MPOC-56 (King, Rosenbaum & King, 1995) as the tool for collecting information about the degree of family-centred practice from the perspectives of families and Scope staff. The MPOC is a measure of family-centred practice from the perspective of families (see Section 2.6), therefore, for the purposes of this study some modifications were needed:

- Small changes were made to the wording of some of the items to make them more reflective of the Australian context, for example, replacing ‘centre’ with ‘early childhood intervention service’. This practice enhances the face validity of instruments, and precedent for this can be found in the study by McConachie and Logan (2003).
- The purpose of this study was to compare family and staff perceptions. Because the MPOC-SP has a different number of items to the MPOC-56, making a direct comparison would have been difficult. Therefore, as in Swaine, Friedman and Montes (1999), the MPOC-56 was modified for use with service providers where service providers were asked to complete the scale on the basis of how they thought they were providing services to families.
- This study also aimed to investigate what is important to families and to staff and to compare and contrast these two views. Therefore, the MPOC-56 was also modified to ask families and staff about what they think should happen in an ‘ideal’ service. This type of analysis has not been undertaken in previous studies.
- In accordance with work undertaken by King, Rosenbaum and King (1996) a self-rating scale to assess parents’ perceptions of the effects of Scope early childhood intervention services on their stress levels was also included as part of this study.

In this study, information was therefore obtained from both families and staff about ideal services and also about the actual services they either believed they provided (staff) or
received (families). The seven-point Likert scale was retained in all questionnaires. Four questionnaires were used in total in this study. These are described below.

**Family Questionnaire 1 (Ideal Service)**
This questionnaire asked families about what they believed would represent an ideal early childhood intervention service according to the items contained in the MPOC-56. Families were asked to … “Indicate how much this event or situation would happen in an ideal service.” Initial demographic information was also obtained in relation to the background of the person/s completing the questionnaire, length of time, frequency and location of services received and the needs or disability of the child receiving the services (see Appendix 3).

**Family Questionnaire 2 (Actual Service)**
The second questionnaire sent to families was the original MPOC questionnaire with the previously mentioned minor changes to wording. This questionnaire also included the self-rating parental stress scale. (Appendix 4 contains the complete scale structure of the 56 items used in each of the four questionnaires.)

**Staff Questionnaire 1 (Ideal Service)**
The first questionnaire sent to Scope staff asked them what they believed would represent an ideal early childhood intervention service according to the items contained in the MPOC-56. Staff were asked to … “Indicate how much this event or situation would happen in an ideal service.” Demographic information was also obtained in relation to professional background, years of experience and employment, and whether or not the person had undertaken training in family-centred practice. (Appendix 5 contains information regarding demographic data collection.)

**Staff Questionnaire 2 (Actual Service)**
The second questionnaire used the items contained in the MPOC-56 but asked staff to … “Indicate how much this event or situation happens at your service.”

Adopting a postal questionnaire format as applied by McConachie and Logan, 2003, questionnaires were sent out in two separate mail-outs with families being sent the Ideal Service questionnaire first. When the first (Ideal Service) questionnaire had been returned
the second (*Actual Service*) questionnaire was forwarded by mail. Each mail-out included stamped, addressed envelopes to promote an optimal response rate. Follow-up phone calls were also made. Staff were sent the first questionnaire in a mail-out. Most staff completed the second questionnaire while attending a Scope in-service training day.

### 3.3.4 Response rate

Of the 203 families across the six Scope regions, 32% (n=65) of families returned the first questionnaire regarding *ideal* service. See Table 3 for a regional breakdown of mail-out and response rates.

<table>
<thead>
<tr>
<th>Region</th>
<th>No. of families</th>
<th>%</th>
<th>No. of families</th>
<th>% (by region)</th>
<th>% (of overall)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barwon</td>
<td>46</td>
<td>22.6</td>
<td>15</td>
<td>32.6</td>
<td>23.1</td>
</tr>
<tr>
<td>Gippsland</td>
<td>34</td>
<td>16.7</td>
<td>13</td>
<td>38.2</td>
<td>20.0</td>
</tr>
<tr>
<td>Hume</td>
<td>53</td>
<td>26.1</td>
<td>12</td>
<td>22.6</td>
<td>18.5</td>
</tr>
<tr>
<td>Loddon-Mallee</td>
<td>18</td>
<td>8.9</td>
<td>9</td>
<td>50.0</td>
<td>13.8</td>
</tr>
<tr>
<td>North West (metropolitan)</td>
<td>19</td>
<td>9.4</td>
<td>5</td>
<td>26.3</td>
<td>7.7</td>
</tr>
<tr>
<td>South East (metropolitan)</td>
<td>33</td>
<td>16.3</td>
<td>11</td>
<td>33.3</td>
<td>16.9</td>
</tr>
<tr>
<td>Total</td>
<td>203</td>
<td>100</td>
<td>65</td>
<td>100</td>
<td></td>
</tr>
</tbody>
</table>

The proportions of questionnaires sent to each region ranged from 8.9% in Loddon-Mallee to 26.1% in Hume. Although Loddon-Mallee received the smallest proportion of the questionnaires sent out, their overall response rate of 50% was well above the average of 33%.

The overall response rate of 32%, although not high, is acceptable for a postal questionnaire particularly for respondents who are especially busy in caring for children
with disabilities. The response rate could also have been influenced by the length of the questionnaire (see Section 2.6.2). Another factor that could have influenced the return rate is the number of families, particularly in the North West region, who are from culturally and linguistically diverse communities, or for whom English is not the primary language. Having questionnaires in alternative languages was not possible within the scope of this study, which may have influenced the number of families who could participate.

Of the 61 questionnaires regarding ideal service that were first sent out to staff, 93% (n=57) were returned. This is clearly an excellent response rate. Subsequently, 50 families (76.9% of respondents to the Ideal Service questionnaire) and 50 Scope staff (87.7% of respondents to the Ideal Service questionnaire) responded to the second questionnaire about the actual service. The response rate of the selected sub-samples is excellent.

3.3.5 Data analysis

In the course of the analysis, responses to the MPOC were combined into the five domains as previously described in Section 2.6.1 these being: Enabling and Partnership; Providing General Information; Providing Specific Information about the Child; Coordinated and Comprehensive Care; and, Respectful and Supportive Care. The detailed assignment of each of the 56 questions to the five domains is shown in Appendix 7.

Although response rates were adequate from both groups, there was some drop-out from both groups between the first and second surveys. In addition, even people who responded to both surveys occasionally omitted one or more questions. Both of these factors meant that there were missing values in the data set. As even a single missing value means the loss of the entire case when overall scores are computed, it was necessary to devise some consistent means of dealing with the missing values. Where there was no second questionnaire, the entire case had to be deleted from the calculation of the five domains of actual care and from the calculation of differences between the ideal and actual care scores. These cases have, however, been included in the analyses of the ideal service that people desired. Where respondents only missed answering a few questions here and there in the data set, those missing values were replaced by zeroes. Using a zero in this way has very little effect on the results but means that the other answers of these respondents could be included in the analysis.
In statistical analysis, the usual shape of data distributions is the ‘bell-shaped curve’. In this analysis, by contrast, most of the continuous variables were markedly negatively skewed. This is the type of distribution that appears when most of the scores cluster at the high scoring end with a small number of cases in the low scoring tail. This distribution occurred because the respondents were very likely to give the rating ‘7 – to a great extent’, particularly in the measurement of views about an *ideal* service. The skew was so marked that the median (the exact mid-point of the distribution) had to be used as a measure of the average to get an accurate indication of the central tendency of the scores. While the data was skewed, this is not atypical as supported by the research evidence described in Section 2.5.2 which indicates that families generally report high levels of satisfaction with services. Unless otherwise specified, all averages in this report are medians.
CHAPTER 4

WHAT WERE THE EXPERIENCES OF FAMILIES?

4.1 INTRODUCTION

This chapter presents the results of the first part of the study that investigated families’ experiences of Scope early childhood intervention services. During the course of this study, participants often made comments about other aspects of services, or of the early childhood intervention sector in general, that may not relate specifically to Scope services. These have been included where they added to the understanding of the experiences and needs of families in general. The ‘voices’ of participants are heard through the use of quotations that illustrate each of the thematic categories.

4.2 PARTICIPANT DEMOGRAPHICS

Of the 48 families who participated in either a focus group or telephone interview, 66.7% (n=32) of families (accounting for 34 people) provided information regarding background and experience with Scope. Of those participants 91.2% (n=31) were mothers and 8.8% (n=3) were fathers. The average time that they had been receiving services was 24.9 months with a range of nine months up to six years. Clearly this was a group that had a great deal of experience of Scope services and therefore were well able to share their experiences through a focus group or telephone interview. Services were most commonly received at home (38.9%) and at a Scope centre (38.9%), with another 16.7% of services being delivered at a community facility while another 5.5% were located within ‘other’ situations. This latter category included a local regional hospital and community parks and playgrounds.

4.3 THE VOICES OF FAMILIES

The focus groups and telephone interviews explored a number of issues with families including:

- Initial reactions and expectations when referred to Scope;
- Families’ experiences of Scope early childhood intervention services;
• Barriers that interfere with access to services and supports; and,
• The sorts of things that in an 'ideal world' families seek.

Data reporting the needs and experiences of families is presented according to the three elements of effective care-giving as described by Dunst and Trivette (1996) in Section 3.

These are:
• **Technical knowledge and skills.** Refers to the help-giver’s specialist knowledge, competence and skills.
• **Help-giver behaviours and attributions.** Help-giver behaviours that positively influence psychological well-being and includes interpersonal skills such as good listening, empathy and warmth.
• **Participatory involvement.** Refers to the behaviours of early childhood intervention staff that promotes (a) parents feeling more in control, and (b) strengthening of parental competencies. For the purposes of the analysis, this final category includes all the domains contained within the MPOC-56 (King, Rosenbaum & King, 1995), that is, Enabling and Partnership; Providing General Information; Providing Specific Information about the Child; Coordinated and Comprehensive Care for the Child and Family; and, Respectful and Supportive Care. However, it is acknowledged that some of these domains also include aspects of interpersonal skills and help-giving behaviours.

### 4.3.1 Initial reactions and experiences of families

When parents were asked to reflect on their initial expectations of Scope services, there was much discussion about the emotional turmoil associated with this first step. Common themes to emerge from the conversations were the overwhelming sense of confusion and uncertainty, and the associated feelings of anxiety, guilt and disbelief.

*I should know what to do for my child.* (FG C)

*I had shit loads of fears. The fear of someone coming into your home and touching your child. Fear of, am I doing the right things, fear of the future.* (TI. 7)

*I just felt, have I made the right decision and what should I be doing, where else should I be going and what was the best thing for him, have I done enough, have I done too much?* (FG A)
4.3.2 Family experiences and needs

Technical knowledge and skills

The majority of parents described their expectation that Scope staff would assist and support their child’s developmental progress and were looking to Scope for regular access to ‘therapy’. The technical competence and skills of staff to assist them with their child’s developmental goals were very important.

*I had been at another early intervention program … it wasn’t hands on therapy, so I was going between the two to try and work out which one was better and hands down this is the one because of the way they are; motor skills, hand-eye development, interaction. I wanted him to be able to do things that normal children could do. That was what I was looking for.* (FG A)

*It may seem like not a lot is happening, but these little milestones are huge things for your children and it very definitely makes you just keep going.* (FG A)

*Seeing my child improving has made a difference for my family as well.* (FG A)

*My Child speaks now!* (TI 6)

*My daughter is now running and climbing when she wasn’t walking (when we started).* (FG B)

Families were also aware that the technical skills of staff needed to be balanced with experience and maturity.

*It’s obvious when she (the therapist) came, she had an expectation, and I think that’s probably the worst thing you can have with these children, probably any child; to walk in and expect to do something.* (FG B)

*… because of the inexperience, this wouldn’t happen with someone with more experience, but this keen, very lovely girl sat down at the table and wanted (child’s name) to do things so she could assess what he could do and of course he went, you know, I’m out of here and he’d get up and walk away and she just couldn’t manage him.* (FG B)

*I think it’s a maturing experience to check out the situation; approach quietly and gently and see what the mood is with him and just sort of improvise and in that improvisation the therapist is then able to watch him and I guess there’s a lot of watching and looking and seeing how he’s moving and what he’s doing and she’s very gentle.* (FG B)

Families valued the gains that can be made by therapists and others, showing families how therapy goals can be included in their child’s natural environments and everyday tasks.

*Initially it was terrifying because it was overwhelming and so much to do, so much to think about and if you did put him down wrong for a second you’d feel guilty … but now it’s like I can’t really do any more. Every time he sits, he sits a certain way …*
every time he does this, it’s for balance, this one’s for motor skills; just everything. (FG C)

It’s a constant thing, it’s not today we’ll do side-sitting or tomorrow we’ll do saddle sitting. … just every day a series of things, and like I said it’s second nature and I sit there and think, gee we’ve done a lot today. (FG C)

The first couple of years, (child’s name) was okay laying down and doing stretches and this and that but after three and a half years, that’s it, they just won’t have a bar of it and you’re making it hard on yourself … (Since incorporating it into his play) I’ve never looked back, it’s the only way to do it, because you’re not fighting against them and it becomes second nature for them too. (Child’s name) is used to sitting down in the positions. (FG C)

… also going to the kindergarten and explaining to the teacher what ways my daughter can do activities whilst she’s there. (FG D)

Other families expressed concern about a perceived blurring between parent and therapist roles when therapy goals were incorporated into everyday tasks. Some families expressed increased stress and anxiety as they described pressure on parents to perform when asked to continue with programs at home.

I feel guilty if I don’t do what therapists ask me to do – there’s this pressure to perform. When you have a child with a disability you always feel guilty as there’s never enough time to do everything that you’re asked to do. (TI 3)

You can’t be your child’s therapist but there’s no one else to do it. (FG D)

Having early intervention staff visit at home, in itself can also create stress initially for families.

Initially you scream around and get the house clean and afterwards it takes ages to find anything you know. But you get over that. (FG C)

Help giver behaviours and interpersonal skills

The individual interpersonal and communication skills of staff were very important to families.

Skills is one thing and technique and so on, but I think when you come into people’s houses and you’re dealing with little people, sometimes with very complicated, special needs and additional needs, sensitivity is probably one of the greatest skills to have. Sensitive to the child and to the parents and if you’ve got that I think it’s very good in my opinion and my physio has that. (FG B)

We only have one person and that person is very competent and very gentle and very experienced. It’s not a hassle. I kind of feel that even on a bad day I could still manage with that person coming out because of the nature of the person that they are. (FG B)
More Than my Child’s Disability …..: A Study of Family Experiences and Family-Centred Practice

Silly fears ... but they subside very quickly I’m glad to say and I think different people and different personalities allow them to subside more quickly. (FG B)

The rapport that’s been developed between the person who comes and my little boy is quite good, not good but very good. It’s all very gentle and appropriate. (FG B)

I’ve had lots of questions along the way and I think she’s taken the time to listen to me and help me with those questions. (FG B)

Enabling and partnerships

A consistent message throughout all of the interviews and focus groups was that families want to be involved in the decision-making about the services and supports that they and their child receive. They believe they are the ‘experts’ (as expressed in the MPOC-56; Question 12) in the needs of their child and the family.

I would always go for what is beneficial for my daughter rather than what other people might say is more beneficial. (FG A)

We know our children better. We know when they’re tired and when to push them. (FG A)

I used to panic a little bit … felt as if I’d lost control … even though it was all constructive, there were times when I thought now, that’s my kid, I should know what to do with him … you know they’re there to guide you and to just show you gently through it, but there was a certain pang of that’s my child I should just know what to do. (FG C)

I was able to say, not at first, it took about four years down the track … I sort of know my own child and I’d say no. Perhaps they think he’s not swallowing properly and they might need to do something, but I know he can eat a chocolate frog or a caramel, now come on, it’s vegetables. So you know yourself, so I think that’s really good. (FG E)

Another important issue for families was the need for flexible services.

I was so scared that she was going to miss out because I couldn’t take her anywhere. So that flexibility was great … I didn’t feel pressured to come here for therapy, I didn’t feel oh my God, I’ve got to hurry up, only one more week of this. It was just that option, “oh if you can’t come we’ll come to you again.” It was really good. (FG A)

I was a bit unsure about having to cart him off with all the oxygen bottles and tubes, taking 20 minutes to get him to the car and three trips to the car just to get everything there. So sometimes to leave the home was really quite difficult … the understanding that people would come and visit me in my own home, that made it pretty amazing. So I guess I was quite impressed and a bit overwhelmed that the services were there and they could come to my house. (FG B)

I said no more home. It has to be in a kinder setting or in a childcare setting. (FG B)
I do think there’s definitely room for a centre-based service. (FG B)

Therefore, the issue for families is not that services and supports should be home-based, centre-based or community-based, but that they should ideally be available in the place that is best for them at that point in time of their lives and that this will change as their family and child’s circumstances change over time.

A number of families said that they were not necessarily given a choice about the type of services that they could access. They felt that these decisions might be based on legitimate reasons such as funding, available resources and staffing levels. Some families felt locked into a particular service delivery model or location for a whole year while their needs changed more frequently. Families often talked about the time of the day that services were available both in terms of getting the best out of their child; being able to access services when they were most needed and the times of the day that were most convenient.

I want to be involved, I certainly want to try. Maybe this might work better instead of doing it at the end when he’s absolutely buggered and almost asleep; (why not) try when he’s okay and maybe he will do it. (FG A)

All of the therapists have got things to do as well to set up the times to have the groups but we never get any input … it's really their (the child’s) sleep time and they're hungry and tired and don't participate in group because they're tired and grumpy and not so alert. We've often said that but it can’t be changed at the moment … but maybe next year … maybe with the parents suggesting a time that might be a little bit better. (FG B)

I remember chatting to some people from Scope and just saying it would be really great if I could do this on a particular day and it wasn’t possible. They said “sorry we don’t work on that day” and you think well that’s okay, it’s no great drama, but it would have been nice just to be able to shuffle things around so that it was a bit more suitable. (FG C)

(I would like) that they work over school holidays. (Child’s name) is having surgery in December which means he’s going to need intensive therapy early January and I know people need holidays. But we've waited years to try and get this boy up and moving and the sooner we do it the better but some people have to take leave. I don’t care if I have to pay for it, just find someone to do it. There must be someone there who sees how desperate we are. If school holidays stop him having the operation it’s just ludicrous. (FG C)

The magical mistake of any organisation like this is they’re 9 to 5 and our children aren’t 9 to 5; they’re seven days a week, 24 hours a day for ever and ever. That’s
probably my biggest complaint, my biggest heartache. Sometimes you think God it would be great for an afternoon or a late evening type thing. (FG E)

Everything shuts down, any school holidays. We’ve got the boys going to EdGym and as soon as the school holidays come, no everything, no playgroup, they all close down. Everything shuts down for two weeks. (FG C)

Not everyone, however, wants to be able to access services during school holiday periods.

