Early intervention services in daily family life: mothers' perceptions of 'ideal' versus 'actual' service provision

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Abstract: *Although the occupational therapy and early intervention literature espouses a family-centred approach to intervention, families have rarely been asked about their experiences of these services. This paper describes a qualitative study that aimed to identify and explore parents' perceptions of occupational therapy services and the impact of these services in their daily family life. Ten mothers of children (aged 0–6 years) with disabilities and high support needs completed questionnaires and semi-structured, in-depth interviews. Analysis revealed that mothers thought in terms of early intervention services in general, rather than in terms of occupational therapy specifically. Mothers used early intervention services primarily to enhance their child's abilities, while considering what was best for their family and, as a lesser priority, themselves. Ideally, relaxed and friendly service providers were perceived as having a greater insight into daily family life, and therefore a greater capacity to provide services to meet family needs (e.g., flexible, home-based services). However, the mothers in this study did not experience many 'ideal' characteristics of services and service providers, suggesting that changes are needed in occupational therapy practice and in the education of therapists. Implications for occupational therapy education and practice are discussed in the context of the family-centred literature, and recommendations are made for future research with families.*

Introduction

In Australia, policy and practice are directed towards a community-based model of care that encourages families to care for their relatives with disabilities in the home (Llewellyn et al., 1996). Despite an expanding definition of families, women, more specifically mothers, continue to assume the primary

caregiving role (New South Wales Government, 1994). Caregiving is frequently discussed in terms of the provision of food, clothing and shelter. However, when a young child has a disability and high support needs, caregivers, usually mothers, also become involved in 'specialist' services to help their child. Occupational therapy is one of the 'specialist' services that comprise what is known as 'early intervention'.

Emphasis on caring for children with disabilities at home has inevitably highlighted the debate regarding who occupational therapists should view as the focus of their services – the family or the individual referred. Traditionally, occupational therapy interventions involved a 'hands-on', 'one-on-one', child-centred approach (Hanft, 1988; Case-Smith, 1989). In this approach, therapy focuses on bringing about changes in the child as distinct from the family (Bazyk, 1989). More recently, there has been an emerging focus on family-centred care whereby it is assumed that supporting families in their caregiving role promote the functional development of the child (Hanft, 1988). This assumption has considerable implications for the skills and approaches used by therapists in early intervention.

What skills are required by occupational therapists working in early intervention? Humphry and Link (1990) ranked 10 basic competencies, of which four related to working with families. These include skills related to developing an understanding of individual family situations, and communicating this understanding to parents. The evidence suggests that these skills may be more prominent in therapists with more clinical experience and higher academic qualifications (Hinojosa et al., 1988; Humphry and Geissinger, 1993).

Extensive guidelines exist for occupational therapy practice with families. These are drawn predominantly from the North American context (for example, Hanft, 1988; Dunn et al., 1989; Grady, 1989). Although these guidelines are reported almost exclusively from therapists' perspectives rather than from families' perspectives, they suggest that occupational therapists support parents in several ways (Humphry and Link, 1990). Primarily, this support is practical (e.g., equipment provision, direct therapy with the child) and/or emotional (e.g., counselling). It is usually directed towards parents in their role as caregivers of a child with a disability.

Occupational therapy guidelines further suggest that supportive services are characterized by therapists and parents working together to develop a service structure and home programme routine that fits into daily family life (Bazyk, 1989). It is suggested that this occurs through the development of a collaborative relationship between therapists and parents (Bazyk, 1989). This relationship is characterized by parents and therapists working as equal partners to identify the needs and resources of each family.

Despite the development of extensive family-oriented guidelines and competencies, the extent to which occupational therapists work with families varies greatly (Redditti, 1983). Therapists have identified numerous barriers to effective collaboration, such as time and schedule inflexibility, and therapists'

lack of experience and education concerning working with families (Hinojosa et al., 1988; Humphry et al., 1993).

Lack of collaboration with parents and dissatisfaction with services is clearly evident in studies that more generically investigated formal support services from the parents' perspective. Several researchers identified parents' beliefs that formal support services were not truly supportive of families (Cunningham et al., 1982; Ayer, 1984; Sloper and Turner, 1992). In each of these studies, parents described experiencing unmet family needs and unhelpful service providers. They highlighted the importance of both practical and emotional support from service providers.

