# **Contents**

Foreword by	/ Ken M. Bleile	vii
Preface		ix
Acknowledg	ments	хi
Contributors	3	xiii
PART I		
Chapter 1	Models of Practice Used in Speech-Language Pathologists' Work with Families Nicole Watts Pappas, Sharynne McLeod, and Lindy McAllister	1
Chapter 2	Speech-Language Pathologists' and Other Allied Health Professionals' Perceptions of Working with Parents and Families Nicole Watts Pappas and Sharynne McLeod	39
Chapter 3	Parents' Perceptions of Their Involvement in Pediatric Allied Health Intervention Nicole Watts Pappas and Sharynne McLeod	73
PART II		
Chapter 4	Working with Families of Young Children with Communication and Language Impairments: Identification and Assessment <i>Elizabeth R. Crais</i>	111
Chapter 5	Working with Families of Young Children with Communication and Language Impairments: Intervention Luigi Girolametto and Elaine Weitzman	131
Chapter 6	Working with Families of Children Who Stutter Ann Packman and Marilyn Langevin	171

# vi Working with Families in Speech-Language Pathology

Chapter 7	Working with Families of Children with Speech Impairment Nicole Watts Pappas and Sharynne McLeod	189
Chapter 8	Working with Families of Children Who Use AAC <i>Julie Marshall and Juliet Goldbart</i>	229
Chapter 9	Working with Families of Children with Dysphagia: An Interdisciplinary Approach Bernice A. Mathisen	245
Chapter 10	Working with Families of Children with Hearing Loss Alice Eriks-Brophy	279
Chapter 11	Working with Families to Facilitate Emergent Literacy Skills in Young Children with Language Impairment A. Lynn Williams and Martha J. Coutinbo	305
Index		335

# **Foreword**

When I was a graduate student (long ago!) we received a few lectures on the importance of family participation in assessment and treatment, the emphasis being on how much more quickly treatment proceeded when a child's family was involved. If I had better understood the crucial importance of working with families, my notes for those lectures would have been more detailed, and the heading "Families" would have been in red ink with large arrows and huge stars circling around it.

As I discovered when I began working, family is the pivot of a child's life, essential as air. Essential because human infants are born too helpless to survive without caregivers and require long apprentices under protective guardians to learn all they must know to survive. I soon learned that families differed enormously in disposition, composition, and child-rearing ability. Some were a "comfort zone" from which a child explored the world, and others a place from which a child needed to escape. Some families included a single parent, other two parents, two women, two men, a grandparent, or parents unrelated biologically to the child. Child-rearing skills of families ranged from awe inspiring to awful. To illustrate, I remember working with two couples. One couple, both of who were mildly retarded, were particularly conscientious parents, and the other couple, both professionals, were so consumed by career goals as to border on inflicting child abuse.

If I were a student today, I would want *Working with Families in Speech-Language Pathology* as a textbook. For a clinician, educator, or researcher *Working with Families* is an invaluable reference. The editors and authors are experienced clinicians and fine writers, and they have assembled an outstanding international cadre of chapter authors. The first part of *Working with Families* provides an excellent description of the editors' theoretical framework. The second and main part consists of eight strong chapters, each focusing on a particular child population, including family issues arising in the care of children with language impairment, speech impairment, stuttering, AAC devices, dysphagia, hearing loss, and emergent literacy.

## viii Working with Families in Speech-Language Pathology

Working with Families in Speech-Language Pathology has something for everyone. Whether as a textbook or a reference, it is an excellent resource that likely will be read and reread for a long time to come.

Ken M. Bleile

# Chapter 1 Models of Practice Used in Speech-Language Pathologists' Work with Families

Nicole Watts Pappas, Sharynne McLeod, and Lindy McAllister



## Introduction

Speech-language pathologists' (SLPs') work with families in pediatric intervention has changed significantly over the past 50 years. Recommended practice for SLPs and other allied health professionals has shifted from very limited involvement with parents to a collaborative relationship with the child's whole family (Andrews & Andrews, 1986; Crais, 1991; Hanna & Rodger, 2002). Three sequential phases of parent and family involvement have been advocated by policy makers and discussed in the literature. These include the therapist-centered model, the parent-as-therapist aide model, and the family-centered model. The models vary, primarily in relation to the extent of parent and family involvement, the focus of the intervention on the child or family, and the amount of family participation and power in the decisionmaking process. This book introduces a new model of practice in working with families in pediatric intervention, the family-friendly model (Watts Pappas, 2007). Table 1-1 summarizes the four different models and their major similarities and differences.

