Parents, Families and Partnerships: Issues and considerations

Deb Keen[*]

Griffith University, Australia

The first contact parents may have with a professional in relation to their child with a disability is often at the point of diagnosis. From that moment onwards, parents embark on a journey that generally involves the formation of many relationships with professionals working in the field. These relationships have the potential to facilitate individual and family outcomes but may also jeopardise these outcomes. It is not surprising that researchers have been interested in examining the components of productive relationships and the impact these may have on the quality of life for individuals with disabilities and their families. This article draws on the work of contributing authors to this special issue to examine some of the research that has led to our current understandings of how parents who have a child with a disability and professionals can form meaningful and productive partnerships. It considers how the nature of these partnerships is changing and some of the issues that have been raised as a result of these changes.

Introduction

The way in which parents of children with a disability and professionals relate to each other has been of interest to researchers and clinicians for some time. Current understandings of the nature and importance of the parent-professional relationship have been informed by history which has shown the changing nature of this relationship over time. At any point in time, this relationship has tended to reflect theories of the causes of disability and/or the perceived roles of parents with respect to the care and education of their child with a disability (Jones, 1998;

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[*] Faculty of Education, Mount Gravatt Campus, Griffith University, Brisbane, Qld 4111, Australia. Email: d.keen@griffith.edu.au

Turnbull & Turnbull, 1986). For example, parents have sometimes been viewed as the source of their child's disability, exemplified by Bettleheim's now discredited theory that autism was in some way caused by the "cold" parenting style of the child's mother (Bettelheim, 1967). Parents were therefore encouraged to institutionalise their children, based on the belief that by replacing the parent with a trained professional the child would grow up in a more nurturing environment (Turnbull & Turnbull, 1986). Relationships between parents and professionals within this context were marked by professionals making judgments about the suitability of parents to raise their own children. Control over the child's life was in many cases arrested from parents and assumed by professionals. Professionals were viewed by many as having the necessary expertise to make decisions in the best interests of the child, the implication being that parents were not fit to do so.

More contemporary conceptualisations have adopted a family systems' perspective that views the child with a disability as a family member. This approach recognises the interrelatedness of family members and the importance of acknowledging the needs of all family members, not just those of the person with a disability (Brown, Nolan, & Davies, 2001; Carpenter, 1997; Dunst, Trivette, & Johanson, 1994; Fox, Vaughn, Dunlap, & Bucy, 1997; Knox, Parmenter, Atkinson, & Yazbeck, 2000; Murray, 2000; Turnbull, Blue-Banning, Turbiville, & Park, 1999). Important to this conceptualisation has been the formation of relationships between professionals and parents that are underpinned by respect, trust, and open communication, with professionals becoming skilled in a variety of communication techniques or strategies that enable them to work effectively with families (Turnbull & Turnbull, 1986).

Characteristics of Parent-Professional Relationships

Relationships between parents and professionals are often considered to be most effective when they represent true partnerships (Morrow & Malin, 2004). Certain key characteristics of effective partnerships have been identified in the literature and include: mutual respect, trust and honesty; mutually agreed upon goals; and shared planning and decision-making.

Mutual respect, trust and honesty. In a survey conducted by Dunst, Trivette, and Johanson (1994), parents and professionals were asked to list the behavioural and attitudinal characteristics they believed to be important if parent-professional relationships were to be considered as true partnerships. Characteristics were ranked separately for parents and professionals and were also combined. There was significant overlap in the characteristics ranked by both parents and professionals as most important. The highest ranked characteristic for the combined group was "trust", followed by mutual respect, open communication, and honesty. Dunst et al. (1994) have argued that it is the mutual nature of these characteristics that distinguish a partnership. A professional may demonstrate respect and honesty in a counselling relationship with a client, for example, but a partnership requires reciprocity.

Developing a trusting and respectful relationship is unlikely to occur automatically or easily (Dunlap, Fox, Vaughn, Bucy, & Clarke, 1997). Identifying and evaluating skills and behaviours of professionals that may facilitate a collaborative helping style, which fosters partnerships with parents, has been and continues to be, an important area of investigation (Dunst, Trivette, Davis, & Cornwell, 1994; Summers et al., 2005). Compatibility between professionals and family is complex when professionals are required to work with a diverse range of families with complex and differing needs. The same professional may successfully build a strong and respectful relationship with one parent but struggle to establish rapport with another (Rodger, Keen, Braithwaite, & Cook, in press). As the research by Rodger et al.

shows, however, it appears that the effectiveness of the relationship is at least in part influenced by the presence or absence of trust, respect, and honesty.