Several studies focused on parents' views of their relationships with service providers (Baxter, 1989; McKay and Hensey, 1990; McKenzie, 1994). In two Australian studies parents described service providers in relation to their professional interest and perceived helpfulness (Baxter, 1989; McKenzie, 1994). Helpful service providers were perceived as those who answered questions, proffered friendship and support to family members, provided practical support and shared information about the child's disability and appropriate services. Service providers perceived as unhelpful did not exhibit these behaviours. Professionals who indicated a genuine interest in the development of the individual child and the concerns of the individual family were highly valued by the parents in both studies.

These studies, and similarly an Irish study by McKay and Hensey (1990), highlighted parents' dissatisfaction with services and considerable unmet family needs. In McKay and Hensey's 1990 study, 70% of parents were dissatisfied with services. This dissatisfaction stemmed from a lack of explanations regarding the child's condition, a dismissal of worries, and a lack of understanding of the problems involved in handling the child. Unhelpfulness and a lack of genuine concern and understanding of the individual child and the family were reported in the Australian studies (Baxter, 1989; McKenzie, 1994).

In these studies, parents clearly identify characteristics of service and service providers that would help them to care for their child with high support needs. However, parents continue to report dissatisfaction with services. This dissatisfaction is somewhat alarming given the supposed reorientation of services towards the documented concerns of families.

Occupational therapy is one service for families of young children with disabilities (Agosta and Bradley, 1985). There is only one study that addresses parents' views of occupational therapy services. This North American study by Jim Hinojosa is reported in two key articles (Hinojosa, 1990; Hinojosa and Anderson, 1991). Hinojosa sought the perspectives of eight mothers, each caring for their young child with cerebral palsy at home. Emergent themes described the impact of a child with cerebral palsy on family functioning and relationships. Other themes described the significant demands faced by families as a consequence of their contact with occupational therapy and physiotherapy services (Hinojosa, 1990). In particular, mothers reported difficulties

associated with home therapy programmes. Overall, mothers had never been involved in, or had ceased or adapted their occupational therapy and physical therapy home programmes, in order to fit them into their family routines (Hinojosa and Anderson, 1991). These adjustments were made because programmes were too frustrating, too difficult, too time-consuming, or something that parents did not want to do with their child.

Hinojosa's work indicated that mothers face significant demands as a consequence of their contact with occupational therapists and physical therapists. This study aimed to build on Hinojosa's work by exploring mothers' perceptions of occupational therapy services and personnel, and, further, to examine the impact of these on daily family life.

Method

A qualitative, ethnographic approach using semi-structured, in-depth interviews and demographic questionnaires was used to explore the parents' perspective. Qualitative methodologies were preferred given the emphasis on context, setting and the subjects' frame of reference (Marshall and Rossman, 1989; Frank et al., 1991).

Sample

This study was undertaken within the context of a larger study that sought, in part, to explore supports and services required by parents of young children with disabilities and high support needs. Families with children aged between 0 and 6 years of age were eligible for this study, which is reported in detail elsewhere (Llewellyn et al., 1996). Those families involved who were identified as recipients of occupational therapy services were subsequently referred to the author. A convenient sample of 10 families was selected from those referred to cover rural, semi-remote and metropolitan areas. Information about the participating families is provided in Table 1. Three case studies are also presented to provide a more detailed view of the diversity and complexity of the circumstances of the families. The families presented in this case study represent varied geographical locations, child age and family structure.

Case studies

The Carroll family

John (30) and Kathy (31) have been living with their son Christopher in their own home in a small New South Wales country town. John travels half an hour to work and Kathy works in town running her own business. Christopher has a severe intellectual disability of unknown origins. He is a 'very happy, easy-going child' who is 'just as happy playing with toys by himself as anyone else'. He

Code	Child's gender	Child's age[a]	Type of disability	Place of residence	No. of people in family[b]
Table 1: Description of study participants					
01	Male	2yrs 7mths	Multiple	Rural	2 parents 3 children
02	Male	3yrs 8mths	Intellectual	Rural	2 parents 1 child
03	Male	3yrs 3mths	Multiple	Semi-remote	2 parents 4 children
04	Female	2yrs 7mths	Physical	Rural	2 parents 2 children
05	Male	5yrs 8mths	Physical	Semi-remote	2 parents 3 children
06	Male	2yrs 7mths	Multiple	Metropolitan	2 parents 4 children
07	Male	2yrs 4mths	Multiple	Metropolitan	2 parents 3 children
08	Male	2yrs 7mths	Multiple	Metropolitan	2 parents 5 children
09	Male	3yrs 5mths	Intellectual	Metropolitan	2 parents 3 children
10	Female	4yrs 2mths	Multiple	Metropolitan	2 parents 3 children

