

**THE CULTURAL WORLD OF PROFESSIONAL PRACTICE WITH
FAMILIES OF CHILDREN WITH A DISABILITY:
A NEW UNDERSTANDING OF FAMILY-CENTRED PRACTICE**

KIRSTY M. THOMPSON

A thesis submitted in fulfilment of the requirements for
the degree of Doctor of Philosophy

Faculty of Health Sciences
The University of Sydney

January
2006

Copyright 2006

by

Kirsty M. Thompson

All Rights Reserved

DECLARATION OF ORIGINALITY

I declare that this thesis submitted in fulfilment of the requirements of the degree of Doctor of Philosophy at the University of Sydney is my own original work.

Kirsty M. Thompson
January 26th 2006

ABSTRACT

Human service professionals provide a range of services to support the health and development of children with a disability and to assist their families. Over the past two decades, family-centred approaches have become widely acclaimed as a means of providing quality services. To date, research has focused predominately on identifying or measuring discrete elements of professionals' practice with families, such as parent-professional partnerships, family-centred practice and family empowerment, often neglecting to consider the broader practice context. What is missing is an empirical and contextually grounded understanding of how professionals interpret and enact the multiple concepts informing practice. This study addresses this gap by exploring how professionals think, feel and act when working with families and by examining more broadly, the multi-dimensional and contextual concept of 'professional practice'.

In this study, professional practice with families is conceptualised as a cultural activity. The study sought to identify and describe the culture of professional practice with families and how this culture is instantiated in daily work practice. The theoretical framework underpinning this study comes from Jerome Bruner's cultural psychology, and specifically his writings on situated action, culture and narrative. Accordingly, narrative was considered a means to identify, describe and understand the daily work practices of professionals 'situated' in their cultural setting and their own intentions when working with families.

One hundred and sixty three stories about professional practice were collected in focus groups and individual interviews with human service professionals in New South Wales, Australia. These narratives were analysed deductively to identify the culture of professional practice. This culture comprised of ten components reflecting professionals' understanding of the culturally acceptable ways of working with families. The cultural components reflected principles underlying family-centred practices as well as traditional medically framed and emerging business-like principles associated with managerialism and economic rationalism. Narrative analysis was employed to inductively develop four cultural core narratives grounded

in participants' stories: *Making it work, having to fight, hopeless struggle* and *making the best of it*. Professionals potentially have all of these narratives available to them to explain their actions in each practice situation.

The results of this study provide a description and analysis of the cultural world of professional practice with families. For family-centred approaches to become a reality, these findings emphasise the critical importance of education, policy and staff development for professionals working with families that addresses the broader practice context. Suggestions are made regarding further exploration of the cross-cultural validity and the application and implications of these narratives for professionals and families. By exposing the culture of professional practice and the four cultural narratives, this study challenges professionals, managers, academics and policymakers alike to critically examine the practice culture and their contribution to creating and sustaining it.

ACKNOWLEDGEMENTS

Undertaking a narrative inquiry for the first time, it occurred to me that the doctoral process in itself is an unfolding story. There are actors, actions, a goal, a setting, instruments, and inevitably, an element or two of trouble. In this doctoral story, I was joined, supported and challenged by many others deserving my heartfelt thanks.

To my supervisor, Professor Gwynnyth Llewellyn – it was your encouragement and support that started me along the research path as an undergraduate, and it was the continuity of this that allowed this PhD to be completed. Thank you for your patience, vision and support as I juggled a PhD with other life commitments. Thank you for inspiring me, amongst others, as a new generation of professionals to critically examine and work in more supportive, empowering and responsive ways with people with a disability and their families. Thanks also to my associate supervisor Professor Joy Higgs. Your insightful feedback and fresh perspective in the final stages in particular were an invaluable resource.

To my family, particularly Mum and Dad – it was your stories that started this journey. I hope that the journey these prompted can contribute to improving experiences for families in the future. Your love, unfailing emotional and practical support and faith in me, provide a foundation upon which things like this doctoral study are possible. To my sister Leigh, thanks for listening, laughing and patiently waiting for me to finish. We will have that holiday some day. To my brother Mark, sister-in-law Kylie, and nephews Blake and Liam, you are an inspiration – for the love and support you provide, and especially the quiet strength you show despite all that life has thrown at you.

To my work colleagues, thank you for your practical and personal support. Headspace for writing is a precious thing, and your flexibility helped create it. Thanks also to research and clinical colleagues that provided valuable feedback and critique that helped refine this study as it was conceptualised, analysed and written up.

To my friends – you know who you are. Thanks for the meals, the laughs, the encouragement, the understanding ‘shoulder’, and most of all for keeping me sane and real. As ever, you kept me feeling grounded, loved and supported throughout this process. Friends are the family you chose, and I couldn’t have chosen better.

Thanks also go to Rae Samuel, Assistant Manager, Service Policy and Standards in Disability Services for the NSW Department of Ageing, Disability & Home Care. Rae provided invaluable access to resources to supplement those available on the Internet and supported me in ‘wading through’ them.

Last, but by no means least, I would like to express my heartfelt appreciation to the professionals who shared their precious time and experiences with me. Thank you for sharing your dreams, visions, hopes and challenges about your work with families of children with a disability. Without your candour and willingness to share, there would not have been a story to tell.

TABLE OF CONTENTS

1	INTRODUCTION.....	1
1.1	BACKGROUND	2
1.2	AIM OF STUDY AND RESEARCH QUESTIONS.....	6
1.3	DEFINITION OF TERMS	7
1.4	SYNOPSIS AND ORGANISATION OF THE THESIS	8
2	PROFESSIONAL PRACTICE WITH FAMILIES IN POLICY DOCUMENTS AND LITERATURE.....	10
2.1	NEW SOUTH WALES SERVICES FOR FAMILIES OF CHILDREN WITH A DISABILITY	11
	2.1.1 <i>The disability service system</i>	11
	2.1.2 <i>Disability service policy</i>	14
2.2	MEDICAL RATIONALE AND ‘TRADITIONAL’ WAYS OF WORKING WITH FAMILIES	16
2.3	FAMILY-CENTRED CONCEPTS FOR WORKING WITH FAMILIES	19
	2.3.1 <i>Child or family focused?</i>	20
	2.3.2 <i>Enhancing a sense of community</i>	21
	2.3.3 <i>Shared responsibility and collaboration</i>	23
	2.3.4 <i>Protecting family integrity</i>	27
	2.3.5 <i>Empowerment and strengthening families</i>	28
	2.3.6 <i>Individualising practices</i>	30
2.4	MANAGERIALISM AND MICROECONOMIC REFORM IN THE HUMAN SERVICE CONTEXT	32
	2.4.1 <i>Accountability</i>	35
	2.4.2 <i>Case management</i>	36
2.5	RATIONALE FOR FRAMING PRACTICE AS A CULTURAL ACTIVITY.....	39
2.6	PRACTICE AS A CULTURAL ACTIVITY	41
2.7	SUMMARY AND REORIENTATION TO THE RESEARCH QUESTIONS.....	46
3	CONCEPTUAL FRAMEWORK AND STUDY METHOD.....	48
3.1	CONCEPTUAL FRAMEWORK OF STUDY	48
	3.1.1 <i>Meaning and situated action</i>	48