Mutually agreed upon goals. The importance of mutually agreed upon goals has been emphasised in much of the partnership literature, particularly in relation to business partnerships (Dunst, Trivette, & Johanson, 1994). In business partnerships, there tends to be agreement between the partners about roles and the pursuit of a joint interest or common goal (Dunst & Paget, 1991; Murray, 2000). Unlike business partnerships, however, neither parent nor professionals generally get to choose the partnership, they have little say over when the partnership commences or ends, and goals are often broadly defined with parents and professionals interpreting goals differently rather than sharing the same understanding (Murray, 2000).

Consequently, there has been recent clinical and research interest in how best to achieve agreement between parents and professionals on goals and priorities (Dempsey & Carruthers, 1997; Lucyshyn, Dunlap, & Albin, 2002; Rodger, Braithwaite, & Keen, 2004; Sperry, Whaley, Shaw, & Brame, 1999). The Individual Education Plan (IEP) has been widely used, and in some cases mandated, to encourage parental participation in educational goal setting for students with disabilities. In the United States (U.S.), for example, the Individuals with Disabilities Education Act (IDEA) amendments of 1997 and 2004 mandated the inclusion of parents as members of the IEP team and in the development of the Individualized Family Service Plan (IFSP) associated with provision of early intervention services. The IFSP focuses on the needs, strengths and resources of the family, including the individual with a disability, reflecting the shift mentioned earlier to a more family-centred approach (Individuals with Disabilities Education Act, 2004).

The actual involvement of parents in IEP or IFSP processes, however, can vary widely within the U.S. and elsewhere (Ashman & Elkins, 2002; Dabkowski, 2004) and parents are not always partners in the decision-making process (Harry, Allen, & McLaughlin, 1995; Salembier & Furney, 1997). Ways of achieving effective partnerships around goal identification have therefore been of interest.

Rodger, Braithwaite, and Keen (2004) used a modified version of the Canadian Occupational Performance Measure (COPM) (Law et al., 1998) to work in partnership with parents to identify parental priorities and establish intervention goals for their children with autism involved with a home-based early intervention programme. The COPM was developed by Law et al. from a family-centred practice framework and has been used to document occupational performance and satisfaction. Rodger et al. used the COPM to discuss with parents their child's performance in areas of self-help, play, behaviour and communication. Parents first rated their child's difficulties in these areas using a 10-point scale to identify priorities for intervention. These ratings were used to select three to five areas to focus on during intervention. Parents then rated their child's current performance and satisfaction with that level of performance for each focus area, again using a 10-point scale. The authors found the COPM to be a useful tool to enable parents to identify intervention goals for their children and to prioritise those goals based on the importance placed on them by parents using the rating scale.

Another approach described in the behavioural literature has been to identify goals as part of a broader focus on a family's ecology (Fox, Vaughn, Dunlap, & Bucy, 1997; Lucyshyn, Albin, & Nixon, 1997; Vaughn, Dunlap, Fox, Clarke, & Bucy, 1997). In this process, family members are interviewed and information about the family's goals, strengths, resources, social supports, and stressors are considered in the development of the intervention plan (Lucyshyn, Albin, & Nixon, 1997). This approach is thought to enhance the contextual fit

between an intervention and the ecology of the family. Behavioural interventions that have been developed in collaboration with families to enhance contextual fit have been found to lead to greater reductions in challenging behaviour and increases in on-task behaviour than interventions based on a more prescriptive treatment package (Moes & Frea, 2000).

These approaches to achieving agreement about goals and priorities provide some encouraging directions and are an important component of the broader issues of shared planning and decision-making.

Shared planning and decision-making. Closely associated with mutually agreed upon goals is shared planning and decision-making (Knox, Parmenter, Atkinson, & Yazbeck, 2000). In a study investigating family control, Knox et al. (2000) canvassed the views of 68 families who had a child with a disability. They found that genuine sharing of decision-making between families and professionals was a critical element to parent's sense of lifestyle control. Parents often felt, however, that control had to be fought for by them being "pushy" and assertive rather than willingly shared by professionals. Stoner et al. (2005) found that this need to be assertive was evident from the parent's first contact with professionals associated with obtaining a diagnosis for their child. "The struggle for a diagnosis initiated a pattern of persistent behaviour, and a sense of distrust with medical professionals, which continued and influenced parent interactions with education professionals" (Stoner et al., 2005, pp. 41-42).