So far as school holidays, we just turn off, we stay in our pyjamas all day and that’s where I get my reprieve – no appointments! (FG C)

Providing general information

Overwhelmingly, the desire of parents is to have more information; in particular information about the different sorts of services and supports as well as information about their child’s disability. The lack of information often started with paediatricians and other doctors, who reportedly are not always able to direct families to the appropriate supports and services. Some families also believed that not enough primary health care services knew about the nature and extent of Scope services specifically.

Paediatricians don’t seem to know. They are directing people who need services and directing them where to go; it’s almost like they don’t know what’s on offer here (at Scope). (FG C)

At the end of the day I thought thank God I went here (Scope) but he (doctor) was very adamant that you go to (different provider) and I thought why? Do you realise what Scope does? I’m sure he doesn’t. (FG C)

Families wanted more information. They spoke of the huge amounts of time and energy that it takes to find out information about available services and supports such as Commonwealth benefits, respite, in-home support etc.

There’s a lot of information I don’t know and people don’t tell you. Things that the paediatrician is supposed to tell you. You can apply for a healthcare card. He didn’t give me the information and you’ve been outlaying for twelve months and someone else said, “do you know you can apply for that?” No. “You know you’re entitled to a ...? No. “You know you’re entitled to a ..? No. “Do you know there’s this school that …? No! (FG A)

Knowing about services and how to obtain funding … I was saying to someone the other day, why don’t they throw a whole package together and say this is how it’s all going for a disabled child, but they don’t. It’s not just Scope; it’s all the community out there. They don’t tell you where to get things or help you. (FG A)
Families who received case management did not experience the same degree of frustration.

(We have had) everything done for us and I guess that was because I had a case manager before they were even born, completely different circumstances have created different experiences. (FG C)

Families said that other parents were often the best source of information. Opportunities to network with other families who had a child with a disability were very much welcomed. Some parents were also willing to take responsibility for developing information for future families who may use the service.

I actually found out some information from parents within the group … we got taken away to a café for a little chat and we suddenly started getting all the information that I didn’t know already, so that was good. (FG A)

It’s nice to meet other mothers who have children with disabilities because you go to regular playgroups and everyone else has got regular kids and you don’t, it’s nice but it would be nice to chat with other people too. (FG C)

It would be good if there was a parent’s resource manual about things that would come in handy … and have a paragraph about what you’ve found is good in that service and what you’ve needed out of that service so a new parent coming in could have a look at it. (FG A)

… what a lot of her friends are doing is writing down what their child’s disabilities are, where they went for help, what the help. They’re going to put it all together in a big thing and then whoever comes into the group will have those bits of information. (FG A)

Parents also wanted access to research information that would assist them in making decisions about options for their child.

With a magic wand I could have research and information right there in front of me that I could read at my leisure and work out a few things. (FG B)

I’d like to see a survey done of perhaps a hundred people with Down Syndrome and of those hundred how many achieved a certain level of skills so that you are able to live with it and say, well, these people have achieved this, and they may be things that we can set our goals towards. (FG C)
However, one parent was also very aware of the limitations of current research and evidence-based practice.

* A lot of these things are not entirely proved by research, perhaps that’s an indication of the research that’s been done (or hasn’t been done) and not necessarily the program. (FG D) 

Although parents wanted information, they did not want to be deprived of hope. Some parents spoke about the heartache they had experienced when provided with information without hope by primary health care providers early on in their child’s life.

* (If) someone could tell you the potential of this child, long-term prognosis but nobody can. When (child’s name) was born they wanted us to turn him off his ventilator on three occasions. He would not have any quality, beanbag case, turn him off … but he’s talking, he knows exactly what’s going on you know, so long term prognosis just gets down to every day. (FG C) 

* I didn’t want to do it, let alone the rest of my family, I mean I never wanted to have them pull the plug but my husband signed the forms and I just prayed like hell, just prayed that he would survive and then when he did, he must have survived for a reason. But it’s that initial no hope, no encouragement, nothing at all, not one skeric, everything we suggested they just cut down. It’s a tearful assessment of everything too, there’s nothing, there’s no room for any special stuff that mothers feel. (FG C) 

* If I showed them the child now and said this is the same one, and it’s nothing like what you said. Thank God we don’t listen to them all the time. (FG C) 

* I expect the truth but I also expect a bit of encouragement. (FG C) 

Families said that early intervention services can support families to look at a more positive outlook.

* They (the ECI staff) start moving away from that really negative picture that was painted, and that’s an incredibly positive thing and it’s really encouraging. That’s where you get your encouragement from and feel like you just want to keep plugging away and do absolutely everything you can to teach that next little step. (FG C) 

Some families were interested in other sorts of information.

* Scope put stuff in a newsletter and I found a lot of good in that, it just helps make the organisation a bit more cohesive and it’s good to know about people you haven’t met and to know about things that are happening. I found it kind of nice getting that. I think that it is good for Scope to be communicating the positive things that they are doing. (FG D) 

* Providing specific information about the child
Families also expressed a need for information more specifically targeted for their child.

They should have a tailored package with information, maybe with the GP, with what the disability is about and what you’re going to need. There should be individual type information. (FG A)

I wanted to know what could we do, what could we buy, what equipment does he need to climb and do all these things. (FG B)

(Information) to know what is appropriate for her level and what to look forward to in the future and goals to set and things like that. (FG A)

She (the therapist) came and I said I just don’t think he’s very good at the moment, blah, blah, blah….and by the end of the session she said I don’t know what you’re talking about, he’s doing this, he’s doing this, I couldn’t see it. It was such a relief. (FG C)

I’ve had lots of questions along the way and I think she’s taken the time to listen to me and help me with those questions. (FG B)

I had a lot of questions that needed answers. I needed information and guidance in terms of goal setting. I wanted someone to say it was going to be OK. I wanted to learn. (TI 3)

Not all families were happy with the support that they had received in this area.

I had a lot of trouble learning how to use the communication board. It was just thrown at me, no explanation on how to use it.. I didn’t know what to do and no one had shown me. I found it extremely frustrating. I’m supposed to teach my son how to use this board, but they haven’t trained me how to do it. It really let me down. The particular staff member who I was supposed to be communicating with didn’t find the time to show me. (FG A)

**Coordinated and comprehensive care for the child and family**

Families’ experiences of a coordinated approach to comprehensive care varied considerably. Some families spoke of having to fight the system to the get the services they needed for their child. Others indicated that they needed to negotiate services from different providers to ensure that they received comprehensive care. This required a great deal of time and energy seeking out various services and community resources, and caused considerable stress and anxiety.

* I felt bombarded at times by the amount of people involved. (TI 3)

* I have as much help as I can cope with. (TI 7)

* I would love to see here in (name of town) all the services together because if all the services were put together rather than one over here and one doesn’t talk over there;
there’s some sort of business going on over there and between here; and it is embarrassing and if they all got together the work would be met. (FG C)

That’s probably my biggest criticism of not only Scope, but possibly all the services, it’s this lack of communication. It seems incredible to me to waste resources by not communicating and I don’t think it benefits children’s outcomes at all. (FG C)

One of the barriers to effective coordination and collaboration between providers that was discussed by parents was the concept of ‘double dipping’.

*I double dip … you don’t really want to hear this … but when Scope come over I feel they’re more professional, more organised and have more of a vision about what they’re trying to achieve and I feel a lot more comfortable with that. But then I wouldn’t knock back anyone who’s going to come and try and help. So it’s crazy that you don’t tell them that Scope are seeing me as well. This silly business of not communicating. (FG C)*

Parents said that one draw back of group programs was that the individual needs of their child were at risk of being compromised and there was often no time to discuss individual issues or problems with staff during group time. This affects how comprehensive families believe the services to be.

*I just feel that some of the other children in the group don’t have the same problem that (child’s name) has and more attention is given to those children because they’re advanced. (FG A)*

*In the groups because that was the only time you could see the therapist if you needed to speak to them. I used to find it very hard to get that minute when you could talk to them about anything. (FG A)*

Other participants were looking for more broadly-based assistance for the family but found that there were difficulties associated with this.

*I know when we first came to Scope, I thought that’s great we can have a counsellor visit our home and speak with my husband … because he wasn’t the type of person to go seeking them out himself, but when we found out that it might impact on the therapy that she was given, then we were reluctant to access that. So I think it would be terrific if there was access for everybody to be supported in that respect. (FG D)*

Another factor that works against coordinated care is excessive staff turnover. Parents spoke of the importance of developing a supportive and trusting relationship with staff and reflected on the disappointment, frustration and sense of loss that was associated with the resignation of staff.

*It feels like we’re starting from scratch again. (TI 1)*
Respectful and supportive care

I have received more help than I ever thought. Nothing was too much trouble. (TI 6)

You know it’s a sort of hand-built type of house, it’s not a brick veneer with carpet. So there were those little things and I’m just being honest, a little bit of fear of can they (the therapists) cope from that point of view. Will they cope with (child’s name), will they see him as a worthwhile person to sort of look after. (FG B)

When I came to Scope I felt really comfortable and they put him (husband) in a position where he felt comfortable because I think both parents need to be involved and (husband’s name) comes pretty much every week to the group. (FG E)

However, not all family experiences were consistent with the views expressed above.

… there were a few things like positioning him in his chair and one day he wasn’t in there correctly and I had just whacked him in and had something else on the go and this particular physio came in and oh no!. (FG C)

I felt the physio was telling me how to run my life…I’d come for physio, not a lecture. (FG E)

Other issues
In addition to the issues raised above there were other matters raised by families during the course of the focus groups and telephone interviews that did not fit within these categories. The most dominant of these issues was the problems related to the needs of their children for specialised equipment and particularly the funding of this equipment. Long waiting periods for equipment funding, in some cases up to twelve months was another problem identified in all regions.

There’s the funding and trying to find out, how frustrating and just having to wait, even for new AFO’s and things like that. The system just doesn’t allow it to happen. (FG C)

Putting in for these things that the kids really need, yet we’ve got to wait twelve months for the funding to come through. (FG C)

(Child’s name) needs special seats and once you find one you think oh this is just brilliant and then they say we just want to take it and try someone else with it and you think no, no don’t take it away but I can understand their point of view because there are other people who want to try things too. But they say you’re really going to have
to look at getting a chair and this and that, but everything is so expensive because it's specialised, but it would be good to just borrow it for the rest of your life. (FG C)

I find it amazing that the equipment and the therapy has to be fought for and I'm learning to be pragmatic but I feel it's really wrong. (FG D)

At one stage we were on the waiting list to receive a pushchair for Alex and finding out six months later that we hadn't been put on the waiting list, that was an awful situation. (FG D)

As well as discussing funding shortfalls regarding equipment, families reported a general disappointment with the overall availability of funding for their child.

I hoped that we would get a lot of help to address (child’s name) needs, like really intense and comprehensive help and I guess it took me a while to learn that the funding was very limited and it wouldn’t be available. (FG D)

I know there’s a lot of shortcomings in the intervention funding, but (child’s name) needs are huge, massive and overwhelming and I still feel that. I think I’ve managed to negotiate the services that he needs from a few sources that we’re reasonably happy with at the moment but it took a lot of research and negotiating to do that. (FG D)

I find it amazing that a child can start their life with so many disabilities and it’s almost like nobody really cares. (FG D)

There was also a complaint by families that all children regardless of need or family circumstances received the same funding allocation. Parents believed the current funding arrangements were inadequate to address the needs of children with complex and multiple needs.

I think the services need to be structured (and funded) around the needs of the child. (FG D)

One bucket of money per child which is administered centrally, which families can access for whatever needs they have, like childcare, kinder or therapy. (TI 7)

4.3.3 Summary
Part One of the study explored the experiences of families who use Scope early childhood intervention services and supports. Of the families who participated, the average length of time that they had been receiving services was just over two years. Clearly, this group which was compromised mainly of mothers, were well able to comment on the services they and their child were receiving.
The issues discussed by families in focus groups and telephone interviews reinforced many of the findings in the literature review. In particular, many of the parents expressed the desire that staff be technically competent so that their child could receive the best support possible in the pursuit of developmental gains. However, families were also strong in their views that this needs to be balanced with good interpersonal skills and maturity on the part of service provider staff. The study also reinforced the need for developmental goals to be supported within the child’s everyday environments. Families did not want ‘home programs’ unless they were included and sustainable in the activities of everyday life for the child and family.

The issue of information was a very strong theme throughout the discussions with families as it was in the literature review. Families said they needed more information, particularly information of a general nature, such as that about other services and supports, general research information and updates, funding arrangements, interrelationships with other agencies etc. Parents generally viewed other families as valuable sources of information about some of these issues. Some families expressed concern that not enough people were aware of the work of Scope, paediatricians and primary health care providers in particular. When it came to specific information about their own child, families were very clear that they wanted information that was reaffirming and which supported the work they were doing. As described in the literature, parents did not wish to be judged for what they may not want or have the time to do. Information with a sense of hope and future was very important to parents in the early stages. They valued Scope early childhood services because they often enabled parents to see a future for their child beyond the often bleak picture that had been painted by primary health care providers.

A sense of control was another issue that emerged. Families want to be in control of their lives and believe that they are the experts when it comes to their child, whilst still acknowledging that the service provider contributes their own knowledge and skills. However, some families would like more flexibility around when and where they receive their services so that the relevant decisions are made more around the needs of their child than around programming issues or the traditional hours generally worked by staff. As described by Roush (1994), flexibility was important to families because what may be the ‘right decision’ at one point in time may not be appropriate later as their needs change. Group programs can have inherent difficulties because, as some families reported, in some
instances they did not leave them with sufficient opportunity to talk individually with staff to work through specific issues.

Funding was an issue that families discussed particularly with regard to two concerns. First, they were concerned that general services to the family such as counselling, took service hours away from their child. This made them reluctant to take up these broader-based family services even though other members of the family may have benefited from them. Second, the lack of funding and the lengthy waiting times associated with equipment prescription were a major source of frustration and anger for parents.

Finally, parents talked about wanting a balance in their lives. They want their family to be respected, consulted and informed so that they can make choices. They want service providers to impart a sense of hope that is honest yet positive and they want services and supports that are responsive and flexible. Above all, they want to be seen as families first and want to view life as more than one that is just about disability.

*My life is just one big appointment!* (FG C)

*I don’t want my whole life to be about disability! I want to salvage at least part of my career. I want to continue with my marriage. I don’t want to think that the next fifty or sixty years is all going to be about my daughter’s disability.* (FG D)
CHAPTER 5
HOW FAMILY-CENTRED ARE WE?

5.1 INTRODUCTION

This chapter presents the results of the second part of the study that measured the level of ideal and actual family-centred practice in Scope early childhood intervention services from the perspective of families and staff, using the MPOC-56. Data is provided regarding the background of participants followed by the comparisons between family and staff responses.

5.2 MEASURING FAMILY-CENTRED PRACTICE

5.2.1 Family and service demographics

Sixty-three out of the 65 families who responded to the Ideal Service (first) questionnaire were parents, with almost 97% of respondents being female. Of the 50 responses to the Actual Service (second) questionnaire 96% were parents and 98% were female. Typically then, the questionnaires were completed by mothers. The children of families who received early childhood intervention services were equally divided by gender with 48.5% (n=32) being boys and 51.5% (n=34) being girls.

The average child was 45 months old or 3.77 years. The breakdown of ages of the children for whom their age was reported is shown in Table 4.

Table 4
Age Breakdown of Children in Sample

<table>
<thead>
<tr>
<th>Age</th>
<th>No. of Children</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to less than one year old</td>
<td>7</td>
<td>16.2</td>
</tr>
<tr>
<td>One year to less than two years old</td>
<td>16</td>
<td>37.2</td>
</tr>
<tr>
<td>Two years to less than three years old</td>
<td>10</td>
<td>23.3</td>
</tr>
<tr>
<td>Three years to four years old</td>
<td>10</td>
<td>23.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>43</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

* Note that 22 respondents did not supply this information.
The largest single age-group was children between one and two years old. These made up over one-third of the children receiving services.

Of those families who responded to the questionnaire, the average time that they had been receiving Scope services was 21.8 months or just under two years. Information on the length of time services were received was not provided by four respondents. The length of time that families had been receiving services is shown in Table 5.

Table 5
Length of Time Families had been Receiving Scope Services

<table>
<thead>
<tr>
<th>Length of Time</th>
<th>No. of Families</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one year</td>
<td>13</td>
<td>21.3</td>
</tr>
<tr>
<td>One year to less than two years</td>
<td>20</td>
<td>32.8</td>
</tr>
<tr>
<td>Two years to less than three years</td>
<td>17</td>
<td>27.9</td>
</tr>
<tr>
<td>Three to four years</td>
<td>11</td>
<td>18.0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>61</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

* Note that four respondents did not supply this information.

Typically the children saw a therapist from the early childhood intervention service between monthly and twice monthly. An average of a fortnight had elapsed since they last saw a Scope member of staff. Services were most commonly received at home (73.8%) or at a Scope site (20.0%) with only 4.6% of clients receiving services at a community facility and only one respondent reporting receiving services at an ‘other’ location.

5.2.2 Child Demographics

Parents were asked to nominate their child’s primary disability, and were given the option of nominating additional secondary disabilities. Table 6 provides details regarding reported primary disability. The broad categorisation of ‘disability groups’ was based on the codes used in the National Community Services Data Dictionary (AIHW, 2003) at the time of the project.
Table 6
Reported Primary Disability

<table>
<thead>
<tr>
<th>Primary Disability</th>
<th>No. of Children</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developmental Delay</td>
<td>25</td>
<td>43.9</td>
</tr>
<tr>
<td>Intellectual</td>
<td>3</td>
<td>5.3</td>
</tr>
<tr>
<td>Autism</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>Physical</td>
<td>14</td>
<td>24.5</td>
</tr>
<tr>
<td>Acquired Brain Injury</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Hearing</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Neurological</td>
<td>7</td>
<td>12.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>57*</td>
<td>100</td>
</tr>
</tbody>
</table>

* Note that eight respondents did not supply this information.