3.1.2	<i>Culture</i>	49
3.1.3	<i>Narrative</i>	50
3.1.4	<i>Assumptions underpinning this study</i>	51
3.2	RESEARCH APPROACH	53
3.3	SAMPLE AND SAMPLING PROCEDURES	54
3.3.1	<i>Procedures</i>	55
3.4	DATA COLLECTION.....	60
3.4.1	<i>Storytelling</i>	60
3.4.2	<i>Focus groups</i>	61
3.4.2.1	<i>Design and procedures</i>	61
3.4.3	<i>Individual interviews</i>	64
3.4.3.1	<i>Design and procedures</i>	64
3.4.4	<i>Field notes</i>	66
3.5	DATA ANALYSIS.....	66
3.5.1	<i>Identifying the cultural core narratives of professional practice with families</i>	67
3.5.1.1	<i>Implications and limitations</i>	76
3.5.2	<i>Identifying the culture of professional practice with families</i>	77
4	CULTURAL CORE NARRATIVES OF PROFESSIONAL PRACTICE WITH FAMILIES.....	84
4.1	MAKING IT WORK	85
4.2	HAVING TO FIGHT	87
4.3	HOPELESS STRUGGLE.....	88
4.4	MAKING THE BEST OF IT	90
4.5	CIRCUMSTANCES THAT INFORM THE NARRATIVES ADOPTED	91
4.6	IMPLICATIONS OF THE NARRATIVES	94
5	THE CULTURE OF PROFESSIONAL PRACTICE WITH FAMILIES	98
5.1	COMPONENTS	99
5.1.1	<i>Helping</i>	99
5.1.2	<i>Positive relationships</i>	101
5.1.3	<i>Working together</i>	102
5.1.4	<i>Individualised practice</i>	103
5.1.5	<i>Empowering practice</i>	104

5.1.6	<i>Inclusive practices</i>	105
5.1.7	<i>Practice as a bandaid</i>	105
5.1.8	<i>Mediation</i>	107
5.1.9	<i>'It's a business'</i>	108
5.1.10	<i>Objective practice</i>	110
5.2	CULTURAL COMPONENTS IN THE CONTEXT OF LITERATURE AND POLICY DOCUMENTS	111
5.3	CONSTRUCTING AND CONVEYING THE CULTURE.....	119
6	FAMILY-CENTRED APPROACHES AND THE CULTURAL UNDERSTANDING OF PROFESSIONAL PRACTICE.....	121
6.1	FAMILY-CENTRED APPROACHES IN PROFESSIONAL PRACTICE	121
6.2	REALISING FAMILY-CENTRED APPROACHES IN PRACTICE	123
7	SUMMARY AND CONCLUSIONS.....	128
7.1	THE STUDY IN REVIEW	128
7.2	REFLECTIONS ON THE RESEARCH PROCESS	129
7.3	THE RELEVANCE OF THIS CULTURAL WORLD TO OTHER CIRCUMSTANCES ..	132
7.4	RECOMMENDATIONS	134
7.4.1	<i>Education</i>	134
7.4.2	<i>Policy and practice</i>	135
7.4.3	<i>Future research</i>	138
7.5	FINAL WORDS	140
	REFERENCES.....	142
	APPENDICES	161
	APPENDIX 1: INFORMATION SHEET & CONSENT FORM	162
	APPENDIX 2: DEMOGRAPHIC INFORMATION SHEET	165
	APPENDIX 3: FINAL ANALYSIS TABLES FOR CORE NARRATIVES AND CULTURE OF PROFESSIONAL PRACTICE WITH FAMILIES	166
	APPENDIX 4: TRANSCRIPTS OF STORIES EMPLOYED TO ILLUSTRATE ANALYSIS	169

LIST OF TABLES

Table 1: Summary of individual interview participants.....	59
Table 2: Example of principle analysis table	80
Table 3: Analysis table distinguishing narratives of professional practice with families	166
Table 4: Components and principles of the culture of professional practice with families	168

LIST OF FIGURES

Figure 1: Interview guide for individual interviews	65
---	----

LIST OF ABBREVIATIONS

ADD	New South Wales Ageing and Disability Department
CSDA	Commonwealth/State Disability Agreement
DADHC	New South Wales Department of Ageing, Disability and Home Care
DoCS	New South Wales Department of Community Services
IEP	Individual Education Plan
IFSP	Individualised Family Service Plan
NGO	Non-Government Organisation
NSW	New South Wales
USA	United States of America

1 INTRODUCTION

The first child of young parents has been born prematurely with a physical disability and immediate health concerns. As a result, they are negotiating a wide range of medical and therapy services to learn how to best support their child. After a long stay in hospital, they bring their child home to their rural community and, almost on autopilot, they attempt to follow hurried instructions from doctors and therapists to “do this ... go there ... see this person”. Both the parents and the child cry through alternate hours of painful therapy and tiring feeding programs. They travel for appointments with the therapists and doctors not available in their area. Mother and child temporarily move away from home to be closer to the required services. The home programs and visits with professionals are often traumatic and hard work. Sometimes the parents are not sure why or how to do these therapy programs. After their initial contact with professionals in hospital they largely feel alone and a little scared that they are doing the right thing to help their child. They are told that it is up to them now if their child walks. So they do these home programs and attend these appointments hoping that their efforts will be enough¹.

I heard this story often as I grew up. It is a story that, at least for me, ended well. My ‘disability’ was relatively minor and has little impact on my daily life. I am able to walk and I barely recall the ‘traumatic’ experiences. Yet the anger and distress associated with my parents’ interactions with services is still palpable in the story my parents tell today. For me, their story started a journey seeking to understand services for children with a disability and, in particular, what shapes the ways that professionals work with families. What is it, for example, that influences how professionals provide instructions to parents?

¹ This and other indented and italicised quotes are narratives based on the data collected in this research.

Families of children with a disability spend a great deal of time negotiating to get support from human service professionals. I am now one of those professionals. Human service professionals are typically university-educated and work for health, welfare and allied health service providers to support the health and development of children with a disability and assist their families (Clear, 1999; Cummins & Baxter, 1997; Jones & May, 1992; Turnbull, Turbiville, & Turnbull, 2000b). In the early years of my professional life as a clinician and researcher, I heard many stories from professionals and families about services that were reminiscent of the challenges and difficulties evoked in my own family's story (Llewellyn, McConnell, Thompson, & Whybrow, 2005; Llewellyn, Thompson, & Whybrow, 2004; Llewellyn, Thompson, Whybrow, McConnell, Bratel, Coles, & Wearing, 2003; Thompson, 1998). These stories fuelled my desire to better understand what influences the ways that professionals work with families of children with a disability. In this chapter I describe the evolution of this study, which brought into sharp focus, my ambition to understand the culture of professional practice with families of children with a disability.

