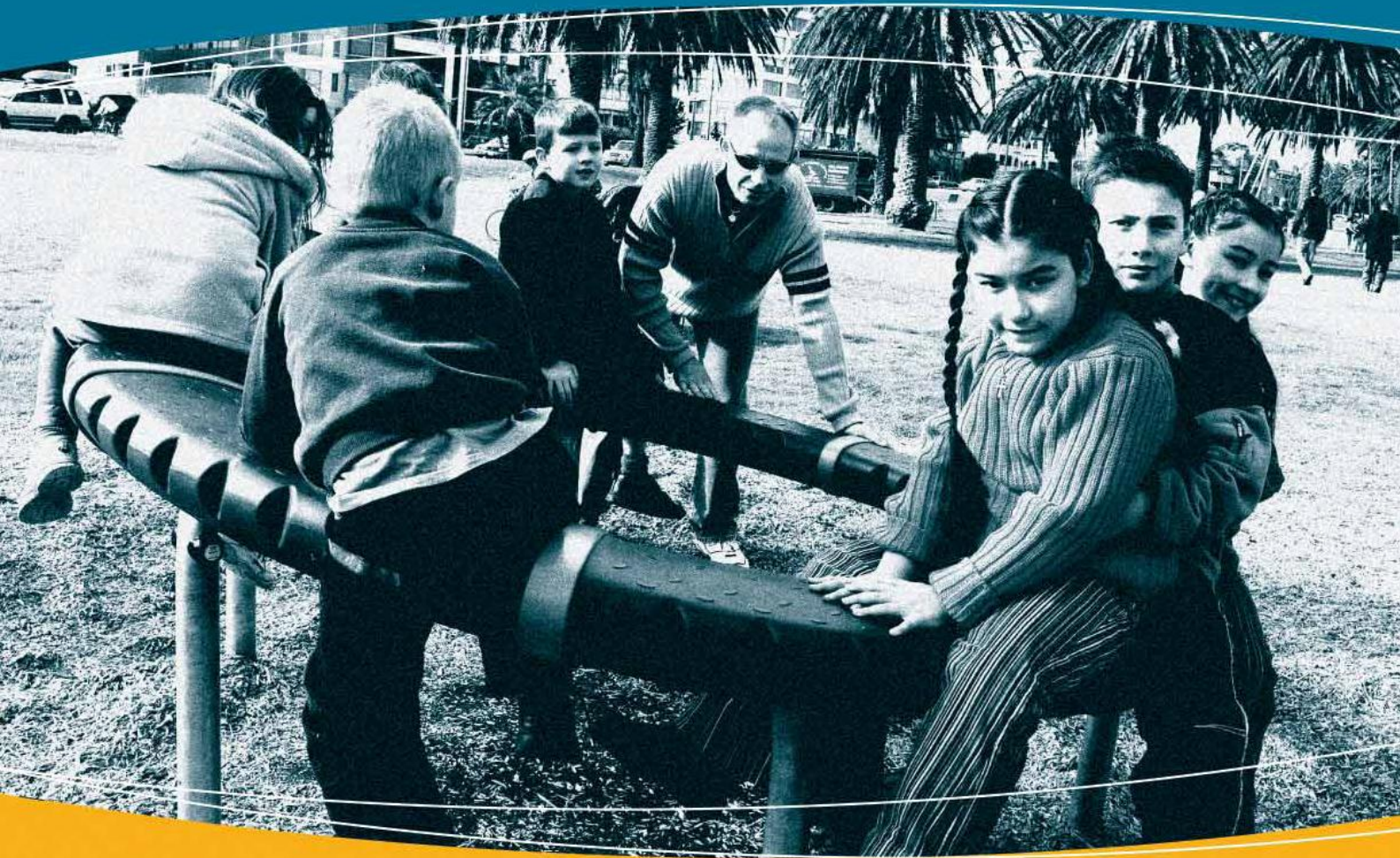# "*More than my child s disability*

A comprehensive literature review about family-centred practice and family experiences of early childhood intervention services.

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With

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December 2005

scope

Disability Means Possibility

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Disability Means Possibility

"More than my child s disability

A comprehensive literature review about family-centred practice and family experiences of early childhood intervention services.

PREFACE

This publication arose out of a research project undertaken by the Specialist Services division of Scope, completed in 2004 and titled "*More than my child s disability   : A study of family experiences and family-centred practices of Scope early childhood intervention services and supports.* (Scope, 2004). We would like to acknowledge and thank all the families who gave so generously of their time to contribute in such a powerful way to the findings of this research.

As we listened to the stories of families throughout the research project, it was clear that families wanted better access to information about a whole range of issues so that they could feel more supported in the choices that they made. Families also said they wanted to have access to the latest research information. If families are to feel confident about their role as experts in relation to their child, and to feel empowered to make decisions that are best for them and their family, access to information about family-centred practice is one important element of this.

Practitioners who work with families in the early childhood intervention sector are familiar with the philosophy of family-centred practice but can sometimes feel overwhelmed by the challenges concerning the most effective ways of embedding these principles into their everyday practice. What do they need to do that clearly demonstrates their understanding of the importance of recognising families as the experts in their child s care? How should they behave?

This publication summarises the key research findings in relation to family-centred practice in the area of early childhood intervention services and supports. We hope that families and practitioners alike will gain benefit from this information, so that families and practitioners can work together towards the development of communities that are welcoming and inclusive of all children and their families.

Helen Larkin & Tim Moore

FOREWORD

Tim Moore and Helen Larkin are to be congratulated on the completion of what will become a very valuable addition to the literature on early childhood intervention with children with disabilities. "More than my child s disability : A comprehensive literature review about family-centred practice and family experiences of early childhood intervention services is timely and draws together a literature that has grown exponentially in the last two decades. Family-centred approaches have proliferated, and with this growth there has been a broadening of the concept and its application.

Moore and Larkin provide an elegantly structured review that clarifies a concept that increasingly underpins the provision of services to children and families. They address the lack of a common approach or understanding with regard to the principles and practices of family-centred practice in a manner that synthesizes and critically analyses the findings of the research across the last fifteen years. Their review will be useful both to families and practitioners as they come to grips with the conceptual and practical implications of family-centred practice.

The report provides a clear summary of the principles and philosophy of family-centred practice and explores the perceptions and behaviours of practitioners working within such an approach. Most importantly it describes the experiences and perspectives of families who have been involved with early childhood intervention services and identifies the issues that are important to them.

They show clearly the benefits and added value that family-centred approaches can contribute in terms of greater parental satisfaction with services, lower stress and enhanced well-being. These benefits flow when family-centred practitioners bring to the intervention good clinical and technical skills, interpersonal skills along with the ability to collaborate with, and empower families. Importantly, the authors show that the benefits of family-centred practice are over and above those produced by factors such as the form and frequency of services and contextual factors such as employment levels, housing quality and availability of health care.

The report is balanced and also highlights the difficulties parents may experience in juggling the demands of early intervention programs and home life. When providers are not sensitive to the realities of daily family life, they can inadvertently add to the stress of parents. As a result, this may interfere with parental capacity to be actively involved with the intervention and support its delivery. Given the complexities of contemporary life and the competing demands and pressures on parents and their children, it is imperative that practitioners recognise these and avoid adding to the burden on families.

The need for parents to be actively involved in setting the goals and determining the form of the home program is a key to developing their skills in meeting their child s needs. Together, these determine the extent to which the intervention can be integrated into daily family routines. As such, Moore and Larkin highlight the importance of practitioners recognising the needs of the whole family and not just those of the child with a disability. This is at the heart of family-centred practice and requires professional preparation that amplifies personal characteristics such as friendliness, optimism and genuineness; inculcates beliefs, values and attitudes, such as being non-judgmental,

and accepting differences; and strengthens interpersonal skills, such as the ability to listen and to communicate effectively. Finally, Moore and Larkin s review underscores the insight that family-centred practice is not a service or an outcome in itself but a vehicle through which services and supports are delivered to children and families.

Again, may I congratulate Tim Moore and Helen Larkin on an excellent review. It will be of widespread value to parents and practitioners alike.