Developmental delay and physical disability were the typical primary disabilities reported by families, accounting for just under three-quarters of the children in the sample. No parent listed vision impairment, specific learning disorder or communication disorder as the primary disability.

The majority of children in the sample had one or more secondary disabilities. Specifically:

- 26.2% of children only had a primary disability;
- 20.0% of children had one secondary disability;
- 15.4% of children had two secondary disabilities;
- 20.0% of children had three secondary disabilities; and,
- 18.4% of children had four secondary disabilities.

Therefore, almost 40% of children in the sample had three or more secondary disabilities. Clearly children with high support needs feature prominently in the case-loads of Scope early childhood intervention teams. The distribution of the secondary disabilities showed a much greater range of disabilities compared with primary disabilities. This is shown in Figure 1.
The most common secondary disability was communication disorder, which did not appear at all as a primary disability. However, of greater interest was the fact that, of those children (n = 25) with three or four secondary disabilities, 48% of them had a communication disorder. Communication impairment was therefore a very prominent secondary disability in the profiles of children who received Scope early childhood intervention services. Autism was not listed as a secondary disability for any of the children.

There was an apparent gender difference in the types of secondary disabilities. Only boys had a specific learning disability (two children) and almost three-quarters (71.4%) of the children with acquired brain injury were male. Girls were slightly more likely to have a vision impairment (62.5%) or a communication impairment (61.5%) listed as a secondary disability than were boys. It was not possible to test for the significance of these apparent gender differences because many children had more than one secondary disability.

5.2.3 Scope staff demographics
The demographic details of staff were obtained in the first questionnaire. Staff were asked to provide details of their role within the service in which they worked. The descriptions of their professional backgrounds are shown in Table 7.
Table 7
Professional Background of Staff Respondents

<table>
<thead>
<tr>
<th>Professional Background</th>
<th>No. of Staff</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapist</td>
<td>13</td>
<td>22.8</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>12</td>
<td>21.1</td>
</tr>
<tr>
<td>Speech Pathologist</td>
<td>13</td>
<td>22.8</td>
</tr>
<tr>
<td>Psychologist</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Family Service Coordinator</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Service Manager</td>
<td>6</td>
<td>10.5</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>15.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>57</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

In the staff sample, three major professions dominated: occupational therapy, physiotherapy and speech pathology, each of which was about equally represented. Of those staff members who reported as ‘other’, there were three Inclusion Support Coordinators, two therapy assistants, two Early Years Development Advisors, an Early Childhood Intervention Teacher and an Early Childhood Transition Officer. Staff were then asked which regional team they worked in. Table 8 provides this information.

Table 8
Regional Distribution of Staff Respondents

<table>
<thead>
<tr>
<th>Region</th>
<th>No. of Staff</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barwon</td>
<td>8</td>
<td>14.1</td>
</tr>
<tr>
<td>Gippsland</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>Hume</td>
<td>19</td>
<td>33.3</td>
</tr>
<tr>
<td>Loddon-Mallee</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>North-West (metropolitan)</td>
<td>6</td>
<td>10.5</td>
</tr>
<tr>
<td>South-East (metropolitan)</td>
<td>16</td>
<td>28.1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>57</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Staff were asked about the length of time they had worked in their professional discipline, in early childhood intervention and for Scope. On average, staff had worked for five years in their chosen discipline, for four years in early childhood intervention and for three years...
with Scope. The length of time staff had worked in their professional discipline is shown in Table 9.

### Table 9

**Length of Time in Professional Discipline**

<table>
<thead>
<tr>
<th>Time in Chosen Profession</th>
<th>No. of Staff</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>9</td>
<td>15.8</td>
</tr>
<tr>
<td>Seven to 11 months</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>One year to less than two years</td>
<td>9</td>
<td>15.8</td>
</tr>
<tr>
<td>Two years to less than five years</td>
<td>6</td>
<td>10.5</td>
</tr>
<tr>
<td>Five years to less than ten years</td>
<td>10</td>
<td>17.5</td>
</tr>
<tr>
<td>Ten years or more</td>
<td>21</td>
<td>36.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>57</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Although staff had worked for an average of five years in their profession, over one-third of them (36.8%) had worked in them for more than 10 years, suggesting a very experienced group of professionals. The percentages of staff working for different periods in early childhood intervention are shown in Table 10.

### Table 10

**Length of Time that Staff had Worked in Early Childhood Intervention**

<table>
<thead>
<tr>
<th>Length of Time</th>
<th>No. of Staff</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>7</td>
<td>12.3</td>
</tr>
<tr>
<td>Seven to 11 months</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>One year to less than two years</td>
<td>10</td>
<td>17.5</td>
</tr>
<tr>
<td>Two years to less than five years</td>
<td>14</td>
<td>24.5</td>
</tr>
<tr>
<td>Five years to less than ten years</td>
<td>12</td>
<td>21.1</td>
</tr>
<tr>
<td>Ten years or more</td>
<td>13</td>
<td>22.8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>57</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Over one-fifth of the staff who responded had worked in early childhood intervention for more than ten years. By contrast, over half the staff had worked in the field for less than
five years. Finally, staff were asked to report on how long they had worked for Scope. Their responses are shown in Table 11.

Table 11
Length of Time Staff had Worked for Scope

<table>
<thead>
<tr>
<th>Length of Time</th>
<th>No. of Staff</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>15</td>
<td>26.3</td>
</tr>
<tr>
<td>Seven to 11 months</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>One year to less than two years</td>
<td>12</td>
<td>21.1</td>
</tr>
<tr>
<td>Two years to less than five years</td>
<td>11</td>
<td>19.3</td>
</tr>
<tr>
<td>Five years to less than ten years</td>
<td>10</td>
<td>17.5</td>
</tr>
<tr>
<td>Ten years or more</td>
<td>5</td>
<td>8.8</td>
</tr>
<tr>
<td>Total</td>
<td>57</td>
<td>100</td>
</tr>
</tbody>
</table>

The largest single group (26.3%) of respondents had worked for Scope for less than six months.

Staff were also asked whether or not they had received training in family-centred practice. Just over 56% of staff reported that they had training in this area, and when staff were asked to describe the type of training, their responses varied from single day workshops through to longer more formalised training.

5.2.4 Effect of Scope services on family-reported stress

In the Actual Service questionnaire, families were asked to … “describe the degree to which care-giving by the Scope early childhood intervention service team has effected the amount of stress and worry you experience in caring for your child.” Results are provided in Figure 2.
Although some families in Part One of the study (see Section 4.3.2) reported increased anxiety and stress due to a perceived pressure to continue with programs at home, this does not appear to be a problem across the parent sample. Indeed, a majority of respondents (86.0%) reported a positive effect of Scope services on their levels of stress and worry, with the largest single group (46.0%) reporting that their levels of stress and worry had been reduced ‘considerably’. Only one respondent said that his/her stress levels had increased ‘considerably’.

5.2.5 Families’ responses to ideal and actual service (Family Questionnaires 1 & 2)
As per the instructions contained in the MPOC manual (King, Rosenbaum & King, 1995), the five domains of service provision were created by combining responses to the individual 56 items. During this process it was noted that the number of items per domain varied from a low of five items for Providing Specific Information to seventeen items for Coordinated and Comprehensive Care. If the ratings had been simply added, the impression would have been gained that families were more concerned about Coordinated Care than they were about Specific Information. It was therefore decided to weight each scale by dividing the total number of ratings by the total number of items in the scale. These weighted average scores obtained on Questionnaires 1 and 2 (that is the ideal and actual) domains and the differences between those domain scores are shown in Table 12.
Table 12
Families’ Weighted Average Scores on Five Domains of Therapy: Ideal and Actual Ratings

<table>
<thead>
<tr>
<th>Domain Name</th>
<th>Ideal</th>
<th>Actual</th>
<th>Actual – Ideal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enabling and Partnership</td>
<td>6.8</td>
<td>5.7</td>
<td>-1.1</td>
</tr>
<tr>
<td>Coordinated and Comprehensive Care</td>
<td>6.2</td>
<td>6.2</td>
<td>0</td>
</tr>
<tr>
<td>Respectful and Supportive Care</td>
<td>7.4</td>
<td>6.5</td>
<td>-0.9</td>
</tr>
<tr>
<td>Providing General Information</td>
<td>6.0</td>
<td>4.2</td>
<td>-1.8</td>
</tr>
<tr>
<td>Providing Specific Information About the Child</td>
<td>6.4</td>
<td>6.0</td>
<td>-0.4</td>
</tr>
</tbody>
</table>

Inspection of the difference scores in this table suggests that the typical family would prefer a stronger emphasis on *Enabling and Partnership* and more *General Information* and more *Respectful and Supportive Care*. The ideal and actual median scores for *Coordinated Care* and *Specific Information* were so close as to suggest that families were reasonably satisfied with those aspects of the interventions that they received.

Before proceeding to a formal analysis of difference scores, the 10 (five ideal and five actual) domains assessed by the families were analysed for subgroup differences amongst the families. Families were assessed for differences in their evaluation of *actual* and *ideal* service according to whether they:

- Lived in a rural or a metropolitan region;
- Had a male or a female child;
- Had a child above or below the average age in years;
- Had a child with developmental delay versus all other disabilities; and,
- Had received Scope services above or below the average length of time.

To deal with the very skewed distributions of the domains, nonparametric tests of significance have to be used. The Mann-Whitney U test is the nonparametric test of choice, used where there are only two groups, and is the equivalent of a t-test. No significant differences amongst families in their evaluation of the domains were found. This finding suggests that the views of families about what is important (*ideal*) and the
satisfaction with the services that they receive (actual) are reasonably homogeneous and cannot be attributed to any of the common demographic or experiential variables.

### 5.2.6 Staff’s responses to ideal and actual service (Staff Questionnaires 1 & 2)

Staff responses to the five domains for ideal and actual services were analysed in the same way as those for families (see Section 4.3.5). The results are shown in Table 13.

<table>
<thead>
<tr>
<th>Domain Name</th>
<th>Ideal</th>
<th>Actual</th>
<th>Actual - Ideal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enabling and Partnership</td>
<td>6.7</td>
<td>5.7</td>
<td>-1.0</td>
</tr>
<tr>
<td>Coordinated and Comprehensive Care</td>
<td>6.8</td>
<td>5.5</td>
<td>-1.3</td>
</tr>
<tr>
<td>Respectful and Supportive Care</td>
<td>6.8</td>
<td>5.8</td>
<td>-1.0</td>
</tr>
<tr>
<td>Providing General Information</td>
<td>6.6</td>
<td>4.3</td>
<td>-2.3</td>
</tr>
<tr>
<td>Providing Specific Information about the Child</td>
<td>6.8</td>
<td>5.7</td>
<td>-1.1</td>
</tr>
</tbody>
</table>

Scope staff perceived the largest gap between ideal and actual in the areas of Providing General Information followed by Coordinated and Comprehensive Care. The remaining three domains all had quite large perceived gaps, but the perceived divergence was roughly equal on all three.

As in the analysis of family responses, the Mann-Whitney U test was performed to investigate whether there were any responses that could be explained by group differences. Staff were assessed for differences in their responses to the test items based on:

- Their professional background;
- Length of time (more or less than average) in their chosen discipline;
- Length of time (more or less than average) in early childhood intervention; and,
- Length of time (more or less than average) having worked for Scope.

In contrast to families where no differences in opinion were found according to demographic variables, some significant differences were found amongst staff responses.
The statistical findings for the staff are shown in Appendix 6. Staff who had worked in their chosen discipline for longer than average periods, typically gave higher scores than other staff for both Providing Specific Information and to Coordinated and Comprehensive in relation to ideal services. Staff members who had worked at Scope for longer than average periods believed that the actual amounts of Specific Information provided were significantly lower compared with those staff who had worked at Scope for shorter periods of time. Longer serving staff also ideally put greater emphasis on the Coordinated and Comprehensive Care domain than those who had worked at Scope for less time.

No differences in staff responses were found according to the amount of time staff had worked in early childhood intervention. Nor were differences found according to the professional backgrounds of the staff, though it should be noted that service managers had to be omitted from this analysis as there were too few of them.

5.2.7 Comparison of families’ and staff’s responses to ideal and actual service

To enable easy comparison between family and staff responses, a combined table has been generated. The average scores of families and staff on the five domains of therapy are shown in Table 14.

<table>
<thead>
<tr>
<th>Domain Name</th>
<th>Family</th>
<th></th>
<th></th>
<th>Staff</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ideal</td>
<td>Actual</td>
<td>Actual - Ideal</td>
<td>Ideal</td>
<td>Actual</td>
<td>Actual - Ideal</td>
</tr>
<tr>
<td>Enabling and Partnership</td>
<td>6.8</td>
<td>5.7</td>
<td>-1.1</td>
<td>6.7</td>
<td>5.7</td>
<td>-1.0</td>
</tr>
<tr>
<td>Coordinated and Comprehensive Care</td>
<td>6.3</td>
<td>6.2</td>
<td>-0.1</td>
<td>6.8</td>
<td>5.5</td>
<td>-1.3</td>
</tr>
<tr>
<td>Respectful and Supportive Care</td>
<td>6.4</td>
<td>6.6</td>
<td>0.2</td>
<td>6.8</td>
<td>5.8</td>
<td>-1.0</td>
</tr>
<tr>
<td>Providing General Information</td>
<td>6.0</td>
<td>4.2</td>
<td>-1.8</td>
<td>6.6</td>
<td>4.3</td>
<td>-2.3</td>
</tr>
<tr>
<td>Providing Specific Information About the Child.</td>
<td>6.4</td>
<td>6.0</td>
<td>-0.4</td>
<td>6.8</td>
<td>5.7</td>
<td>-1.1</td>
</tr>
</tbody>
</table>

In the table above, columns showing the differences are shown in **bold** to facilitate comparisons. Families’ and staffs’ perceptions of the difference between actual and ideal diverged markedly. Only on Enabling and Partnership were the domains seen as of
comparable importance and the size of the gap between actual and ideal was very similar. Families perceived that actual Coordinated and Comprehensive Care was much better than staff perceived it to be, and for this reason the gap families perceived between actual and ideal coordinated care was much smaller than that perceived by the staff. A similar pattern of ratings was found for Respectful and Supportive Care, with families rating what was actually provided much more highly than the staff did. Both families and staff rated actual Provision of General Information as the lowest of all the five domains, but staff gave this a higher ideal rating than the families did, resulting in a larger perceived gap for staff than for families. On Providing Specific Information, families reverted to what appeared to be a typical pattern; that is, rating the actual service more highly than the staff did and rating the ideal service as less important than that perceived by the staff. This resulted in a smaller perceived gap for families than for staff. Overall, the findings in Table 14 confirm the impression that the staff were both more critical and more idealistic than families.

5.2.8 A framework of item-by-item analysis: Bench-marking

One of the aims of the research was to “establish base line measures in relation to family-centred practice for future re-evaluation purposes and for benchmarking with other organisations” (see Section 1.3). The reason for this is to look to the research evidence to inform Scope about the need for service improvement as well as being able to recognise and celebrate areas of good practice. Therefore, an analysis that was similar to that recommended by King, Rosenbaum and King (1995) where two types of percentages were calculated for family and staff actual and ideal responses to the MPOC (see Appendices 7 & 8) was undertaken. These percentages were:

- The percentage of families or staff who reported ‘sometimes or less’ on each of the 56 MPOC items which corresponds to a response with values of 1-4 on the seven point scale.
- The percentage of families or staff who reported ‘more than sometimes’ on each of the 56 MPOC items which corresponds to a response with values of 5-7 on the seven-point scale.

Items where 33% or more of families reported that actual behaviour only occurred “sometimes or less” have been highlighted in Appendix 7 as indications of where improvements may need to be made (King, Rosenbaum & King, 1995). Note that most of these instances occurred under the domain Providing General Information, further
reinforcing the finding that performance was relatively poor in this area. However, it is also worth noting that several items (interestingly enough they relate to information) come close to the 33% score in the domain Enabling and Partnership. This also supports the findings reported in Section 5.2.5 that this is an area where improvement can also be identified.

Items where 85% or more of families reported that actual behaviour occurred “more than sometimes” have been highlighted in Appendix 7 as examples of good practice. It is interesting to note that Respectful and Supportive Care scores many items where good practice has been achieved according to the parameter of a score of 85% or more, yet Section 5.2.5 reported that families ideally would like to see a higher level of service than that which they actually reported receiving. Clearly families have very high expectations in this area. A similar analysis was undertaken for staff responses. While it is important to note that it is the family responses regarding areas where there is room for improvement or areas of good practice that are most important, it is also interesting to note the comparison between the two sets of responses. Clearly, staff agree with families that Providing General Information is not as well done as other areas of practice and that Respectful and Supportive Care is well done and is a very important aspect of services and supports. Appendices 7 and 8 contain information that can be used in the future by Scope for the purpose of re-evaluation or by other organisations for the purpose of bench-marking.
5.2.9 Framework of item-by-item analysis: Convergence and divergence

The second item-by-item analysis undertaken was to investigate where there was convergence and divergence of opinion between families’ and staff’s responses to the ideal service and their perception of the actual service provided by Scope early childhood intervention services. This analysis was done using two matrices. The first compared families’ and staff’s responses in relation to ideal services (Figure 3).

- **Divergence (Cell 1)**: Families rate aspects of practice as more important than staff believe them to be.
- **Convergence (Cell 2)**: Families and staff are in agreement that certain aspects of practice are very important.
- **Convergence (Cell 3)**: Families and staff are in agreement that certain aspects of practice are relatively less important.
- **Divergence (Cell 4)**: Families rate aspects of practice as less important than staff believe them to be.

**Figure 3.** A comparison of families’ and staff’s perceptions of ideal services

Figure 3 shows the areas of convergence and divergence between families and staff regarding their perceptions of ideal services. The areas of most concern in relation to service evaluation are those cells where divergence is evident. In Cell 1, it could be argued that staff underestimate the importance to families of certain areas of practice while in Cell 4, staff overestimate the importance of particular practices. However, it is very important at this stage to remember the skewing of the data (see Section 3.3.4) where families’ and staff’s responses were clustered at the high scoring range; that is, all practices are important to a greater or lesser extent. So when importance is debated, it is relative importance that needs to be kept in mind. In Figure 3, the highlighted areas of divergence

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need to be addressed in any program or service evaluation strategy. It is also important to know what is uniformly held to be important by both families and staff.