1.1 Background

The fifteen years of my professional career has occurred in the era when a family-centred approach became widely endorsed as an organising framework for quality services for children with a disability and their families (Summers, Poston, Turnbull, Marquis, Hoffman, Mannan, & Wang, 2005; Turnbull, Beegle, & Stowe, 2001). Within this approach, supporting the family is assumed to benefit the health and development of the child with a disability as well as the family (Bradley, 1992; Hutchfield, 1999; Johnson, 2000). Professionals who adopt a family-centred approach have been defined as holding "... a particular set of beliefs, principles, values and practices for supporting and strengthening family capacity to enhance and promote child development and learning" (Dunst, 2002, p. 139).

My study initially focused on three issues that were evident from an analysis of the empirical literature on family-centred practices. The first issue was that the

investigative focus in much of the literature is on *discrete components of practice* with families. There is a focus on features of family services examining, for example, parent–professional relationships and collaboration and empowerment (Clear, 1999; Dempsey & Dunst, 2004; Jivanjee & Friesen, 1997; Katz & Scarpati, 1995; McWilliam, Tocci, & Harbin, 1998; Trivette, Dunst, & Hamby, 1996b; Valentine, 1998). There is also a focus on family services program models and policies (e.g., Dempsey & Dunst, 2004; Dunst, Johanson, Trivette, & Hamby, 1991; Trivette et al., 1996b). A third focus is on whether professionals are well prepared to work in a family-centred manner, centring on, for example, professional education, skills, behaviours and attitudes (Bailey, Buysse, Edmondson, & Smith, 1992; Dunst, Trivette, & Hamby, 1996; Humphry, Gonzales, & Taylor, 1993; McWilliam et al., 1998). Although helpful to understanding family-centred practice, these typically neglected how professionals think, talk and feel about their practice with families.

The second issue concerned the apparent *lack of consistent application of family-centred principles* despite the popularity of this approach. A number of studies had identified a gap between family-centred principles as outlined in the literature and the services professionals provided (see for example, Bailey et al., 1992; Bruder, 2000; Dunst, 2002; Dunst & Trivette, 1996; Dunst et al., 1996; Lawlor & Mattingly, 1998; Mahoney, O'Sullivan, & Fors, 1989; McWilliam, Maxwell, & Sloper, 1999; Viscardis, 1998).

The third issue concerned *challenges that have been identified to implementing family-centred principles*. Some of the challenges identified were: difficulty reorienting the focus of services from the child to the family; system policies that restrict opportunities to building relationships with families; reduction in direct hands-on services with the child; inadequate resources including funding and staff; and, professionals inadequately prepared to work with families (Humphry et al., 1993; Lawlor & Mattingly, 1998; Litchfield & MacDougall, 2002; Mahoney et al., 1989; Turnbull et al., 2000b). These challenges suggest contextual factors are critical to whether or not professionals are able (or not) to apply family-centred principles in their daily work practices (Galvin, Boyers, Schwartz, Jones, Mooney, Warwick, &

Davis, 2000; Harbin, McWilliam, & Gallagher, 2000; Lawlor & Mattingly, 1998; McWilliam et al., 1998; Trivette et al., 1996b).

Building on this last issue, the likely importance of context, I began this study by exploring how professionals implemented family-centred principles in daily practice according to their broader ecological and cultural context. However, capturing the depth of how and why professionals practice as they do, proved elusive when based only on context. In the early stages of data collection and analysis, it became apparent that focusing on practice context alone did not capture the complex and multi-dimensional nature of professional practice with families. I came to understand that the depth of professionals' stories was in the more personal, private or 'human' features of practice. For example, their understanding of themselves as individuals, and as professionals, and what they believe and want for families and for themselves. Personal features such as these appeared to influence, and in turn be influenced by how each professional framed and shaped their practice within their specific context. My initial focus only on family-centred principles seemed to constrain understanding of possible inter-relationships between personal features and practice context. I realised I needed to take a 'step back' and examine the concept of professional practice more broadly, moving beyond although still incorporating context to also encompass professional culture.

As part of this process, I found other investigators had already endorsed a more systematic approach to the multi-layered systems surrounding professional practice with families. What I term my 'a-ha' moment came when I found a 'cultural interpretation of practice' had been proposed as a way of understanding professional practice with families. Several researchers suggest that this approach, that is a cultural interpretation of practice, will help to clarify the underlying values, beliefs, assumptions and meanings held by professionals about their work (Bailey, Palsha, & Simeonsson, 1991; Bengtsson, 2003; Bruder, 2000; Humphry et al., 1993; Katz & Scarpati, 1995; Lawlor & Mattingly, 1998). The notion that cultural matters influence practice had already been used to frame earlier investigations of teacher practice in classrooms (Gallimore & Coots, 1996; Kardos, Moore-Johnson, Peske, Kauffman, & Liu, 2001), general medical practice (Marshall, Sheaff, Rogers,

Campbell, Halliweel, Pickard, Sibbald, & Roland, 2002), and service plans for children with a disability in early intervention (Katz & Scarpati, 1995).

To assist my understanding of how to conceptualise professional practice with families in cultural terms, I turned to the work of cultural psychologist Jerome Bruner (Bruner, 1990a; Bruner, 1996a; Bruner, 1996b). Bruner's writing in the 'new' cultural psychology on situated action, culture and narrative provides a framework for understanding rather than predicting human action. He places emphasis, for example, on the interpretive processes involved in constructing meaning around action and the importance of exploring these processes to understand why people do what they do (Bruner, 1990a).

In brief, Bruner proposes that the nature and cultural shaping of meaning are a central influence on human beliefs, thoughts and action (Bruner, 1990a; Bruner, 1996b). Fundamental to understanding these interpretive processes is the concept of 'situated action'. That is, action situated in a cultural setting and in the intentional states of members of that cultural community. Bruner advocates situated action as a means of understanding human action stating that:

In the end, even the strongest causal explanations of the human condition cannot make plausible sense without being interpreted in the light of the symbolic world that constitutes human culture (Bruner, 1990a, p. 138).

