Constructing the 'ideal' family for family centred practice: challenges for delivery.

Family centred practice positions families as the key decision makers, central to, and experts in, the wants and needs of their child. This paper discusses how families interviewed for a Western Australian study describe their relationships with a range of allied health professionals in the paediatric disability sector. The allied health professionals, in turn, describe how they characterise the role of families caring for children with disabilities. We argue that the successful implementation of family centred principles in service delivery need to move beyond the individualising of responsibility and acknowledge the structural and systemic limits to family centred practice as well as the social complexity within which diverse families live.

Keywords: Family centred practice, family ideology, responsibility, involvement, allied health professionals, professional boundaries, family relationships with professionals.

Introduction

A number of western developed countries have experienced philosophical and policy shifts away from medical to more social models of disability in recent years that have required disability services, and the allied health and other professionals employed within them, to reflect on how they can best respond to the needs and wants of families caring for children and young people with a disability (Corlett & Twycross, 2006; Dokken & Ahmann, 2006; Moore & Larkin, 2005; Oliver 1996; Saggers *et al.,* 2002; Shakespeare & Watson 2002; Wade *et al.,* 2007; Wiart, 2002. The extent to which the philosophy of the social model of disability has been implemented at the disability service provision level in these countries varies and is subject to ongoing debate. For example, Shakespeare & Watson (2002) assert that the social model of disability which is the 'ideological litmus test of disability politics in Britain' has its own limitations and they argue for a shift beyond the dichotomous construction of

abled bodies and disabled bodies to a 'continuum of disability' that includes all people (p.9).

In our study the different organisations involved in the paediatric disability sector in Western Australia were varied in how closely aligned they were to medical or social models of disability, as were the allied health professionals working for them. Family centred practice as a principle and philosophy underpinning service delivery is one such response to implementing a social model of disability and occurs within a context where increasingly the role of the consumer as an empowered individual, negotiating the web of 'expert' services, is viewed as a desired objective (Cowden & Singh, 2007). Family centred practice positions families as the key decision makers, central to, and experts in, the wants and needs of their child (Rosenbaum et al., 1998). The potential for family centred practice as a philosophy informing services for children and families in Australia has reflected moves since the 1990s to social and family-centred models of disability in other western, developed countries such as Britain, Canada and the United States of America (Franck & Callergy, 2004; Nielsen, 2006; Oliver 1996; Paliadelis, 2005; Rosenbaum *et al.*, 1998; Shakespeare & Watson 2002;Wayde *et al.*, 2007). The changing focus of service models in the disability sector in Western Australia towards family centred practice is reflected in the strategic aims of the state government organisation Disability WA with its explicit aim to 'promoting citizenship for people with disabilities and the important role of families, carers and friends and strengthening communities to welcome and include people with disabilities, families and carers' (www.disability.wa.gov.au).

This paper discusses these shifts in disability policy and philosophy as well as the familial and individualistic ideologies that influence their take up and delivery. Families interviewed for a Western Australian study describe how they interact with a range of allied health professionals in the paediatric disability sector, and the allied health professionals in turn, describe how they characterise the role of families caring for children with disabilities. We argue that the successful implementation of family centred principles in service delivery requires more than focussing on individual characteristics of families or the assumption that all families are able, or even want to embrace pro-active roles.

Methodology

This paper is based on part of a Western Australian study, which investigated the practical application of a family centred approach to service delivery in the paediatric disability sector. The research team interviewed families who were clients and allied health professionals who were employees of two non-government services, a state government department, a children's hospital and a state-wide child development centre. Each of the five organisations provided information about their service delivery models through strategic plans, related policies and informal documents that described the mission and culture of each organisation. Each of these organisations was selected because, on the basis of their published mission statements and associated services, they could be positioned on different parts of a service continuum with a medical or professional based practice at one end and family and community centred practice at the other.

The study adopted a qualitative research design, where the perspectives and experiences of families and allied health professionals were central to the study. Thirteen families were interviewed, all of whom were caring for children with a disability, with ages ranging from two to 17 years. The families were clients of the five organisations and efforts were made to include a wide range of social and cultural family backgrounds. Although efforts were made to include families from diverse cultural and ethnic backgrounds including Indigenous Australian families we cannot draw on definitive conclusions from this study about the cultural appropriateness of family centred approaches for these families due to the small number of families interviewed. We can speculate that (in theory at least) family centred approaches may have the potential to be more responsive to the particular needs of culturally diverse families but qualify this with the observation that more comprehensive and targeted studies need to be conducted to establish the best ways to deliver disability services in culturally appropriate ways to Indigenous Australian families and families from culturally diverse backgrounds. Research into other services such as child-care, health and substance misuse for example, has shown that those models that enable and empower the communities they target, that address the social and lifestyle factors of local communities and are inclusive of Indigenous Australians at all levels of

implementation have been the most effective (Saggers *et al.*, 2007; Brady 2007; Gray *et al.* 2008).