The second matrix (Figure 4) illustrates the pattern that emerges where families’ and staff’s responses regarding actual services are compared.

<table>
<thead>
<tr>
<th></th>
<th>Families’ Responses (Actual)</th>
<th>Staff’s Responses (Actual Services)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Divergence</strong></td>
<td>Families rate the practice as better than the staff believe it to be. (Highlights areas where staff may be overly critical)</td>
<td></td>
</tr>
<tr>
<td><strong>Convergence</strong></td>
<td>Families and staff are in agreement that the practices are well done. (Highlights areas of good practice.)</td>
<td></td>
</tr>
<tr>
<td><strong>Convergence</strong></td>
<td>Families and staff are in agreement that certain aspects of practice are not as well performed. (Highlights areas where there is room for improvement)</td>
<td></td>
</tr>
<tr>
<td><strong>Divergence</strong></td>
<td>Families rate aspects of practice as less well done than staff believe them to be. (Highlights areas where there is room for improvement)</td>
<td></td>
</tr>
</tbody>
</table>

Figure 4. A comparison of families’ and staff’s perceptions of actual services

Figure 4 shows the areas of convergence and divergence between families and staff regarding their perceptions of actual services. The areas of most concern in relation to family-centred practice in this case are Cells 7 and 8 where for different reasons, areas needing improvement are highlighted. Equally important, however, is Cell 6 where areas of good practice are acknowledged and should be celebrated. These findings also need to take into account the relative importance ascribed to them by families. As discussed before, there is an inherent danger in viewing some aspects of practice as unimportant. Responses showed a high level of importance ascribed to all of the items, so it is essential to think of them in terms of relative importance.

Appendix 9 provides details of the differences between families and staff on ideal and actual mean scores. Using this information it is possible to identify items of interest.
according to the diagrams above. Given that this analysis is being done in the absence of previous base line data, it is not possible to establish an objective quantitative criterion by which the degree of convergence or divergence may be described. Thus a qualitative analysis has been undertaken and the figures contained in Appendix 9 will be used as base line measures for future research activities.

5.2.10 Convergence and divergence for ideal service

Using the above framework, and the findings contained in Appendix 9, it is possible to describe the trends and identify differences between staff and family perceptions about ideal services. These are shown in Figure 5.

A glance at Appendix 9 shows that overall, staff have higher expectations than do families regarding what is important. There are relatively few items where family expectations exceed those of staff. Overall, families are markedly less concerned than staff about Providing General Information. However, this needs to be considered in the light of the fact that it is only relatively less important. It is possible to surmise why this may be so. Is it because this is not seen as the role of Scope early childhood intervention teams, or is it that families see it as less important than child-focused services and do not want to take time or service delivery time away from these activities?

The finding that families do not perceive staff seeing them as the expert on their child (Item 12) as important as staff, appears on the surface to run counter to the findings of the literature review and family consultations. However, as discussed in Section 2.5.2 it may support the view that what parents value is shaped by the services that are offered. This finding is therefore of concern because it may tend to support the view that there is still a gap between rhetoric and practice in Scope services, and the possibility that more work needs to done to ensure that services are less child-focused and more family-centred.
### Figure 5. Analysis of families’ and staff’s perceptions of ideal services

<table>
<thead>
<tr>
<th>Family Responses (Ideal Services)</th>
<th>Staff Responses (Ideal Services)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Divergence</strong> (Cell 1)</td>
<td><strong>Convergence</strong> (Cell 2)</td>
</tr>
<tr>
<td><strong>Enabling and Partnership</strong></td>
<td></td>
</tr>
<tr>
<td>17 Let you choose when to receive information and the type of information you want</td>
<td></td>
</tr>
<tr>
<td><strong>Providing Specific Information about the Child</strong></td>
<td></td>
</tr>
<tr>
<td>26 Tell you about the results from assessments</td>
<td></td>
</tr>
<tr>
<td><strong>Coordinated and Comprehensive Care</strong></td>
<td></td>
</tr>
<tr>
<td>40 Seem aware of your child’s changing needs as he/she grows.</td>
<td></td>
</tr>
<tr>
<td><strong>Respectful and Supportive Care</strong></td>
<td></td>
</tr>
<tr>
<td>47 Have support staff that are polite and courteous to your family</td>
<td></td>
</tr>
<tr>
<td>41 Provide enough time to talk so you don’t feel rushed.</td>
<td></td>
</tr>
<tr>
<td>29 Provide a caring atmosphere rather than just give you information</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Convergence</strong> (Cell 3)</th>
<th><strong>Divergence</strong> (Cell 4)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Enabling and Partnership</strong></td>
<td></td>
</tr>
<tr>
<td>3 Offer you positive feedback or encouragement</td>
<td></td>
</tr>
<tr>
<td>12 Trust you as the expert on your child</td>
<td></td>
</tr>
<tr>
<td><strong>Providing General Information</strong></td>
<td></td>
</tr>
<tr>
<td>(all items in this domain)</td>
<td></td>
</tr>
<tr>
<td><strong>Providing Specific Information about the Child</strong></td>
<td></td>
</tr>
<tr>
<td>39 Provide you with written information about your child’s progress.</td>
<td></td>
</tr>
<tr>
<td>52 Notify you about the reasons for upcoming case conferences, meetings etc about your child</td>
<td></td>
</tr>
<tr>
<td><strong>Coordinated and Comprehensive Care</strong></td>
<td></td>
</tr>
<tr>
<td>5 Spend the time to establish rapport with you or your child when changes occur in your services.</td>
<td></td>
</tr>
<tr>
<td>4 Explain things to your child in a way that your child understands.</td>
<td></td>
</tr>
<tr>
<td><strong>Respectful and Supportive Care</strong></td>
<td></td>
</tr>
<tr>
<td>33 Treat you as an equal rather than just as the parent.....</td>
<td></td>
</tr>
</tbody>
</table>
5.2.11 Convergence and divergence for actual services

Using the findings contained in Appendix 9, it is now possible to describe the trends and identify the differences between families’ and staff’s perceptions of Scope early childhood intervention services. These are shown in Figure 6.

Overall, the data contained in Appendix 9 shows that families believe that the practice in Scope early childhood intervention teams is more family-centred than staff believe it to be on most items of the MPOC. Cell 8 highlights those items where the opposite is the case; that is, where families believe that practice is not as good as staff believe it to be. Once again this relates mostly to aspects of making information available to families. Overall Cells 7 and 8 highlight areas where the trends suggest that improvement may be required.

The items highlighted in Cell 6 are important as they highlight areas of good practice agreed upon by both staff and families. It is important to recognise that generally families were happy with many aspects of services and supports provided by Scope but Cell 6 highlights items where practice was rated highly by both staff and families. In particular, it is pleasing to note the items relating to Respectful and Supportive Care. Cell 5 shows those items where staff may be considered to have been overly critical of their practice compared with families.

5.2.12 Summary

Part Two of the study has explored the comparisons between the responses of families and staff regarding ideal services and their perceptions of the services actually provided by Scope early childhood intervention teams.

Respondents were primarily mothers with a great deal of experience with Scope services and supports. Developmental delay and physical disability amounted to just under three-quarters of the children identified in the sample. Of more interest, however, is the number of children who were identified by their families as having secondary disabilities. Forty percent or more had three or more secondary disabilities, with communication disorder being the most common secondary disability reported. Of the children with three or more secondary disabilities, 48% had a communication disorder. Clearly Scope continues to support a large number of children with multiple and complex needs with a strong emphasis on communication impairment.
### Divergence (Cell 5)

**Enabling and Partnership**
17 Let you choose when to receive information and the type of information you want.

**Coordinated and Comprehensive Care**
40 Seem aware of your child’s changing needs as he/she grows.
7 Make sure that your child’s skills are known to all persons working with your child, so the skills are carried out across services and service providers.
41 Provide enough time to talk so you don’t feel rushed.
29 Provide a caring atmosphere rather than just give you information.

### Convergence (Cell 6)

**Enabling and Partnership**
3 Offer you positive feedback or encouragement……
25 Recognising that your family has the final say when making decisions........

**Providing Specific Information about the Child**
26 Tell you about the results from assessments.

**Respectful and Supportive Care**
42 Treat you and your family as people rather than as a ‘case’…..
33 Treat you as an equal rather than as the parent of the patient……
31 Treat you as an individual rather than as a ‘typical parent of a child with a disability.’

### Convergence (Cell 7)

**Enabling and Partnership**
2 Fully explain treatment choices to you
16 Make sure you have a chance during visits to the centre to say what is important to you
30 Tell you details about your child’s services such as the reason for them, type of therapies……

### Divergence (Cell 8)

**Enabling and Partnership**
43 Listen to what you have to say about your child’s needs for equipment, services etc
28 Consult with you when discussing equipment or services.

**Providing General Information**
56 Have general information available about different concerns…………
46 Have information available to you in various forms such as booklet, kit, video etc
48 Give you information about the types of services offered at the Centre or in the community.
53 Have information about your child’s disability……
54 Provide advice on how to get information or to contact other parents……

**Providing Specific Information about the Child**
52 Notify you about the reasons for upcoming case conferences, meetings etc about your child.

---

**Figure 6.** Analysis of family and staff perceptions of actual services.
The profile of Scope early childhood intervention team members who participated in the research revealed a group that were generally highly experienced in their chosen profession. However, over half of the staff had worked in early childhood intervention for less than five years and a quarter of staff had worked for Scope for less than six months.

Amongst families, over 80% of respondents felt that Scope services had contributed to reducing their stress levels, with the biggest single group (46%) reporting that Scope services had contributed to considerably reducing family stress levels. When considered in conjunction with the findings of Thompson et al. (1997) that family-centred services were more likely to reduce the amount of stress reported by families, this study lends support to Scope having adopted a family-centred model of services and support.

Analysis of family responses generally revealed that families tended to rate services similarly regardless of the region in which they lived, the gender, age or disability of their child or the length of time they had been receiving services. Typically families wanted a stronger emphasis on having more general information made available to them. This was the domain where there was the most difference between what families wanted versus what they believed they received. This is a very consistent theme within both the literature review and the results of Part One of this study. Stronger emphasis was also sought by families in relation to Enabling and Partnerships and Respectful and Supportive Care, although the gap between the ideal and the actual was not as great as it was with Providing General Information.

Staff, by comparison, also agreed that the biggest gap between ideal and actual service delivery was Providing General Information followed by Coordinated and Comprehensive Care. In contrast to those of families, the responses by Scope staff varied depending on several factors. Findings showed that staff who had worked in their chosen discipline for longer periods had higher expectations in relation to Specific Information, and Coordinated and Comprehensive Care. Staff who had worked for Scope for longer periods when compared to other staff, believed that the actual amount of specific information provided was not as good as it should be. Longer serving staff also put a greater emphasis on Coordinated and Comprehensive Care.

When comparing the responses between families and staff, families generally rated Scope services higher than the staff’s perceptions of them. Interestingly families and staff both rated the provision of general information as the lowest of all the five domains in terms of
actual service delivery although staff thought that it was more important than did families. This confirms once again the literature, particularly that of CanChild where families and staff agree that providing general information to families needs to improve. Overall the findings suggested that staff are both more critical and idealistic than families are. This contrasts to the findings by McWilliam et al. who found that staff rated services more highly than did families although they found the groups did not differ on their vision of ideal service. McWilliam et al. also found that families who had been receiving services for longer periods were more likely to rate the service higher from a family-centred perspective. This was not the case in the Scope study. Nor was the finding by Granat et al. that rural families were likely to be more satisfied than were families in urban communities supported in this study.

As discussed in the literature review (see Section 2.5.3), it is a common finding for parents to report high levels of satisfaction. This accounts for the skewed results with scores clustered around the high end in this study. It is therefore important not to be carried away with the responses of families in this area. Even given the overall positive response, gaps and room for improvement could still be identified. Second, there is a view that families can only rate what they know and are not in a position to rate the level of family-centred practice if they know of nothing else. Finally, as discussed in the literature review, family-centred practice is an evolving process, and in the time that needs to be taken to establish new measures, practice has already moved on into new and other areas for which instruments have not yet been designed. In this sense, the search for truly measuring family-centred practice will continue to be somewhat illusory and it may feel like constantly chasing rainbows. It is therefore important for any evaluation activities to look at multiple methods and sources to answer the questions about what is important to families.

Whilst it is necessary to identify gaps and room for improvement, it is equally important to take the time to acknowledge and celebrate good practice. This study demonstrates that Scope team members set high standards of practice and in many areas are achieving these standards.
CHAPTER 6

DISCUSSION

6.1 INTRODUCTION

This chapter draws together the key findings and results from the literature review, focus groups and telephone interviews, and questionnaires. At the conclusion, recommendations are presented that arise out of the study. These recommendations have relevance for Scope early childhood intervention services but are also designed to support the early childhood intervention sector generally regarding gaps and areas of need.

A number of common themes have emerged from the literature review and study findings. These are:

- **A context for family-centred practice:** The need to put the philosophies, principles and practices of family-centred practice within a context of overall service provision;
- **First messages and other information:** The need of families to have a range of information and the way this information is communicated;
- **Finding the balance:** The importance of families having a balance in their lives and having access to services that can support this balance;
- **Inclusive practices and natural environments:** Recognising the importance of delivering services and supports in the child’s natural environments; and,
- **Challenges for future evaluation and research:** What has been learnt about the issues associated with future evaluation and research in early childhood intervention.

What follows is a discussion around each of these themes.

6.2 A CONTEXT FOR FAMILY-CENTRED PRACTICE

There is clearly a very 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. The literature is not easily synthesised nor the definitions clearly understood by all. However, there are very important messages that can be drawn.
The literature shows that families prefer family-centred services and supports over professionally-centred services, and that there are clear benefits for parents in terms of satisfaction with parenting, empowerment and parental and family well-being. There are other program characteristics, however, that influence child/parent and family functioning. Indeed, 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 has been offered other options in a real sense.

Family-centred practice is therefore not a service or an outcome in itself. It is the vehicle through which services and supports (for example, therapy, case management, parent support etc.) are delivered to children and families. It is a means to an end, not an end in itself. Family-centred practice cannot be defined by a particular set of forms/procedures or practices. Instead, it is a willingness to embrace a set of values and to behave in a way that reflects those values. If agencies and services are to be truly family-centred it is necessary to recognise the centrality of the family to everyday practice. Families need to be included in all stages of the establishment, development, evaluation and everyday activities of services and agencies.

The challenge for providers is to build this level of family collaboration into their processes and practices in a very real way, rather than as an after-thought, which runs the risk of being tokenistic at best. Service managers and practitioners need to continually ask how this can be done. How are families being empowered through power-through relationships rather than simply having a family-focused approach (see Section 2.2.2)? Power-through relationships empower all partners, thus allowing families, practitioners and others to become powerful agents of change within communities. In this way, the capacity of
communities can be enhanced to be welcoming and inclusive of children with disabilities and their families.

If family-centred practice is the path upon which managers and practitioners wish to travel, how can this be made to occur? What changes need to occur? One implication is that the behaviour of practitioners needs to be reflective of the principles of family-centred practice. Training on its own cannot be relied upon to result in changed behaviours. Management structures and processes also need to support the expected behaviours. Families also need to be assisted to understand and engage in the partnership. Families are an under-utilised resource. How can we make better use of this resource in a way that is meaningful, and is seen to be valued by families and does not simply place an extra demand on them?

Finally, 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.

Family-centred practice demands a commitment by managers and practitioners along a pathway where the journey is as important as the destination. As practices evolve and families and societies change, the destination continues to be elusive like the pot at the end of the rainbow. When a service or a practitioner believes that they are family-centred the time has probably come to re-evaluate what they are doing and to commence another journey.
6.3 FIRST MESSAGES AND OTHER INFORMATION

This study clearly showed that families have a substantial need for all types of information, and that 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 is it provided, in what sort of format, and when is it provided?

This study demonstrated that Scope performs reasonably well in providing information to families regarding their own child. However, of all of the domains of care as measured in the MPOC-56, the biggest service delivery gap was in the provision of general information to families. This was also supported by the focus groups and telephone interviews, although 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? This is the challenge. Too often families experience delays in being referred for support, or they spend long periods on waiting lists. How much damage is being done in the meantime by these delays and the consequent lack of information? Families generally believed that Scope practitioners provided positive messages, but how can these messages get to families earlier in their journey? There is also a message for Scope in this study that some primary health care providers do not know enough about what Scope early childhood intervention teams are able to offer.

If Scope is to improve its practices in relation to providing general information to families, strong links and partnerships with key specialist and universal child and family services need to be in place if families are to receive the full range of services and supports they need. If the aim of family-centred practice is to empower families, this can only occur when they have the information they need on hand.
Now that it has been 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 is a resource that is probably under-utilised at present and 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.

What strategies will support families in their sharing of information with practitioners? Clearly the interpersonal skills of practitioners will have an influence. It takes a considerable investment in time to develop the sort of relationship with families in which they can share the sort of information they may need and want to. In an environment where therapists and others feel pressured to deliver services and outcomes with limited funding, this aspect can be tested to the fullest. However, without information from families, the contribution of practitioners is indeed limited. When families feel they are part of a collaborative partnership with practitioners it is easier for them to provide information and take control of the services and supports that they receive. In the focus groups, some families reported that it took them a considerable period to get to that point. The challenge for agencies is how this delay can be reduced so that family empowerment happens earlier, ideally even before a family enters the service.
Finally, 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.

### 6.4 Finding the Balance

Providing services and supports that are family-centred means that many competing demands need to be balanced and managed from the perspective of families, practitioners and service managers.

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 care-giving 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 strengthen parental competencies.

Clearly, any one of these service characteristics in isolation will not deliver effective outcomes for children and families. It is important that team and individual professional development activities present a focus on the need for a balance between all three aspects.
of effective care-giving as outlined by Dunst and Trivette. Whilst the personal characteristics of practitioners are not always easily modified, beliefs and attitudes can be modified and communication skills can be improved through training. Closing the gap between the rhetoric and reality of family-centred practice can be achieved through appropriate reflection, supervision, and parental feedback. Knowledge can be gained through experience and professional development. Early childhood intervention agencies need to ensure that they address each of these three aspects, as neglect of any one will be to the detriment of service quality and outcomes.