Table 1-1. The Four Models of Practice

Model	Family Involvement in Intervention Provision	Family Involvement in Intervention Planning	Primary Decision- Maker	Primary Client
Therapist- centered	No	No	Professional	Child
Parent-as- therapist aide	Yes	No	Professional	Child
Family- centered	Varies according to families' wishes	Varies according to families' wishes	Family	Usually the family (varies according to families' wishes)
Family- friendly	Families supported to be involved in the intervention	Varies according to families' wishes	Professional	Usually the child (varies according to families' wishes)

In this chapter each of the four models of practice is described, outlining the foundation for each model, their theorized advantages and disadvantages, and the existing evidence base for each model's effectiveness. Although the models are discussed historically in order of emergence in professional practice, any of the four may currently be in use in intervention services for young children. Actual practice may not always be aligned with recommended practice. The information presented here therefore is a reflection of the discussion of family-professional relationships in the literature rather than actual practices of professionals, which may vary between services (Mahoney & O'Sullivan, 1990; McWilliam, Synder, Harbin, Porter, & Munn, 2000). For a discussion of the literature on the reported practices and beliefs of SLPs and other allied health professionals regarding working with parents and families see Chapter 2. Chapter 3 includes a discussion of the literature on parents' views of working with SLPs and other allied health professionals. The remaining chapters in this book discuss working with families of children presenting with language impairment, stuttering, speech impairment, hearing impairment, complex communication needs, dysphagia, and early literacy concerns.

# Therapist-Centered Model

# Description

Traditionally, intervention services for young children were provided using a therapist-centered model of service delivery (Bailey, McWilliam, & Winton, 1992a; Bazyk, 1989). In the therapist-centered model or, as it is also known, the expert model of practice, professionals assume hierarchical control over the planning and provision of intervention services for young children (Rosenbaum, King, Law, King, & Evans, 1998) (Table 1–2). The professional assesses, diagnoses and treats the child and the family has little or no involvement in either the planning or provision of the intervention (Lawlor & Mattingly, 1998). Using this model, professionals considered the child in isolation rather than in the context of the family and parents were seen as part of the problem rather than the solution (Leviton, Mueller, & Kaufmann, 1992; Wehman, 1998). For example, in his article on parental influences on speech production, Wood (1946, p. 272) stated, "Functional articulatory defects of children are definitely and significantly associated with

## 4 Working with Families in Speech-Language Pathology

**Table 1–2.** Contextualizing the Therapist-Centered Model

Model	Family Involvement in Intervention Provision	Family Involvement in Intervention Planning	Primary Decision- Maker	Primary Client
Therapist- centered	No	No	Professional	Child
Parent-as- therapist aide	Yes	No	Professional	Child
Family- centered	Varies according to families' wishes	Varies according to families' wishes	Family	Usually the family (varies according to families' wishes)
Family- friendly	Families supported to be involved in the intervention	Varies according to families' wishes	Professional	Usually the child (varies according to families' wishes)

maladjustment and undesirable traits on the part of the parents, and such factors are usually maternally centered". This view, although no longer prevalent, supported a therapist-centered approach.

# Advantages

No advantages for the therapist-centered model of practice have been discussed in the literature, perhaps because the practice was taken for granted at the time, and because practice itself was not seen as a topic of investigation. However, some studies of parents' and professionals' perceptions of family involvement in intervention for young children have indicated a preference for selected features of the therapist-centered model of practice. For example, a number of researchers have found that parents prefer the professional to take the lead in intervention planning for their child (MacKean, Thurston, & Scott, 2005; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993; Piggot,

Hocking, & Patterson, 2003; Watts Pappas, McAllister, & McLeod, 2009b) and that professionals believe that parents need and/or want this guidance (Bailey et al., 1992a; Litchfield & MacDougall, 2002; McBride et al., 1993; Minke & Scott, 1995; Watts Pappas, McAllister, & McLeod, 2009a). Both of these beliefs are compatible with the therapist-centered model of practice.