Professor Alan Hayes
Director
Australian Institute of Family Studies
November, 2005

AUTHORS

Tim Moore trained as a teacher and psychologist at the University of Melbourne, subsequently completing his Doctoral studies at the University of Surrey on self-esteem and self-concept in children. He has worked as an educational and developmental psychologist for over 30 years, both in Australia and England, in a variety of mainstream and specialist settings. Prior to taking up his present position in 2000, he was Co-ordinator at Monnington Early Intervention Centre, a statewide early childhood intervention service for deaf children, for twelve years.

In his current position at the Centre for Community Child Health (CCCH), Dr. Moore works with colleagues from different disciplines in providing advice to state and federal government and non-government agencies on best practices in early childhood, and in conducting research and project work in generalist and specialist early childhood services and in service development. He has been the principal writer on several recent major CCCH reviews and reports, including a national study of the training needs of those working with young children and their families, and a review of principles and evidence for family-centred practice. He has been particularly active in promoting family-centred practice and has run numerous workshops and training courses in Victoria and interstate. Most recently, he has written a series of CD ROM-based training modules for those working with young children and their families.

Helen Larkin trained as an occupational therapist and subsequently completed a research Masters at LaTrobe University, on factors that influence the employment participation of people with a psychiatric disability. She has worked in a variety of disability, health, and consultancy settings for over 27 years with an increasing focus on research and program evaluation.

Helen previously held the position of Specialist Services Planner at Scope (Vic) Ltd. In this role, Helen worked with colleagues to support a shift in specialist services models and practices to those that build the capacity of communities to be welcoming and inclusive of people of all abilities. She has also been particularly interested in developing methods and strategies that identify and describe person-centred outcomes in the context of therapy and psychology services.

In 2005 Helen took up a position as a lecturer in Occupational Science and Therapy in the Faculty of Health and Behavioural Sciences at the Waterfront, Geelong campus of Deakin University.

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INTRODUCTION

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 delay to be considered as families first, and for services to reflect the strengths, needs and desires of the whole family. The role of families in determining the shape and extent of the services, supports and resources they receive is now seen as an essential element of service planning and provision in early childhood intervention.

There is a great deal of literature about the importance of a family-centred approach. It is now recognised as one of the most important principles for the provision of services to children and families. However, the literature is difficult to summarise because of the wealth of research that has been done in this area internationally, combined with the lack of a common approach or understanding with regard to the principles and practices. This publication attempts to bring together the findings of the significant research that has been undertaken around the world in the last ten to fifteen years and to assist families and practitioners alike to understand what it means to be family-centred.

Specifically, this publication aims to:

> Provide a summary of the principles and philosophy of family-centred practice;
> Explain the behaviors of practitioners that are characteristic of a family-centred approach;
> Describe the experiences of families who have used early childhood intervention services and their perspective of family-centred practice;
> Identify what is important to families; and,
> Describe the perceptions of practitioners about family-centred practice.

Section One looks at definitions of family-centred practice and summarises key statements of the underlying principles and practices. Section Two reviews the literature regarding the evidence of the effectiveness of family-centred practice, while Section Three explores what is known about the experiences of families using early childhood intervention services. Section Four reviews the evidence regarding the actual delivery of services to families, and the extent to which these are family-centred. Finally, there is a discussion that identifies the themes that are woven throughout this review of the literature, and further comment in relation to each of these themes.

SECTION ONE

PRINCIPLES AND PRACTICE

1.1   What is meant by family-centred practice?

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 a 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) 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) have 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.

1.2   What are the principles and practices of a family-centred approach?

Reaching agreement on underlying principles and practices is complicated by the fact that work on family-centred practice has been done by several groups across the globe, more or less independently of each other over many years. Cross-fertilisation of ideas between groups is sometimes limited because their work has been 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 each of 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 book *Enabling and Empowering Families* (Dunst, Trivette & Deal, 1988) to a recent review of their work (Dunst, 2000). Their recent work has emphasised the need to embed intervention and support in the everyday environments of the child and family and the importance of mobilising 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 train practitioners 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 the relationship between parents and practitioners.
> 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 within rehabilitation settings initially, they have emphasised the importance of families receiving a range of general and specific information.
> 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, that is, building on the existing strengths of families and children rather than focussing on deficits.

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

Featured below is a summary of the 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 socioeconomic 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 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 also stressed that effective family-centred practice depends upon practitioners behaving in a particular way that is characteristic of a family-centred approach. These behaviour styles are described in Section 2.5.

The Frank Porter Graham Model

The Frank Porter Graham team has worked on a number of aspects of family-centred practice including how to identify family needs (Bailey, 1995), training practitioners 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*, 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 partnerships between parents and practitioners. Allen and Petr (1996) argued that family-centred service delivery is based on two key elements: *family choice*, and the adoption of a *strengths and capabilities* perspective.

With respect to f*amily choice*, the family is both the director and consumer of services 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 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-practitioner relationship will be (e.g., parent-directed, professional-controlled or transitional);
> How information is shared (both information given and received);
> What the family needs and goals are; and,
> What will be the family s level of involvement in the intervention?

With respect to *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 practitioners (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 resources. Traditionally and historically, parent-professional partnerships have 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 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 recognising the competence of many. There is also 'mind and heart communication, and the creation of new and preferred environmental resources. This sort of synergistic decision-making results in decisions and effects that are greater than the sum of the parts.

Whereas empowerment was originally thought of in terms of empowering families, there is now 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 building the capacity of communities. 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 practitioners 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. These are shown in Box 1.

Box 1

The CanChild Model

PREMISE 1: Parents know their children best and want the best for their children.

Guiding principles:
> Each family should have the opportunity to decide the level of involvement they wish in decision-making for their child
> Parents should have the ultimate responsibility for the care of their children

Service provider behaviours:
> Encourage parent decision-making
> Assist in identifying strengths
> Provide information
> Assist in identifying needs
> Collaborate with parents
> Provide accessible services
> Share information about the child

PREMISE 2: Families are different and unique.

Guiding principle:
> Each family and each family member should be treated with respect (as individuals)

Service provider behaviours:
> Respect families
> Support families
> Listen
> Provide individualised services
> Accept diversity
> Believe and trust parents
> Communicate clearly

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.

Guiding principles:
> The needs of all family members should be considered
> The involvement of all family members should be supported and encouraged

Service provider behaviours:
> Consider the psychosocial needs of all family members
> Encourage the participation of all family members
> Respect coping styles
> Encourage the use of community supports
> Build on strengths

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 summary of the research literature and the key features of community-based family support services (Dunst, 1995), and culminating in a set of key statements of best practice (Family Resource Coalition, 1996, 1997).

The principles of family support practice that the Family Resource Coalition (1996) identified were:

> Staff and families work together in relationships based on equality and respect;
> Staff enhance families capacities to support the growth and development of all family members;
> 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 generic family support services, these principles demonstrate a striking similarity to those articulated by the early childhood intervention sector.

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 & 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.

Beckman (2002), on the other hand, identified five key elements of working in a family-centred way. These were:

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

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).

All of the models described above were 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 practitioners:

> *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 on family-centred practice for early childhood intervention workers: *Partners: Recommended Practices in Family-Centred Early Childhood Intervention (1998).* This package 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 focussing 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.

There are, therefore, numerous recurring themes around the world, although each approach varies in emphasis. These approaches are summarised later in this document. However, it is useful to first consider the wider application of family-centred practice

1.3   Where else is a family-centred approach applicable?

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,
> International family policy and practice (Briar-Lawson, Lawson, Hennon & Jones, 2001).

The last two of these applications deserve particular mention.

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

> Recognise that the family is the constant in a child s life, while the service systems and personnel within those systems fluctuate;
> Facilitate parent/practitioner collaboration at all levels of health care: care of an individual child; program development; implementation and evaluation; and, policy formation;
> Honour the racial, ethnic, cultural and socioeconomic diversity of families;
> Recognise family strengths and individuality and respect different methods of coping;
> Share with parents complete and unbiased information on a continuing basis and in a supportive manner;
> Encourage and facilitate family-to-family support and networking;
> Understand and incorporate the developmental needs of infants, children, adolescents, and their families into the health care systems;
> Implement comprehensive policies and programs that provide emotional and financial support to meet the needs of families; and,
> Design accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs.