How can services balance the needs of families for flexible services that respond to the changing needs of families over time within the constraints of the real-life demands of staffing a program and managing services and facilities? It is important to ensure that the services that are offered are in response to the needs of families. Group programs need to be balanced by providing opportunities for families for individualised support. Family-centred services do not mean that services are always offered at home. The issue for families is not whether services are centre-based, home-based or community-based. Family-centred services and supports are ideally available in the place that is best for the family at particular points of time in their journey. This may change as their child’s and their own circumstances change.

Therefore, if agencies are to be family-centred, it is important that the Human Resources policies and employment conditions of staff enable the flexible delivery of services at times suitable to families, for example, outside the usual nine-to-five day, five days per week.

6.5 INCLUSIVE PRACTICES AND NATURAL ENVIRONMENTS

Evidence discussed in the literature review suggested 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?

Using the ICF framework (WHO, 2001) as the basis for analysis, it is possible to argue that children can derive most benefit in the early years from intervention focussed at improving impairments. However, in the isolation of family and community environments, the benefits
gained will not be fully realised for the child or the family. Through collaboration with families, goals need to be directed to the priorities of families so that the developmental goals are those that are going to make the most difference to the family. For example, to work on impairment in relation to swallowing, in the absence of understanding what the real mealtime issues are for families would not be the best use of valuable intervention time. How much more useful it is to look at the most important mealtime occasions and issues for the family, whether it be their evening meal or eating at the local fast food outlet. All of this is dependent on the needs and priorities of families.

All too often, providing services within natural environments becomes 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 ‘home programs.’ It should not be an either/or situation. Focus group participants were clearly able to describe 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 (therapy or otherwise) 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 (e.g., “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 (e.g., making use of natural learning environments rather than clinical settings), parents can make an informed choice about what they want. Therapy is not an end in itself. It is one mechanism that can be used to support families to meet their needs and priorities. Children and families do not have a need for therapy. Children have a need to be able to participate in everyday tasks and activities with their peers, while families need to be able to continue to participate as members of their own communities.
Children do not have to earn the right or opportunity through countless hours of therapy services delivered in isolation, to participate in activities with their peers. They have the right to participate already. Providing services in the natural environments of the family and child should be the rule and not the exception, and practitioners should be asked to justify occasions of service where this has not occurred.

6.6 CHALLENGES FOR FUTURE EVALUATION AND RESEARCH

This research project 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. Using the ICF framework (WHO, 2001) 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.

This study has chosen to focus on the family, providing an opportunity for their stories to be told, and has measured the processes of care as measured by the MPOC-56 (King, King, Rosenbaum & King, 1995). The literature tells us that measures of parental satisfaction including questionnaires, interviews and telephone surveys generally show relatively 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.

The study showed that the MPOC-56 was a useful measure in determining the degree of family-centred practice within Scope early childhood intervention services. However, future users need to be aware that some modifications may need to be made to the wording to
make it relevant to Australian circumstances. There is also a fairly heavy emphasis on information giving. Most important, it is not a measure that includes the capacity of service providers to work in natural environments, however, there are currently no measures in existence that address this issue.

The research findings do not indicate that family questionnaires and the MPOC or its derivatives, do not have a place in future service evaluation, rather, they merely have the capacity to form only one part of the answer. Service managers and researchers need to be aware that evaluation in this field is evolutionary. In the time it takes to develop an instrument and undertake the validation and reliability trials, practice has often moved on. 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 researchers is, however, 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.

6.7 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. The study has made an important contribution to the research evidence in relation to early childhood intervention services and has addressed a gap in the literature generally, but more particularly in Australian evidence-based practice.

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.

6.8 RECOMMENDATIONS

An attempt has been made to develop recommendations that are designed to inform the early childhood intervention sector generally regarding gaps and areas of need. From these, Scope will develop specific action plans that will be incorporated into the early childhood intervention strategic plan.

As a result of the findings and evidence contained in this study, it is therefore recommended that:

Partnerships
a) Early childhood intervention teams continue to work on building stronger links and partnerships with generic family and parenting agencies to ensure that families access the full range of necessary services and supports.

b) Strategies that embed family collaboration in service design, development and review, and in the provision of staff training and development be identified.

c) Services and early childhood intervention networks collaborate with primary health care providers to ensure that the first messages families receive are accurate and positive.

d) Service providers ensure that primary health care providers and families have accurate information regarding the range and type of services available.

e) Agencies explore ways that families can share their knowledge and experience with other families and have an opportunity to learn from the lived experiences of other families.
Learning
a) Professional development and learning activities for practitioners ensures a balance between the three components of effective care-giving; that is, interpersonal skills, technical competence and strategies that facilitate collaborative practices with families.
b) Documented competencies for early intervention team members reflect the balance of these three areas.
c) Induction and personal development and review plans are linked back to the competencies of practitioners against each of these three areas.

Provision of Information
a) Strategies that enable families to receive positive first messages at an early stage in their journey, either before or at the time of referral, be identified.
b) Families receive information via a variety of methods and formats that facilitates their ability to be partners in the relationship, and supports them in their role as experts in relation to their child.
c) There is a need for the development of information for families and intervention practitioners about how services can be delivered effectively in natural environments and routines.
d) Families have access to relevant research information in accessible formats.
e) Families are provided with both specific and general information in a variety of formats and methods through the use of traditional, electronic and web-based methods.

Service Development
a) Services ensure that the behavioural needs of children are addressed, where appropriate, so that a major determinant of family stress levels is managed.
b) Provision of services and supports revolves around the needs of families as their starting point, particularly in the provision of group programs.
c) Families receiving group programs also have individual time available to address other needs and issues.
d) Service managers ensure that appropriate Human Resources policies and processes are in place so that practitioners may work with families in environments and times of the day/week that are relevant.
e) Consideration be given to making the delivery of services in natural environments mandatory unless teams can justify why this has not been able to occur in specific instances.

**Future Evaluation and Research**

a) Further resources be expended to identify how family-centred practice transfers and relates to different cultural contexts and environments.

b) Strategies for finding ways to engage fathers in service evaluation, review and research be identified.

c) The sector continues to investigate alternative ways of obtaining feedback from families rather than relying on satisfaction questionnaires.

d) The MPOC-56 be used to assist sector benchmarking activities and to identify changes in service delivery over time.
REFERENCES


http://canchild.interlynx.net/patches/FCSSheet1.pdf


APPENDICES
Appendix One:

Other Measures of Family-Centred Practice
Besides the MPOC-56 and the MPOC-SP, there are a number of other measures of family-centred practice for use with practitioners and parents. In addition, there are measures of the family-centredness of family support plans.

1. MEASURES OF FAMILY-CENTRED PRACTICE FOR USE BY AGENCIES

- **Checklist of Indicators for Family Centered Practice Within Agencies** (Walter & Petr, 2000)
  This questionnaire consists of 28 items in four sections: Mission statement; family consumer advisory committee; policies and procedures; and treatment of staff.

- **The Family-Centered Program Rating Scale** (Murphy, Lee, Turnbull and Turbiville, 1995)
  Both a parent version and a service provider version are available.

- **The Family-Focused Intervention Scale** (Mahoney, O’Sullivan and Dennebaum, 1990).

  These guidelines, which form part of the Partners Training Package, include short questionnaires regarding first contacts with parents, provision of information, child assessment, developing and implementing FSPs, and supporting transition to subsequent services. Both service provider and parent versions are included.

- **FOCAS: Family Orientation of Community and Agency Services** (Bailey, 1992)
  This questionnaire is designed to measure service providers’ perceptions of how families are included in their early intervention program or community. There are 12 items addressing different aspects of service. Each item is rated twice, once for how things are currently, and once for how the provider would like them to be.

  This is a self-rating instrument for early childhood intervention service providers that covers four areas of service provision: first contact with families, identifying goals for intervention, intervention planning, and day-to-day service provision.

- **Recommended Practices in Family-Based Practices** (Trivette and Dunst, 2000)
  Although not a formal scale, this set of recommended practices can be used as a checklist or converted into a scale.

2. MEASURES OF FAMILY-CENTRED PRACTICE FOR PARENTS

- **Help-Giving Practices Scale** (Dunst, Trivette and Hamby, 1995)
  This 25-item scale measures a variety of help-giving behaviours and practices. Each item includes five responses from which the respondent selects a behaviour that best describes a particular help-giver practice. The scale gives an overall score as well as four subscale scores, each measuring a particular aspect of help-giving beliefs and practices: empowerment ideology (helpgiver beliefs about the capabilities of people), participatory actions (help-giving processes used to promote help-seeker knowledge and competencies), help-giver traits (behaviours associated with effective help-giving, such as active listening, honesty, and empathy), and help-seeker reactions to aid (response-cost consequences of accepting or refusing help).

  Dunst, Boyd, Trivette and Hamby (2002) reported the use of a 12-item short form of this scale, half the items describing relational help-giving practices (empathy, warmth, genuineness, beliefs about help-seeker capabilities) and half describing participatory help-giving practices (behaviours
that actively involve people in identifying goals and courses of action, and which strengthen capacities and skills).

- **Brass Tacks: Part 2 – Individual Interactions with Families** (McWilliam and Winton, 1991b)
  This is a self-rating instrument for early childhood intervention service providers that covers four areas of service provision: first contact with families, identifying goals for intervention, intervention planning, and day-to-day service provision.

- **Enabling Practices Scale** (Dempsey, 1995)
  This 24-item scale measures the perceptions of parents of children with disabilities of the extent to which the services they receive use enabling practices. The items were based on 12 enabling and empowering practices identified by Dunst, Trivette and Deal (1988).

- **Family Empowerment Scale** (Koren, DeChillo and Friesen, 1992)
  This 34-item scale was designed to assess empowerment in parents and other family caregivers whose children have emotional disabilities. It is based on a conceptual framework consisting of two dimensions: the level of empowerment and the way that empowerment is expressed.

  Level of empowerment can occur at three levels:
  - *the family* – involves parent management of day-to-day situations;
  - *the service system* – involves parents working actively with service providers to get services that the child needs; and,
  - *community / political* – involves parents advocating for improved services for children in general.

  Empowerment can be expressed in three ways:
  - *attitudes* – what a parent feels and believes;
  - *knowledge* – what a parent knows and can potentially do; and,
  - *behaviours* – what a parent actually does.

  Combining the three categories on each of the three dimensions results in nine possible combinations as to how empowerment may be experienced or expressed at any point in time:

3. **MEASURES OF FAMILY-CENTREDNESS OF FAMILY SERVICE AND SUPPORT PLANS**


  A 21-item rating scale.

- **Goodness of Fit Survey** (Albin, Lucyshyn, Horner and Flannery, 1996)

  A 20-item scale to measure the extent to which parents feel that a support plan fits the values and life-style of their family.
Appendix Two:

Family Demographics Questionnaire: Focus Groups and Telephone Interviews
Participant Background Demographics

1 Region: _______________________________________________

2 Date of telephone interview/focus group: ______________________

3 Person being interviewed:
   Parent.......................................................... 1
   Guardian ..................................................... 2
   Other (please specify)................................. 3

4 Are you: Male............................................................ 1
   Female ........................................................ 2

5 What is the gender of your child with special needs?:
   Male .......................................................... 1
   Female ........................................................ 2

6 Your postal code is: ______________________________________

7 How old is your child? ____________ Years ____________ Months

8 What language does your family speak at home? __________________

9 How long have you and your child been receiving services from Scope Early Childhood Intervention Services? (You may respond in terms of years, months or weeks.)
   _____ Years or _______ Months or _______ Weeks

10 How often do you see members of the Early Childhood Intervention Service?
   Weekly or more frequently......................................................... 1
   or
   More than once a month .............................................................. 2
   or
   Monthly .................................................................................... 3
   or
   Less frequently than monthly ..................................................... 4

Please specify how many weeks have passed since your last appointment with a staff member from the ECI service: ____________________________ weeks
11 When you see someone from the Scope Early Childhood Intervention Service, where do you or your child usually see them? You may choose more than one response.

At your home ........................................................................................................... 1
At a Scope Centre .................................................................................................... 2
At a community facility (for example, child care centre, kindergarten, community play group) ........................................................................................................ 3
Other, please specify: ............................................................................................. 4

12 Could you please describe the special needs or disability that your child has. Please place \textit{one tick} in the primary column that best describes the condition that most affects your child’s everyday life. You may place \textit{more than one tick} in the secondary column to describe other conditions that affect your child’s everyday life.

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<tr>
<th>NEEDS / DISABILITY TYPE</th>
<th>PRIMARY (tick one only)</th>
<th>SECONDARY (tick 1 or more)</th>
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<tbody>
<tr>
<td>01 Developmental delay</td>
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<td>02 Intellectual</td>
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<td>03 Specific learning disorder / ADD</td>
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<td>04 Autism (including Asperger’s syndrome)</td>
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<td>06 Acquired Brain Injury</td>
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<td>07 Deafblind (dual sensory disability)</td>
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<td>08 Vision</td>
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<td>10 Communication impairment</td>
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<tr>
<td>11 Neurological</td>
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\textbf{WOULD YOU LIKE TO TELL US ANYTHING ELSE OR DO YOU HAVE ANY OTHER COMMENTS?}

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
Appendix Three:

Family Questionnaire 1 (Ideal Service)
SCOPE SPECIALIST SERVICES

FAMILY-CENTRED PRACTICE IN EARLY CHILDHOOD INTERVENTION: A FAMILY PERSPECTIVE

PURPOSE

Scope wants to find out more about the services we provide to children and their families. To help us understand our strengths and weaknesses and improve our services, we are asking you to complete the attached questionnaire “Measure of Processes of Care”. This is the first of two questionnaires. So we can understand some of the detail, as well as the ‘big picture’ we are asking you to first complete some background information about you and your child. Please remember that, as described in the covering letter, all of the information you provide will be treated confidentially and your specific responses will not be discussed with Scope staff or anyone else.

BACKGROUND QUESTIONS

Please answer the following questions by writing in the space provided or by circling the number that best matches your response.

1. Date: / / 

2. Person(s) completing the questionnaire. You may tick more than one response:
   - Parent ____________________________ 1
   - Guardian ____________________________ 2
   - Other ____________________________ 3
   - If ‘Other’ (please specify) ____________________________ 4
   Are you ____________________________ Male 1
   ____________________________ Female 2

   Total number of people contributing to this questionnaire ________________

3. Gender of your child with special needs:
   - Male…………………………………………………………………………………………………… 1
   - Female………………………………………………………………………………………………… 2
4. Your postal code is: ____________________________________________

5. How old is your child? ________________ Years ______________ Months

6. What language does your family speak at home? ____________________

7. How long have you and your child been receiving services from Scope Early Childhood Intervention Services? You may respond in terms of years, months or weeks.
   _______ Years or ________ Months or ________ Weeks

8. How often do you see members of the Early Childhood Intervention Service?
   Weekly or more frequently .............................................................. 1
   or
   More than once a month................................................................. 2
   or
   Monthly .......................................................................................... 3
   or
   Less frequently than monthly......................................................... 4

   Please specify how many weeks have passed since your last appointment with a staff member from the ECI service: ________ weeks

9. When you see someone from the Early Childhood Intervention Service, where do or your child you usually see them? You may choose more than one response.
   At your home.................................................................................. 1
   At a Scope Centre.............................................................................. 2
   At a community facility (for example, child care centre, kindergarten, community play group).................................................. 3
   Other, please specify:......................................................................... 4
10. Could you please describe the special needs or disability that your child has. Please place *one tick* in the primary column that best describes the condition that most affects your child’s everyday life. You may place *more than one tick* in the secondary column to describe other conditions that affect your child’s everyday life.

<table>
<thead>
<tr>
<th>Needs / Disability Type</th>
<th>Primary (tick one only)</th>
<th>Secondary (tick 1 or more)</th>
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<tbody>
<tr>
<td>01 Developmental delay</td>
<td></td>
<td></td>
</tr>
<tr>
<td>02 Intellectual</td>
<td></td>
<td></td>
</tr>
<tr>
<td>03 Specific learning disorder / ADD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>04 Autism (including Asperger’s syndrome)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>05 Physical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>06 Acquired Brain Injury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>07 Deafblind (dual sensory disability)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>08 Vision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>09 Hearing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Communication impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Neurological</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. Could you please describe what it is that you expect Scope Early Childhood Intervention Services to help you and your child with? For example, you might require help so your child can develop or improve a skill, such as walking. You might be looking for advice about how to manage your child or how to help other children and your child play together. There are many different things that parents want from a service. What is it that you want from Scope’s Early Childhood Intervention Service?

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

**Please continue on and complete the “Measure of Processes of Care”.
Thank you.**
**Processes of Care Questionnaire**

We would like to understand and measure the experiences of parents who have a child with a disability or special needs. At this stage we wish to know about what people believe would be an *ideal service* for children and their families.

The questions in this section are based on what parents, have told us about the way care is sometimes offered. We would like you to indicate the extent to which the event or situation *would happen in an ideal service*. You are asked to answer each question on a scale from 7 (To a Great Extent) to 1 (Never).

The care that parents and children receive from an Early Childhood Intervention Service may bring them into contact with many individuals. The questions on this form are grouped by *who* these contacts are, as described below.

1. **People**: refers to those individuals who work directly with you or your child.
   
   These *may include* physiotherapists, occupational therapists, speech pathologists, psychologists, family service coordinators etc.

2. **Service**: refers to all staff from the ECI Service, whether involved directly with your child or not. In addition to therapists they *may include* support staff such as office staff, administrative personnel, etc.
The following is an example of the kinds of questions you will be asked.

This example also shows what your answer could mean.

In an ideal service indicate how much each event or situation would happen.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT SHOULD THE PEOPLE WHO GIVE YOU QUESTIONNAIRES...</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>... provide you with clear instructions on how to complete them?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you circled #7 (To a Great Extent) it means that, in an ideal service, the people who give you questionnaires would always provide very clear instructions in what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires should be clear in what they want you to do some of the time, and some of the time the instructions might not be so clear.

If your circled #0 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.
We would like you to think about what you believe would be an *ideal* experience in an ECI service. We are interested in your personal thoughts and would appreciate you completing this questionnaire without discussing it with any ECI team members or staff with whom you may come into contact.

For each question, please indicate **how much** the event or situation would happen in an *ideal service* by circling one number (from 1 to 7) that you feel best fits your views.