Others have found a high level of dissatisfaction amongst parents in relation to their diagnostic experiences (Sloper & Turner, 1993), and a sense of disempowerment (Howlin & Moore, 1997; Midence & O'Neill, 1999; Smith, Chung, & Vostanis, 1994). In an attempt to investigate in more detail the relationship between empowerment factors and parental satisfaction with the diagnostic process, Keen, Davey, and Grimbeek (2006) surveyed 154 parents of children with autism about their diagnostic experiences. They identified a number

of factors related to parental satisfaction. Satisfaction was higher in parents who felt more able to take action for their child and who had a greater awareness of available resources. Satisfaction was lower in parents who reported higher levels of commitment to meet the needs of their child. The authors suggested that perhaps these parents felt frustrated by delays or barriers they experienced while trying to obtain a diagnosis and that they perceived this as an impediment to meeting the needs of their child, thereby impacting commitment.

The studies cited above highlight that control and decision-making in relationships with professionals is a concern shared by many families with varying circumstances. Parents of children with disabilities with varying aetiologies and across the lifespan appear to value shared decision-making and control within these relationships. It is evident, however, that from the early contacts families have with professionals around diagnosis there are threats to the development of true partnerships. Morrow and Malin (2004) suggest that power in a relationship can shift when one of the parties takes on more decision-making. They describe this type of power as relationship power, as distinct from personal power. Relationship power concerns the ability to influence others. Experiences that discourage parent participation in decision-making may entrench an imbalance in power sharing within the relationship and act as a barrier to engaging with parents around decision-making in future relationships.

True partnerships require professionals to view parents as key decision-makers rather than simply consumers or clients of a service (Brown, Nolan, & Davies, 2001; Knox, Parmenter, Atkinson, & Yazbeck, 2000; Murray, 2000). It is apparent from the studies reported above that both current and future relationships with professionals can be undermined when parents perceive a need to be assertive in order to participate in decisions related to their child with a disability. It is as if they have to struggle to be "allowed" to participate which runs contrary to notions of partnership and shared planning. Research on parental satisfaction with the diagnostic process suggests that perceptions of parents about the need to be assertive in order

to retain some control over decisions affecting family members can occur from the very first contacts they have with professionals about their child's disability.

In summary, the parent-professional literature suggests that relationships are most effective when based on mutual respect, trust and honesty; where decision-making and planning around mutually agreed upon goals are shared between parents and professionals. These ideals may not always be reflected in practice and less than optimal relationships may encourage the adoption of specific behaviours to overcome a loss of control in planning and decision-making. To date, partnerships have been discussed in terms of the relationship between parents and professionals. With the growing influence of family systems theory and family-centred practice, however, there has been a reconceptualisation of the parent-professional relationship to better embrace the family within the relationship (Carpenter, 2003). This has introduced a level of complexity to the partnership dynamic as relationships extend to include other family members, not just the individual with a disability.

Family Partnerships

According to family systems theory, the family is a dynamic entity with unique characteristics and needs but is also comprised of individuals who each have their own unique characteristics and needs. Members of the family are interrelated, with any one member affecting the others (Begun, 1996; Turnbull & Turnbull, 2001). From this perspective, the family member with a disability should not be the sole focus of attention for professionals; rather the entire family, of which the individual with a disability is an integral part, should be considered (Mitchell & Winslade, 1997). This shift toward partnerships with families has brought with it a level of complexity that has yet to be fully explored in the research literature.

Individual and family needs. As professionals look to build partnerships with families, they potentially face multiple relationships involving individual family members and the family "collective". An area of complexity that is particularly challenging concerns the drawing of boundaries between accessing information about the family that enables facilitation of family goals and the family's rights and needs to privacy (Keen & Knox, 2004). It is certainly understood that caring for a family member with a disability may compromise the quality of life of the carer (Dowling & Dolan, 2001). Recent research, however, suggests that having a member of the family with a disability does not necessarily lead to problems of adjustment or poor well-being (Cuskelly & Gunn, 2006; Eisenhower & Blacher, 2006; Emerson, Hatton, Llewellyn, Blacher, & Graham, 2006). Within-family processes and socio-economic status appear more likely to contribute to the well-being of family members than caring for, or being the sibling of, a person with an intellectual disability (Cuskelly & Gunn, 2006; Eisenhower & Blacher, 2006; Emerson et al., 2006). This highlights the importance of family circumstances in understanding the needs of individuals with disabilities and their families, but also raises questions about the role of the professional within the partnership.