## Disadvantages

Some disadvantages to the therapist-centered model of practice have been theorized in the literature. For example, in the therapist-centered model, parents' knowledge about their child is not utilized. This loss of parental perspective means that intervention goals and plans may be irrelevant to the child and family (Appleton & Minchom, 1991) and intervention effectiveness may be diminished by a lack of knowledge about the child's skills in contexts outside the clinic. The therapist-centered model also gives parents limited opportunity to participate in the intervention and thereby acquire new skills to help their child (Dunst & Trivette, 1996). This encourages families to be dependent on the professional, placing parents in a position of powerlessness and perhaps engendering a lack of confidence in their caregiving skills (Dunst, 1985).

## Evidence Base

The many intervention efficacy studies that have been conducted without mention of parent involvement in service planning or delivery testify to the fact that intervention for young children without family involvement can be effective. For example, intervention approaches for children with speech impairment (Gierut, 1989; Williams, 2000), phonological awareness difficulties (Gillon, 2000), and language impairment (Goldstein, 1984; Wilcox, Kouri, & Caswell, 1991) have all been demonstrated to be effective without parental involvement.

However, other studies have demonstrated parent dissatisfaction with the therapist-centered model of service delivery. Parents in a number of studies have reported discontent with professionals' disregard for their opinions and knowledge about their child (Baxter, 1989; Case-Smith & Nastro, 1993; Glogowska & Campbell, 2000; Minke &

Scott, 1995), which can be associated with the limited parental involvement of the therapist-centered model. For an in-depth review of parents' perceptions of intervention see Chapter 3.

## Parent-as-Therapist Aide Model

As parents became dissatisfied with the expert model of service delivery, they campaigned for more involvement in their child's intervention (Turnbull & Turnbull, 1982). Partly due to the pressure applied by these parent groups as well as legislative changes in the United States, professionals began giving parents greater involvement in their child's intervention (Bailey et al., 1992a; Bazyk, 1989; Hanna & Rodger, 2002; Rosenbaum et al., 1998). The parent-as-therapist aide model of working with parents in intervention for young children has been described by previous authors as the "transplant model" (Appleton & Minchom, 1991, p. 28), "parents as teachers and therapists" (Bazyk, 1989, p. 724), and the "family-allied model" (McBride et al., 1993, p. 415). In this book the model is identified as the parent-as-therapist aide model. This redefinition was made on the basis of the limited parental involvement in decision-making in the model, thereby placing the parent in the position of therapist's aide.

# Description

Although the legislation in the United States mandated that parents should have a decision-making role in intervention services for their child, this appeared to be actualized as a role in the delivery of intervention, mostly by requesting that parents conduct home activities (Bazyk, 1989). As Andrews and Andrews (1986, p. 359) commented in their description of speech-language pathology practice at this time, "Input from the client is of course appreciated but it is the expert professional who evaluates the problem, sets the goals, and determines the course of treatment."

In the parent-as-therapist aide model, parents mostly participate in intervention by conducting activities at home which are planned and designed by the professional (Appleton & Minchom, 1991) (Table 1–3). These activities could be given in conjunction with intervention sessions or as a complete replacement, with the professional acting as a consultant and the parent as the primary agent of intervention. The

Professional

Usually the

child (varies

according to families'

wishes)

Family **Family** Involvement in Involvement in Primary Intervention Intervention Decision-Model **Provision Planning** Maker **Primary Client** Therapist-No No Professional Child centered Professional Parent-as-Yes No Child therapist aide Family-Varies Varies **Family** Usually the centered according to according to family (varies families' wishes families' wishes according to families' wishes)

Varies

according to

families' wishes

**Table 1–3.** Contextualizing the Parent-as-Therapist Aide Model

intervention is still child-centered in that it focuses on the child in isolation rather than in the context of their family (Andrews & Andrews, 1986) and although parents were now given the opportunity to be involved in their child's intervention provision, they still had limited participation in decision-making about their child's care (Case-Smith & Nastro, 1993; McBride et al., 1993).