Although much of the work that has been done on family-centred practice is based around children who have additional needs, and their families, recent work has focussed on the area of **international family policy and practice.** Briar-Lawson and Lawson

(2001) 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 these 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:

> *Parent/professional partnership:* Darling (2000), Darling and Baxter (1996), Davis, Day and Bidmead (2002), Dinnebeil and Rule (1994), Dinnebeil, Hale and Rule (1996), Hanna and Rodger (2002), Peterander (2000), Porter and McKenzie (2000);
> *Strengths-based approaches:* Chapin (1995), Early (2001), Early and GlenMaye (2000), Saleeby (1992, 1996);
> *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).

1.4   Summary: Defining best practice

On the basis of all the accumulated work described in the previous sections, the US Council for Exceptional Children (Division of Early Childhood) has synthesised the best practice principles of family-centred practice (Trivette & Dunst, 2000), and developed a family-centred practice assessment tool (Hemmeter, Joseph, Smith & Sandall, 2001).

Box 2

Recommended Family-Based Practices
(US Council for Exceptional Children: Division of Early Childhood)

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.

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.

Further elaboration of these principles has been provided by McBride (1999) who 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. These practice indicators give more detail of the ways that professionals behave when they are working in a truly family-centred manner.

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 and practices described in Section One provide some practical guidance to agencies as they examine how to ensure that services and supports are based on relationships with, and through families, and continue to build the capacity of families and communities.

SECTION TWO

....

DOES FAMILY-CENTRED PRACTICE MAKE A DIFFERENCE?

Now that the key principles and features of family-centred practice have been identified, the next issue to examine is what evidence is there for the effectiveness of this approach? In particular, what needs to be known is:

> Can families discriminate between services that provide different levels of family-centred support?
> Do families prefer services that are more family-centred?
> What effects do family-centred services have on parents and families?
> What effects do family-centred services have on children?
> What are the elements of effective intervention?

Section Two considers the evidence in relation to these issues.

2.1 Can families discriminate between services providing different levels of family-centred service?

One of the ways of testing the effectiveness of family-centred practice is to see if families receiving different types of services have a more positive attitude to those services that are more family-centred than they do to services that are less so. Dunst and colleagues identified four program models that fall along a continuum of family-centred practice (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' practitioners and families play in promoting changes in family development and functioning.

Table 1

Typology of Human Services Programs

Model	Characteristics
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 their guidance and tutelage.
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 promote the acquisition of new skills. > Interventions emphasise 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 this comes from a Canadian survey that found when service providers report they are providing a higher level of family-centred service, parents from the same service report receiving better family-centred service (King, Kertoy, King, Hurley, Rosenbaum & Law, 2000).

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

2.2   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 childhood intervention programs (which were family-centred).

The mothers rated the characteristics of the help they received from the different agencies, using the *Help-giving 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.

Again, 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 the 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, evidence regarding the effects of family-centred practice on parents and families needs to be examined.

2.3 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 other notable studies including Judge, 1997; King, King, Rosenbaum & Goffin, 1999; Trivette et al., 1996a and b; and Van Riper, 1999.

Rosenbaum et al. (1998) conducted a literature review on the effectiveness 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 various service types. All the studies incorporated some elements of family-centred practice and all demonstrated evidence of the effectiveness of this approach 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 cautioned 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)

Other studies have shown that parents who receive family-centred services experience a greater sense of control (Judge, 1997; Trivette et al., 1996b) than do their peers who receive non-family-centred services. In the study by Trivette et al., mothers involved in three contrasting types of human services programs were asked 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 why parents varied in their 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. The results showed that, regardless of the characteristics of the parent and family, parents felt they had more control over services, resources and supports they needed when the program and the helpers were more family-centred in their approach than when they were less so.

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. She found that when the mothers believed that their families relationships with health care providers was 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 their child was receiving. Furthermore, those mothers who believed they had positive family-centered relationships with providers, and who felt satisfied with the care they 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;
> Reduced family stress levels; and,
> Better parental well-being.

However, *the most important predictors of parental well-being* were the absence or presence of behavioural problems in their children, the general social support available to the family and whether or not they had 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. Family-centred care-giving increased the benefits experienced by parents, but it was not the most important factor contributing to positive outcomes for them.

In the light of these findings, Dunst and colleagues (Dunst, 1997; Dunst, Brookfield & Epstein, 1998) have suggested that family-centred practices have value-added benefits for families beyond the benefits that arise out of the frequency and type of services or the general social, health and economic supports available to families. Thus, the full benefits of family-centred services 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 focussing on the fact that family-centred service delivery has both direct and indirect effects. Thus, Thompson, Lobb, Elling, Herman, Jurkiewicz and Hulleza (1997) found that parents who were receiving family-centred services were more likely to report feeling more empowered (direct effect) and that they had more social support and experienced less stress, which, in combination, were associated with a greater sense of empowerment (indirect effect), than were parents who were receiving non-family-centred services.

The evidence therefore suggests that family-centred practice does have direct 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.

2.4 What effects do family-centred services have on children?

According to a review by McBride (1999), studies have shown that parent/practitioner partnerships are important components of healthy environments for children and parents. Children respond positively, become more involved in 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 practitioners work successfully as partners than when they do not. However, is there any evidence that children make better progress when the services they receive are more family-centred than when they are not? Some evidence that children can so benefit comes from a series of studies by Law, Darrah, Pollock, King, Rosenbaum, Russell, Palisano, Harris, Armstrong and Watt (1998) which were designed to develop and evaluate a family-centred approach to the provision of therapy services for 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 who received this approach made measurable improvements in functional performance over the course of intervention, although the lack of a control group meant it was not possible to separate the effects of the intervention from the effects of maturation. However, this study does support the view 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.

2.5 What are the elements of effective intervention?

What are the elements of practice that practitioners need to be effective in with regard to the way that they work with families, and what aspects of help-giving or care-giving are associated with better outcomes for families and children?

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 or intervention. These are:

> *Technical knowledge and skills.* This refers to the practitioner s specialist knowledge and skills. High quality technical competence and skills result in the implementation of appropriate developmental, educational, therapeutic and medical interventions. Help which is of a high technical quality but 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 such as parental resentment and disempowerment as a result of the manner in which the services are delivered.

> *Help-giver behaviours and attributions.* The interpersonal skills of practitioners positively influences the psychological well-being of families. Skills such as good listening, empathy and warmth result in: (a) greater parental satisfaction with and acceptance of helping; and (b) greater psychological and emotional well-being. Good interpersonal skills alone 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 involves true collaboration between families and practitioners where families are offered information about intervention options, decision-making is shared, and families are directly involved in acting on decisions. Effective participatory involvement results in: (a) parents feeling more in control than they might feel in less collaborative situations of service provision; and (b) the strengthening of parental competencies.

All of these three elements are needed for intervention to be truly effective. The second and third elements provide value-added benefits, and, according to Dunst and Trivette (1996), interpersonal skills and family collaboration 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 has found that help-giving that incorporates the above features is associated with enhanced 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 than those that do not (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).

2.6   Can family-centred practice be measured?

Several measures of family-centred practice are available in the early childhood intervention research literature. It is not the role of this publication to review these scales, however, the Appendix provides further information for those people who would like to investigate this area.

2.7   Summary of family-centred principles, practices and effectiveness

Sections One and Two 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. What follows is a summary of this body of knowledge that aims to guide practitioners and families.

Summary of principles

> Services recognise that all families are unique, and provide support in ways that are respectful and non-judgmental of particular family styles, values and abilities.

> Services are sensitive and responsive to family cultural, ethnic, and socioeconomic diversity.
> Services recognise that parents know their children best and want the best for them.
> Services accept that parents have the ultimate responsibility for the care of their children and for all decisions made about them.
> Services understand that children s needs are best met when families are supported in making informed decisions about them and their families, and in developing competencies to meet their needs.
> Services recognise that children, families and service providers all benefit most when services are based on true collaborative partnerships between families and professionals.
> The way in which services are delivered is as important as what is delivered.
> Children s needs are most likely to be met when the needs of all family members and of the family as a whole are also met.