**PEOPLE** refers to those individuals who work directly with children. These may include physiotherapists, occupational therapists, speech pathologists and psychologists etc.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT WOULD THE PEOPLE WHO WORK WITH THE CHILDREN...</th>
<th>Indicate how much this event or situation would happen in an <em>ideal</em> service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ... suggest therapy plans that fit with each family’s needs and lifestyle?</td>
<td>To a Great Extent</td>
</tr>
<tr>
<td>2. ... fully explain treatment choices to families?</td>
<td>7</td>
</tr>
<tr>
<td>3. ... offer positive feedback or encouragement (e.g., in carrying out a home program)?</td>
<td>7</td>
</tr>
<tr>
<td>4. ... explain things to children in a way that children understand?</td>
<td>7</td>
</tr>
<tr>
<td>5. ... take the time to establish rapport with the family or child when changes occur in their services?</td>
<td>7</td>
</tr>
<tr>
<td>6. ... discuss with each family, everyone’s expectations for their child, so that all agree on what is best?</td>
<td>7</td>
</tr>
</tbody>
</table>

MPOC Family Questionnaire Number 1
## MPOC Family Questionnaire Number 1

To What Extent Would The People Who Work With the Children...

<table>
<thead>
<tr>
<th></th>
<th>Indicate how much this event or situation would happen in an ideal service</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>To a Great Extent</td>
</tr>
<tr>
<td>7</td>
<td>... make sure that each child’s skills are known to all persons working with the child, so the skills are carried across services and service providers?</td>
</tr>
<tr>
<td>8</td>
<td>... tell families about options for treatment or services for their child (e.g., equipment, school, therapy)?</td>
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<td>9</td>
<td>... accept each family in a non-judgemental way?</td>
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<td>... provide ideas to help families work with the health care “system”?</td>
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<tr>
<td>12</td>
<td>... trust parents as the “expert” on their children?</td>
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<td>13</td>
<td>... look at the needs of the “whole” child (e.g., at mental, emotional, and social needs) instead of just at physical needs?</td>
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<td>14</td>
<td>... show sensitivity to each family’s feelings about having a child with special needs (e.g., their worries about their child’s health or function)?</td>
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<tr>
<td>15</td>
<td>... anticipate family concerns by offering information even before families ask?</td>
</tr>
<tr>
<td>16</td>
<td>... make sure families have a chance during visits to the centre to say what is important to them?</td>
</tr>
<tr>
<td>17</td>
<td>... let families choose when to receive information and the type of information wanted?</td>
</tr>
<tr>
<td>Event Description</td>
<td>To a Great Extent</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>18. ... remember personal details about each child or family, when speaking with the family?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>19. ... tell families about the reasons for treatment or equipment?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>20. ... follow up at the next appointment on any concerns a family discussed at the previous one?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>21. ... make sure that at least one team member is someone who works with the family over a long period of time?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>22. ... provide opportunities for families to make decisions about treatment?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>23. ... answer family questions completely?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>24. ... explain what they are doing when families are watching their children in therapy?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>25. ... recognize that the family has the final say when making decisions about their child’s treatment?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>26. ... tell families about the results from assessments?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>27. ... provide families with written information about what their child is doing in therapy?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>28. ... consult with families when discussing equipment or services?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>29. ... provide a caring atmosphere rather than just give families information?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>Item</td>
<td>Description</td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
</tr>
<tr>
<td>30.</td>
<td>Tell families details about their child’s services, such as the reasons for them, the type of therapies and the length of time?</td>
</tr>
<tr>
<td>31.</td>
<td>Treat parents as individuals rather than as a “typical” parent of a child with a disability?</td>
</tr>
<tr>
<td>32.</td>
<td>Develop both short-term and long-term goals for each child?</td>
</tr>
<tr>
<td>33.</td>
<td>Treat parents as an equal rather than just as the parent of a child with special needs (e.g., by not referring to you as “Mum” or “Dad”)?</td>
</tr>
<tr>
<td>34.</td>
<td>Plan together so they are all working in the same direction?</td>
</tr>
<tr>
<td>35.</td>
<td>Make sure families have opportunities to explain what they think are important treatment goals?</td>
</tr>
<tr>
<td>36.</td>
<td>Make families feel like a partner in their child’s care?</td>
</tr>
<tr>
<td>37.</td>
<td>Make sure families are informed ahead of time about any changes in their child’s care (e.g., therapists, programs, equipment)?</td>
</tr>
<tr>
<td>38.</td>
<td>Help parents to feel competent as a parent?</td>
</tr>
<tr>
<td>39.</td>
<td>Provide families with written information about their child’s progress?</td>
</tr>
<tr>
<td>40.</td>
<td>Seem aware of children’s changing needs as they grow?</td>
</tr>
</tbody>
</table>
## TO WHAT EXTENT WOULD THE PEOPLE WHO WORK WITH THE CHILDREN...

<table>
<thead>
<tr>
<th>Statement</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. ... provide enough time to talk so families don’t feel rushed?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>42. ... treat families as people rather than as a “case” (e.g., by not referring to people by diagnosis, such as “the spastic diplegic”)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>43. ... listen to what families have to say about their child’s needs for equipment, services etc.?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>44. ... make themselves available as a resource (e.g., emotional support, advocacy, information)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>45. ... give families information about their child that is consistent from person to person?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

SERVICE refers to all staff from the ECI Service, whether involved directly with the children or not. In addition to therapists, these people may include support staff such as office staff, administrative personnel; etc.

## TO WHAT EXTENT WOULD THE SERVICE

<table>
<thead>
<tr>
<th>Statement</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>46. ... have information available to families in various forms, such as a booklet, kit, video, etc.?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>47. ... have support staff that are polite and courteous to families?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

MPOC Family Questionnaire Number 1
<table>
<thead>
<tr>
<th>Question</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>48. ... give families information about the types of services offered at the Service or in their community?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>49. ... promote family-to-family gatherings for social, informational or shared experiences?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50. ... provide opportunities for special guests to speak to parents on topics of interest?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>51. ... provide support to help cope with the impact of childhood disability (e.g., by advocating on families behalf or informing families of assistance programs)?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>52. ... notify families about the reasons for upcoming case-conferences, meetings etc., about their child?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>53. ... have information available about the children’s disability (e.g., its causes, how it progresses, future outlook)?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>54. ... provide advice on how to get information or to contact other parents (e.g., Centre’s parent resource library)?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>55. ... provide opportunities for the entire family to obtain information?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
56. ... have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, dating and sexuality)?

<table>
<thead>
<tr>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

**WILL YOU LIKE TO TELL US ANYTHING ELSE, OR DO YOU HAVE ANY OTHER COMMENTS?**

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

**THANK YOU FOR YOUR TIME!!**
Appendix Four:

Family Questionnaire 2 (Actual Service)
SCOPE SPECIALIST SERVICES

FAMILY-CENTRED PRACTICE IN EARLY CHILDHOOD INTERVENTION: A FAMILY PERSPECTIVE

PURPOSE

Scope wants to find out more about the services we provide to children and their families. You may have recently completed another similar questionnaire about what you thought an ideal service should be. This is the second and final questionnaire that we are asking you to complete to provide feedback specifically about Scope Early Childhood Intervention services.

Please remember that, as advised previously, all of the information you provide will be treated confidentially and your specific responses will not be discussed with Scope staff or anyone else.

Could you please provide the following information by writing in the space provided or by circling the number that best matches your response.

1. Date:       /       /

2. Person(s) completing the questionnaire. You may tick more than one response:
   Parent __________________________________________________ 1
   Guardian __________________________________________________ 2
   Other ______________________________________________________ 3
   If ‘Other’ please specify____________________________________ 4

   Are you____________________________________________Male 1
   ___________________________________________________________Female 2

   Total number of people contributing to this questionnaire ________________

Please continue on and complete the “Measure of Processes of Care”.
Thank you.
**Processes of Care Questionnaire**

We would like to understand and measure the experiences of parents who have a child with a disability or special needs. In particular we wish to know about your perceptions of the care you have been receiving from your child’s *Scope Early Childhood Intervention (ECI) Service*.

The questions in this section are based on what parents, like yourself, have told us about the way care is sometimes offered. We would like you to indicate how much the event or situation happens (or doesn’t happen) to you at your Scope ECI service. You are asked to answer each question on a scale from 7 (To a Great Extent) to 1 (Never).

The care that you and your child receive from the Scope Early Childhood Intervention Service may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

1. **People**: refers to those individuals who work directly with you or your child.
   
   These may include physiotherapists, occupational therapists, speech pathologists and psychologists, family service coordinators etc.

2. **Service**: refers to all staff from the Scope ECI service, whether involved directly with your child or not. In addition to therapists they may include support staff such as office staff, administrative personnel, etc.
The following is an example of the kinds of questions you will be asked.

This example also shows what your answer could mean.

Indicate how much each event or situation happens to you.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT DO THE PEOPLE WHO GIVE YOU QUESTIONNAIRES...</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>... provide you with clear instructions on how to complete them?</td>
<td>7 6 5 4 3 2 1 0</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you circled #7 (To a Great Extent), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Never), it means that although you have received questionnaires, the instructions are never clear.

If your circled #0 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.
We would like you to think about your experiences with **Scope ECI services**. We are interested in your personal thoughts and would appreciate your completing this questionnaire without discussing it with any Scope staff members.

For each question, please indicate how much the event or situation happens to you by circling a number (from 1 to 7) that you feel best fits your experience.

**PEOPLE** refers to those individuals who work directly with you or your child. These may include physiotherapists, occupational therapists, speech pathologists and psychologists, family service coordinators etc.

<table>
<thead>
<tr>
<th>To What Extent Do The People Who Work With Your Child...</th>
<th>Indicate how much this event or situation happens to you at Scope</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>To a Great Extent</td>
</tr>
<tr>
<td>1. ... suggest therapy plans that fit with your family’s needs and lifestyle?</td>
<td>7</td>
</tr>
<tr>
<td>2. ... fully explain treatment choices to you?</td>
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<td>5. ... take the time to establish rapport with you or your child when changes occur in your services?</td>
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</tr>
<tr>
<td>6. ... discuss with you everyone’s expectations for your child, so that all agree on what is best?</td>
<td>7</td>
</tr>
<tr>
<td>TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...</td>
<td>Indicate how much this event or situation happens to you at Scope</td>
</tr>
<tr>
<td>----------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td>7. ... make sure that your child’s skills are known to all persons working with your child, so the skills are carried across services and service providers?</td>
<td>To a Great Extent: 7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>8. ... tell you about options for treatment or services for your child (e.g., equipment, school, therapy)?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
<tr>
<td>9. ... accept you and your family in a non-judgemental way?</td>
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<td>14. ... show sensitivity to your family’s feelings about having a child with special needs (e.g., your worries about your child’s health or function)?</td>
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<td>15. ... anticipate your concerns by offering information even before you ask?</td>
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<td>16. ... make sure you have a chance during visits to the centre to say what is important to you?</td>
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<tr>
<td>17. ... let you choose when to receive information and the type of information you want?</td>
<td>7 6 5 4 3 2 1 0</td>
</tr>
</tbody>
</table>

MPOC Family Questionnaire Number 2
## TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...

<table>
<thead>
<tr>
<th>Event</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>... remember personal details about your child or family when speaking with you?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>... tell you about the reasons for treatment or equipment?</td>
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<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>... follow up at the next appointment on any concerns you discussed at the previous one?</td>
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<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>... make sure that at least one team member is someone who works with you and your family over a long period of time?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
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<td>... provide opportunities for you to make decisions about services?</td>
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<td>6</td>
<td>5</td>
<td>4</td>
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<tr>
<td>... answer your questions completely?</td>
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<td>4</td>
</tr>
<tr>
<td>... recognize that your family has the final say when making decisions about your child’s services?</td>
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<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>... tell you about the results from assessments?</td>
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<td>6</td>
<td>5</td>
<td>4</td>
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</tr>
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<td>Indicate how much this event or situation happens to you at Scope</td>
<td>To a Great Extent</td>
<td>Sometimes</td>
<td>Never</td>
<td>Not Applicable</td>
</tr>
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<tr>
<td>37. ... make sure you are informed ahead of time about any changes in your child’s program (e.g., therapists, programs, equipment)?</td>
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<td>38. ... help you to feel competent as a parent?</td>
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</tbody>
</table>
### TO WHAT EXTENT DO THE PEOPLE WHO WORK WITH YOUR CHILD...

<table>
<thead>
<tr>
<th>Event/Question</th>
<th>Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>41. ... provide enough time to talk so you don’t feel rushed?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>42. ... treat you and your family as people rather than as a “case” (e.g., by not referring to you by diagnosis, such as “the spastic diplegic”)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>43. ... listen to what you have to say about your child’s needs for equipment, services etc.?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>44. ... make themselves available to you as a resource (e.g., emotional support, advocacy, information)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>45. ... give you information about your child that is consistent from person to person?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

**SERVICE** refers to all staff from the centre, whether involved directly with your child or not. In addition to therapists, these people may include support staff such as office staff, administrative personnel, etc.

### TO WHAT EXTENT DOES THE SERVICE:

<table>
<thead>
<tr>
<th>Event/Question</th>
<th>Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>46. ... have information available to you in various forms, such as a booklet, kit, video, etc.?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>47. ... have support staff that are polite and courteous to you and your family?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Event or Situation</td>
<td>Great Extent</td>
<td>Sometimes</td>
<td>Never</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>--------------</td>
<td>-----------</td>
<td>-------</td>
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</tr>
<tr>
<td>48. Give you information about the types of services offered at the Centre or in your community?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>49. Promote family-to-family gatherings for social, informational or shared experiences?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>50. Provide opportunities for special guests to speak to parents on topics of interest?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>51. Provide support to help cope with the impact of childhood disability (e.g., by advocating on your behalf or informing you of assistance programs)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>52. Notify you about the reasons for upcoming case conferences, meetings, etc., about your child?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>53. Have information available about your child’s disability (e.g., its causes, how it progresses, future outlook)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>54. Provide advice on how to get information or to contact other parents (e.g., Centre’s parent resource library)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>55. Provide opportunities for the entire family to obtain information?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>56. Have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, dating and sexuality)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

Please continue to the next page...
Please circle the number that best describes the degree to which caregiving by the Scope Early Childhood Intervention service team has affected the amount of stress and worry you experience in caring for your child.

The Scope ECI service has…

Considerably reduced my stress and worry ____________ 1
Somewhat reduced my stress and worry ____________ 2
Not had any effect on my stress and worry ____________ 3
Somewhat increased my stress and worry ____________ 4
Considerably increased my stress and worry ____________ 5

WOULD YOU LIKE TO TELL US ANYTHING ELSE, OR DO YOU HAVE ANY OTHER COMMENTS?
______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________
______________________________________________________________

THANK YOU FOR YOUR TIME !!
Appendix Five:

Staff Questionnaire 1 (Ideal Service)
SCOPE SPECIALIST SERVICES

FAMILY-CENTRED PRACTICE IN EARLY CHILDHOOD INTERVENTION: A FAMILY PERSPECTIVE

PURPOSE
Scope wants to find out more about the services we provide to our Early Childhood Intervention children and their families. To help us understand our strengths and weaknesses and improve our services, we are asking you to complete the attached questionnaire “Measure of Processes of Care”. This is the first of two questionnaires. So we can understand some of the detail as well as the ‘big picture’ we are asking you to first complete some background information.

Please remember that, as described in the covering letter, all of the information you provide will be treated confidentially and your specific responses will not be discussed with other Scope staff or anyone else.

BACKGROUND QUESTIONS
Please answer the following questions by writing in the space provided or by circling the number that best matches your response.

1. Date: / / 

2. Person completing the questionnaire:
   - Occupational Therapist________________________ 1
   - Physiotherapist______________________________ 2
   - Speech Pathologist____________________________ 3
   - Psychologist__________________________________ 4
   - Family Services Coordinator____________________ 5
   - Service Manager______________________________ 6
   - Other (please specify:) __________________________ 7
   ________________________________________________
3. In what region do you work in Scope (ECI) services (you may circle more than one):
   - North West ____________________________________________ 1
   - South East __________________________________________ 2
   - Barwon _____________________________________________ 3
   - Gippsland __________________________________________ 4
   - Hume ________________________________________________ 5
   - Loddon Mallee _________________________________________ 6

4. How long have you worked in your chosen discipline (ie the category that you ticked in Question 2)
   - Less than 6 months _________________________________ 1
   - 7 months to 12 months _______________________________ 2
   - Up to 2 years __________________________________________ 3
   - Up to 5 years ______________________________________ 4
   - Up to 10 years ______________________________________ 5
   - More than 10 years ___________________________________ 6

5. How long have you worked in the area of Early Childhood Intervention
   - Less than 6 months _________________________________ 1
   - 7 months to 12 months _______________________________ 2
   - Up to 2 years ______________________________________ 3
   - Up to 5 years ______________________________________ 4
   - Up to 10 years ______________________________________ 5
   - More than 10 years ___________________________________ 6
6. How long have you been working with Scope in their Early Childhood Intervention Services?
   - Less than 6 months ______________________________________ 1
   - 7 months to 12 months _________________________________ 2
   - Up to 2 years __________________________________________ 3
   - Up to 5 years __________________________________________ 4
   - Up to 10 years __________________________________________ 5
   - More than 10 years ______________________________________ 6

7. Have you undertaken any training in Family Centred Practice.
   - Yes __________________________________________________ 1
   - No ___________________________________________________ 2
   - If yes, in what year did you do this training? ______________
   - If yes, please describe the nature of the training.
     __________________________________________________________________________________________________________________________
     __________________________________________________________________________________________________________________________
     __________________________________________________________________________________________________________________________
     __________________________________________________________________________________________________________________________
     __________________________________________________________________________________________________________________________
     __________________________________________________________________________________________________________________________

Please continue on and complete the “Measure of Processes of Care”.

Thank you.
This questionnaire is based on the Measure of Processes of Care developed by King, Rosenbaum and King (1995). To provide us with a better understanding of the responses of parents, and our own views of our services, we are asking staff to complete the same rating as completed by parents but with reference to staffs’ views as to the extent to which our service meets the criteria specified. At this stage we are wanting to know about what you believe is an ideal service for children and their families.

The questions in this section are based on research that has shown what parents believe about the way care is sometimes offered. We would like you to indicate the extent to which the event or situation would happen in an ideal service. You are asked to answer each question on a scale from 7 (To a Great Extent) to 1 (Never).

The care that parents and children receive from an Early Childhood Intervention service may bring them into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

1. **People**: refers to those individuals who work directly with children and their families. These may include physiotherapists, occupational therapists, speech pathologists, psychologists, family service coordinators, etc.