## **Advantages**

Family-

friendly

**Families** 

supported to be

involved in the

intervention

Many benefits of involving parents in intervention provision have been theorized in the literature. As parents had the ability to work with their child in natural settings such as the home environment, it was considered that family involvement could facilitate generalization of skills to settings outside of the clinic (Bazyk, 1989; Costello & Bosler; 1976; Jansen, Ketelaar, & Vermeer, 2003; Shelton, Johnson, Willis, & Arndt, 1975; Wing & Heimgartner, 1973). Parental involvement was also suggested as a strategy to increase the cost-effectiveness of intervention,

as the professional was not required to give all the intervention to the child (Dodd & Barker, 1990; Fey, 1986; McPherson, Morris, & Ferguson, 1987). Advantages for the parent and family were also suggested. Authors surmised that if parents learned how to help their child it would decrease parental stress (Turnbull, Turnbull, & Wheat, 1982) and provide them with greater knowledge and confidence in their caregiving role (Jansen et al., 2003). Professionals working in a clinical setting also supported parental involvement in intervention, with many studies indicating that professionals believed parental involvement in intervention for young children was important and could improve intervention outcomes (Hinojosa, Anderson, & Ranum, 1988; Hinojosa, Sproat, Mankhetwit, & Anderson, 2002; Iversen, Poulin Shimmel, Ciacera, & Meenakshi 2003; Leiter, 2004; MacKean et al., 2005).

## Disadvantages

Some disadvantages of the parent-as-therapist aide model of service delivery have been discussed. For example, a study of parents' perceptions of home programs revealed that some parents found participation in these programs difficult and time consuming (Hinojosa & Anderson, 1991). Many authors cautioned professionals about having unrealistic expectations of parental involvement in their child's intervention (Allen & Stefanowski Hudd, 1987; Bazyk, 1989; Rodger, 1986; Turnbull & Turnbull, 1982). It was suggested that when parents adopt the role of the professional it may affect child-parent relationships by making the parent-child interaction take on the role of work (Allen & Stefanowski Hudd, 1987). Additionally, the authors cautioned that attempting to implement a home program could increase the stress of a family that already had the additional time requirements of caring for a child with a disability (Rodger, 1986).

Additionally, the parent-as-therapist aide model assumed that all parents would wish to take an active role in intervention for their child. However, a number of studies have demonstrated that this was not true for all parents (Andrews, Andrews, & Shearer, 1989; McKenzie, 1994; Piggot et al., 2003). Although the model gave parents an opportunity to be involved in the intervention, it did not give them a choice about whether to be involved or not, or in what way to be involved (Turnbull & Turnbull, 1982). The parent-as-therapist aide model also did not consider the individual needs and preferences of families, label-

ing parents as noncompliant if they did not do the activities requested of them (Giller Gajdosik & Campbell, 1991; Mayo, 1981; Short, Schkade, & Herring, 1989). For example, Short and colleagues (1989, p. 446) wrote: "Some mothers seemed to respond negatively to the increased performance demands with apparent avoidance behaviors."

## Evidence Base

Numerous studies have been conducted to investigate the effect of parental involvement in intervention provision for young children. A number of reviews of this body of research have also been conducted (Table 1-4). Most of the studies have focused on the effect of parental involvement on specific intervention outcomes for the child.

Table 1-4. Reviews of the Effect of Parental Involvement on Intervention Outcomes

Review	Number of Studies Reviewed	Children's Difficulty (as Specified in Review)	Age of Children	Service Provided (as Specified in Review)
Ketelaar, Vermeer, Helders, & Hart, 1998	7	Cerebral palsy	Younger than 5 years	Early intervention services
Law, Garret, & Nye 2003a	33 (15 of which involved parents' opinions/ involvement)	Speech/language delay/disorder	0-15 years	Speech- language pathology
Shonkoff & Hauser-Cram, 1987	31	"Disabled"	Younger than 3 years	Early intervention services
White, 1985	27 involving parents compared to 80 with no parental involvement	Disabled, disadvantaged, or at risk	Not specified	Early intervention services
White, Taylor, & Moss, 1992	172	"Disabled, disadvantaged, or at risk"	Not specified	Early intervention services

## 10 Working with Families in Speech-Language Pathology

Few have included investigation of the effect of parental involvement on outcomes for the parents and family. Three different types of question primarily have been addressed in these studies:

- 1. Are intervention programs that incorporate parental involvement effective?
- 2. Are parent-administered interventions as effective as professional-administered interventions?
- 3. Can parental involvement increase the effectiveness of intervention provided by a professional?

Research addressing the above three questions is briefly reviewed here. Due to the large number of studies investigating these questions, the discussion is limited to consideration of previous systematic reviews of the research, rather than critique of individual studies. Where possible, the review focuses on studies incorporating speechlanguage pathology intervention. However, intervention generally was provided by a combination of allied health and other professionals such as nurses and teachers, rather than a specific professional discipline.