[a]Child's age at the time the questionnaire was completed
[b]Number of people in the family (inclusive of the child with a disability) living at the same address as the child with a disability

attends a long-daycare centre five days a week. Most visits by early intervention service providers occur at this centre. When possible, appointments are scheduled for lunchtime so that Kathy can attend. Although Kathy and John share the household responsibilities, Kathy is primarily responsible for coordinating and monitoring the therapy services that Christopher receives. Both John and Kathy work with Christopher in play-like therapy at home. They don't like to push him too much, preferring to spend their limited time with him as 'quality time'. Both parents are frustrated and anxious that services are not available at times when they can attend, believing that this means that Christopher cannot get the maximum benefit from services. They believe their anxiety is exacerbated by lack of feedback from service providers.

The Wilson family

Luke is a five-and-a-half-year-old 'happy-go-lucky' child who lives with his family in a small village about 50 minutes from the nearest town. Luke was

involved in an accident when he was two years old. Following the accident, his parents Andrew (40) and Jacinta (37) were told that Luke would be extremely developmentally delayed for the rest of his life. They steadfastly refused to accept such a negative diagnosis and, with the assistance of Luke's sisters and grandparents, set about an intensive rehabilitation programme to 'prove them all wrong'. Luke and his parents were originally involved in 3 months of daily 4-hour therapy sessions in Sydney. Nowadays, Luke maintains half-yearly contact with these services in Sydney and has steadily decreasing contact with local therapists. Andrew is a freight worker and often works away from home, and Jacinta works part time in a local store. This has made it difficult for them to be as involved in Luke's therapy sessions as they would like. Luke has progressed from the expectation of being wheelchair-bound, to that of walking, attending school and participating, albeit as a uniformed supporter, in the local junior football team. Jacinta describes Luke's therapy programmes as gradually becoming an integral part of both Luke and the family's daily routine. She feels lucky that Luke is aware of the importance of 'doing therapy' and is therefore very self-motivated. She feels that, in part, this motivation can be attributed to his age and his personality.

The Madigan family

Alan (39) and Robyn (32) live with their two daughters Jessica (9) and Michelle (6) in their southern Sydney home. Their son Paul (4) was born with severe intellectual and physical disabilities. Paul was placed out of home about 18 months before the interview. His mother provided a detailed description of the daily life of her family during the two-and-a-half-year period that Paul lived with them, and noted that this routine was one of the factors leading to the decision to seek out-of-home placement for Paul. The increasing demands and responsibilities on Paul's siblings were also key factors in the placement decision.

Robyn had been getting up early each morning to feed and dress her children and get Jessica off to school. The rest of the day was devoted to housework, arranging childcare, attending Paul's medical and therapy appointments and implementing home programmes. Paul received physiotherapy and occupational therapy from the same centre on separate days each week. Each therapy session involved 3 hours, including travel. Siblings were prohibited from attending these sessions, so Robyn relied heavily on neighbours and friends for childcare. Since Allan works long hours, he was only involved in Paul's care on evenings and weekends. He preferred to spend his limited time as 'quality time' rather than as therapy sessions. Robyn stressed that the hectic routine involved in care and therapy with Paul was 'wearing her down'. She felt tired enough that she feared she might somehow hurt or drop Paul during the considerable handling that he required. She still monitors the therapy services that Paul receives at his residence on her weekly visits to him.

Data collection

The author made initial contact with all families by telephone. At this time and throughout the project, all parents were assured of anonymity and the right to withdraw from the study at any time. Following verbal consent to participate, the primary caregiver in each family was sent an information package containing a consent form, a project summary sheet, a family information sheet and several copies of the pre-interview questionnaire. The pre-interview questionnaire contained demographics of the occupational therapy service(s) that the child had contact with. On receipt of completed family information sheets and pre-interview questionnaires, analysis of the information guided the subsequent semi-structured, in-depth interviews.