Summary of practices

> Families and family members are treated with dignity and respect at all times.
> Services are based on the needs and priorities of families.
> Service providers seek to engage parents in collaborative partnerships based on mutual trust and respect.
> Service providers acknowledge and respect the family s expert knowledge of their child and the family circumstances as complementing their own professional expertise.
> Service providers take account of the needs of all individual family members as well as the needs of the family as a whole.
> The information that families need to make informed choices is shared in a complete and unbiased manner.
> Service providers offer families choices about the goals and nature of the services, and support and respect the choices that families make.
> Services are provided in a flexible fashion according to the evolving needs and circumstances of particular families.
> Family needs are met through a broad range of informal, community and formal supports and resources, rather than through formal resources alone.
> 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.

Summary of practitioner skills

> 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.

Summary of the effectiveness of family-centred practice

> Families who receive family-centred services are more likely to report greater satisfaction with services, lower parental stress and better parental well-being.
> Children derive most benefit and show improved functional performance when interventions are embedded in the everyday environments of families.
> However, the most important predictors of parental well-being were the absence or otherwise of behavioural problems in children and the social support networks that they had experienced.
> Children derive most benefit from services when they incorporate intervention into everyday environments and activities.
> For services to be effective, they need to incorporate the three elements of good clinical or technical skills, good interpersonal skills on the part of practitioners and finally these skills delivered through a family-centred approach to collaboration with, and empowerment of, families.
> Thus, 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).

This review has found that family-centred practice is a philosophy that can be operationalised into a set of practices, and that families prefer services that are delivered in this way. Furthermore, the research that has been conducted to date indicates that family-centred practice is generally beneficial. Clear benefits for parents and families have been found, with indirect benefits for children. 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 when 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. There have been no studies that involved objective measures of how services were actually delivered.

As will be seen when the evidence regarding parents experiences of service delivery is examined in Section Three, 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.

SECTION THREE

WHAT ARE THE EXPERIENCES OF FAMILIES USING EARLY CHILDHOOD INTERVENTION SERVICES?

An investigation of the literature in relation to family-centred practice would not be complete without looking at what the research tells us about the experiences of families who use early childhood intervention services. 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.

A great deal of research explores the reactions of parents and their 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. A major longitudinal study underway in the USA, the National Early Intervention Longitudinal Study, should provide a comprehensive picture of what families in the USA receive, but this study is not yet complete. However, a small study by Thompson (1998) provides some insights into how Australian mothers of young children with disabilities experience early childhood intervention services. There are also a number of studies that have explored family experiences of early childhood intervention and disability services with specific questions in mind, and these studies are the focus of the information that is contained in Section Three.

3.1 What are the experiences of families using early childhood intervention services?

In a small study conducted in New South Wales (Thompson, 1998), parents of young children with high support needs completed questionnaires and were interviewed about the early childhood intervention services that they received. This 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 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 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 which were 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 care-givers.
> They also saw them as important providers of information about other services.

A recurrent theme in these comments from mothers is the difficulties experienced by parents 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.

3.2   What aspects of services do families value?

Several 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) involved different models of service delivery, and used different research methods. Although some common themes emerged, there were 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 included:

> A need for constant reassurance and feedback;
> Help in determining the family s own comfortable level of involvement in therapy services;
> Assistance in helping them promote their child s development 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,
> A family-oriented approach that could assist in bringing the family closer together and therefore strengthens 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 practitioners to provide facts and information, particularly in the early stages of diagnosis, which is one of the most stressful periods that parents experience in their entire lives. Parents also reported that a sincere, caring attitude from practitioners, even when they do not know all the answers, was noticed and appreciated.

Parents commented that in the early stages they also wanted the 'right choices to be presented to them but that in the end most families wanted to make their own decisions. They depended on practitioners, however, to provide honest, unbiased information, delivered at a level appropriate to parents knowledge and experience. Most families sought practitioners who would support and encourage them along the pathways 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 choices they made, 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 also sought and needed 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 practitioners found 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 pathways they chose, they wanted practitioners 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 factors most commonly mentioned were:

Most helpful/beneficial aspects of early intervention experiences
> Technical knowledge and skills of practitioners (reported by 40% of parents);
> Direct child-focussed 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-practitioner communication (30%);
> Insufficient level of service provision (28%); and,
> Difficulties in finding childcare 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 needs and about available community resources. Second, they wanted practitioners 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 in this study were:

> Parents felt increasingly 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 another 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 the need for sensitivity. Families wanted practitioners 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. They also wanted:
> Acknowledgement of the family as the ultimate decision-maker;
> Acknowledgment of the diversity of families and family preferences;
> Clear communication;
> Consideration of the whole family; and,
> Enhanced social support for families.

Identification of family strengths and needs
Families expressed 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 they 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 specific needs, and available services and resources. They wanted this information to be available in several different formats and repeated at different points in time, as families changing emotional states allowed them to attend to the information.

Other family outcomes that were identified in this study as being important included:

> Meeting the needs of the family as a whole and considering the individual well-being of all family members;
> Helping families develop skills to work with practitioners and service systems that will be useful in their future relationships with programs and practitioners; and,
> Enhancing family skills in meeting their children s basic and special needs.

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 practitioners and parents were then asked to rate the importance and relative priority of these aspects of care-giving. Parents and practitioners ranked the following issues as most important:

> *Parent involvement:* Recognising the role that parents have in decision-making.
> *Education and information to child and family about the child s condition:* Providing initial and continuous explanations about the child s condition, its causes, course and prognosis. Suggesting reading materials and parent groups as sources of information and acting as a resource for questions about the condition and relevant interventions.
> *Treatment of disability:* Providing continuous evaluation of the child s progress, necessary treatment and therapies, including the provision of equipment.
> *Accessible and available care:* Providing prompt response to referral; a convenient location, parking and office hours; and a reasonable waiting time.
> *Coordination of care:* Recognising the need for services from other sources and making appropriate referral. Ensuring information is shared among others involved and acting as a liaison with school, specialists, agencies and others.
> *Continuity and consistency of care:* Providing continuity over time so that the same practitioners act as regular providers of care. Linking information from one visit to another and one practitioner to another.
> *Family-centred approach to care:* Recognising the potential social and emotional impact of the child s disability on all family members, and demonstrating 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 practitioners, what they expect from cooperation with practitioners, 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 their 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 their 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 relieved 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 service (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 went for intervention sessions (95%);
> Had 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 practitioners were clearly the 'experts and there was little emphasis on 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 practitioners.

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. She identified that services need to:

> Take a holistic approach to assessing and meeting family needs;
> Recognise the importance of relationship-building between parents and practitioners;
> 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 generally 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 counseling skills and using parent/partnership service delivery models.

Despite the differences internationally, some 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 change;
> Practitioners who use empowerment approaches that build on family strengths; and,
> Practitioners who are sensitive to family issues and communicate effectively.

3.3   Satisfaction as a dimension of service delivery

The level of family satisfaction often defines evaluation of services. A number of the studies that have been undertaken tell us what can be learnt from this method of evaluation. 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 a result of a high level of family-centred practice in the services that were investigated. However, several other factors are likely to have contributed to these high ratings. First, most parents have usually only had experience with the particular service that they are being asked to rate, and therefore cannot compare it with others. Second, parents often feel 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 tested in a study by King, Cathers, King and Rosenbaum (2001) in which they treated satisfaction as a global concept and explored the major features of care associated with both satisfaction and dissatisfaction. Donabedian (1988) also saw 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 three elements, Donabedian found that the manner in which services are delivered and the interpersonal processes involved were the most important contributors to reported satisfaction and that *outcomes had little bearing on levels of satisfaction*.

King, Cathers, King and Rosenbaum (2001) also explored the major features of care associated with satisfaction and dissatisfaction. They used the three elements described by Donabedian in a study involving 645 parents of children with special needs. This study explored issues related to family satisfaction. They compared the responses of families who had been previously assessed as being highly satisfied or relatively dissatisfied. Their main findings were that:

> 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.