# Are Intervention Programs Incorporating Parental Involvement Effective?

A substantial evidence base exists to support the proposition that intervention incorporating parental involvement can be effective (Law, Garrett, & Nye, 2003a; White, 1985). For example, in a review of parental involvement in intervention for young children, White (1985) listed 27 studies demonstrating the effectiveness of intervention programs involving parent participation. However, when compared to studies which did not involve parents, the effect sizes were similar. In the field of speech-language pathology, a Cochrane review of the effectiveness of speech-language pathology intervention (Law et al., 2003a) included a total of 27 studies, four of which compared parent-administered intervention to no intervention (Gibbard, Coglan, & MacDonald, 1994; Girolametto, Steig Pearce, & Weitzmen, 1996a; Girolametto, Steig Pearce, & Weitzmen 1996b; Shelton, Johnson, Ruscello, & Arndt, 1978). The review found that in three of these studies, the intervention involving parents was more effective than no intervention (Gibbard et al., 1994; Girolametto et al., 1996a; Girolametto

et al., 1996b). For example, in a study of parent-administered intervention for young children with expressive vocabulary delays (Girolametto et al., 1996a), the 12 children in the experimental group exhibited a larger increase in expressive vocabulary than the 13 children in the control group who received no intervention over the 4-month time period of the study. However, in the study conducted by Shelton and colleagues (1978), a parent-administered program did not improve the children's receptive phonological knowledge in comparison to no intervention. Although the majority of these studies demonstrated that intervention involving parents could be effective, they did not investigate the effectiveness of the intervention in comparison to intervention provided by professionals.

# Is Parent-Administered Intervention as Effective as Professional-Administered Intervention?

The Cochrane review study (Law et al., 2003a) also incorporated studies that compared primarily parent-administered intervention to primarily professional-administered intervention. This review found that intervention conducted by parents was just as effective as intervention conducted by a SLP (Law et al., 2003a). Of the 27 studies that met the criteria for the review, five compared parent-administered to SLPadministered intervention (Fey, Cleave, & Long, 1993; Gibbard, 1994; Lancaster, 1991 [unpublished], cited in Law et al., 2003a; Law, 1999 [unpublished], in Law et al., 2003a; Tufts & Holliday, 1959). Three of the studies focused on intervention for early language delay (Fey et al., 1993; Gibbard, 1994; Law, 1999 [unpublished], cited in Law et al., 2003a) and two of the studies on intervention for speech impairment (Lancaster, 1991 [unpublished], cited in Law et al., 2003a; Tufts & Holliday, 1959). These studies all demonstrated similar improvements in the outcomes of intervention provided by trained parents as compared to that provided by SLPs. For example, Gibbard (1994) compared the outcomes of a parental training group to individual direct speech-language pathology treatment for a group of children with early language delay. At the end of the 6-month period of the study the two groups showed similar gains in their expressive language skills. The Cochrane review suggested therefore that intervention programs primarily conducted by trained parents can be just as effective as professional-conducted intervention.

# Can Parental Involvement Increase the Effectiveness of Intervention Provided by a Professional?

Research investigating whether the involvement of parents can make intervention provided by a professional more effective has produced differing findings. For example, Ketelaar, Vermeer, Helders, and Hart (1998) reviewed seven studies of parental involvement in intervention for children with cerebral palsy. They concluded that parental participation mostly had a positive effect on child-related outcomes. Additionally, in a meta-analysis of intervention for young children with disabilities conducted by Shonkoff and Hauser-Cram (1987), pediatric intervention programs that included work with parents and children together were found to be more successful than programs that did not encourage parental involvement.

However, conflicting results have also been reported. For example, a second review conducted by White and colleagues (1992) of 172 intervention studies, reported no evidence of larger effect sizes for intervention programs that included parental involvement. The only exception was intervention for speech impairment in which one reviewed study (Eiserman, McCoun, & Escobar, 1990) demonstrated that parental involvement had a positive effect on speech intervention outcomes. (A comprehensive review of the effectiveness of parental involvement in intervention for speech impairment [including further details of the study conducted by Eiserman and colleagues] is provided in Chapter 7.) Additionally, whereas the White (1985) review found that intervention programs involving parents were effective, it showed that the programs that included parents were no more effective than those that did not involve parents.