A combined semi-structured and open-ended interview technique was used in this study. An interview guide was developed, pilot-tested and used following a thorough review of the literature and in association with a mother of a young child with a disability and a paediatric occupational therapist. Five basic areas provided an outline for addressing parents' perceptions: (i) the focus of the service; (ii) the fit of services into family routines; (iii) the values and attitudes of the therapists working with families; (iv) the coordination between services and different occupational therapists; and (v) parents' descriptions of occupational therapy.

Nine of the interviews were conducted with only the mother present. In one interview, the father was also present. Interviews ranged from 50 minutes to 1.5 hours and were each held in the family's home. All interviews were taped and transcribed and fieldnotes written and organized as outlined by Minichiello et al. (1990).

Additional probes were developed from the literature, thematic analysis of questionnaires and ongoing interviews. Following each interview, interview transcripts were analysed as described below. In this way, developing themes were presented and discussed in following interviews.

Data analysis

Transcripts were analysed in accordance with the methods outlined by Strauss and Corbin (1990). Constant comparative analysis was conducted on all transcribed interview material to identify similarities and differences in the data.

Strauss and Corbin (1990) refer to the first stage of coding as open coding. During this process, descriptive categories were developed to reflect the basic concepts proposed as fundamental to the lives of families of a child with a disability. Therefore, each category was a grouping of the resources, constraints, values, beliefs, concerns, priorities and adjustments affecting families (Gallimore et al., 1989) as a result of their contact with early intervention services. Examples include: relationships, characteristics of ideal services and service providers, perceived roles of families, and the effects of services on

family life. Re-analysis and refinement of these descriptive categories identified mothers' descriptions as action-oriented concepts, for example, comparing, monitoring and seeking.

The process of axial coding was then employed to determine the primary phenomenon in the data (Strauss and Corbin, 1990). Axial coding is the process where categories or concepts are refined in terms of condition, the context in which they exist, the actions or strategies taken, and the potential consequences of these actions. Thirty-three concepts and their dimensions were developed from the categories identified during open coding.

Data analysis progressed by further employing axial coding to group the 33 concepts into four major categories. The four major categories were named as follows: (i) 'Doing the best for my child'; (ii) 'Helping the child to develop skills'; (iii) 'I have to think of my whole family'; and (iv) 'What does that do?'– the place of services. These categories focused on the mother, the child, the family, and the early intervention services respectively. Each of the four major categories comprised subcategories pertaining to the actions, beliefs and feelings of those concerned.

The intention of this study was to explore parents' perceptions of occupational therapy services in daily family life. However, from the first interview, it was clear that mothers did not differentiate between the various early intervention service providers. Rather, they talked of 'therapists' in general when referring to physiotherapists, speech therapists, special educators and occupational therapists. Results presented here, therefore, reflect parents' perceptions of early intervention services and service providers in general.

Results

'Doing the best for my child'

This category is mother-centred. Mothers outlined their feelings and actions as they sought to care for their child, and to use early intervention services. Mothers talked about evaluating their efforts by comparing these with their child's progress and development. When the child was progressing well, mothers perceived their efforts in accessing and participating in early intervention services as worthwhile and consistent with the needs of their child.

Mothers talked about constantly seeking reassurance and feedback from service providers about their child. As one mother emphasized, 'parents need this support so as not to blame themselves and so as to feel that they are doing everything that they can that is within their power to help their child'. Mothers also compared their efforts with those of other mothers, often declaring that those mothers were not assertive with service providers and 'did not get answers'.

From the data, it was clear that mothers were involved in an ongoing cyclical process of seeking, waiting, participating in, adjusting to and analysing the

early intervention services their child received. In particular, mothers emphasized what they feared was a lifelong search and struggle for services to help their child in a 'system' they perceived as having a vast shortage of service providers. The ensuing wait for services and associated delay in the progress and development of their child left mothers feeling anxious, angry and frustrated.

Once ongoing contact with an early intervention service was established, mothers made substantial efforts to accommodate and monitor these services. Often this involved developing and adapting strict personal and family routines in order to incorporate direct-contact time with therapists and the home programmes they recommended. As one mother described her family routine, 'I have got to know ahead of time what I have planned, whether I have got OT or speech or whether he has got a different physio to go to or an appointment with the neurologist ... my calendar is a month-and-a-half ahead.' When these adaptations to family routines proved too difficult, mothers began to selectively adapt home therapy programmes to their routines. Additionally, all the mothers that participated in this study had forgone opportunities (e.g., employment) in order to pursue early intervention services for their child.