Our study focussed on what the families interviewed stated they wanted for their young people and what they needed to know to achieve their expectations. Interviews were conducted with mothers and fathers who responded together; partnered mothers who responded alone and single-parent mothers. Twenty-three allied health professionals from a range of disciplines including occupational therapy, physiotherapy, speech pathology, social work and psychology were also interviewed and asked about the service models they used and were asked to compare their every day experience in light of their employing organisation's service philosophy. They were also asked how they engaged with families and what they considered to be the strengths of the ways they worked with families.

This paper interrogates how family ideology, professional relationships with families de-centralisation of services and professional boundaries may act as limits to family agency and may place undue emphasis on families being responsible while at the same time they have limited ability to be central to decision making in the care of their child.

Family ideology and the gendered nature of caring

Family ideology refers to the generally accepted societal views that are often unspoken and taken for granted (although at other times forcefully argued) about what a 'normal' or 'functional' family is. Despite the diversity of different family types Australian government policy reflects as standard a couple (heterosexual) family with one main breadwinner, usually male, and one main carer of the children and domestic sphere usually female (Saggers & Simms, 2005). This is also seen historically as the 'ideal' family with other types of family considered to be less well equipped to enable optimal functioning of children (Pinkney, 1995). Another analysis of work and family policy in Australia from 1996 to the present demonstrates that this family 'ideal' is pervasive and influential and is also under-pinned by economically rationalist ideas about support payments to families. The financial support available to families through the family tax benefit (not means tested and paid directly to most

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Australian families) is most generous to single-income couple families and less so to dual-income couple families and single parents. Once the child of a single parent turns six years of age the parent is obliged to work up to fifteen hours of paid work per week; failure to do so results in a reduction in assistance. This rule is not applied to married mothers who do not need to undertake paid work and yet still receive the full family tax benefit (Hill, 2006). The families most rewarded under this economic system are then those considered closest to the Australian government's 'ideal' nuclear or traditional family.

Since the 1980s Australian social policy in the areas of welfare, health and disability has increasingly adopted economically rationalist approaches to social programs reflecting similar trends to Britain, the United States and Canada (Bleasedale, 2007; Cahill & Beader, 2005; Gibilisco, 2006; Staples, 2006). The influence of economic rationalism and ideas about 'mutual obligation' also extends to the ways in which the privatisation of the public provision of goods and services has meant the delivery of these (including disability, education and health services) has become increasingly the responsibility of individual 'users' or 'consumers' (Caputo, 2007; Cowden & Singh, 2007; Gibilisco, 2003; Gibilisco, 2006).

A range of welfare and social policies that promulgate either implicitly or explicitly particular kinds of families as 'ideal' has also resulted in what Caputo (2007) describes as the 'intensive mothering role.' This role is best played out by a full-time, heterosexual mother who practices 'self-sacrifice' and ensures that her world revolves around the needs of her child (Caputo, 2007). Despite the general acceptance that fathers may also play a more active role in caring for their children, Nielsen (2006) notes that in her experience as a paediatric nurse it is the mother who is most involved in the day to day care of children (p.2).). The gender neutrality of terms such as 'family' simplifies the complexity of the every-day situations where workers may be more likely to be working consistently with mothers (Nielsen, 2006). The focus by allied health and other professionals on the mother's role is also described in a study by MacKean and colleagues (2005) who relate the enormous pressure experienced by mothers to 'quit work and stay at home with the child so that they could work with their child at home,'(p.80).

Generally the family which cares for children with disabilities is deemed to have particular qualities necessary for the optimum development and care of these children. These qualities are that the family is functional, intact, maintains stable daily routines, is a constant support for the child, practices problem solving, is highly educated and develops home-environments that provide opportunities for child stimulation, growth and learning (Abery, 2006; Mactavish *et al.,* 2006; Shogren, 2006; MacKean *et al.,* 2005). Parents who have secure attachments to their children and adopt parenting styles that are authoritative, rather than permissive or authoritarian are also considered to enable the development capacities of young children with disabilities (Shogren, 2006). To meet these time consuming, on-going and intensive demands the assumption is that there is a father who is the full time wage earner thus enabling the main care-giver who is 'naturally' seen as the mother to stay at home (Caputo, 2007).