The reasons for the differences in the findings of these reviews are unclear. The much larger number of studies included in the reviews conducted by White (1985) and White and colleagues (1992) may have provided a broader picture of the effect of parental involvement in pediatric intervention. Alternatively, both the reviews by Shonkoff and Hauser-Cram (1987) and Ketelaar and colleagues (1998) exclusively included studies of young children (under 5 or 3 years of age). It is possible that the effects of parental involvement are greater in intervention for younger children, thus explaining the larger effects of parental participation reported by these reviews.

It should be noted that the studies reviewed by the authors in Table 1-4 evidenced a number of limitations, including nonrandom-

ization of groups, nonblinded examiners, and limited longitudinal measures. The studies also differed vastly in terms of the intervention provided, the type and amount of parental involvement, the age, difficulties, and severity of the children serviced, and the characteristics of the parents. The diversity of the studies makes it difficult to draw conclusions about their group findings. However, it appears that although there is evidence to suggest that parent-administered intervention can be just as effective as that administered by a professional, it has not been proven that parental involvement in allied health intervention provided by a professional makes that intervention any more effective.

## Family-Centered Model

In the 1990s, the family-centered model emerged as a new model of practice and basis for relationships between families and professionals (Rosenbaum et al., 1998). Although this model was initially developed for use in the disability field, the family-centered movement has influenced all areas of SLP and other pediatric allied health intervention, including services for children in hospital (Franck & Callery, 2004). Two major factors influenced the development of this model of practice:

1. Theories of child development, such as human ecological theory (Bronfenbrenner, 1979), that highlight the role of the family and the community in a child's development and health and wellbeing. Human ecological theory suggests that a child's development is not only determined by properties innate to the child but is also influenced by the child's interaction with the immediate environment and the larger contexts in which that environment is embedded. For example, children's development may be influenced by their interactions with their immediate family, their participation in other environments (such as preschool), the impact of environments in which they do not participate but are linked to their immediate environment (for example, their parent's place of work), and, finally, the culture of the society in which they live. Therefore, for children with developmental difficulties, focusing intervention on the family as well as the child was postulated to facilitate the child's development.

## 14 Working with Families in Speech-Language Pathology

2. A series of legislative acts which were passed in the United States beginning with the Education for All Handicapped Children Act of 1975 (Turnbull & Turnbull, 1982) and later the Individuals with Disabilities Education Act (IDEA) of 1990 (Wehman, 1998) that extended the role of families in decision-making in intervention for young children and introduced the concept of the family as client rather than solely the child. A similar trend occurred in the United Kingdom, with government policy mandating the use of family-centered practices in intervention for children from 1991 (Franck & Callery, 2004).

## Description

Family-centered practice is a model of practice in intervention for young children that focuses on supporting and strengthening the child's whole family. In Table 1-5 the features of family-centered practice

Table 1-5. Contextualizing the Family-Centered Model

Model	Family Involvement in Intervention Provision	Family Involvement in Intervention Planning	Primary Decision- Maker	Primary Client
Therapist- centered	No	No	Professional	Child
Parent-as- therapist aide	Yes	No	Professional	Child
Family- centered	Varies according to families' wishes	Varies according to families' wishes	Family	Usually the family (varies according to families' wishes)
Family- friendly	Families supported to be involved in the intervention	Varies according to families' wishes	Professional	Usually the child (varies according to families' wishes)

with regard to the extent of parent involvement in intervention provision and intervention planning and the focus of services (i.e., who is considered the primary client) are outlined in comparison with the therapist-centered and parent-as-therapist aide model. The practices in this table refer to the usual way in which family-centered practice is conducted. However, considering that another major feature of family-centered service is family choice-making, it should be considered that the family's involvement in intervention planning and the identity of the primary client may vary according to the family's wishes.

Several terms have been used to refer to pediatric intervention practices that are synonymous with the family-centered model. The most notable of these include family empowerment (Dunst, Trivette & Deal, 1988), family-focused intervention (Bailey et al., 1986), and family-centered service, practice, or care (Bailey et al., 1992a). The term *family-centered* has become the most widely used and accepted of these labels (Dunst, 2002). In this book, application of the family-centered model is referred to as family-centered service or practice. Descriptions of the family-centered model vary and no universal definition has been agreed on in the literature. However, some major assumptions are similar in all approaches. These features are now discussed.