'Helping the child to develop skills'

In contrast to the previous mother-centred category, this category focuses on mothers' perceptions in relation to their children. Apart from good health, what the mothers in this study most wanted was for their child to further develop. Continuity, rate and maintenance of child development formed the standard against which mothers measured all efforts and accommodations of the family and the early intervention service. Mothers measured their child's development in terms of functional goals such as 'communicating' and 'walking'. In contrast, mothers believed that therapists measured a child's progress in terms of component skill such as 'muscle strength'. To determine the rate at which their child was developing, mothers compared the development of their child with high support needs to the development of other children both with and without disabilities, and to their child's own previous level of development. This constant comparing often left mothers feeling overwhelmed and stressed by their own and others' expectations about their child's development.

Mothers perceived that the development of their child was unquestionably linked to their efforts as the primary caregivers. Additionally, child development was influenced by a number of service characteristics. First, mothers believed that the amount of contact time that the child had with therapists impacted on the child's development. Greater improvement was expected with more frequent contact with services, greater numbers of services, more continuous contact, and less delay prior to contact with services. Second, mothers believed that if the different early intervention service providers

worked together on common goals, then the child was more likely to develop.

Family characteristics, in particular those of the child and the primary caregivers, were thought to both influence and be influenced by the development of the child with high support needs. Mothers reported believing that the more time they were able to spend repeating and reinforcing therapy sessions at home, the more likely it was that their children would progress and develop. Similarly, mothers believed that when a child's health, medication, routine and temperament were stable, and the level of disability lower, the child was more likely to develop. Finally, mothers described a decline in the strictness and child focus of the family routine with improved child skill level.

'I have to think of my whole family'

Mothers not only thought of their role and the development of their 'special needs' child, they also considered the impact on their family of being involved in early intervention services. This category therefore describes the mothers' family-focused actions and concerns. Mothers appeared to be continuously balancing the demands placed on them by their home, their family and the early intervention services their child received. As one mother suggested, '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.' Many of these demands were balanced by the use of a strict set of routines and procedures that allowed mothers to 'get everything done'. Balancing therapy and home-related demands involved considering both home programmes and direct-contact therapy sessions. Despite difficulties balancing these demands, the belief that these services were vital to their child's development led mothers to often declare that, 'we make it [therapy] fit'.

Mothers' attempts to incorporate early intervention services into daily family life were often thwarted by the incompatibility of family and therapist routines. These often-unsuccessful comparisons of family and therapist routines proved stressful to mothers who were attempting to plan their daily family life. For example, appointments that did not fit into normal family routines often required organizing childcare for siblings. Mothers were also comparing their past and present family routines in order to monitor the impact of early intervention services on family members and routines.

Mothers described the significant impact that a child with high support needs has on siblings. Substantial increases in the responsibilities allotted to siblings and periods of jealousy were emphasized. It was not surprising, then, that mothers highly valued those early intervention services that fostered sibling participation, thus allowing siblings to become involved in home programmes and promoting a sense of inclusion. Those early intervention services that used a family-oriented approach were perceived as having the potential to bring the family unit closer together and to strengthen family relationships.

For the mothers in this study, family participation in early intervention ser-vices was influenced by both practical and personal factors. The availability of childcare, the attitude of service providers towards siblings, the employment situation of caregivers, and transport difficulties were identified as barriers to family participation in services. In addition to these barriers, mothers also reported that family participation in early intervention services varied over time in response to the different demands on family routines and caregivers. At a more personal level, mothers emphasized the need for therapists to help them determine their own 'comfortable' level of involvement in therapy ser-vices. That is, some mothers felt therapists were 'the experts' and therefore left 'therapy' to them, whereas other mothers preferred to be very involved in therapy sessions. When therapists were perceived as friendly, families were more involved. Conversely, when therapists were perceived as unfriendly, mothers were less involved in their child's programmes, as one mother empha-sized: 'I mean, if you can't approach them, and it has happened, then you get very standoffish and don't want to go to the sessions ... I didn't feel comfort-able with her ... so I would just keep out.'

'What does that do?' – The place of services

The mothers in this study were candid in describing the ideal characteristics for services and service providers based on their own experiences and prefer-ences. This category describes, first, the potential benefits of these ideal ser-vice characteristics. Second, this category describes mothers' experiences of the 'reality' of many early intervention services in terms of the difficulties they generate in family routines.