The idea that secure and early attachment to family care-givers positively influences the development of children generally (and is even more important for children with disabilities) increases the professional scrutiny of families caring for children with disabilities. The social isolation often experienced by these families may also result in a greater emphasis on, and pressure about, the quality and nature of family relationships, particularly where families have limited opportunities for developing friendships or wider social support networks (Mactavish, *et al.,* 2006). Once again responsibility often falls on the mother to care take relationships between family members and to initiate connections with wider social support or friendship networks (Caputo, 2007; Mactavish*, et al.,* 2006; MacKean*, et al.,* 2005). In contrast to the functional family ideal, families of minority status or living in situations where they experience poverty, family violence or substance misuse are considered to be at increased risk of 'poor family and child functioning outcomes' (Farber & Maharaj, 2005, p. 512).

The effects of ideas about individual responsibility are also played out in privatised disability services. Families and mothers in particular often sacrifice their own needs for their child sometimes to the detriment of their own mental and physical health and well-being (Caputo, 2007; Darrah, *et al.,* 2007; MacKean, *et al*., 2005; McConnell & Llewellyn, 2006; Paliadelis, *et al.,* 2005; Saggers *et al.,* 2002). A woman who is a nurse and the parent/carer of a child with complex medical needs describes her

experience of caring for her child as "a bit like running a small business" and describes how her relationship with her other two children has been compromised because of it (Kingdom & Mayfield, 2001, p. 38). A study that examined the health status of mothers caring for children with disabilities found that health status was compromised even for those who had the support of a partner and were relatively well off. It is suggested that the health status of single mothers or those who have limited access to social and economic resources may be even worse (McConnell & Llewellyn, 2006).

Considerations of how families play out their role within services that espouse a family centred perspective need to be understood within these wider social understandings as well as the meanings attached to 'family' and how a 'functional family' or 'good parent' is pre-supposed as a caring subject. The intensification of the desirable characteristics deemed necessary for caring for children with disabilities and the greater scrutiny of parenting roles also requires consideration in terms of the potential for adverse physical and mental health effects for families.

Responsibility and involvement

The role of parents in their disabled child's care has evolved from passively receiving treatment from experts, being more involved in providing treatment themselves under the direction of the expert, to the family centred 'ideal' of collaborative parent-therapist partnerships (Hanna & Rodger, 2002). The extent to which parents are able to collaborate in partnerships will be discussed in this paper. For now, the discussion will turn to the persistence of the idea that parental involvement equates to being responsible for the provision of treatment under the guidance of the expert (Corlett & Twycross, 2006; Hanna & Rodger, 2002; MacKean, *et al.,* 2005).

Characteristics of the 'ideal' family type that allied health professionals in this study found most positive to work with varied depending on the individual worker's philosophy toward parental 'responsibility' and what, for the worker, family 'involvement' meant. For some, the family 'taking responsibility' and being 'involved,' particularly in physiotherapy or speech pathology interventions, were key elements that were inextricably linked. A senior occupational therapist describing the

transition from early intervention to school aged services describes an attitude toward family centred practice where the 'ideal' parent takes responsibility:

> Families often find it difficult coming to school age from early intervention, where they receive a more intensive therapy service. With us, we are saying they need to grow up. You need to find your own feet. My job is to link you with other services. That is hard – because they want the one-to-one direct therapy to continue throughout their child's life.

These workers' attitudes reflect the medically oriented training that workers undertake in those occupations that privilege the 'intervention' and position the parent as being responsible for continuing with that 'intervention' as most important. It also assumes that all parents are equally well equipped to take on this responsibility and that if they do not they are making the wrong decision, or are being irresponsible.

The attitude that ideal 'families' take on more responsibility for facilitating the professional's intervention assumes all members of the family are equally motivated. It also does not take account of how the families want to be motivated or self directed and is also a particularly specific interpretation about what delivering family centred services means. In response to a question about how well a parent felt that the therapist knew her family a mother replies:

> It's a hard thing isn't it? In some families, or some situations, that [child's disability] might be all you have to worry about, but – that's probably not true. Everybody has other things – [such as] money issues in a family, there's everything. It's like, it's not just that [child's disability] and I feel like…I was talking to the co-ordinator the other day…I suffer from depression and have been taking medication for it for a couple of years and some days I just find it a struggle to get through the day. But that's just me – and I find with M [child] I feel like saying NO – this is just too hard. You know?