## Family as Client

One of the key concepts of family-centered practice is the acceptance of the family as the client rather than just the child. Based on the view that change to one family member affects all other family members, intervention then focuses not only on making direct changes to the child but also on helping the child's whole family (Andrews & Andrews, 1986; Goetz, Gavin, & Lane, 2000).

## Positive Parent-Professional Relationships

Some authors have suggested that the cornerstone of family-centered practice is the formation of positive relationships between parents and professionals (Hanna & Rodger, 2002; McWilliam, Tocci, & Harbin, 1998). This is achieved by professionals' interpersonal skills (such as being caring and empathetic) and their attitudes toward parents—treating them as capable and deserving of respect (Dunst, 2002).

## **Parental Decision-Making**

Family-centered service acknowledges the parents' and family's right to make the final decisions about their child's intervention and these choices are supported and accepted by professionals even if they do not agree with them (Bailey et al., 1992a; Bazyk, 1989; King, Rosenbaum, & King, 1997; Leviton et al., 1992). Professionals act as consultants and are responsible for providing parents with information and support for their decision-making role (Dinnebail & Rule, 1994). Underlying this process is the professionals' belief that parents are capable of making decisions about their child and have the right to do so (Dunst & Trivette, 1996; Viscardis, 1998).

#### Parent Choice of the Level of Involvement

Although family-centered practice encourages parents and families to be involved in all aspects of intervention, this involvement is not considered mandatory. The extent of the family's involvement in any aspect of intervention planning or provision is always their choice (Brown, Humphry, & Taylor, 1997; Rosenbaum et al., 1998). For example, if a family decides they do not wish to be involved in intervention provision this would be accepted by professionals.

#### **Individualization of Services**

Family-centered practice recognizes the individuality and diversity of parents and families and adapts services to take into account each family's beliefs, culture, and the environment in which they live (Crais, 1991; Law et al., 1998). Family-centered services are designed to fit the needs of families and are flexible and accessible (Dunst, 2002).

## **Empowering and Enabling Families**

Family-centered services reflect an enabling model of helping, thereby fostering the skills of families to care for their child with special needs (Dunst & Trivette, 1996). The aim of family-centered practice is to identify and enhance child and family strengths rather than focusing on weaknesses, and to promote competence rather than dependence on service providers (Andrews & Andrews, 1986).

## **Advantages**

Many advantages of family-centered practice have been suggested in the literature. It has been theorized that providing services to the child's whole family indirectly facilitates the child's development (Mahoney & Bella, 1998). For example, organizing housing support for a family would also benefit the child, relieving stress on the family and allowing more time to be spent on the child's intervention. It has also been suggested that allowing parents choice and control over their child's intervention may increase their satisfaction with the service (Viscardis, 1998). The model's focus on providing participatory experiences for parents has been hypothesized to encourage parental competency-building and feelings of empowerment (Dunst & Trivette, 1996). In addition, the utilization of parents' knowledge about their child and parental involvement in service planning may result in intervention activities and outcomes that are more relevant to the child and family (Crais, 1991; Hanna & Rodger, 2002). Finally, the focus of the family-centered practice model on forming positive relationships between professionals and parents has been proposed to increase the outcomes of intervention. For example, Kalmanson and Seligman (1992, p. 48) stated, "The success of all interventions will rest on the quality of provider-family relationships."

# Disadvantages

Many of the disadvantages of family-centered practice that have been discussed in the literature center around the concept of parental decision-making. Whether parents are capable of making appropriate decisions regarding their child's health is a concern that has been voiced by a number of researchers and clinicians (Allen & Stefanowski Hudd, 1987; Appleton & Minchom, 1990; Bailey et al., 1992a; Brotherson & Goldstein, 1992; Litchfield & MacDougall, 2002). These studies have suggested that parents need and want the guidance of an expert professional in determining intervention plans for their child and that allowing parents to make the final, possibly inappropriate decisions about intervention could be unethical. It has also been suggested that not all families may want the best for their children. As Allen and Stefanowski Hudd (1987, p. 135) stated, "The occurrence of child abuse

is a harsh reminder that the needs of parents and their children are not always isomorphic."