2. **Service**: refers to all staff from the Service, whether involved directly with children and their families or not. In addition to therapists they may include support staff such as office staff, administrative personnel etc.
The following is an example of the kinds of questions you will be asked.

This example also shows what your answer could mean.

Indicate how much each event or situation would happen in an ideal service.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT WOULD PEOPLE WHO GIVE YOU QUESTIONNAIRES...</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>... provide you with clear instructions on how to complete them?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

If you circled #7 (To a Great Extent), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (Sometimes), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instructions are not clear.

If you circled #1 (Never), it means that although you have received questionnaires, the instructions are never clear.

If your circled #0 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.
We would like you to think about your experiences as a specialist services staff member working in an ECI service. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone else.

For each question, please indicate how much the event or situation **would happen in an ideal service** by circling one number (from 1 to 7) that you feel best fits your views.

**People** refers to those individuals who work directly with children and their families. These may include physiotherapists, occupational therapists, speech pathologists, psychologists family service coordinators etc.

<table>
<thead>
<tr>
<th>TO WHAT EXTENT WOULD THE PEOPLE WHO WORK WITH THE CHILDREN...</th>
<th>TO A GREAT EXTENT</th>
<th>SOMETIMES</th>
<th>NEVER</th>
<th>NOT APPLICABLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. ... suggest therapy plans that fit with each family’s needs and lifestyle?</td>
<td>7 6 5 4 3 2 1</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. ... fully explain treatment choices to families?</td>
<td>7 6 5 4 3 2 1</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. ... offer positive feedback or encouragement (e.g., in carrying out a home program)?</td>
<td>7 6 5 4 3 2 1</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. ... explain things to children in a way that children understand?</td>
<td>7 6 5 4 3 2 1</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. ... take the time to establish rapport with the family or child when changes occur in their services?</td>
<td>7 6 5 4 3 2 1</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. ... discuss with each family everyone’s expectations for their child, so that all agree on what is best?</td>
<td>7 6 5 4 3 2 1</td>
<td>0</td>
<td></td>
<td></td>
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## MPOC Staff Questionnaire Number 1

**Indicate how much this event or situation would happen in an ideal service.**

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<tr>
<td>7. ... make sure that each child’s skills are known to all persons working with the child, so the skills are carried across services and service providers?</td>
<td>7</td>
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<td>5</td>
<td>4</td>
</tr>
<tr>
<td>8. ... tell families about options for treatment or services for their child (e.g., equipment, school, therapy)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>9. ... accept each family in a non-judgemental way?</td>
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<tr>
<td>10. ... provide ideas to help families work with the health care “system”?</td>
<td>7</td>
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<tr>
<td>11. ... recognize the demands of caring for a child with special needs?</td>
<td>7</td>
<td>6</td>
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<td>4</td>
</tr>
<tr>
<td>12. ... trust parents as the “expert” on their children?</td>
<td>7</td>
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<td>13. ... look at the needs of the “whole” child (e.g., at mental, emotional, and social needs) instead of just at physical needs?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>14. ... show sensitivity to each family’s feelings about having a child with special needs (e.g., their worries about their child’s health or function)?</td>
<td>7</td>
<td>6</td>
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<td>4</td>
</tr>
<tr>
<td>15. ... anticipate family concerns by offering information even before families ask?</td>
<td>7</td>
<td>6</td>
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<tr>
<td>16. ... make sure families have a chance during visits to the centre to say what is important to them?</td>
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<td>6</td>
<td>5</td>
<td>4</td>
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<tr>
<td>17. ... let families choose when to receive information and the type of information wanted?</td>
<td>7</td>
<td>6</td>
<td>5</td>
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<td>Question</td>
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<td>----------</td>
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<tr>
<td>18. ... remember personal details about each child or family, when speaking with the family?</td>
<td>7</td>
<td>6</td>
<td>5</td>
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</tr>
<tr>
<td>19. ... tell families about the reasons for treatment or equipment?</td>
<td>7</td>
<td>6</td>
<td>5</td>
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</tr>
<tr>
<td>20. ... follow up at the next appointment on any concerns a family discussed at the previous one?</td>
<td>7</td>
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<td>5</td>
<td>4</td>
</tr>
<tr>
<td>21. ... make sure that at least one team member is someone who works with the family over a long period of time?</td>
<td>7</td>
<td>6</td>
<td>5</td>
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</tr>
<tr>
<td>22. ... provide opportunities for families to make decisions about treatment?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>23. ... answer family questions completely?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>24. ... explain what they are doing when families are watching their children in therapy?</td>
<td>7</td>
<td>6</td>
<td>5</td>
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</tr>
<tr>
<td>25. ... recognize that the family has the final say when making decisions about their child’s treatment?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>26. ... tell families about the results from assessments?</td>
<td>7</td>
<td>6</td>
<td>5</td>
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<td>27. ... provide families with written information about what their child is doing in therapy?</td>
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<td>32. Develop both short-term and long-term goals for each child?</td>
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</tr>
<tr>
<td>34. Plan together so they are all working in the same direction?</td>
<td>7</td>
<td>6</td>
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<tr>
<td>40. Seem aware of children’s changing needs as they grow?</td>
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</tr>
<tr>
<td>42. ... treat families as people rather than as a “case” (e.g., by not referring to people by diagnosis, such as “the spastic diplegic”)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>43. ... listen to what families have to say about their child’s needs for equipment, services etc.?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>44. ... make themselves available as a resource (e.g., emotional support, advocacy, information)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>45. ... give families information about their child that is consistent from person to person?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

**Please continue onto the next page.................**
**Service** refers to all staff from the ECI service, whether involved directly with children and families or not. In addition to therapists, these people **may include** support staff such as office staff, administrative personnel; etc.

### Indicate how much this event or situation would happen at an ideal service.

<table>
<thead>
<tr>
<th>Event/Question</th>
<th>To a Great Extent</th>
<th>Sometimes</th>
<th>Never</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>46. ... have information available to families in various forms, such as a booklet, kit, video, etc.?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>47. ... have support staff that are polite and courteous to families?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>48. ... give families information about the types of services offered at the Service or in their community?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>49. ... promote family-to-family gatherings for social, informational or shared experiences?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>50. ... provide opportunities for special guests to speak to parents on topics of interest?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>51. ... provide support to help cope with the impact of childhood disability (e.g., by advocating on families behalf or informing families of assistance programs)?</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>
52. ... notify families about the reasons for upcoming case conferences, meetings, etc., about their child? | 7 6 5 4 3 2 1 0
53. ... have information available about the children’s disability (e.g., its causes, how it progresses, future outlook)? | 7 6 5 4 3 2 1 0
54. ... provide advice on how to get information or to contact other parents (e.g., Centre’s parent resource library)? | 7 6 5 4 3 2 1 0
55. ... provide opportunities for the entire family to obtain information? | 7 6 5 4 3 2 1 0
56. ... have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, dating and sexuality)? | 7 6 5 4 3 2 1 0

**WOULD YOU LIKE TO TELL US ANYTHING ELSE, OR DO YOU HAVE ANY OTHER COMMENTS:**
____________________________________________________________________________________________
____________________________________________________________________________________________
____________________________________________________________________________________________
____________________________________________________________________________________________

THANK YOU FOR YOUR TIME!!

MPOC Staff Questionnaire Number 1
Appendix Six:

Statistical Findings: Staff Questionnaires
Statistical findings on the domains for staff members

These relationships were tested using the Mann-Whitney U test (M-W U) because medians were being compared. The M-W U performs the same function as a t-test, indicating whether there is a significant difference between the midpoints of two groups.

Staff respondents who had worked in their chosen discipline for above average periods of time would ideally give higher scores to both ‘specific information’ (M-W U = -2.486, p = .013) and to ‘coordinated care’ (M-W U = -2.309, p = .021) than other staff respondents. Staff members who had worked at Scope for above average periods of time believed that the actual amounts of specific information provided were significantly lower (M-W U = -2.777, p = 0.005) than those who had worked at Scope for below average periods of time. These staff would ideally put greater emphasis on the ‘coordinated care’ domain (M-W U = -2.12, p = 0.027) than those who had worked at Scope for less time. No differences in evaluations of any of the domains were found according to the professional backgrounds of the staff, though it should be noted that only the clinical staff could be included in this analysis. Administrators had to be omitted – there were too few of them.

Statistical findings on the differences between ideal and actual: Staff

No significant differences about ideal versus actual perceptions amongst staff with differing professional backgrounds, or who worked in metropolitan or rural regions. Staff who had worked for an above average length of time in their chosen discipline perceived less differences between ideal and actual for ‘specific information’ (M-W U = -2.209, p = 0.27) and ‘coordinated care’ (M-W U = -2.309, p = 0.021) than staff who had worked for shorter periods. Length of time working at Scope was a strong predictor of variation in perceived differences. Staff respondents who had worked for less than the average time at Scope consistently perceived larger differences between ideal and actual in ‘general information’ (M-W U = -2.747, p = 0.006), ‘specific information’ (M-W U = -3.531, p < 0.001), ‘respectful care’ (M-W U = -2.409, p = 0.016), ‘enabling and partnership’ (M-W U = -2.680, p = 0.007) and ‘coordinated care’ (M-W U = -2.581, p = 0.01). Staff without training in early childhood intervention perceived larger differences in ‘specific information’ than staff who had this training (M-W U = -2.242, p = .025).

(Felicity aren’t these two saying the same things)
Appendix Seven:

Item by Item Response Percentages for Families: Ideal and Actual
<table>
<thead>
<tr>
<th>ITEMS BY DOMAIN</th>
<th>FAMILY IDEAL</th>
<th>FAMILY ACTUAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% RESPONSE: “sometimes” or less</td>
<td>% RESPONSE: more than “sometimes”</td>
</tr>
<tr>
<td><strong>Enabling and Partnership</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Fully explain treatment choices to you?</td>
<td>13.8</td>
<td>86.2</td>
</tr>
<tr>
<td>3 Offer you positive feedback or encouragement (eg. in carrying out a home program)?</td>
<td>9.2</td>
<td>90.8</td>
</tr>
<tr>
<td>8 Tell you about options for treatment or services for your child (eg. equipment, school, therapy)?</td>
<td>6.2</td>
<td>93.8</td>
</tr>
<tr>
<td>12 Trust you as the ‘expert’ on your child?</td>
<td>12.3</td>
<td>87.7</td>
</tr>
<tr>
<td>15 Anticipate your concerns by offering information even before you ask?</td>
<td>26.2</td>
<td>73.8</td>
</tr>
<tr>
<td>16 Make sure you have a chance during visits to the centre to say what is important to you?</td>
<td>9.2</td>
<td>90.8</td>
</tr>
<tr>
<td>17 Let you choose when to receive information and the type of information you want?</td>
<td>26.2</td>
<td>73.8</td>
</tr>
<tr>
<td>19 Tell you about the reasons for treatment or equipment?</td>
<td>6.2</td>
<td>93.8</td>
</tr>
<tr>
<td>22 Provide opportunities for you to make decisions about services?</td>
<td>4.6</td>
<td>95.4</td>
</tr>
<tr>
<td>23 Answer your questions completely?</td>
<td>4.6</td>
<td>95.4</td>
</tr>
<tr>
<td>25 Recognise that your family has the final say when making decisions about your child’s services?</td>
<td>6.2</td>
<td>93.8</td>
</tr>
<tr>
<td>28 Consult with you when discussing equipment or services?</td>
<td>7.7</td>
<td>92.3</td>
</tr>
<tr>
<td>30 Tell you details about your child’s services, such as the reason for them, the type of therapies and the length of time?</td>
<td>7.7</td>
<td>92.3</td>
</tr>
<tr>
<td>35 Make sure that you have opportunities to explain what you think are important treatment goals?</td>
<td>9.2</td>
<td>90.8</td>
</tr>
<tr>
<td>36 Make you feel like a partner in your child’s care?</td>
<td>4.6</td>
<td>95.4</td>
</tr>
<tr>
<td>43 Listen to what you have to say about your child’s needs for equipment, services etc.?</td>
<td>6.2</td>
<td>93.8</td>
</tr>
<tr>
<td>Providing General Information</td>
<td></td>
<td></td>
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<tr>
<td>-------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>46</td>
<td>Have information available to you in various forms, such as a booklet, kit, video etc.?</td>
<td>20.0</td>
</tr>
<tr>
<td>48</td>
<td>Give you information about the types of services offered at the Centre or in your community?</td>
<td>9.2</td>
</tr>
<tr>
<td>49</td>
<td>Promote family-to-family gatherings for social, information or shared experiences?</td>
<td>46.2</td>
</tr>
<tr>
<td>50</td>
<td>Provide opportunities for special guests to speak to parents on topics of interest?</td>
<td>36.9</td>
</tr>
<tr>
<td>51</td>
<td>Provide support to help cope with the impact of childhood disability (eg. by advocating on your behalf or informing you of assistance programs)?</td>
<td>23.1</td>
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<tr>
<td>53</td>
<td>Have information about your child’s disability (eg. its causes, how it progresses, future outlook)?</td>
<td>20.0</td>
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<tr>
<td>54</td>
<td>Provide advice on how to get information or to contact other parents (eg. Centre’s parent resource library)?</td>
<td>26.2</td>
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<tr>
<td>55</td>
<td>Provide opportunities for the entire family to obtain information?</td>
<td>20.0</td>
</tr>
<tr>
<td>56</td>
<td>Have general information available about different concerns (eg. financial costs or assistance, genetic counselling, dating, sexuality etc.)?</td>
<td>29.2</td>
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<table>
<thead>
<tr>
<th>Providing Specific Information about the Child</th>
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</thead>
<tbody>
<tr>
<td>24</td>
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<td>26</td>
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<td>39</td>
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<td>52</td>
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<table>
<thead>
<tr>
<th>Coordinated and Comprehensive Care</th>
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<td>45</td>
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<tr>
<td><strong>Respectful and Supportive Care</strong></td>
</tr>
<tr>
<td>9</td>
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<tr>
<td>18</td>
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<td>29</td>
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<td>41</td>
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<tr>
<td>42</td>
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<tr>
<td>47</td>
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</table>

“Sometimes or Less” = Responses with values of 1-4 on the seven-point Likert scale.

“More than sometimes” = Responses with values of 5-7 on the seven-point Likert scale.

Note 1: Percentages may not add up to 100% due to items being answered as “not applicable” or omitted.

Note 2: To help make sense of the data, items where 33% or more of families reported that actual behaviour only occurred “sometimes or less” have been highlighted as items where improvement may be necessary.

Note 3: Items where 85% or more of families reported that actual behaviour occurred “more than sometimes” have been highlighted as examples of good practice.
Appendix Eight:

Item by Item Response Percentages for Staff: Ideal and Actual
<table>
<thead>
<tr>
<th>ITEMS BY DOMAIN</th>
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<td>94.7</td>
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<td>3.5</td>
<td>96.5</td>
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<td>8 Tell you about options for treatment or services for your child (eg. equipment, school, therapy)?</td>
<td>3.5</td>
<td>96.5</td>
</tr>
<tr>
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<td>1.8</td>
<td>98.2</td>
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<tr>
<td>15 Anticipate your concerns by offering information even before you ask?</td>
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<td>80.7</td>
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<td>3.5</td>
<td>96.5</td>
</tr>
<tr>
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<td>3.5</td>
<td>96.5</td>
</tr>
<tr>
<td>35 Make sure that you have opportunities to explain what you think are important treatment goals?</td>
<td>3.5</td>
<td>96.5</td>
</tr>
<tr>
<td>36 Make you feel like a partner in your child’s care?</td>
<td>0.0</td>
<td>100.0</td>
</tr>
<tr>
<td>43 Listen to what you have to say about your child’s needs</td>
<td>1.8</td>
<td>98.2</td>
</tr>
<tr>
<td></td>
<td>Providing General Information</td>
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<tr>
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<td>-----------------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>46</td>
<td>Have information available to you in various forms, such as a booklet, kit, video etc.?</td>
<td>14.0</td>
</tr>
<tr>
<td>48</td>
<td>Give you information about the types of services offered at the Centre or in your community?</td>
<td>0.0</td>
</tr>
<tr>
<td>49</td>
<td>Promote family-to-family gatherings for social, information or shared experiences?</td>
<td>15.8</td>
</tr>
<tr>
<td>50</td>
<td>Provide opportunities for special guests to speak to parents on topics of interest?</td>
<td>10.5</td>
</tr>
<tr>
<td>51</td>
<td>Provide support to help cope with the impact of childhood disability (eg. by advocating on your behalf or informing you of assistance programs)?</td>
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<td>53</td>
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<tr>
<td>54</td>
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</tr>
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<td>Provide opportunities for the entire family to obtain information?</td>
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</tr>
<tr>
<td>56</td>
<td>Have general information available about different concerns (eg. financial costs or assistance, genetic counselling, dating, sexuality etc.)?</td>
<td>10.5</td>
</tr>
<tr>
<td></td>
<td>Providing Specific Information about the Child</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Explain what they are doing when you are watching your child in therapy?</td>
<td>5.3</td>
</tr>
<tr>
<td>26</td>
<td>Tell you about the results from assessments?</td>
<td>5.3</td>
</tr>
<tr>
<td>27</td>
<td>Provide you with written information about what your child is doing in therapy?</td>
<td>7.0</td>
</tr>
<tr>
<td>39</td>
<td>Provide you with written information about your child’s progress?</td>
<td>3.5</td>
</tr>
<tr>
<td>52</td>
<td>Notify you about the reasons for upcoming case conferences, meetings etc., about your child?</td>
<td>3.5</td>
</tr>
<tr>
<td></td>
<td>Coordinated and Comprehensive Care</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------------------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>1</td>
<td>Suggest therapy plans that fit with your family’s lifestyle?</td>
<td>1.8</td>
</tr>
<tr>
<td>4</td>
<td>Explain things to your child in a way that your child understands?</td>
<td>3.5</td>
</tr>
<tr>
<td>5</td>
<td>Take the time to establish rapport with you or your child when changes occur in your services?</td>
<td>5.3</td>
</tr>
<tr>
<td>6</td>
<td>Discuss with you everyone’s expectations for your child so that all agree on what is best?</td>
<td>5.3</td>
</tr>
<tr>
<td>7</td>
<td>Make sure that your child’s skills are known to all persons working with your child, so the skills are carried across services and service providers?</td>
<td>5.3</td>
</tr>
<tr>
<td>10</td>
<td>Provide ideas to help you work with the health care ‘system’?</td>
<td>8.8</td>
</tr>
<tr>
<td>11</td>
<td>Recognise the demands of caring for a child with special needs?</td>
<td>3.5</td>
</tr>
<tr>
<td>13</td>
<td>Look at the needs of the ‘whole’ child (eg. at mental, emotional and social needs) instead of just at physical needs?</td>
<td>1.8</td>
</tr>
<tr>
<td>14</td>
<td>Show sensitivity to your family’s feelings about having a child with special needs (eg. your worries about your child’s health or function)?</td>
<td>5.3</td>
</tr>
<tr>
<td>20</td>
<td>Follow-up at the next appointment on any concerns you discussed at the previous one?</td>
<td>0.0</td>
</tr>
<tr>
<td>21</td>
<td>Make sure that at least one team member is someone who works with you and your family over a long period of time?</td>
<td>8.8</td>
</tr>
<tr>
<td>32</td>
<td>Develop both short-term and long-term goals for your child?</td>
<td>3.5</td>
</tr>
<tr>
<td>34</td>
<td>Plan together so they are all working in the same direction?</td>
<td>3.5</td>
</tr>
<tr>
<td>37</td>
<td>Make sure that you are informed ahead of time about any changes in your child’s program (eg. therapists, programs, equipment)?</td>
<td>0.0</td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>1.8</td>
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</tr>
<tr>
<td>40</td>
<td>Seem aware of your child’s changing needs as he/she grows?</td>
<td>14.0</td>
</tr>
<tr>
<td>44</td>
<td>Make themselves available to you as a resource (eg. emotional support, advocacy, information)?</td>
<td>7.0</td>
</tr>
<tr>
<td>45</td>
<td>Give you information about your child that is consistent from person to person?</td>
<td>7.0</td>
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</table>