While professional awareness and sensitivity to the needs of carers and siblings is important, the need for more direct involvement of the professional in meeting these needs should not be assumed. Research conducted by Knox and Bigby and reported in this Special Issue, involved gathering information from families living with a family member who had a disability and was of middle age. Using in-depth interviews of different family members, the authors describe how family members work together to ensure the well-being of the family as a whole and of individual family members. Their work highlights the interdependence of family members and the complex relationships that underpin the support of the family member with a disability. They caution that these relationships are at risk of being undermined or disrupted if professionals fail to acknowledge the family dynamics at work

and the critical roles played by immediate and extended family. Keen and Knox (2004) have stressed that professionals need to determine from the family what the boundaries of the partnership are, given the potential for these to become blurred within a family partnership framework.

When a partnership is formed around a child with a disability, the focus is clear, and the child is more easily identified by the professional as "the client". When partnerships are formed with families, in a sense the family may become the "client" which raises questions about who is involved in the partnership, for what purpose and which intended outcome(s) (Murray, 2000).

Outcomes. Family-professional partnerships have the potential to influence outcomes for all family members, not only the child with a disability. However, there has been little research undertaken to investigate how different partnership variables influence various outcomes that may be desirable for families (Summers et al., this issue). Outcomes may be associated with the family as a whole but may also be specific to individual family members, including parents and the member with a disability. This suggests that in a family-professional partnership approach, multiple outcomes are possible. This was highlighted in research conducted by Summers et al. (this issue) who looked at relationships between parent perceptions of services they received, the quality of their partnerships and family quality of life. In the area of parental perceptions of the adequacy of levels of services received for themselves and their children, the authors found that families more often believed they were receiving adequate amounts of services for their child than they did for their family. They also found that partnership quality partially mediated ratings of service adequacy.

One of the challenges for researchers and professionals is to gain a deeper understanding of how to effectively promote individual and family outcomes within the context of the

family-professional partnership. This will require greater knowledge about how partnerships can contribute to the identification and prioritising of diverse and possibly competing needs of family members and ways in which partnerships may support families to meet those needs. Dunst et al. (this issue) have suggested that parent-professional partnerships may best be conceptualized as comprising at least two types of practices: partnerships that promote parent and family outcomes and partnerships that promote child outcomes. This approach warrants further exploration as it may provide a means of better understanding the complexities of multiple partnerships associated with promoting family outcomes.

Evaluation of partnership practices. A related area of need in terms of research and practice concerns evaluation of partnership practices. There is now some evidence to suggest that partnerships do impact on families and family quality of life (Summers et al., this issue) but there is still much to learn about the significance of various components of partnership and how these relate to family characteristics and outcomes.

A single measure of service quality and partnership is unlikely to be sufficient to evaluate partnership practices, particularly in light of the complexities involved in multiple relationships. In their study of parental satisfaction of an early intervention service, Rodger et al. (in press) used the *Measure of Processes of Care* (MPOC) (King, Rosenbaum, & King, 1995) to ask parents how family-centred they believed the service they had received to be. Areas covered by the MPOC include supportive, respectful and comprehensive care, enabling partnerships, and the provision of information. The MPOC yielded relatively high scores for all participants, a result consistent with previous research in the area of early intervention services (Summers et al., this issue). The authors further investigated the satisfaction of two families with the service using questionnaires and parent interview data. These additional measures proved useful in identifying concerns the families had about the quality of the

family-professional partnership and revealed a number of areas where parental satisfaction was lower than for other participants. Further research of this nature is necessary to contribute to the growing body of evidence about which components of partnership are important to families and the particular characteristics of families and professionals that influence the quality of those partnerships.

Beliefs about how best to foster the growth and development of children with disabilities have changed radically in the past 50 years and these changes are no more evident than in the nature of the parent-professional relationship. Current best practice advocates a family-centred approach in which professionals foster true partnerships with families that involve joint decision making and planning. There is still much to learn about the components of quality partnerships and how they can be used most effectively as a means to promote individual and family outcomes.

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