Following this, Bruner also suggests narrative is the means by which individuals and cultures order their experience and construct reality (Bruner, 1996a, 1997; Bruner & Kalmar, 1998; Bruner, 1996b). To understand humans and their dilemmas therefore from this perspective, requires examining the 'narrative mode of thought'. In this narrative mode of thought, the meaning of individuals' experiences and what they know, think, and do is represented. Further to this, the 'narrative mode of culture' is the way meaning is constructed within a culture. Bruner suggests therefore that the meaning within the culture can be understood by the narratives or stories told by its members. For Bruner, narrative constitutes a shared understanding and expression of a particular culture's worldview. In essence Bruner believes that:

It is through our own narratives that we principally construct a version of ourselves in the world, and it is through its narrative that a culture provides models of identity and agency to its members (Bruner, 1996b, p. xiv).

Bruner's new cultural psychology approach offered, I believed, a way to overcome the stumbling block I had encountered when first focusing on context and family-centred principles alone.

I therefore moved to adopt a cultural interpretation of professional practice with families of children with a disability. Using Bruner's (1990a) conceptualisation, I sought to identify and understand the culture of professional practice with families. Further, I aimed to understand how professionals construct and substantiate this culture in their day-to-day thoughts, actions, and through their experience. In doing so, I intended to build on and at the same time expand the considerable body of work that exists on discrete components or approaches to practice with families. By adopting a cultural view of practice, my study aimed to address the values, beliefs and underlying meanings held by professionals of their practice with families. My purpose was to provide an understanding about the world in which professionals live and make decisions. Identifying, exposing and naming the dimensions of professional practice in this way has the potential, I believe, to shape policy, professional education and practice to achieve more supportive and beneficial relationships with families facing their child's disability.

1.2 Aim of study and research questions

This study had two broad aims: (i) to identify and explore how professionals work with families of children with a disability from a cultural perspective, and, (ii) to identify and describe the cultural context of these work practices from the professional perspective.

Employing Bruner's concepts of situated action, culture and narrative, I derived the following research questions for this study:

1. What are the core narratives in professionals' practice with families of children with a disability?
2. What is the culture of professional practice with families of children with a disability?

This study has sought to understand professional practice with families from the perspective of human service professionals. Professionals' stories, including their experiences and interactions with families' stories were examined and interpreted. This study was cross-sectional in nature and did not attempt to examine professional practice over time. Nor did I set out to examine the perspective of other people who may influence professional practice with families such as policy-makers, service managers or the families of children with a disability. The culture of human services more generally, the family perspective, and patterns in professional practice over time, are questions worthy of in-depth examination in their own right.

1.3 Definition of terms

As noted, this study adopted a Brunerian cultural framework. 'Culture' according to Bruner is shared symbolic systems and traditional ways of living and working together as represented in, for example, language, myths, rituals and literature, and which reflect the accepted ways of life in a culture (Bruner, 1990a). Bruner's concept of culture is explained in detail in Section 3.1.2.

Bruner's concept of 'situated action' is also central to this study. Situated action is defined as the actions including mental activity which are given meaning by being 'situated' in a cultural setting and in the values, beliefs, intentions, desires and commitments of the members of that cultural community (Bruner, 1990a). Situated action is described in detail in Section 3.1.1.

For the purpose of this study, the single term 'professional' is used to refer to human service personnel as defined in Australian papers by Jones and May (1992) and Clear

(1999) and noted in the first paragraph of this introduction. Specifically, 'professionals' refers to university-educated employees in the human service system, including counsellors, nurses, occupational therapists, psychologists, physiotherapists, social workers and speech therapists.

The term 'family' is increasingly used to define a wide diversity of family types and lifestyles, including for example, single-parent, blended, nuclear and communal families (Australian Institute of Family Studies, 1994). For the purpose of this study, the term 'family' was purposefully broad as employed by the professionals who participated in this study.

1.4 Synopsis and organisation of the thesis

Over the past two decades, family-centred practice has become the framework of choice for the delivery of quality services to children with a disability and their families. To date, studies in this area have focused on discrete practice components and often failed to consider the context in which practice occurs. To fill the gap in understanding about professionals' values, beliefs, assumptions and meaning of practice with families, a cultural interpretation of professional practice with families informed this study.

This study sought to identify and describe the culture of professional practice with families, following a Brunerian concept of culture, and to understand how professionals instantiate this culture within their daily practice. The purpose in doing so was to achieve an understanding of the cultural world in which professionals live and make decisions in their practice with families. Exposing a deeper view of the cultural world in which professionals think, feel and act has the potential, I believe, to shape policy, professional education and practice to achieve more supportive and beneficial relationships with families of children with a disability.

In the next chapter, I examine the cultural world of professional practice as presented in the literature and policy documents. Chapter 3 describes Bruner's concepts of

culture, narrative and situated action that underpin the conceptual framework for this study as well as the methodology employed in the study. The following two chapters present and discuss the findings from the study. Chapter 4 presents the cultural core narratives of professional practice with families. Chapter 5 presents the principles comprising the culture of professional practice. Chapter 6 considers family-centred practice within this new understanding of professional practice. Chapter 7 summarises the findings and puts forward recommendations on research, education, policy and practice.

2 PROFESSIONAL PRACTICE WITH FAMILIES IN POLICY DOCUMENTS AND LITERATURE

In this chapter, I explore the cultural world in which professionals think and act as depicted in service system documents and the literature. This review provides a context for the research questions in two ways. First it exposes the values, beliefs and assumptions to which professionals may be acculturated in their daily work. Second, it identifies current empirical knowledge about how professionals think, feel and act in relation to these values, beliefs and assumptions.

The literature on practice with families of children with a disability as a cultural activity is a discrete one, originating almost exclusively from the United States of America. This review of the literature therefore also identifies key concepts to which human service professionals working with families of children with a disability in NSW may be acculturated. Concepts are drawn from relevant Australian and NSW legislation, human service policy documents, and international literature on practice with families. The literature reviewed comes from the professions of occupational therapy, speech therapy, physiotherapy, psychology, nursing and social work, and includes empirical studies and issue papers that are primarily program focused, for example, in early intervention or school-aged services.

The disability service system provides a framework for professional socialisation into disability services in NSW. The structure of this service system and Commonwealth (Federal) and State legislative requirements are outlined in Section 2.1 as a context for the concepts identified in the following sections. Reflecting the historical interpretive approach of Bruner's cultural psychology, these sections (2.2 to 2.4) trace the historical movements that have influenced practice with families. Specifically, Section 2.2 addresses medical interpretations of professional practice; Section 2.3 addresses concepts that reflect a family-centred approach to practice. Section 2.4 reviews concepts that reflect managerialism and economic rationalism that influence practice. Section 2.6 includes a review of the small and discrete body

of literature on practice with families as a cultural activity. This review is summarised and the research questions restated in Section 2.7.

2.1 New South Wales services for families of children with a disability

2.1.1 The disability service system

At the outset of this study, there were several key players in the provision of services for children with a disability and their families in NSW. The first of these, the NSW Department of Ageing and Disability (ADD), was the principal department governing the policies, funding and provision of services for children with a disability and their families in NSW. It was not however, a direct service provider (NSW Ageing and Disability Department, 2000b). Service provision came from the second and third major contributors to the disability services sector.