These findings indicate that both process and structural elements are important for parental satisfaction and that measures of satisfaction should contain items tapping elements of both process and structure. Confirmation that parental dissatisfaction is more likely to focus on structural aspects of service comes from a study by McWilliam, Lang, Vandivere, Angell, Collins and Underdown (1995) in which they surveyed over 500 parents of infants, toddlers, and preschoolers receiving early intervention service in North Carolina. Families were generally extremely pleased with the quality of the services they were receiving, particularly with the personal support provided by individual practitioners. When there was dissatisfaction, it was most often related to difficulties in finding out about, getting, and monitoring services.

Another implication of King et al. s findings is that satisfaction and dissatisfaction are not simply opposites. Certain elements of service delivery appeared to operate as dimensions (e.g., respectful and supportive care), whereas others were unipolar or categorical. For example, the availability of services was related to satisfaction but the lack of availability was not related to dissatisfaction. Again, difficulties in accessing services were related to dissatisfaction, but ease of access was not related to satisfaction.

Confirmation of the proposal that satisfaction and dissatisfaction are distinct constructs comes from a UK study by Stallard and Hutchison (1995) that 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, some specific areas of dissatisfaction emerged:

> 73% of parents felt their concerns were not fully understood by practitioners;

> 45% felt that the practitioners did not know who else was involved with their child;
> 41% had received differing advice from practitioners;
> 37% did not feel involved in the decisions made about their child; and,
> 21% were not in agreement with the decisions made.

These findings lend further support to the proposal that parental satisfaction and dissatisfaction are not simply opposite ends of the same continuum. Despite the fact that this UK sample of parents were highly satisfied with the services overall, many of them reported what would seem to be major causes for dissatisfaction with particular aspects of service delivery.

Another description of the features of services 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 as 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 lives of families;
> 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. This has implications for the design of satisfaction survey methods. How services are delivered appears to be more important to parents than what is delivered. Parents particularly value respectful and supportive care from practitioners, and being treated as equals. When they are dissatisfied with aspects of service, it is most often because practitioners 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)

3.4 Comparing parents and practitioners views about family-centred practice

Several studies have explored the views of parents and practitioners about 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) (King Rosenbaum & King, 1995), 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 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 practitioners alike, and two further aspects of care that were important to parents but less so to practitioners. They then asked practitioners to rate which of these were 'routinely offered at their service. 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, aspects that were less highly valued by parents (such as *Evaluation of disability*, *Advice on present concerns about development*, and *Team approach*) were seen to be more likely to be offered.

In a study of the experiences of American parents and practitioners of parent/practitioner partnerships in early intervention programs, Brotherson and Goldstein (1992) found that both groups reported that time was critical to parents and practitioners, both as a resource and a constraint. Parents reported that practitioners could make the best use of 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 service providers and lack of services generally for families and children in the community. Parents and practitioners 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 practitioners 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 practitioners rated services as more family-centered than did parents, but the two groups did not differ in their views of what the services should ideally be. The most significant determining factor with regard to whether services were family-centred or not was the level of experience of both the practitioners and the families. The more experienced the practitioners were, the more likely they were to report that they were 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 practitioners to work in a family-centred way. It also suggests that relatively inexperienced families are less likely than experienced families to be provided with family-centred services, perhaps because they find it hard to work as partners with service providers until they gain experience and confidence. If this is true, it indicates the two-way nature of family-centred practice. It requires both parties to understand and engage in genuine partnerships, and it is not a way of working that can be adopted by either parents or practitioners unilaterally.

Also in the USA, Wesley, Buysse and Tyndall (1997) explored the differing experiences and perspectives of parents and practitioner regarding inclusion and early intervention. They conducted a series of focus groups involving parents of young children with disabilities, and practitioners representing service providers and administrators from an array of human services programs and agencies such as childcare, early intervention, social services, public health, mental health, and public schools.

An analysis of participant responses revealed important similarities and differences between families and practitioners with regard to how they viewed the early intervention system. These similarities and differences represent four overarching themes:

1. When compared to parents, practitioners 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 that they be provided with research findings related to these issues in a form that they could understand and use.

3. Although parents and practitioners appeared to agree on many obstacles that exist to prevent full access to inclusive early childhood settings, practitioners identified more barriers than did parents. This is not surprising given that practitioners were better able to describe comprehensively the early intervention system and had a broader base of experience within the system than parents. Whereas both parents and practitioners described aspects of the classroom that served to inhibit the inclusion of children with a range of abilities (class size, teacher-child ratio, staff qualifications), practitioners 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 service providers, parents offered numerous clearly articulated ideas for an ideal system of early intervention services. Most notably, parents mentioned competent and caring human services practitioners as essential in the ideal system. This confirms the findings of other studies that families look to early intervention practitioners as an important source of emotional sensitivity and support.

3.5   How can services best engage families?

Wesley et al. believed that the findings described in Section 3.4 emphasised the value of parental participation in long-term strategic planning. They questioned whether services could be truly family-centred without building upon families ideas to design a service system from the ground up. Rather than waiting until the program was 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 practitioners 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 the programs should strive to create opportunities for dialogue with parents as a means of enriching collaborative partnerships and promoting shared decision-making.

> Evaluators should seek family and practitioner 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 practitioners.
> Finally, ways of involving parents in research should be explored in order to increase its relevance to, and utilisation by, families.

3.6 Summary

The studies comparing parental and practitioner views of early childhood intervention services reveal some common ground as well as some important differences between these two groups. In terms of their judgments of how family-centred services are, both parents and practitioners felt that services were generally good at treating the families in a supportive and caring manner, 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 practitioners judged to be most important and therefore offered to a greater extent.

These studies also provide other valuable insights into the different experiences of parents and practitioners. They show that service providers 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 system that is more effective than the one with which they are involved, and practitioners should seek 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 practitioners and parents are more likely to establish true collaborative partnerships than are their less experienced counterparts.

Given the general acceptance within the early childhood intervention sector that services should be family-centred, what evidence is there that services are actually delivered in this way? One way of establishing the extent to which services to families are family-centred is to analyse family service plans to see if they reflect these qualities. Section Four explores the relevant evidence.

SECTION FOUR

WHAT IS THE FOCUS OF THE SERVICES AND SUPPORTS THAT FAMILIES ACTUALLY RECEIVE?

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 identified needs and expectations, the actions to be taken, and who is 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) described 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? Section Four explores the literature relating to the following questions:

> 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 free of jargon and easily understandable?
> Are the goals in family service plans appropriately pitched and achievable?
> Do the outcomes identified in family service plans address the needs identified by parents?
> Are the services provided family-focussed or child-focussed?
> What is the nature of parental involvement in implementing service plans?
> What actually happens on home visits?
> Does true parent-practitioner collaboration occur?
> Is the use of informal rather than formal resources encouraged?

Finally, the question of whether it is possible to train service providers to make family service plans more family-centred is explored.

4.1   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 to be 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 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 practitioners was introduced. Evaluations showed that this process was well received, with 92% of parents and 96% of practitioners reporting high levels of satisfaction. Parents reported feeling fully involved in decision-making, with 80% feeling their views were understood and 100% agreeing with treatment goals.

Another strategy for improving parental involvement in decision-making was described by Campbell, Strickland and la Forme (1992). They recognised that, despite the faith in parents abilities that is embodied in family-centred practice, it was by no means easy for parents to become equal partners with service providers, 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.

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 practitioners (Pretti-Frontczak & Bricker, 2000), for parents (Campbell, Strickland & la Forme, 1992) or for both practitioners and families (Stallard & Hutchison, 1995). Another approach is to use scales that are specifically designed to measure the family-centredness of service plans as described in the Appendix. These scales can be used to provide practitioners with feedback about the extent to which family service plans reflect family-centred principles.

4.2   Do families receive and use all the services agreed to 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 to in plans. This is not as simple a question as it may seem, since there is more than one explanation of 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, et al. 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 that were hypothesised to influence service utilisation: age; race; primary diagnosis (whether having an established condition, developmental delay, or being substantially at risk); or complexity of support needed. 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 uptake 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 available services related to the particular characteristics of their service providers. Practitioners who were younger and who were teachers (rather than therapists) produced higher utilisation rates than their older colleagues who were not teachers.
> 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) practitioners 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. However, there are several 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 practitioners should be the primary providers of service, suggesting that the families had not been introduced to more family-centred ways of working in which action plans focussed 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 relevant to them and used methods that did not involve them developing new skills and competencies.