As the above excerpt shows the sharing of responsibilities between professionals and families may not always benefit the family. Rather this excerpt suggests that the every

day complexity of the lives of parents or their children may not always be appreciated by allied health and other professionals. A study about family centred care in the management of chronic conditions such as Asthma in children draws similar conclusions where: 'the hidden and ad hoc nature of children's families [presents] challenges in providing indvidualised care (Franck & Callery, 2004, p.269).

The interpretation of what family centred service means, that is, a truncated involvement in the treatment of their child under the direction of the expert, does not address how families can be enabled to guide allied and other health professionals in ways that are less limiting. A social worker makes a comment that is an exception and results in a different interpretation about what being 'family-centred' means:

> For social workers it is really hard to simply say 'oh, that family isn't taking responsibility or doesn't want to be involved' because more often than not than are bigger things causing their reduced capacity to be involved. …I think that empowering people is a great influence on getting families more involved. I don't see family centred practice as families needing to get involved. I see it more as listening to what families have to say, and helping to facilitate what they want.

This excerpt suggests that the social worker does not assume that providing services in a family centred way means that the family has to take on more responsibility or be more involved. Here the relationship with the family is more important, listening to what the family needs and thinking about how to help families achieve those needs.

Relationships with professionals

The philosophy and rhetoric of family centred disability paediatric models assumes a move away from top down, professional approaches toward more equal partnerships with families – where interventions (if any) are decided by families themselves and a variety of options discussed and negotiated (Blue-banning *et al.,* 2004; Moore &

Larkin, 2005). While family centred perspectives advocate the empowering of consumers, too often this may simply be read by professionals as expecting families to be always pro-active and energetic in their pursuit of care for their child. The importance for professionals to be 'intuitive listeners' is advocated by Rice and Lenihan (2005) who warn against professionals being overly energetic about parents taking on more responsibilities. They argue that sometimes parents do not have the energy or inclination to be 'empowered' and that timing pushes for more involvement need to be considered carefully. Franck & Callery (2004) also support this view suggesting that children and families should be enabled to choose whether they are want to adopt active or passive roles. In our study a mother describes the limits to what she is able to achieve:

> I think there's a lot more [I could do]. Without me beating myself up – there is a lot more she [my daughter] needs to do. Like she needs to go to private speech [therapy] and it's all a bit bamboozling. [Mother, child diagnosed with Autism].

Hanna and Rodger (2002) assert that allied health professionals should acknowledge that when parents are implementing home therapy programmes they may need to balance this with many other competing demands that are not directly related to the provision of therapy. A mother in our study makes a similar point:

> How have I got to that point? [where boundaries are set]. Through realisation of what I can and can't do. And through realisation that there are still other children in my life; through my life in other areas falling apart because I was trying to do it all and suddenly realising that, excuse me, yes I do have responsibilities with my daughter but I am entitled to a life and so are my other two [children]. And we can have some fun in this. What actually can happen when you have a child with a disability is that your whole life becomes therapy, equipment, meetings and you actually forget how to have any joy in it – because you've got this new therapist saying: well we've got this new program sorted out but you've got to do this at home because…dadadada. And what happens is the whole family turns into this…[therapy] it was horrible. [Single mother: Child with intellectual disability].

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The demands on this single mother being directly involved in new therapy programmes are at times overwhelming, and the excerpt illustrates a lack of recognition by the therapist about how the rest of the family may be adversely affected by its implementation. The therapist's request that the mother 'has' to do this [therapy programme] at home also illustrates a lack of negotiation and sensitivity about this particular family's situation where the mother does not have the support of a partner and is likely to have fewer financial resources at her disposal compared to other families.

For other families a lack of information and the allied health professional prescribing an intervention with little or no negotiation is also disempowering. The following is a mother's response to the interviewer's question about parental involvement in decision making about the child's therapy:

> Well to a certain extent [we are]. I do get the feeling that if we started requesting more there would have to be…I get the feeling that it has to be within their framework. So they say to us "we have this available." We don't say we want it then. They say that in the last 10 years it has really changed from having therapists in a room making decisions for your child. And it has, but there are still, unfortunately, in the training of some of those professionals a tendency to want to make decisions, [because] of knowing it all. And I understand that they have a certain amount of expertise but sometimes you can really pick that up [Mother, child with neurological condition].

This excerpt illustrates recognition by the mother interviewed that there are limitations to what the family can realistically 'demand.' The effects of professional training and how these may clash with family-centred, collaborative partnerships with parents are also noted. This dilemma is addressed by Litchfield and MacDougall (2002) who found in their study of physiotherapists attempting to work in family-centred ways, that shifting decision making power to families may eventuate in perceptions by the professionals involved that 'best-practice' in a professional or 'evidence-based' sense is not being followed (p. 111).