The second major contributor was the NSW Department of Community Services (DoCS). Community Support & Resource Teams within DoCS were funded by the NSW government via ADD to provide support services for children and their families in the community. In April 2001, a new state government department was formed, known as the NSW Department of Ageing, Disability and Home Care (DADHC). This new department incorporated the disability component of DoCS, Home Care Services and ADD. There were no direct changes to the physical locations of existing services, service activities or operational staff within DoCS, but rather a renaming and realignments of these services with DADHC (NSW State Government, 2001). Therefore, Community Support and Resource Teams continued to provide support operating however under the auspices of DADHC. With no changes to service activities or operational staff, many of the relevant policies and procedures developed by DoCS and ADD were continued by DADHC.

The third major contributor to services for children with a disability and their families was the non-government sector. Non-government organisations (NGOs)

were contracted by ADD (later DADHC) to provide specialist services for children with a disability and their families, including recreation, respite, counselling and therapy services (NSW Department of Community Services, 2001d). Historically, parents, frustrated by a lack of opportunities and services, initiated many of the non-government services for people with a disability (Bradley, 1992). In NSW, some of the larger non-government disability services contracted by the NSW government to provide services for children with a disability and their families at this time were The Spastic Centre of NSW, The Northcott Society and The Royal Blind Society (NSW Department of Community Services, 2001d).

At the time of this study, human service professionals were working with, or for these key players, providing specialist support services to children with a disability and their families in the community in NSW. These services included: therapy, respite and recreation, counselling and financial assistance – although not all families received all services. Services were usually based on the age of the child with a disability. Early intervention services were targeted at children between birth and six years of age with, or at risk of disability. These services included medical, therapeutic, educational, and/or social interventions provided through home visits or centre-based services (Early Intervention Coordination Project, 1994; Linfoot, 1998).

School-aged children with a disability in NSW were generally enrolled in one of three educational programs: special schools for children with a disability, support classes in regular or 'mainstream' schools, or in regular classes in mainstream schools (NSW Department of Ageing Disability and Home Care, 2003). Decisions on which educational program a child with a disability attended were made by a District Education Panel based on consultations with parents or caregivers and consultants, including human service professionals, who may be involved in, for example, diagnosis or functional assessments of the child or school environment (NSW Department of Education and Training, 1997). The student's support needs in areas such as curriculum, mobility, social skills, personal care and communication as well as available educational resources such as support teacher availability or funding for building modifications were taken into account (NSW Department of Education and Training, 1997). Human service professionals usually provided

services to support children with a disability and their families in, or allied to their school environment. Professionals also worked with children and families in centre-based services where the child and family visited one or more professionals at the service centre or in home-based services where the professionals visited the child and family at home.

At that time (2000–2001), government based Community Support and Resource Teams were the primary providers of disability services to school-aged children with a disability in NSW (NSW Department of Community Services, 2001a). They consisted of multi-disciplinary teams of human service professionals for school therapy, generic resources and behaviour management (NSW Ageing and Disability Department, 2000a). School therapy teams provided specialised therapeutic services including occupational therapy, physiotherapy, speech therapy and support to school-aged children with the aim of enabling them to achieve their individual child and family and educational goals. They often worked in association with generic resource teams who assisted children and families with accessing appropriate resources (including financial assistance, home and school modifications and equipment). They may also have worked in association with behaviour management teams that work with schools, families and the child to manage challenging behaviours through training, intensive child and family interventions, education, programming and consultations with other professionals (NSW Ageing and Disability Department, 2000a).

NGOs also provided services to support school-aged children with a disability and their families in NSW. These services varied in structure, with some teams being task-based (e.g., communication teams) and others profession-based (e.g., occupational therapy). However, most followed more aged-based team structures in line with their government counterparts (e.g., school-aged team). They provided a variety of school, centre and home-based services, including for example, therapy, environmental assessments and modification, counselling and coordinating respite.

2.1.2 Disability service policy

There are several legal directives that govern disability services in Australia. These directives however do not specifically target children with a disability or their families. This contrasts to legislation in the United States of America (USA), briefly mentioned here because much of the literature on working with families has arisen in the context of these laws. Part H of American Public Law 99–457 The Education for Handicapped Children Act Amendments (1986) (later amended to Part H of Public Law (PL) 102–119) and the passage of the Individuals with Disabilities Education Act (IDEA)(1990), (later reauthorised as IDEA (1997)), specifically legislate on working with children with a disability and their families in ways that promote family strengths, capacities and active participation in services. They emphasise viewing the child in the context of the family unit and stress services must address family priorities, build on family strengths and meet family needs (Polmanteer & Turbiville, 2000). These laws seek to encourage multifaceted partnerships among society, professionals and the family (Sokoly & Dokecki, 1992).

In 1986 the Commonwealth Government of Australia enacted the Commonwealth Disability Services Act, which legislated for equal rights and opportunities for people with disabilities. In 1991 the Commonwealth, State and Territory governments signed the Commonwealth/State Disability Agreement (CSDA) which agreed: (i) that all parties would be guided by the principles and objectives of the Commonwealth Act; (ii) that all states and territories would enact legislation with complementary principles and objectives; and (iii) to a national approach to needs based planning for disability services.

Eight National Disability Service Standards were subsequently developed that, while not part of the Act, translate the Principles and Objectives into standards for service practice. These standards were later incorporated into the relevant state disability service standards known in NSW as the NSW Disability Service Standards, described below.

The NSW Disability Services Act (1993) was developed following the Commonwealth/State Disability Agreement and reflects the philosophies of the

Commonwealth Disability Services Act (1986). The NSW Disability Service Standards, whilst not part of the Act, were developed to assist NSW services to conform to the principles and objectives outlined in the Act. Together, the NSW Disability Services Act (1993) and the NSW Disability Service Standards are benchmarks for quality services for people with disabilities and their families in NSW.

The ten NSW Disability Service Standards are as follows:

1. *Standard service access* is concerned with ensuring each consumer has access to a service on the basis of relative need and available resources.
2. *Individual needs* describes ensuring each person with a disability receives a service designed to meet his or her individual needs and personal goals.
3. *Decision making and choice* states each person with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life and in relation to the services he or she receives.
4. *Privacy, dignity and confidentiality* is concerned with recognising and respecting each consumer's right to privacy, dignity and confidentiality in all aspects of his or her life.
5. *Participation and integration* is about ensuring each person with a disability is supported and encouraged to participate in and be involved in community life.
6. *Valued status* states each person with a disability should be given the opportunity to develop and maintain skills and to participate in activities that enable him or her to achieve valued roles in the community.
7. *Complaints and disputes* seeks to ensure processes are in place where each consumer feels free to raise and have resolved any complaints or disputes he or she holds about the agency or service they receive.
8. *Service management* regards adopting sound management practices that maximise service outcomes for consumers.
9. *Family relationships* concerns ensuring each person with a disability receives a service which recognises the importance of preserving family relationships

and informal social networks and is sensitive to their cultural and linguistic environments.