Mothers in this study repeatedly emphasized the role of the therapist as a 'teacher' of therapy techniques to both caregivers and children. They stated a belief that therapists could act as a vital link to other forms of information and support. Direct links to other useful services such as referrals to speech pathologists and resource centres were highly valued. Additionally, therapists were regarded as providing desirable reassurance and guidance by sharing information about their experiences with other children with disabilities and their families. One mother commented: 'For the therapists to relay stories to you, you think "Ah – someone else is doing the same thing I am doing".'

Therapists were also supporters in addition to their roles as teachers and 'information providers'. Mothers described needing and sometimes receiving informal support such as open, friendly and relaxed relationships, and envi-ronmental support, such as the adaptation of the environment and the provi-sion of equipment. Mothers particularly emphasized the value of informal support to themselves as primary caregivers. As one mother noted: 'I found that they became friends with us, so they were a support for the family. They asked questions about what we were all doing as well as dealing with Michael.'

Of all the aspects of the study, mothers felt most strongly about the way

that therapists related to mother and child. On the whole, mothers emphasized the value of genuine, open, relaxed, reciprocal and friendly relations with therapists. As one mother stated emphatically, 'It is not just professional. Having a professional bond with each other is no good. You have got to be friends before you can have them as therapists.' Therapists' attitudes determined mothers' responses. So, if therapists were guarded or unfriendly, then mothers felt less 'open' about participating in services and providing therapists with a 'true' picture of family life.

The place of early intervention services in family life for these families with children with high support needs was significant indeed. Often, early intervention services added considerable pressure to families already straining under the pressure of busy family routines. As one mother explained, 'You would think "She has to go to physio – so what?" You wouldn't have thought about the amount of time involved, the child not wanting to do it, and you knowing that they have to do it, the child screaming and biting at you ... it has been an experience.' Frequently, the added pressure was a result of families' efforts to adjust routines and resources in order to use early intervention services. Transport to and from early intervention centres was difficult for many families and often was a precursor to mothers' requests for home visits. Difficulty organizing such frequent childcare for siblings was also noted by mothers as a practical and stressing obstacle to accessing and participating in early intervention services. Mothers noted significant financial costs associated with accessing early intervention services. In particular, the cost of transport to services, childcare for siblings and loss of income was considerable. Additionally, several mothers described accessing costly private intervention services while on the waiting list for public early intervention services. Overall, mothers described early intervention services as an additional time stress in the strict, time-constrained family routines they associated with caring for young children with high support needs and their families.

Discussion

Mothers' perceptions relating to early intervention practice in daily family life can be grouped into three basic concerns. First, mothers talked about the ways that services should ideally respond to and work with families. Second, mothers described the impact of the service actually provided. Finally, mothers discussed the method they believed would help reach their more ideal service provision – that is, a relaxed and friendly relationship between families and therapists. Issues relating to each of these areas are outlined below, with particular emphasis on family-centred care.

The findings in this study in relation to what mothers want from early intervention service providers are consistent with research concerning generic support services. Appeals for therapists to provide information (Ayer, 1984; Baxter, 1989); to develop open, trusting communications with caregivers

(Hinojosa et al., 1988; Humphry and Link, 1990); and to advocate for child and family needs (Humphry and Link, 1990) are repeatedly emphasized. Services continue to fail to meet family needs and parent requests, despite the consistency of these findings.

Despite the substantial emphasis in the professional literature on the family-centred model of service provision, almost all occupational therapy services received were perceived by mothers as being focused on their child with high support needs. These findings are more consistent with the traditional child-centred approach (Case-Smith, 1989). That is, therapists were primarily providing 'hands-on' direct interventions with the child with high support needs. This contradicts the views expressed by the mothers in this study, who perceived that the personal support provided to them by therapists was as important as 'hands-on' intervention with the child. Interestingly, the professional literature falls far short of similarly acknowledging the value of personal support provided to caregivers by therapists.

The notion that mothers develop and adjust their personal and family routines to fulfil the extra caregiving demands associated with a child with a disability is not new (Bowman and Virtue, 1993). However, mothers in this study also adjusted their personal and family routines in order to obtain, maintain and monitor early intervention services. Many of the ideal characteristics of services and service providers that mothers noted were not experienced in reality. Why do mothers perceive these adjustments as necessary? Why were these characteristics not a part of service provision with families? It would seem vital to ask these questions in the face of the increasing volume of 'family-centred' literature promoting consideration of families and their needs.