4.3 Are the goals in family service plans free of jargon and easily understood?

The importance for parents of practitioners being able to communicate effectively has been confirmed in a number of studies (e.g., McWilliam, Ferguson, Harbin, Porter, Munn & Vandiviere , 1998; Wehman & Gilkerson, 1999). One aspect of effective communication is the ability of practitioners to write plans and reports in plain language that is easily understood by parents. There are two relevant studies that address this issue (Boone, McBride, Swann, Moore & Drew, 1998; Pretti-Frontczak & Bricker, 2000).

Boone, McBride, Swann, Moore and Drew (1998) compared family service plans from two USA states to investigate the amount of professional versus family-friendly (lay) language. They found that the majority of plans used professional language and discipline-specific jargon to describe children s current level of functioning. Similarly, the outcomes were often written in behavioural terms, with specific criteria and timelines, rather than functional terms.

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

4.4   Are the goals 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 whether they are 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 than of the children needing to practice the relevant skills extensively in order to learn them.

4.5   Do the goals address the needs identified 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 another study 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. These findings suggest that practitioners felt confident in their ability to facilitate children s developmental needs but less confident in their ability to assist families with other identified concerns of a more general nature.

The study by Mahoney and Filer (1996) explored the responsiveness of services by examining the type and scope of services provided 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 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.

4.6   Are the services provided family-focussed or child-focussed?

Many studies show that family support plans in the USA still tend to stress child outcomes to the exclusion of more broadly 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).

Boone, McBride, Swann, Moore and Drew (1998) looked at a sample of family service plans in two USA states and found that plans primarily focussed on facilitating the child s development. They noted, however, that this orientation might in fact have been what parents chose at the time.

In another American study, Mahoney and Filer (1996) used a written questionnaire   the *Family Focused Intervention Scale* (Mahoney, O Sullivan and Dennebaum, 1990)   to explore the focus of service delivery. Results indicated that early intervention programs were predominantly focussed on the development and functioning of the child rather than the family. Thus, they provided significantly higher levels of services related to information about the child and instruction regarding the child s activities compared to personal/family and resource assistance. Thus, they focussed on family needs only as they related to the development of the child, at the expense of broader family needs.

These findings pose a considerable challenge to the early childhood intervention field. If family-centred practice has long been accepted as the preferred model for service delivery, why are services still focussed 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).

McWilliam, Tocci and Harbin (1995) conducted 75 in-depth interviews with parents of young children with developmental disabilities involved in early childhood intervention programs in three different USA states. They found that the services provided were primarily child-focussed, and that the families both expected and preferred it to be that way. From a family-centred perspective, this is a disconcerting finding. McWilliam et al. acknowledged that it is not inconsistent with family-centred practice to focus on child needs if that is what the family says they want. But they suggested that responding solely to what families want implies a uni-dimensional understanding of family-centeredness: that the aim is to make families happy. They argue that family-centeredness has at least four dimensions: responding to family priorities; empowering family members;

taking a holistic approach to the family; and being insightful and sensitive to families. The services being provided in their study appeared to be family-centered on the first dimension, were probably not on the second, were certainly not on the third and therefore were probably not on the fourth.

McWilliam et al. (1995) further explored the process whereby services end up being child-focussed and why parents might prefer this. They suggested that the focus of services is determined by the interaction between parental priorities and professional preferences. Families who concentrate on child issues are likely to encourage such a focus in service providers, especially if that is what the practitioners are most comfortable with. Similarly, practitioners who begin interactions with families by assessing the child and then move on to planning intervention and finding services for the child, are more likely to encourage such a focus in families.

In another study, McWilliam, Lang, Vandivere, Angell, Collins and Underdown (1995) surveyed over 500 parents of infants, toddlers, and preschoolers receiving early childhood intervention services in North Carolina. Responses to open-ended questions on the survey indicated that parents spent much time and energy in securing more services, particularly therapies, for their children. McWilliam and colleagues note a tension between parents focus on the child s need for therapy and the practitioners focus on the needs of the family and using a family-centred approach. They noted that a child-focussed service can be family-centred if the family has deemed such a focus their main priority. However, this only applies if they are aware that a family focus is also possible; that is, if they have been offered options. For families, this is likely to be a developmental process: while they may have exclusively child-focussed goals initially, they will come to see the value of broader family-focussed goals in time, as they develop a relationship with their service providers.

Further light on this complex issue is shed by another study by this group of researchers (McWilliam, Young & Harville, 1996), this time involving focus groups with parents, service providers and agency managers. There was much talk in the groups about children s need for therapy and the shortage of paediatric therapists. However, none of those involved could provide a clear definition of when and why a child ʻneeded therapy. Instead, there were unquestioned assumptions shared by practitioner and parents alike that children with certain disabilities needed therapy, that the more they got the better, and that the best form of therapy was individual hands-on therapy. All of these beliefs are debatable, and moreover violate key principles of effective service delivery (including collaboration, integrated programming and functionality). Therapy is a means to an end, not an end in itself. It is the role of practitioners to help parents identify what ends or outcomes are most desirable, and by what means these can best be achieved. When practitioners fail to do this, the choices families make about what they and their children need are not based on a full understanding of how the best results may be achieved.

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 practitioners explicitly or implicitly present ʻhands-on therapy as the most effective way to help their child, parents will tend to perceive this as what their child needs. If practitioners 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 therapists do not always make these options available to parents and that parents therefore opt for traditional child-focussed services.

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) noted 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.

Finally, the studies by McWilliam and colleagues, show that the kinds 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 usually 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 parents may 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 practitioners that 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 service providers 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.

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

The issue of parental involvement in the intervention program or therapy can be a source of confusion for practitioners as well as a source of tension for parents (e.g., Jansen, Ketelaar & Vermeer, 2003; Ketelaar, Vermeer, Helders & Hart, 1998; Thompson, 1998).

In an analysis of family service plans from two USA states, Boone, McBride, Swann, Moore and Drew (1998) looked at the allocation of responsibilities for carrying through the various goals identified. In family-centred practice, action plans should be described in terms of what families can expect of practitioners rather than prescribing programs for families. In the family service plans analysed in this study, whenever family concerns were noted, the resulting outcome statements were directive in terms of what families should do. Examples included, 'mother will follow through with recommendations to help with his development' or 'parents will search for sign language videos'.

What this study highlights is that parental involvement can have two meanings. On the one hand, it can mean parents being involved in the direct treatment of their children, implementing therapy programs at home and thereby acting as aides to the practitioners. (This appears to have been the experience of the parents in the study by Boone et al. just described.) On the other hand, parental involvement can mean parents

being involved in the decisions about the goals and form of intervention, thereby acting as partners with the practitioners. In family-centred practice, this is the true meaning of parental involvement.

These two different forms of parental involvement can have profoundly different effects on parents. Reviews of the literature on the effects of parental involvement in intervention programs for children with cerebral palsy have been conducted by Ketelaar, Vermeer, Helders and Hart (1998) and Jansen, Ketelaar and Vermeer (2003). Ketelaar et al. reviewed studies that examined the effects on the children of parental involvement in therapy. 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. Two features distinguished programs with positive parental effects from programs with limited parental effects. These were the degree to which:

> Parents were involved in setting goals and carrying out programs for their children; and,
> Parent s problem-solving skills and independence were promoted.

The authors concluded that   an active role of parents in all phases of the program is preferable; parents must be included as integral participants   (p. 116). This involves four components:

> First, the program must focus on the child s and family s needs and priorities;
> Second, parents must be included in goal-setting and these goals must be directed to the needs and priorities of the child and family;
> Third, the program must be adapted to the family s capabilities, situation, and daily schedule; and,
> Fourth, parents must be given regular opportunities to evaluate and re-formulate goals.

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 the 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.