Parent and family advocates have highlighted another potential disadvantage of family-centered practice relating to parental decision-making. Considering that families are a heterogeneous rather than a homogeneous group and have different time, abilities, priorities, and beliefs, Viscardis (1998) argued that not all families may wish to participate in the planning or delivery of their child's intervention. Although true family-centered practice advocates family choice of level of involvement, if misconstrued, involvement in intervention may be considered a parental responsibility rather than a right. Professionals may then require parents to take a lead role in their child's intervention, even if this is not the parents' wish (Espezel & Canam, 2003; MacKean et al., 2005).

From an administrative perspective, using a family-centered approach to service delivery has been suggested to be more time-intensive than traditional approaches because of the need to negotiate the content of intervention goals and activities with parents (Lawlor & Mattingly, 1998). The use of this form of service therefore may be

**Table 1–6.** Details of Studies Investigating Outcomes of Family-Centered Intervention

Study	Outcomes Evaluated	Type of Investigation	Control Group	No. of Participants
Law et al., 1998	Child intervention outcomes	Experimental study	No	12 children
Mahoney & Bella, 1998	Child intervention outcomes Parent stress and well-being	Experimental study	No	47 families

at odds with the current focus on effectiveness and accountability in allied health practice (Litchfield & MacDougall, 2002).

#### Evidence Base

Although the advantages of family-centered practice have been theorized in the literature and gained widespread acceptance, limited empirical evidence exists as to the effect of this service model on intervention outcomes (Franck & Callery, 2004; Hanna & Rodger, 2002; Jansen et al., 2004; Mahoney & Bella, 1998). Table 1-6 provides a summary of studies that reported allied health intervention outcomes (or allied health intervention in combination with other intervention) of family-centered practice for children with developmental delays or disabilities. The first studies investigating family-centered intervention were conducted in the late 1990s. In the studies identified, the outcome measures investigated included child intervention outcomes, parental satisfaction, and parental well-being. Results relating to each of these outcomes is discussed in the following sections.

(in Chronologic Order)

	Discipline of Professionals	Child's Difficulty	Age of Children	Family- Centered Aspects of Service	Major Findings
	Physio- therapists and occupational therapists	Cerebral palsy	1–4 years	Family involvement in all aspects of planning and provision	Eleven of the 12 children demonstrated changes that were considered by the researchers to be clinically important
	Early intervention staff	A variety of conditions, the most prevalent being Down syndrome	0–3 years	Varied	Family-centered service not associated with better intervention outcomes for child, decreased parent stress or improved parent-child attachment

continues

Table 1-6. continued

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Study	Outcomes Evaluated	Type of Investigation	Control Group	No. of Participants	
King, King, Rosenbaum & Goffin, 1999	Parent stress and well-being Parent satisfaction with service	Survey	No	164 parents	
Van Riper, 1999	Parent stress and well-being Parent satisfaction with service	Survey	No	94 parents	
Ketelaar, Vermeer, Hart, Beek, & Helders, 2001	Child intervention outcomes	Experimental study	Yes Randomized	55 children	
Law et al., 2003b	Parent satisfaction with service	Survey	No	494 parents, 411 service providers, 15 managers	
McGibbon Lammi & Law, 2003	Child intervention outcomes	Experimental study	No	3 children	

	Discipline of Professionals	Child's Difficulty	Age of Children	Family- Centered Aspects of Service	Major Findings
	Early intervention staff	Non- progressive neuro- developmental disorders (primarily spina bifida, cerebral palsy or hydrocephalus)	3–5 years	Not specified	Family-centered service found to be positively related to parental satisfaction, stress and well-being
	Health professionals	Down syndrome	0–22 years	Not specified	Parents' perception of relationship with health professionals linked to satisfaction with care and emotional well-being
	Physio- therapists	Cerebral palsy	2–7 years	Family involvement in all aspects of planning and provision	Children in functional therapy group (family- centered) improved more on functional outcomes than control group receiving traditional intervention
	Early intervention professionals, most frequent being occupational therapists, SLPs, and physio- therapists	A variety of conditions, the most prevalent being cerebral palsy	Majority between 3–8 years	Not specified	Satisfaction linked to parents' perception of the family- centeredness of the service
	Occupational therapists	Cerebral palsy	3–3.5 years	Family involvement in all aspects of planning and provision	Improvement on at least one of the two targeted tasks for all three of the children in the study