The importance of shared understandings about how a collaborative partnership between families and professionals can be implemented is discussed by King and colleagues (2003) who advocate for the development and validation of a 'Measure of Beliefs about Participation in Family Centred Service' tool. They describe the tool as a useful consciousness raising tool for professionals maintaining that reflection on their professional processes may result in a better, shared understanding between service providers and parents (King *et al;* 2003). The lack of shared understandings was also found to be a limiting factor to equal partnerships between families and allied health professionals in our study. Here a mother describes her level of discomfort in talking about her child's therapy program:

> No. I felt like saying, you know when you come away and you think – I should have said this, I should have said that. Well at the time I felt as if they said well this is it, and they didn't give me an alternative. I'm sure there was another way of doing it. I felt very uncomfortable. I didn't know what to expect, I didn't know what I was entitled to. And when I was coming away I felt; ok…I should have said this or that [Mother, child with Cerebral Palsy].

Both of the excerpts show that there are a number of limitations to families' abilities to work with allied health professionals in a truly collaborative way. Apart from the propensity for the allied health professionals to prescribe treatment or intervention programs, the second example also shows how a lack of understanding about the mother's position has left her feeling dissatisfied with the encounter. A lack of information has also contributed to her feelings of discomfort about how to raise her concerns with the allied health professional, not knowing about potential alternatives that she could have perhaps used to challenge the allied health professional's prescribed course of action.

The importance for professionals to be knowledgeable and sensitive to individual family preferences and concerns is stressed by Rice and Lenihan (2005). They emphasise the importance for professionals to be intuitive and perceptive about families changing needs with regard to information and to not necessarily view families as inconsistent when they change their minds or preferences. MacKean and colleagues (2005) are sympathetic to this stance noting that families may want more

autonomy in that they receive comprehensive information; but this does not mean they want to make all the decisions on their own or to be entirely responsible for implementing or even choosing treatment programmes. The excerpts also show that some families are better placed than others to take on more responsibility; they may have a more supportive family and social network, or more financial resources at their disposal. There may also be times when families are able to take on more active roles and times when they need to be more passive. Allied health and other professionals need to recognise these differences in family types and adjust their responses accordingly.

To better respond to the diverse needs of families allied health and other professionals may also need to reflect on the ways in which their personal and professional values may effect how they relate to other professionals as well as the families who are part of their caseload.

Professional boundaries and de-centralisation of services as a limit to family agency

Some of the allied health professionals interviewed for this study stated that whilst they did their best to work in family centred ways these methods were not always recognised by other professionals they were working with, either within the same organisation or externally. This was particularly the case in some medical and educational settings (Saggers *et al.,* 2002). Bradshaw and colleagues (2003) also identify this as a major barrier stating that 'family centred care is not necessarily a multi-professional or inter-professional philosophy' (p. 30). An example of how this can directly affect a family is described by one mother in our study in response to a question about the level of professional involvement with her child:

> [There were] three allied health people from the one agency: a conductive education person[1] one woman, and a Feldenkrais practitioner. We also see a chiropractor/kinesiologist. We don't tell anyone about that actually because we understand that physios in particular have a real thing about chiropractors.

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[1] Conductive education: a holistic approach to education for people with disabilities.

But we did ask in our family planning session if the physio could liaise with the conductive education person and the Feldenkrais practitioner because we felt that it was really important. That if they were going to be like the overall coordinator and they were being paid to service our child that they understand what other things were coming in. So we have had the physiotherapist to come out to see Feldenkrais. The conductive education facilitator had a problem with it, well for various reasons, and she said look: I really can't see the point if they're not going to work one on one (in a way that she does with our child).

The excerpt shows there are inter-professional rivalries and a hierarchy of professional philosophies with which families may need to grapple. These tensions are not helpful to families, as parents are forced to ask the professionals to liaise with each other, rather than this being accepted as the obvious and most effective way for all to work. A collaborative, co-ordinated or case-managed approach to children is also very important, as this father relates:

I'd like to see a more co-ordinated approach. When you talk about the services [their child] has been seeing you've got the neurologist, the psychologist, occupational therapist, paediatrician, speech pathologist - what ever. I'd like to see that [co-ordination] straight away, from the outset of diagnosis and a strategy put in place where all these services can come together and encapsulate the problem and then work with you to put that child into the best possible care. [Father, son diagnosed as globally delayed].