**Respectful and Supportive Care**

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>1.8</th>
<th>98.2</th>
<th>10.0</th>
<th>90.0</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Accept you and your family in a non-judgmental way?</td>
<td>1.8</td>
<td>98.2</td>
<td>10.0</td>
<td>90.0</td>
</tr>
<tr>
<td>18</td>
<td>Remember details about your child or family when speaking with you?</td>
<td>5.3</td>
<td>94.7</td>
<td>2.0</td>
<td>98.0</td>
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<td>29</td>
<td>Provide a caring atmosphere rather than just give you information?</td>
<td>19.3</td>
<td>80.7</td>
<td>24.0</td>
<td>76.0</td>
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<tr>
<td>31</td>
<td>Treat you as an individual rather than as a ‘typical’ parent of a child with a disability?</td>
<td>1.8</td>
<td>91.2</td>
<td>4.0</td>
<td>96.0</td>
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<tr>
<td>33</td>
<td>Treat you as an equal rather than just as the parent of the patient (eg. by not referring to you as “Mum” or “Dad”)?</td>
<td>7.0</td>
<td>93.0</td>
<td>10.0</td>
<td>90.0</td>
</tr>
<tr>
<td>38</td>
<td>Help you feel competent as a parent?</td>
<td>5.3</td>
<td>94.7</td>
<td>10.0</td>
<td>90.0</td>
</tr>
<tr>
<td>41</td>
<td>Provide enough time to talk so you don’t feel rushed?</td>
<td>3.5</td>
<td>96.5</td>
<td>30.0</td>
<td>70.0</td>
</tr>
<tr>
<td>42</td>
<td>Treat you and your family as people rather than as a ‘case’ (eg. by not referring to you by diagnosis such as “the spastic diplegic”)?</td>
<td>5.3</td>
<td>94.7</td>
<td>2.0</td>
<td>98.0</td>
</tr>
<tr>
<td>47</td>
<td>Have support staff that are polite and courteous to you and your family?</td>
<td>5.3</td>
<td>94.7</td>
<td>12.0</td>
<td>88.0</td>
</tr>
</tbody>
</table>

“Sometimes or Less” = Responses with values of 1-4 on the seven-point Likert scale.

“More than sometimes” = Responses with values of 5-7 on the seven-point Likert scale.

Note 1: Percentages may not add up to 100% due to items being answered as “not applicable” or omitted.

Note 2: To help make sense of the data, items where 33% or more of staff reported that actual behaviour only occurred “sometimes or less” have been highlighted as items where staff believe improvement may be necessary.

Note 3: Items where 85% or more of staff reported that actual behaviour occurred “more than sometimes” have been highlighted as examples where staff believe good practice occurs.
Appendix Nine:

Differences Between Family and Staff on Ideal and Actual Mean Scores.
Differences between Family and Staff on Ideal and Actual Mean Scores.

<table>
<thead>
<tr>
<th>ITEMS BY DOMAIN</th>
<th>FAMILY Ideal Mean</th>
<th>STAFF Ideal Mean</th>
<th>FAM/ST Ideal DIFF. Mean</th>
<th>FAMILY Actual Mean</th>
<th>STAFF Actual Mean</th>
<th>FAM/ST Actual DIFF. Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enabling and Partnership</td>
<td></td>
<td></td>
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<tr>
<td>2 Fully explain treatment choices to</td>
<td>6.18</td>
<td>6.58</td>
<td>-0.4035</td>
<td>5.56</td>
<td>5.18</td>
<td>0.0000</td>
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<tr>
<td>you?</td>
<td></td>
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<tr>
<td>16 Make sure you have a chance during</td>
<td>6.17</td>
<td>6.42</td>
<td>-0.2982</td>
<td>5.89</td>
<td>5.54</td>
<td>0.0000</td>
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<td>visits to the centre to say what is</td>
<td></td>
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<td>important to you?</td>
<td></td>
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<tr>
<td>23 Answer your questions completely?</td>
<td>6.43</td>
<td>6.53</td>
<td>-0.1579</td>
<td>6.00</td>
<td>5.72</td>
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<td>30 Tell you details about your child’s</td>
<td>6.20</td>
<td>6.60</td>
<td>-0.4211</td>
<td>5.65</td>
<td>5.30</td>
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<td>services, such as the reason for them,</td>
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<td>the type of therapies and the length</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>of time?</td>
<td></td>
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<tr>
<td>12 Trust you as the ‘expert’ on your</td>
<td>6.08</td>
<td>6.46</td>
<td>-0.4386</td>
<td>6.13</td>
<td>5.78</td>
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<td>19 Tell you about the reasons for</td>
<td>6.43</td>
<td>6.65</td>
<td>-0.2632</td>
<td>6.08</td>
<td>5.94</td>
<td>-0.1220</td>
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<td>treatment or equipment?</td>
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<td>15 Anticipate your concerns by</td>
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<td>6.53</td>
<td>-0.3158</td>
<td>6.06</td>
<td>5.92</td>
<td>-0.1250</td>
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<td>36 Make you feel like a partner in</td>
<td>6.51</td>
<td>6.74</td>
<td>-0.2456</td>
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<td>3 Offer you positive feedback or</td>
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<td>8 Tell you about options for</td>
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<td>6.58</td>
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<td>(eg. equipment, school, therapy)?</td>
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<td>25 Recognise that your family has the</td>
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<td>6.53</td>
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<tr>
<td>43 Listen to what you have to say</td>
<td>6.45</td>
<td>6.70</td>
<td>-0.3158</td>
<td>6.08</td>
<td>6.18</td>
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<td>services etc.?</td>
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<td>28 Consult with you when discussing</td>
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<td>17 Let you choose when to receive</td>
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<td>information and the type of</td>
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<td>information you want?</td>
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## Items by Domain

<table>
<thead>
<tr>
<th>Providing General Information</th>
<th>FAMILY Ideal Mean</th>
<th>STAFF Ideal Mean</th>
<th>FAM/ST Ideal DIFF Mean</th>
<th>FAMILY Actual Mean</th>
<th>STAFF Actual Mean</th>
<th>FAM/ST Actual DIFF Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>50 Provide opportunities for special guests to speak to parents on topics of interest?</td>
<td>4.88</td>
<td>5.91</td>
<td>-0.9825</td>
<td>4.25</td>
<td>3.90</td>
<td>-0.2500</td>
</tr>
<tr>
<td>49 Promote family-to-family gatherings for social, information or shared experiences?</td>
<td>4.92</td>
<td>5.82</td>
<td>-0.9298</td>
<td>4.36</td>
<td>4.28</td>
<td>-0.5263</td>
</tr>
<tr>
<td>56 Have general information available about different concerns (eg. financial costs or assistance, genetic counselling, dating, sexuality etc.)?</td>
<td>5.05</td>
<td>6.11</td>
<td>-1.0351</td>
<td>4.05</td>
<td>4.26</td>
<td>-0.6571</td>
</tr>
<tr>
<td>46 Have information available to you in various forms, such as a booklet, kit, video etc.?</td>
<td>5.80</td>
<td>6.19</td>
<td>-0.4912</td>
<td>4.34</td>
<td>5.08</td>
<td>-0.9500</td>
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<tr>
<td>48 Give you information about the types of services offered at the Centre or in your community?</td>
<td>6.18</td>
<td>6.60</td>
<td>-0.4912</td>
<td>4.92</td>
<td>5.52</td>
<td>-0.9512</td>
</tr>
<tr>
<td>55 Provide opportunities for the entire family to obtain information?</td>
<td>5.68</td>
<td>6.21</td>
<td>-0.6491</td>
<td>4.16</td>
<td>4.40</td>
<td>-0.9730</td>
</tr>
<tr>
<td>51 Provide support to help cope with the impact of childhood disability (eg. by advocating on your behalf or informing you of assistance programs)?</td>
<td>5.58</td>
<td>6.26</td>
<td>-0.5263</td>
<td>4.42</td>
<td>4.88</td>
<td>-0.9737</td>
</tr>
<tr>
<td>53 Have information about your child’s disability (eg. its causes, how it progresses, future outlook)?</td>
<td>5.66</td>
<td>6.46</td>
<td>-0.8070</td>
<td>3.76</td>
<td>4.98</td>
<td>-1.5000</td>
</tr>
<tr>
<td>54 Provide advice on how to get information or to contact other parents (eg. Centre’s parent resource library)?</td>
<td>5.34</td>
<td>6.44</td>
<td>-1.1228</td>
<td>3.82</td>
<td>4.84</td>
<td>-1.5135</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Providing Specific Information about the Child</th>
<th>FAMILY Ideal Mean</th>
<th>STAFF Ideal Mean</th>
<th>FAM/ST Ideal DIFF Mean</th>
<th>FAMILY Actual Mean</th>
<th>STAFF Actual Mean</th>
<th>FAM/ST Actual DIFF Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 Explain what they are doing when you are watching your child in therapy?</td>
<td>6.11</td>
<td>6.37</td>
<td>-0.2807</td>
<td>5.83</td>
<td>5.56</td>
<td>-0.1026</td>
</tr>
<tr>
<td>27 Provide you with written information about what your child is doing in therapy?</td>
<td>6.09</td>
<td>6.30</td>
<td>-0.2564</td>
<td>5.96</td>
<td>5.48</td>
<td>-0.4857</td>
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<tr>
<td>39 Provide you with written information about your child’s progress?</td>
<td>6.02</td>
<td>6.47</td>
<td>0.0526</td>
<td>5.63</td>
<td>5.16</td>
<td>-0.2564</td>
</tr>
<tr>
<td>26 Tell you about the results from assessments?</td>
<td>6.48</td>
<td>6.42</td>
<td>0.0526</td>
<td>6.02</td>
<td>6.12</td>
<td>0.1026</td>
</tr>
<tr>
<td>52 Notify you about the reasons for upcoming case conferences, meetings etc., about your child?</td>
<td>5.78</td>
<td>6.49</td>
<td>-0.7895</td>
<td>5.05</td>
<td>5.28</td>
<td>-0.2564</td>
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<tr>
<td>Coordinated and Comprehensive Care</td>
<td>FAMILY Ideal Mean</td>
<td>STAFF Ideal Mean</td>
<td>FAM/ST Ideal DIFF Mean</td>
<td>FAMILY Actual Mean</td>
<td>STAFF Actual Mean</td>
<td>FAM/ST Actual DIFF Mean</td>
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<td>------------------------</td>
</tr>
<tr>
<td>21 Make sure that at least one team member is someone who works with you and your family over a long period of time?</td>
<td>6.34</td>
<td>6.35</td>
<td>-0.0526</td>
<td>5.57</td>
<td>5.20</td>
<td>0.0263</td>
</tr>
<tr>
<td>37 Make sure that you are informed ahead of time about any changes in your child’s program (eg. therapists, programs, equipment)?</td>
<td>6.34</td>
<td>6.49</td>
<td>-0.2281</td>
<td>5.87</td>
<td>5.70</td>
<td>-0.0270</td>
</tr>
<tr>
<td>20 Follow-up at the next appointment on any concerns you discussed at the previous one?</td>
<td>6.43</td>
<td>6.67</td>
<td>-0.2982</td>
<td>6.02</td>
<td>5.82</td>
<td>0.0488</td>
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<tr>
<td>5 Take the time to establish rapport with you or your child when changes occur in your services?</td>
<td>6.06</td>
<td>6.47</td>
<td>-0.4912</td>
<td>5.80</td>
<td>5.46</td>
<td>0.0732</td>
</tr>
<tr>
<td>6 Discuss with you everyone’s expectations for your child so that all agree on what is best?</td>
<td>6.09</td>
<td>6.42</td>
<td>-0.3333</td>
<td>5.69</td>
<td>5.32</td>
<td>0.0952</td>
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<tr>
<td>4 Explain things to your child in a way that your child understands?</td>
<td>5.98</td>
<td>6.60</td>
<td>-0.7018</td>
<td>5.74</td>
<td>5.70</td>
<td>-0.1176</td>
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<tr>
<td>45 Give you information about your child that is consistent from person to person?</td>
<td>6.32</td>
<td>6.37</td>
<td>-0.1404</td>
<td>5.76</td>
<td>5.60</td>
<td>-0.1500</td>
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<tr>
<td>34 Plan together so they are all working in the same direction?</td>
<td>6.46</td>
<td>6.54</td>
<td>-0.1053</td>
<td>5.88</td>
<td>5.80</td>
<td>-0.1951</td>
</tr>
<tr>
<td>10 Provide ideas to help you work with the health care ‘system’?</td>
<td>6.14</td>
<td>6.28</td>
<td>-0.1754</td>
<td>5.28</td>
<td>5.08</td>
<td>-0.2051</td>
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<tr>
<td>13 Look at the needs of the ‘whole’ child (eg. at mental, emotional and social needs) instead of just at physical needs?</td>
<td>6.42</td>
<td>6.67</td>
<td>-0.2982</td>
<td>5.90</td>
<td>5.76</td>
<td>-0.2143</td>
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<td>32 Develop both short-term and long-term goals for your child?</td>
<td>6.49</td>
<td>6.53</td>
<td>-0.0351</td>
<td>5.88</td>
<td>5.34</td>
<td>0.2683</td>
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<td>44 Make themselves available to you as a resource (eg. emotional support, advocacy, information)?</td>
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<td>6.44</td>
<td>-0.4386</td>
<td>5.72</td>
<td>5.72</td>
<td>-0.2683</td>
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<tr>
<td>11 Recognise the demands of caring for a child with special needs?</td>
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<td>6.63</td>
<td>-0.2281</td>
<td>5.80</td>
<td>5.60</td>
<td>-0.2683</td>
</tr>
<tr>
<td>1 Suggest therapy plans that fit with your family’s lifestyle?</td>
<td>6.20</td>
<td>6.56</td>
<td>-0.4211</td>
<td>5.71</td>
<td>5.48</td>
<td>-0.2857</td>
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<tr>
<td>14 Show sensitivity to your family’s feelings about having a child with special needs (eg. your worries about your child’s health or function)?</td>
<td>6.43</td>
<td>6.53</td>
<td>-0.1228</td>
<td>5.90</td>
<td>6.00</td>
<td>-0.4250</td>
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<tr>
<td>40 Seem aware of your child’s changing needs as he/she grows?</td>
<td>6.46</td>
<td>5.88</td>
<td>0.5789</td>
<td>5.92</td>
<td>5.32</td>
<td>0.4390</td>
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<tr>
<td>7 Make sure that your child’s skills are known to all persons working with your child, so the skills are carried across services and service providers?</td>
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<td>6.40</td>
<td>-0.0702</td>
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</tr>
<tr>
<td>18</td>
<td>Remember details about your child or family when speaking with you?</td>
<td>6.18</td>
<td>6.37</td>
<td>-0.2632</td>
<td>6.06</td>
<td>5.86</td>
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<td>38</td>
<td>Help you feel competent as a parent?</td>
<td>6.32</td>
<td>6.51</td>
<td>-0.1930</td>
<td>6.08</td>
<td>5.62</td>
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<tr>
<td>47</td>
<td>Have support staff that are polite and courteous to you and your family?</td>
<td>6.63</td>
<td>6.44</td>
<td>0.1404</td>
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</tr>
<tr>
<td>42</td>
<td>Treat you and your family as people rather than as a ‘case’ (eg. by not referring to you by</td>
<td>6.57</td>
<td>6.70</td>
<td>-0.1754</td>
<td>6.41</td>
<td>6.38</td>
</tr>
<tr>
<td></td>
<td>diagnosis such as “the spastic diplegic”)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>33</td>
<td>Treat you as an equal rather than just as the parent of the patient (eg. by not referring to</td>
<td>6.09</td>
<td>6.56</td>
<td>-0.4912</td>
<td>6.16</td>
<td>6.06</td>
</tr>
<tr>
<td></td>
<td>you as “Mum” or “Dad”)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>31</td>
<td>Treat you as an individual rather than as a ‘typical’ parent of a child with a disability?</td>
<td>6.63</td>
<td>6.72</td>
<td>-0.1228</td>
<td>6.12</td>
<td>6.08</td>
</tr>
<tr>
<td>41</td>
<td>Provide enough time to talk so you don’t feel rushed?</td>
<td>6.49</td>
<td>6.44</td>
<td>0.0175</td>
<td>5.96</td>
<td>5.18</td>
</tr>
<tr>
<td>9</td>
<td>Accept you and your family in a non-judgmental way?</td>
<td>6.65</td>
<td>6.65</td>
<td>-0.0351</td>
<td>6.37</td>
<td>5.74</td>
</tr>
<tr>
<td>29</td>
<td>Provide a caring atmosphere rather than just give you information?</td>
<td>6.48</td>
<td>5.54</td>
<td>0.9298</td>
<td>6.27</td>
<td>5.08</td>
</tr>
</tbody>
</table>