From the mothers' perspective, adjustments to personal and family routines were often a result of service providers' failure to adequately involve families in the development or implementation of therapy services. Despite emphasis in the literature promoting family-focused services, this situation appears widespread. Ninety per cent of mothers in this study were not involved in the development of an Individualized Family Service Plan (IFSP) or similar plan. The IFSP has emerged as a key method of helping service providers consider the needs, resources, concerns and strengths of families (Decker, 1992) and therefore its use could potentially reduce the need for family adjustments to utilize early intervention services. In a recent study by Harrison et al. (1996), almost half of the respondents had not been involved in the development of an IFSP. It is important to consider, though, that use of an IFSP does not necessarily generate optimum family involvement. Evaluations of instances where IFSPs were used have revealed that despite requirements for full family involvement, early intervention personnel maintain beliefs about themselves as primary decision-makers within the IFSP process (Katz and Scarpati, 1995). Although use of IFSPs and similar plans can assist service providers to make their services more family-centred, it is the attitudes and values of the therapists that are more likely to determine family involvement.

Mothers in this study felt that therapists often failed to consider mothers' roles that were not related to direct therapy provision. Yet occupational therapists are described as being concerned with the occupational role balance of the family, in addition to that of the child (Bazyk, 1989; Esdaile, 1994). Why is such a vital occupational therapy role apparently being ignored?

In this study, mothers wanted therapists to be friendly people with good communication skills. Therapists needed to be able to communicate sensitivity to and understanding of family needs and priorities and a genuine concern for their resolution. As Hinojosa (1990) noted, 'Often it appeared that the therapist as a person was more important than the therapy itself' (p. 154). Therapists who possess the desired qualities were described as more likely to develop an insight and understanding of family needs, priorities, concerns and resources. Accordingly, such therapists structured their services to meet the personal (e.g., emotional support) and practical needs (e.g., home visits, sibling involvement) of individual families. McKenzie (1994) also noted the critical value that parents place on the development of friendships with service providers.

Why were many families continuing to experience unfriendly therapists, poor parent–therapist relationships and, consequently, unmet family needs? Mothers in this study thought that personnel shortages and the associated time constraints were major factors. The literature, however, suggests that many therapists, particularly those with less experience or education, do not have the skills required to work with families (Hinojosa et al., 1988; Humphry et al., 1993). Such findings suggest a need for provision of continuing education or in-service training for early intervention service providers on working effectively with families. Additionally, occupational therapists' views with regard to their perceived role in daily family life need to be sought to determine if and how occupational therapists work with families of children with disabilities.

Although the aim of this study was to specifically investigate occupational therapy services, mothers actually perceived services and service providers more broadly in terms of early intervention. Why did mothers have difficulty differentiating occupational therapists from other early intervention service providers? Perhaps the sheer number of different service providers working with families of young children with high support needs made it difficult to determine 'who is who' on the team, thus implying a need for a more transdisciplinary approach. Similarly, mothers might not care to distinguish among these service providers as long as the child is being assisted. Alternatively, mothers may not have been aware of any unique role of occupational therapists, perhaps representing the considerable debate surrounding the way occupational therapists define their role. Should we as occupational therapists be concerned that families are not able to distinguish our role, or is this comparatively unimportant on the proviso that family interests are served?

Conclusion

Mothers in this study clearly described 'ideal' characteristics of services and service providers. These descriptions have significant implications for, and present a challenge to, occupational therapy practice, education and research. To be truly family-centred therapists we need to reflect on and re-orient to the expressed need of families. We need to work with other professions and with families on common functional goals. We need to provide relaxed, friendly support to family members as individuals, not exclusively in relation to the child with a disability. We need to foster family involvement in services, with particular emphasis on sibling participation. To do so, we need to develop the skills and knowledge required to work with families. Occupational therapists need to be educated in family-related expertise in addition to the child-related skills that dominate undergraduate studies in paediatrics. As researchers, we need to further investigate the needs of families and the best ways of meeting these needs. First and foremost, developments in all areas of family-centred occupational therapy practice, education and research will require us to listen to families. To do less would negate our fundamental concern as occupational therapists – to support the health and wellbeing of the clients we serve.

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