A range of international literature has shown that where key workers assume the role of co-ordinating services to meet the individual needs of families, this is associated with families experiencing fewer unmet needs, being more satisfied and becoming more involved (Sloper *et al.,* 2006; King & Meyer, 2006). This co-ordination needs to work on a number of levels: at an interpersonal level between the different allied health and other professionals within the same agency, at an inter-agency level and at a wider sector level (Bradshaw *et al.,* 2003; King *et al.,* 2001; King & Meyer, 2006).

In Western Australia, key workers (locally known as 'local area co-ordinators') are employed by the state run Disability Services Commission to assist families in

accessing a range of services and co-ordinating their access to these. Whilst some families did occasionally mention local area co-ordinators (LACs) in passing, it was not in their capacity to co-ordinate services, but rather as occasionally referring families to other services in the area where they lived. For most families interviewed in the study the onus for co-ordination was their individual responsibility. One parent describes her interaction with her LAC during a time of crisis:

> I'm doing most of it [co-ordination]. But when I wasn't functioning very well for a period of time and was quite stressed, I rang the Local Area Co-ordinator to talk to her about something and she actually said: if you're not having a good time, you can ring us and we can do it. So I'm now aware that can happen. I didn't actually realise that. I haven't used it as yet but she said that it's not something they would want to do all the time, but if there was a crisis or something they could do it. So if I needed it that's where I'd go [Mother: Child with cerebral palsy].

The excerpt shows that although the LACs may help families in crisis to co-ordinate their services it is made clear this is not something they will routinely do. Our research demonstrates that one of the things families most value is co-ordination of services and inter-professional collaboration and commonality of purpose, although the responsibility for assuring and managing this process once again seems to fall mainly on the shoulders of individual families.

Family centred practice – where to from here?

Our research has shown that that for the most part family centred practice has been implemented by allied health professionals in ways that incorporate particular ideas about individual responsibility and how 'ideal' families should function. Some allied health professionals were better than others at recognising the limitations of family centred practice as played out in the every day experiences of families and the children they were caring for. Our research also shows that family centred practice has different meanings for different allied health professionals and families. Ideally family centred practice should begin to shift power from allied health professionals or at least share this in a more equitable fashion with families. In our research there are

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very few instances where this has occurred. Allied health professionals often position parents as being responsible for interventions but do not always acknowledge how families and individual family members (particularly mothers) may be limited in their ability to make informed decisions or access the information and resources needed to take on this role.

Family centred practice theoretically has much to offer families caring for children with disabilities with its emphasis on decision making that is driven by families' needs and wants. Our research has shown however, that this may be difficult for allied health professionals to implement when they are working within services that are funded under economically rationalist models that promulgate ideals of 'mutual obligation' and individual responsibility. Allied health professionals currently have little time to reflect on processes and even less to evaluate whether a particular organisation's interpretation of family centred practice is useful and empowering for the families who use the service. Some allied health professionals in our study were less cognizant than others about the effects of gender, competing demands on families (in addition to caring for a disabled child) and families being at different places and different times more or less able to take on 'responsibility.' The lack of clarity and shared understanding about what family centred practice means in theory and practice for both allied health professional and family research participants in our study presents challenges for suggesting ways forward.

One initial and essential step does seem to be that less emphasis is placed on 'responsbibility' and that instead allied health professionals are properly supported and resourced to run family centred interventions that are more responsive and flexible to families needs. Our study shows that families often do not want to take on all of the responsibility for implementing an intervention but what they do want is adequate and timely information and support and a sharing of ideas and suggestions about how to move forward. Family centred practice should not be all about allied health professionals 'directing' and families 'doing.' To facilitate this allied health professionals in turn, need to be provided with enough funded hours, information, resources and support to take 'time out' to meaningfully negotiate and reflectively listen to what families need. Our research also shows that there needs to be greater emphasis placed on reaching some kind of shared understanding about what family

centred practice means and how it should be implemented not only between allied health professionals and families but also between the different professional groups and diversity of services involved in the paediatric disability sector.

Conclusion

We have argued that the focus on family centred services needs to move beyond individualising of parental responsibility which obscures the social complexity within which many families live. The 'ideal' functioning family considered most able to care for a disabled child is a stable, intact, single-income, heterosexual couple family with a mother who can cope, fight for what her child needs and can consistently sacrifice her own (and in some cases other family members) needs (Caputo, 2007; Kingdom & Mayfield, 2001; MacKean *et al.,* 2005). Allied health and other professionals often do not take account of the gendered nature of much of caring, may conflate ideas of involvement with individual parent's (usually mother's) responsibility for their child's therapy and may inadvertently place the onus on individual families to co-ordinate the confusing array of services and manage the relationships of the diversity of professionals with whom they need to interact.