10. *Rights and freedom from abuse* ensures the legal and human rights of people with a disability are upheld in relation to the prevention of sexual, physical and emotional abuse within the service (NSW Ageing and Disability Department, 1998).

DADHC is responsible for ensuring that all programs that receive funding for disability services conform to the principles of the NSW Disability Services Act (1993). The Standards in Action Manual provides guidelines on the implementation of the NSW Disability Service Standards (NSW Ageing and Disability Department, 1998). As a condition of funding, DADHC monitors both government and non-government services against these practice requirements through a process of audits and the completion of annual self-assessment packages (NSW Ageing and Disability Department, 1999, 2000a). These packages serve as a framework for accountability. The granting or continuation of funding is contingent on service activities demonstrating compliance via this accountability process to the ten NSW Disability Service Standards and the NSW Disability Services Act (1993).

As stated previously, this review identifies key concepts of the cultural world of disability services. The first of these reflects a traditional view of practice with children with a disability and their families, which is framed within a medical discourse. This concept is explored in Section 2.2.

2.2 Medical rationale and ‘traditional’ ways of working with families

According to Clear (1999) Australian formal care systems for people with a disability have traditionally been aligned with medical and scientific rationales. Internationally, Lawlor and Mattingly (1998) referred to the rationale underlying service delivery with families as the ‘culture of biomedicine’, noting that professional preparation programs continue to prepare professionals in line with this

approach. Dunst (2000) described this traditional, medically framed way of conceptualising, developing, and implementing services for children with a disability and their families as direct treatment-focused, deficit-based, service-based and professional-centred.

In this traditional medical view of practice with families, the professional is central. Professionals are viewed as the experts, acting in a paternalistic fashion towards children and families whose contribution is deemed to be limited: to providing information and passively complying with an intervention plan proposed by the professional (Bazyk, 1989; Dunst et al., 1991; Lawlor & Mattingly, 1998; Singh, 1995). The ‘expert’ professional is positioned as the primary determinant of child and family service needs (Larson, 1998). According to Clear (1999), professionals determine and address these needs through an interaction process where the professional assesses and identifies the problem, measures the extent of the problem, prescribes a program or regime of treatment, monitors the effects of that intervention and evaluates the status of the intervention.

In this approach, the child with a disability, according to Bailey and colleagues (1990) is the traditional focus of intervention (Bailey, Simeonsson, Yoder, & Huntington, 1990). In a survey with USA early intervention service providers, for example, Mahoney et al. (1989) found most service goals were reported as child-centred, noting that by focusing their interventions on the child, professionals were better able to measure the effectiveness of their interventions. Similarly families in Australia (Thompson, 1998) and the USA (Katz & Scarpati, 1995) have reported the services they received were primarily child-focused.

Being child-focused, professionals working within this traditional view of practice provide direct, hands-on treatment to address the problems or deficits they identify. In a discussion paper based on ethnographic research in the USA, Lawlor and Mattingly (1998) identified this direct practice as “real work” or “real treatment”. The real work is this: grounded within a medical model, professionals identify problems in the child’s body or behaviour, often using standardised assessments. They provide treatment techniques based on their training and restrict interventions

to address outcomes that can be measured and reported to others (Lawlor & Mattingly, 1998; Mattingly, 1991). According to these authors and others (McWilliam, 1996), professionals in the USA continue to express concern about their ability to help support children and families when they are not able to work directly with the child suggesting professionals may not be acculturated to working in any other way.

This may not be so surprising as over twenty years ago, Donnellan and Mirenda (1984) reported that professional training programs were treatment oriented, emphasising the acquisition of techniques and methods for working directly with the child with a disability. At that time, little or no attention was given to supporting professionals to work with families. According to many authors, in the decade or so that followed, professional preparation programs in the USA continued to prepare practitioners to be treatment oriented, child-focused experts that hold authority over their client (Bailey et al., 1992; Bailey et al., 1991; Bailey et al., 1990; Johnson, 2000; Whitehead, Jesien, & Ulbanski, 1998).

To date, Australian professional preparation programs have not been critically examined and reported in the literature. One unpublished report by Rodgers and Brown (2004) compared the paediatric components of occupational therapy preparation programs in Australian, New Zealand and Canada. Paediatric intervention strategies and methods for treating children were the most frequent elements of programs in all three countries. Educating parents was the second most frequently taught practice in Australia and New Zealand and was represented in 90% of the programs. As no further detail was offered about what 'education of parents' entailed, it is unclear if this involves more than the traditional view in which parents are taught to carry out programs determined by professionals.

Internationally, some authors have observed that the education and socialisation of professionals to these traditional role expectations is a major barrier to working with families and advancing child and family health and wellbeing (Bailey et al., 1992; Clear, 1999; Donnellan & Mirenda, 1984; Dunst et al., 1991; Lawlor & Mattingly, 1998; McWilliam, 1996).

2.3 Family-centred concepts for working with families

In the literature it is possible to identify a move away from the traditional medical ways of working with families outlined in Section 2.2 to the principles and practices identified as ‘family-centred,’ sometimes called ‘family support’, ‘family-focused’ and ‘parental empowerment’ (Bailey et al., 1992). For consistency, the most frequently found term, family-centred, is used in this review. According to Turnbull and colleagues (2001) family-centred approaches are now established core concepts of disability policy and practice in the USA. Similarly, Bruder (2000) noted this family-centred approach has guided research, training and service delivery since the mid 1980s, an assumption not necessarily shared by other authors as noted in the previous section.

Within the family-centred approach professionals are required to realign their usual focus on the child to recognise families as active participants in services (Dunst, Trivette, & Deal, 1988; Polmanteer & Turbiville, 2000). As noted in Chapter 1, Section 1.1, professionals who adopt this family-centred approach have been defined as holding “... a particular set of beliefs, principles, values and practices for supporting and strengthening family capacity to enhance and promote child development and learning” (Dunst, 2002, p. 139).

A great deal of the literature is devoted to identifying and exploring the principles and practices of this family-centred approach. There is also a significant amount of research on operationally defining and measuring outcomes when this approach is implemented. NSW service policy documents do not specifically declare a family-centred approach. However six key concepts in these service policies reflect family-centred principles also evident in literature and research. These are a child or family focus, enhancing a sense of community, shared responsibility and collaboration, protecting family integrity, empowerment and strengthening families, and individualising practice. The literature pertaining to the nature and practice and understanding of each of these concepts is reviewed below.

2.3.1 Child or family focused?

Despite the reported ideological shift towards more family-centred practice, debate continues as to who is the client in human services for children with disability and their families: the child, the family or both (Dunst et al., 1991; Lawlor & Mattingly, 1998). Though client needs are considered central to the rationale for services, professionals may receive and help sustain conflicting ideas about who is the client while this debate continues.