Based upon the 18 studies they were able to identify, Jansen et al. (2003) summarised the findings thus:

> *Current literature on the subject is sparse and methodologically too varied to be able to make any clear-cut recommendations about the value of parental participation for the well-being of parents of children with severe physical impairments. The current opinion that parents should be more and more actively involved in the physical therapy of their children seems to be based on the*

positive effect on the children only, and on some very limited studies looking at effects on parents, sometimes only involving compliance with the therapy. More recent studies reviewed in this paper suggest that parental participation may be beneficial for some parents, but not for all of them. (pp. 66-67)

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 practitioners to be 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 may take. When this occurs, parents are better able to carry out the home program and feel more competent as parents than when it does not occur.
> *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 too stressful.
> *Contact with other parents during therapy can be valuable.* Parents who are attempting to implement therapy in the home may find informal contact with others in the same situation to be helpful.

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

> Are involved in setting and evaluating goals;
> Help determine what form the home program will take;
> Are helped to develop skills in meeting their child s needs; and,
> Find home programs are easy to integrate into daily family routines.

4.8   What actually happens on home visits?

Another way of establishing whether services are truly family-centred is to analyse what happens on home visits. Home visits that are truly family-centred should 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 the competencies of parents 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 early childhood intervention practitioners 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 (89%), with very little time being 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 indicated that practitioners were operating in a child-focussed way with the practitioner 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 actually recorded during the 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 the indicators (as distinct from the principles) of family-centred practice and collaborative partnerships may never have been operationally defined. It is often difficult for practitioners to be clear about what is needed. To address this issue, 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 practitioners to become more truly collaborative and family-centred in their work.

4.9   Does true parent-practitioner collaboration occur?

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

In the USA, Dinnebeil et al. wanted to find out what characteristics enhanced or detracted from collaboration between parents and practitioners. Respondents were asked to describe the variables that each person in the partnership brought to the relationship that either enhanced or interfered 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 practitioners 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 practitioner 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 easily changed, 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.

On the basis of a large-scale survey of German parents, Peterander (2000) concluded that the key conditions that promote effective cooperation between parents and practitioners were:

> A high standard of professional competence matching parental expectations;
> A family-centred approach on the part of the parents, resulting in their active involvement;
> A positive family climate involving positive interaction and communication with the child and which is conducive to the child s development;
> A lively exchange of information between parents and practitioners; and,
> Numerous sessions of child-oriented talks and counseling.

Peterander identified the following indicators that make effective parent/practitioner cooperation more likely. These were:

> Talking with practitioners and learning from modeling during intervention sessions are the most helpful ways for parents to 'learn how to help their child;
> A high level of agreement between parents and specialists regarding aims and methods of intervention is vital for cooperation; that is, consensus facilitates cooperation;
> Intervention within a family environment has a positive effect on cooperation and real partnerships are easier to establish under these circumstances;
> Efforts on the part of interventionists to involve fathers have a positive effect on the cooperation of mothers;
> A family-oriented approach helps bring about more intensive cooperation; that is, parents must be convinced of the importance of their cooperation;
> The quality of the relationship between parents and practitioners is also important. Better relationships lead to better communication and outcomes;
> The emotional stability of parents has a lasting effect on cooperation. Parents experiencing greater strain are less able to work cooperatively;
> Parents who are committed to doing as much for their child as possible are more likely to work cooperatively with practitioners; and,
> Continuity of service provider promotes greater cooperation.

In another effort to make clear the qualities of effective family-centred practitioners, McWilliam, Tocci and Harbin (1998) analysed transcripts of actual service delivery sessions and identified six practitioners from a pool of 43 service providers as matching the practices and philosophies identified in the literature as family-centered. These providers and some of the families they served were interviewed. Five underlying components of family-centered services were identified. These were:

> *Positiveness* - a philosophy of thinking the best about the parents without passing judgment;
> *Responsiveness*   paying attention to and taking action regarding parents concerns;
> *Orientation to the whole family*   a willingness to orient services to the whole family, rather than just to the child;
> *Friendliness*   going beyond rapport and establishing a friendship-based relationship; and,
> *Sensitivity*   a willingness and ability to put themselves in the parents shoes

A sixth quality displayed by these practitioners was technical competence, both in working with children and with the broader community.

In interpreting this body of research, it is important to recognise that researchers own perceptions of parents who have children with disabilities may influence the kind of research questions they ask and the studies they conduct. To explore this question, Dunst, Humphries and Trivette (2002) reviewed the research conducted between 1970 and 2000 regarding the parenting capabilities of parents of preschool children with disabilities and developmental delay. They analysed the three types of attributes described by researchers about parenting capabilities: parenting competence, parenting enjoyment, and overall approach or orientation. They found that, over this period, researchers tended to characterise parents and parent-child interactions in a primarily negative light, although there was some movement toward more positive views over this time. Despite this tendency, the overall trend was for parents to be viewed more often than not, as lacking in one or more aspects of parenting competence, and as deficient in their interactional behaviour.

Overall, these studies suggested that the key qualities that practitioners need to promote collaboration with parents are as follows:

> *The personal characteristics of the practitioners*   friendliness, optimism, patience, sincerity, genuineness, integrity, and sensitivity;
> *The beliefs, values and attitudes of the practitioners*   family-centred beliefs (recognising family strengths, trusting in family problem-solving abilities) and attitudes (being non-judgmental, accepting differences, mutual trust);
> *The people skills of the practitioners*   open communication, good listening skills, honesty and tact;
> *The professional/technical competence of the practitioners;* and,
> *The practices of practitioners*   open exchange of information, consideration of the needs of the whole family and not just the child.

4.10 Do family service plans encourage the use of informal rather than formal supports?

One of the principles of family-centred practice is that families should be encouraged to identify and make use of informal family and community resources rather than relying exclusively on formal professional resources. In their analysis of family service plans from two USA states, Boone, McBride, Swann, Moore and Drew (1998) looked at whether the informal or formal sources of support were specified. They found that recommending informal supports was more common in one of the states than the other.

They attributed this to the fact that the state in question used a more informal service plan format that allowed for greater individualisation across families and communities.

4.11 Can family service plans become more truly family-centred?

Several studies have shown that it is possible to enhance the family-centredness of family service plans by providing specific training in their use either for practitioners (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 the Appendix. These scales can be used to provide practitioners with feedback about the extent to which family service plans reflect family-centred principles.

4.12 Summary of evidence regarding the focus of services experienced by families

Section Four 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 could be that they are based on goals that were not truly important for them and which use methods that did not involve parents 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 practitioners 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 practitioners rather than the parents regard as important.
> Services tend to be predominantly child-focussed instead of reflecting a balance between the needs of the child and those of the family. The tendency to focus mainly on the child appears to be the result of a complex interaction between what practitioners 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-focussed approach.
> Parental involvement in implementing their children s intervention programs is usually of direct benefit to the children but it can have a positive or negative effect on parents, depending upon the nature of their involvement. Parents only benefit if they help set the goals and determine what form a home program will take, increase their ability to meet their child s needs themselves, and find interventions that are easy to integrate into daily family routines.

> On home visits, practitioners tend to operate in a child-focussed way and act as the major agent of change, rather than dividing their time equally between child and family issues, and seeking to make parents the major agents of change.
> The key qualities that practitioners need to promote collaboration with parents include their personal characteristics, that is: 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.

4.13 Summary

Sections Three and Four have 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 at parents subjective experiences and views of service, as well as at 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 all of the studies examined.

> 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, they increase the stress levels of parents and the likelihood that they will carry through the program concerned 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-focussed and family-focussed 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 practitioners, and being treated as equals. In practice, the evidence suggests that practitioners generally do provide services that are respectful and supportive, but that they are less consistent in treating parents as equals and involving them in all decisions.
> Parents want practitioners who use empowerment approaches that build on family strengths. In practice, the evidence suggests that practitioners tend to see

themselves as the major agents of change, rather than as supporters whose primary responsibilities include helping parents develop the skills to become the major change agents.

> The key qualities that practitioners 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 (such as the ability to listen and to communicate effectively).

> The degree to which parents value working collaboratively with practitioners depends upon how much practitioners 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-focussed approach.

> The degree to which parents and practitioners can work together according to family-centred principles depends partly upon their level of experience: the more experienced the practitioners 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 practitioners 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 practitioners to be technically competent, both in terms of knowing how to work effectively with young children who have developmental disabilities, and knowing how to help families access other relevant services. By and large, parents feel that early childhood intervention practitioners 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.