This emphasis on individual parental responsibility occurs at a number of different levels in the paediatric disability sector and is a major obstacle to achieving equitable family/professional relationships and the delivery of services that reflect family centred principles. Family centred practice does not necessarily mean leaving the decision making (without adequate support and information) to parents and allied health and other professionals need to consider when to be more or less interventionist. While the building of capacity at the individual family level is important our research has shown there is a danger in this being narrowly interpreted within a framework that constructs parents in ways that leave them individually responsible and disempowered. There also needs to be an acknowledgement of limits to how pro-active families can be in policy and programme contexts that emphasise 'mutual obligation' and 'responsibility' but that at the same time do not provide families or allied health workers with adequate information, support and resources to enable a more equitable negotiation of roles within this model.

References:

Abery, B., H. (2006) Family adjustment and adaptation with children with Down syndrome, *Focus on Exceptional Children,* 38, (6), 1-19.

Brady, M. (2007) Equality and difference: persisting historical themes in health and alcohol policies affecting Indigenous Australians, *Journal of Epidemiology. Community Health,* 61, 759-763.

Bleasedale, M. (2007) Supporting the housing of people with complex needs, *AHURI Research and Policy Bulletin,* 90, 1-4.

Bradshaw, M., Coleman, V., Smith, L. (2003) Interprofessional learning and family-centred care, *Paediatric Nursing,* 15, (7), 30-33.

Blue-banning, M., Summers, A., J., Frankland C., H., Lord Nelson, L., Beegle, G. (2004) Dimensions of family and professional partnerships: constructive guidelines for collaboration, *Exceptional Children,* 70, (2), 167-185.

Cahill, D., & Bader, S. (2005) Neo-liberal think tanks and neo-liberal restructuring: Learning the lessons from Project Victoria and the privatisation of Victoria's electricity industry. University of Wollongong.Faculty of Arts Papers (Downloaded from http://ro.uow.edu.au/artspapers/34).

Caputo, V. (2007) She's from a 'good family': performing childhood and motherhood in a Canadian private school setting, *Childhood,* 14, (2), 172-191.

Corlett, J., & Twycross, A. (2006) Negotiation of parental roles within family-centred care: a review of the research, *Journal of Clinical Nursing,* 15, 1308-1316.

Cowden, S., & Singh, G. (2007) The 'user': friend, foe or fetish?: A critical exploration of user involvement in health and social care, *Critical Social Policy,* 27, (1), 5-23.

Darrah, J., Magil-Evans, J., Adkins, R. (2002) How well are we doing? Families of adolescents or young adults with cerebral palsy share their perceptions of service delivery, *Disability & Rehabilitation, 24 (10),* 542-549.

Dokken, D., & Ahmann, E. (2006) The many roles of family members in "family-centred care" – Part 1, *Pediatric Nursing,* 32, (6), 562-565.

Farber, M. L. Z., & Maharaj, R. (2005) Empowering high-risk families of children with disabilities, *Research on social work practice,* 15, (6), 501-515.

Franck, L. S., & Callery, P. (2004) Re-thinking family-centred care across the continuum of children's healthcare. *Child: Care, Health & Development,* 30, 3, 265-277.

Gibilisco, P. (2003) A just society: inclusive of people with disabilities. *Journal of Australian Political Economy,* 52, 128-142.

Gibilisco, P. (2006) The state disability plan – rhetoric and reality. *Just Policy,* 39, 45-48.

Gray, D., Saggers, S., Atkinson, D., & Wilkes, E. (2008) In Couzos, S., Murray, R. (eds). Aboriginal Primary Health Care (3rd edn). Melbourne: Oxford University Press, Ch 20: 755-787.

Hanna, K., & Rodger, S. (2002) Towards family-centred practice in paediatric occupational therapy: A review of the literature on parent-therapist collaboration, *Australian Occupational Therapy Journal,* 49, 14-24.

Hill, S. (2006) Howard's 'choice': the ideology and politics of work and family policy 1996-2006. Symposium: A decade of Howard Government. The University of Sydney. http://www.familypolicyroundtable.com.au.

King, G., Cathers, T., King S. & P. Rosenbaum (2001) Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Children's Health Care,* 30, (2), 111-134.