In NSW, professionals may receive these mixed messages at both policy and procedural level. For example, the NSW DADHC Strategic Directions paper states people with a disability, their families and carers are their clients (NSW Department of Ageing Disability and Home Care, 2002b). In contrast, the eligibility parameters for program funding emphasise the person (or child) with a disability (NSW Department of Community Services, 2001d).

The way in which family-centred practice is described in much of the literature also presents some ambiguity about who is the client. Many authors describe family-centred support services as involving “clients and their families”. This suggests, in line with the traditional practice described earlier, that the child is the focus of professional intervention, followed in second place, by the family (Galvin et al., 2000; Munford & Sanders, 1999; Singh, 1995). In contrast, other scholars have suggested more in line with a family-centred approach that the family is valued above and beyond their role as the child’s carer (Allen & Petr, 1998; McWilliam et al., 1999).

This ambiguity may lead to uncertainty for professionals about who should be their focus as noted by Lawlor and Mattingly (1998). They linked the uncertainty to professionals’ difficulty in shifting roles and involving families, leaving professionals unsure about how to measure the effectiveness of their intervention – in the child or in their family.

Alternatively, professionals may assume that child and family focused interventions are interwoven as intervention with one, influences the other, whether intentional or not, thus bypassing the question of who is the primary client (Bailey et al., 1992). In NSW, whether professionals regard the child, their family or both as the focus of services has yet to be explored.

2.3.2 Enhancing a sense of community

In the early 1970s, a movement towards normalising the experience of people with a disability began (Wolfensberger, 1983). In Australia, legislation arising from the principles of this normalisation movement governs equal rights and opportunities for people with a disability. A core principle in the NSW Disability Service Act (1993) states: “Persons with disabilities have the same basic human rights as other members of Australian society”. One such right is that the family is considered the natural and best environment for supporting and nurturing a child with a disability (NSW Department of Ageing Disability and Home Care, 2002a). In NSW service policy and the literature, professionals are therefore charged with supporting the integration of children with a disability and their families into their local communities – a concept also noted in the international literature (Agosta & Melda, 1995; Dunst & Bruder, 2002; NSW Ageing and Disability Department, 1998, 1999; Roberts, Rule, & Innocenti, 1998; Vandiver, 2004).

In the literature, the term integration and inclusion are often used interchangeably to describe practices aimed at promoting the community and families of children with a disability coming together around shared values and support needs (Dunst, 1990). Bradley (2000) used the term inclusion to describe a conceptual evolution from an ‘inclusion-like’ geographical focus to an ‘integration-like’ one tied to social, personal and political elements of participation, choice and relationships (Bradley, 2000).

Derived from the principles of normalisation, Bradley (2000) asserted that the values underlying integration are based on affirmative notions of equality and accommodation of difference. These ideas are emphasised in NSW service

documents directing services to ensure the individual's right to be a part of his or her local community. The fifth NSW Disability Service Standard states, "Each person with a disability is supported and encouraged to participate and be involved in the life of the community" (p. 7). Accordingly, service vision, values and key performance areas of both government and non-government services reflect this notion (Eastern Suburbs Developmental Disability Service, 2002; NSW Ageing and Disability Department, 1999, 2000a; NSW Department of Community Services, 2001a, 2001c; Spastic Centre of NSW, 2001).

Strengthening a local community is considered a key performance area for services as they strive to ensure that people with disabilities feel included in the community at large (NSW Department of Community Services, 2000). This involves professionals working with and educating communities to recognise the valuable skills of people with disabilities and the roles they can adopt within the community (Disability Service Standard, No 6 – Valued Status). These policies describe what the literature refers to as empowering communities (Ackerson & Harrison, 2000). Empowerment is explored further in Section 2.3.5.

The literature provides professionals with guidelines on the actions they might take to enhance community integration in this way. For example, Harbin and colleagues (2000) asserted that professionals must address the major barriers to integration of children with a disability and their families into mainstream community life and opportunities. They named these barriers as including fear, lack of physical access to service programs and community spaces, a lack of integrated social activities, and a lack of skills and knowledge in the community on disability and how to include families in community opportunities (Harbin et al., 2000). In addition, literature, and NSW human service policy and procedures increasingly direct professionals to build relationships with families and share responsibility for developing, implementing and evaluating interventions.

2.3.3 Shared responsibility and collaboration

The electronic Encarta World English Dictionary (Microsoft Corporation, 1999) defines collaboration as the act of working together with one or more people in order to achieve an outcome. According to Dunst (1990) collaboration between professionals and parents involves developing partnerships based on mutual respect and sharing information as a means to strengthen family functioning and address child and family needs.

In a review of a research paper, Dunst (2002) highlighted that parents and professionals needed to work together throughout all stages of the service delivery process. In sum, he noted that professionals and families should collaborate in determining child and family needs, setting goals and intervention plans and implementing, monitoring and evaluating the services provided. In contrast, Beckman, Frank & Newcomb (1996) suggests collaborating only on identifying family needs. The contrast between these points of view suggests that professionals learn different perspectives, a potential reason for why they may collaborate in different ways with families. Beckman and associates (1996) implies a more professional-centred approach, where professionals collaborate in order to get information for designing services. In contrast, Dunst (2002) promotes family–professional collaboration throughout the whole process. Lawlor and Mattingly (1998) highlighted the complexities of parent consultation in more professional-centred practices, noting that, in these instances, parents were more likely merely to provide information and carry out professionally developed programs, than to be truly collaborative partners.

NSW Disability Service Standards and service policies and procedures direct professionals in NSW to establish and maintain partnerships with people with disabilities, their families, other services, and the community as a whole (e.g., NSW Department of Ageing Disability and Home Care, 2002b; NSW Department of Community Services, 2000; NSW Department of Community Services, 2001c; Spastic Centre of NSW, 2001). The core features of these partnerships receive considerable attention in NSW policy and literature. Common features identified include collaboration, teamwork, trust, and communication.

It is generally thought that collaborative partnerships are based on open communication (Hutchfield, 1999; MacKean, Thurston, & Scott, 2005). DoCS and DADHC recommend clear and direct communication between clients and services. They direct services to establish protocols that ensure professionals' written and verbal communications define intent and expectations of their interventions clearly and transparently. For example, service protocols direct professionals to document and distribute their intervention goals and plans to the family and other professionals involved with the child and family (NSW Department of Community Services, 1996).