> Practitioners 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 service system that is more effective than the one in which they are involved, and practitioners should be seeking to engage parents in the planning and evaluation of services much more than they currently do.

Overall, the literature indicates 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 practitioners 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 individually and collectively clarify their values about why and how early childhood intervention is implemented. 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 practitioners should place a higher value on evidenced-based practices than they do on interventions that are 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 who have a child with a disability.

SECTION FIVE

DISCUSSION

Clearly, there is a great deal of available literature in relation to family-centred practice. However, it is possible to identify some common threads that are woven throughout many of the studies described in this literature review. These include:

> *A context for family-centred practice:* The need to put the philosophies, principles and practices of family-centred practice within a context of overall provision of services and supports;
> *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; and,
> *Inclusive practices and natural environments:* Recognising the importance of delivering services and supports in the child s natural environments.

What follows is a discussion around each of these themes.

5.1   A context for family-centred practice

There is a very large body of knowledge in relation to family-centred practices and principles. These are relevant not only to the early childhood intervention sector but to a much broader range of community services and supports. It is not always easy to understand how this knowledge can be transferred into everyday practice that can make a difference in the lives of families who have a child with a disability. However, there are some important messages.

The literature shows that families prefer family-centred services and supports to professionally-centred services, and that there are clear benefits for parents in terms of satisfaction with parenting, empowerment and parental and family well-being. Other program characteristics, however, do influence child/parent and family functioning. Indeed, the most important predictors of parental well-being are the presence or otherwise of behaviour management issues in their children and the level of general social support networks that all families need. Family-centred practice is therefore a benefit of a value-added nature, where the full benefits are only felt when other supports are in place. This has implications for the partnerships and links that specialist early childhood intervention agencies need to establish with universal, community agencies.

If agencies and practitioners are to be truly family-centred, they need to be aware that the journey for individual families is always their own journey and that it cannot be assumed to be the same as for other families. Practitioners need to listen to the stories of families and understand where they are in their journey at any point in time. Only then can practitioners 'walk with families in these journeys and not walk their own path or the path that practitioners believe the family need to be walking. It is only then that practitioners can start to be truly family-centred.

Yet, it is possible to be family-centred but primarily child-focussed if that is the priority of the particular 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 in a real sense have been offered other options.

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 that they 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 systems, processes and practices in a very real way, rather than as an afterthought. Otherwise, it runs the risk of being tokenistic at best. Service managers and practitioners need to continually ask how this can be done. How can families be empowered through *power-through* relationships rather than simply having a family-focussed approach (see Section 2.1)? Power-through relationships empower all partners, thus allowing families, practitioners and agencies to become important agents of change within communities. In this way, the capacity of communities to be welcoming and inclusive of all children can be enhanced.

If family-centred practice is the pathway upon which managers and practitioners wish to travel, how can this be facilitated? What changes need to occur? One implication is that the behaviour of practitioners needs to reflect 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. Agencies need to find ways to make better use of this resource in a way that is meaningful and valued and does not merely place extra demands on families.

Finally, it is important to honour the racial, cultural, ethnic and socioeconomic 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 be 'the expert' and 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 communities change, the destination may be ever changing and as elusive as the pot at the end of the rainbow. When a service or a practitioner believes that they are truly family-centred, the time has probably come to re-evaluate what they are doing and to commence another journey.

5.2   First messages and other information

Information plays an important role in the quest to support family-centred practice. If information leads to knowledge and knowledge leads to increased wisdom, access to information by families is one way in which they can become empowered to engage in the relationships with practitioners and agencies.

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

According to the literature, early childhood practitioners are generally good at providing information to families about the specific aspects of the child s program or functioning. However, they are often poor at providing information of a more general nature that may be relevant to broader family needs and expectations.

The first messages provided to families by primary health care providers are 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 shows 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 early childhood sector work towards ensuring that families receive such positive first messages early on in their journey with their child? 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?

If service providers are to improve their 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. It is only in this way that families can start to benefit from a full range of services and supports. If the aim of family-centred practice is the empowerment of families, this can only occur when they have available all the information they need. The role of practitioners is to assist families to navigate their way through what is often a complex and overwhelming maze of people, services, supports and funding streams. The challenge is also to communicate some clear messages about family-centred practice to families so that they not only understand, but demand services and supports based on *power-through* relationships that recognise and develop the competencies of all parties.

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

Families are also an under-utilised resource when it comes to the giving and sharing of information. They often seek support and information from other parents and are willing to share with them the knowledge they have gained. This is a resource that is

often under-utilised and also further reinforces a need for a greater emphasis on the centrality of families in the development of systems, policy and practice.

Families are the experts with respect to their child and they bring to a collaborative relationship with practitioners, a great deal of information and knowledge about their child. It is important for practitioners not only to recognise but also to value this, and ensure that families have opportunities to share their expertise. To do this, families need to feel comfortable in sharing their experiences. Practitioners need to use strategies, find the time and provide environments where families can comfortably tell their stories.

What strategies support families to share these stories? Clearly, the interpersonal skills of practitioners has an influence. It takes a considerable investment in time to develop the sort of relationship where families are able to share the information they may need and want to do so. In an environment where practitioners often feel pressured to deliver services or to 'do the therapy that they believe they are funded to do, taking the time to have the necessary conversations with families can be challenging for practitioners. However, without this sort of relationship and the information and knowledge that is shared as a result, the contribution that practitioners can make is indeed limited. Listening to the stories of families is an integral part of 'therapy or any other type of service provision or support. When families feel they are part of a collaborative partnership with practitioners, it is easier for them to share information and to take control of the services and supports that they receive. In many instances, it takes families some time to get to this point. The challenge for agencies is to determine how this delay can be reduced so that the empowerment of families happens early on in their journey, ideally even before a family enters the early childhood intervention service.

5.3   Finding the balance

Providing services and supports that are family-centred requires the careful balancing of competing demands 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 counseling 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 in control and that strengthens parental competencies.

Clearly, any one of the above 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, because 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 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 a particular 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 that are suitable to families, for example, outside the usual nine-to-five day, five days per week.

5.4   Inclusive practices and natural environments

Evidence from the literature suggests that children do better when 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?

It is possible to argue that children 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 individual families so that the developmental goals are those that are going to make the most difference for those families. For example, to work on impairment in relation to swallowing, in the absence of understanding what the real mealtime issues are for a particular family 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 is 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 feel pressured 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 . The literature supports the view that what works best for families 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, therefore, 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 real and informed choices about what they want and need. 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 needs to become the rule and not the exception, and practitioners should be asked to justify occasions of service where this has not occurred.

5.5   Finally

This publication has reviewed the key research in relation to family-centred practice in the area of early childhood intervention services and supports. It is hoped that families, practitioners and service providers can benefit from the information and discussion presented so that by working together, communities can become more welcoming and inclusive for families and children of all abilities.

Finally, as practitioners continue to question how they can become more family-centred in their practice, it is worth reflecting on the words of one mother:

> *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.* (Scope, 2004 p. 93)

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APPENDIX

MEASURES OF FAMILY-CENTRED PRACTICE FOR USE BY AGENCIES

> Measure of Processes of Care (MPOC-56, MPOC-20 and MPOC SP) These instruments have been developed by CanChild and are designed to measure the degree of family-centred practice within agencies from the perspective of families and service providers. (www.fhs.mcmaster.ca/canchild)

> 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).

> Recommended Practices in Family-Centred Early Childhood Intervention - Evaluation Guidelines (NSW Ageing and Disability Dept. and ECIA-NSW, 1998) 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.

> Brass Tacks: Part 1 - Program Policies and Practices (McWilliam and Winton, 1991a) 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.

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.

MORE THAN MY CHILD S DISABILITY

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:

MEASURES OF FAMILY-CENTREDNESS OF SERVICE AND SUPPORT PLANS

> IFSP Family-Centredness Rating Scale (McWilliam, R.A. (1993) Unpublished instrument Chapel Hill; North Carolina; University of North Carolina, Chapel Hill. 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.

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Disability Means Possibility

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