King, G. Kertoy M., King, S. Law, M. Rosenbaum, P, & P. Hurley (2003) A measure of parents' and service providers' beliefs about participation in family-centred services. *Children's Health Care,* 32, (3), 191-214.

King, G., & K. Meyer (2006) Service integration and co-ordination: a framework of approaches for the delivery of co-ordinated care to children with disabilities and their families. *Child: Care, Health and Development,* 32, (4), 477-492.

Kingdom, S & Mayfield C. (2001) Complex disabilities: parents preparing professionals. *Paediatric Nursing,* 13, (7), 34-38.

Litchfield, R., & MacDougall, C. (2002) Professional issues for physiotherapists in family-centred and community-based settings, *Australian Journal of Physiotherapy,* 48, 105-112.

Mactavish, J. B., MacKay, K. J., Yoshitika, I., Betteridge, D. (2007) Family care-givers of individuals with intellectual disability: perspectives on life quality and the role of vacations, *Journal of Leisure Research,* 39, (1), 127-129.

MacKean, G. L., Thurston, W. E., Scott, C, M. (2005) Bridging the divide between families and health professionals' perspectives on family-centred care, *Health Expectations,* 8, 74-85.

McConnell, D., & Llewellyn, G. (2006) Health of mothers of school-age children with disabilities, *Australian and New Zealand Journal of Public Health,* 30, (6), 572-574.

Moore, T., & Larkin, H. (2005) *More than my child's disability,* (Glenroy, Australia, Scope (Vic) Ltd.)

Nielsen, H. (2006) Where is the mother in family-centred care? *Kai Tiaki Nursing New Zealand,* July, 2.

Oliver, J. (1996) *Understanding disability from theory to practice*. Basingtoke: Macmillan.

Paliadelis, P. Cruickshank, M. Wainohu, D., Winskill, R., Stevens, H. (2005) Implementing family-centred care: an exploration of the beliefs and practices of paediatric nursing, *Australian Journal of Advanced Nursing*, 23, (1) 31-36.

Pinkney, S. (1995). Fights over 'family': competing discourses in the two decades before the Year of the Family, *Just Policy,* 2, 17-25.

Rice, G. B., & Lenihan, S. (2005) Early intervention in auditory/deaf education: parent and professional perspectives, *The Volta Review,* 105, (1), 73-96/

Rodger, S., Braithwaite, M., Keen, D. (2004) Early intervention for children with autism: parental priorities, *Australian Journal of Early Childhood,* 29, (3), 34-41.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998) Family-centred service: A conceptual framework and research review. *Physical and Occupatinal Therapy in Pediatrics,* 18, (1), 1-20.

Saggers, S., Guilfoyle, A., Hutchins, T., Jackiewicz, S., Sims, M., Targowska, A., & Dunbar, T. (2007) *Towards an Indigenous Child Care Plan,* Centre for Social Research, (Perth: Edith Cowan University).

Saggers, S., Paskevicius, A., Tilley, F., Payne, L., Ghose, A., Wildy, H., McNamee, A. (2002) *Changing models of care: Tools toward best practice for consumers and professionals in the paediatric disability and health services sectors,* (Perth: Edith Cowan University.)

Saggers, S. & Simms, M (2005) Diversity: Beyond the nuclear family, in, M. Poole (ed) *Family: changing families, changing times.* Sydney:Allen & Unwin.

Shogren, K., A. & Turnbull, P. (2006) Promoting self-determination in young children with disabilities: the critical role of families. *Infants & Young Children,* 19, (4), 338-353.

Shakespeare, T. & Watson, N. (2002) The social model of disability: An outdated ideology? *Research in Social Science and Disability,*2, 9-28.

Sloper, P., Greco, V., Beecham, J., & R. Webb (2006). Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families? *Child: Care, Health & Development,* 32 (2) 147-157.

Staples, J. (2007) NGO's out in the cold: Howard government policy toward NGO's. *Democratic Audit of Australia Discussion Paper No. 19/06.*University of New South Wales. Faculty of Law Research Series.

Wade, C, M., Mildon, R. L., Matthews, J. M. (2007) Service delivery to parents with an intellectual disability: Family-centred or professionally centred? *Journal of Applied Research in Intellectual Disabilities,* 20, 87–98.

www.disability.wa.gov.au/dscwr/_assets/main/guidelines/documents/pdf/dsc2006strategicplan (Downloaded 30 June 2007).

Wiart, L., & Darrah, J. (2002). Changing philosophical perspectives on the management of children with physical disabilities-their effect on the use of powered mobility, *Disability and Rehabilitation,* 24, (9), 492-498.