Honesty, integrity and trust are additional values underlying the provision and funding of disability services in NSW. DoCS (2001c) identifies trust as one of their core values defining it as "doing what we say we will do. Delivering on our promises" (p. 1). Later, DADHC (2002b) suggested trust is achieved through honesty and integrity with clear, open communication of service guidelines and procedures, thus outlining expectations of services and delivery of services in accordance with these guidelines. The literature has also highlighted the importance of these features to achieving professional–family collaborations (e.g., Beckman et al., 1996; Bolton, 2000; Dunst et al., 1996; Hutchfield, 1999; MacKean et al., 2005, Turnbull, 2006, in press).

There is an expanding literature on family–professional collaboration. Parents have identified their preference for services where professionals communicate in ways that portray a genuine interest in the child and family, share information and invite and respect family viewpoints (Baxter, 1989; MacKean et al., 2005; McKenzie, 1994). Families also report experiencing interactions with professionals that do not include these preferred characteristics (Baxter, 1989; Leiter, 2004; McKenzie, 1994). The mismatch here appears to be between what families want and expect from professionals in a relational sense, and what they experience.

A recent Canadian study by MacKean et al. (2005) supported the importance of the relational elements of practice and particularly collaborative partnerships. However

they also found that when family-centred care is operationalised, collaborative processes often disappear and are replaced by transferring responsibility to parents. They highlighted four contributing factors to difficulties in establishing true collaborative relationships and the related inclination to conceptualise family-centred practice as training parents to take more responsibility. First, the history of family-centred care, which was founded in parents advocating for more responsibility for their child has contributed to training parents to take responsibility rather than engage in collaborative care. Second, the business discourse of efficiency and cost effectiveness suggests shifting responsibility to parents is cheaper. Third, the traditional medical model emphasises the ‘expert’ professional who tends to define the roles parents are expected to play. Fourth, traditional biomedical ethics, with an emphasis on autonomy and self-determination undermine recognition of the importance of relationships and working together (MacKean et al., 2005).

Similarly, in an Australian study reviewed fully in Section 2.6, parents also reported valuing the more personal elements in their partnerships with professionals. Clear (1999) noted that when genuine partnerships were present, parents consistently commented on the “personal quality” of the relationship when professionals made efforts to “step outside their professional self” (p. 2). However like MacKean et al. (2005), Clear (1999) found that these parent–professional partnerships were undermined by an inequality and objectivity born of the more traditional medical rationale for practice.

Two studies have explored, from the professional perspective, other barriers and difficulties in achieving collaboration between professionals and families (Bailey et al., 1992; Dinnebeil, Hale, & Rule, 1999). Findings in both studies highlight the relevance of service context and the socialisation and preparation of professionals for working with families. In the earlier study, Bailey and colleagues identified several barriers to parent involvement in early intervention services. Family barriers (e.g., knowledge, skills, attitudes, resources, family functioning) and system barriers (e.g., institutional policies, lack of resources, and established and or inflexible systems) accounted collectively for more than 70% of the barriers identified. Barriers associated with professional lack of knowledge and their skills and attitudes

accounted for 15% of the barriers identified and raised questions about the extent professionals were prepared and able to work with families. The final obstacle to parent involvement in services arose from the lack of reliable, valid and practice assessment instruments that incorporated family involvement.

In the more recent study, Dinnebeil and colleagues (1999) noted similar barriers to those identified by Bailey et al. (1992). In a qualitative analysis of open-ended survey questions, they identified five categories that most enhanced and hindered parent–professional collaboration: the program philosophy and climate; service delivery options; teaming approaches (concerning how various personnel and families work together); administrative policies and practices (including the quality of program personnel); the community context; and, the wider service system in which the individual program is situated.

An Australian study by Litchfield and MacDougall (2002), whilst not specifically focused on partnerships, did explore parent involvement in services. In-depth interviews were conducted with ten physiotherapists working in family-centred community based paediatric services. They found that the physiotherapists saw their role as working together with parents to identify and reach shared goals, a role endorsed by the family-centred service policy. However they also identified other service conditions and policies that worked against professionals fully adopting policies on parental involvement. These tensions with family involvement included a mismatch between family desires and available resources, and pressure to document their work process and outcomes within evidence-based practice.

It appears therefore that professionals are directed in service policy to develop collaborative partnerships with families and disregard this approach in practice as reported in the empirical and discussion-based literature. Parents when asked for their preferences endorse qualities of the professional–family relationships identified in policy, including respect, open communication, trust and integrity. Despite this agreement, several studies report that professionals still struggle to develop collaborative partnerships (e.g., Bailey et al., 1992; Clear, 1999; Dinnebeil et al., 1999; MacKean et al., 2005). Studies that describe the barriers to parent–professional

partnerships raise questions about how professionals interpret their responsibilities in their relationships with families and how the broader service context informs the way in which the relationship proceeds.

2.3.4 Protecting family integrity

Protecting family integrity is identified by Dunst (1990) as a major principle of family support. According to Dunst (1990) this involves respecting and protecting the beliefs and values of individual families and individual family members. Resources and supports are provided with the aim of developing and maintaining healthy relationships between family members. This includes ensuring all family members are involved and considered in the program (Dunst, 2002; Rosenbaum, King, Law, King, & Evans, 1998).

Service policies and literature value practices that aim to preserve family relationships. In NSW, professionals are accountable in terms of the Ninth Disability Service Standard, which asserts that each person with a disability should receive a service that recognises the value of and seeks to preserve family relationships and informal social networks (NSW Ageing and Disability Department, 1998, p. A4.6).

A component of preserving family relationships is supporting families to continue to care for their child with a disability at home rather than seek out-of-home placement. Preventing out-of-home placement has been the focus of much research attention in Australia and internationally (e.g., Agosta & Melda, 1995; Hannerman & Blacher, 1998; Llewellyn et al., 2005; Llewellyn et al., 2003). This body of research has predominately focused on identifying the child, family and support factors that help predict families at-risk of out-of-home placement, providing guidance to professionals on how they might support families to continue caring for the child with a disability at home. There is little in this body of research that explores how professionals interpret and make decisions about maintaining family relationships.

2.3.5 Empowerment and strengthening families

Empowerment of people with a disability and their community is a feature of the literature and policies on working with families (e.g., Agosta & Melda, 1995; Bradley, 2000; Dunst, 2000; Itzhaky & Schwartz, 2000; Kirshbaum, 2000; Singer & Powers, 1993). Empowerment is defined as “the process of helping individuals, families, groups, and communities increase personal, interpersonal, socio-economic and political strength and influence toward improving their circumstances” (Barker, 1991, cited in Ackerson & Harrison, 2000).

According to a review of the literature by Dunst (1991), a key principle of family-centred services is promoting family strengths and abilities to enable their performance of caregiving responsibilities in ways that have empowering consequences. Empowering practices involve families retaining control and decision-making power over the services they receive and professionals sharing information to allow families to make informed choices, and respecting their decisions (Bailey et al., 1992; Rosenbaum et al., 1998).

NSW service policies also guide professionals to empower and respect clients as the primary decision-makers in practice. Disability Service Standard Number Three demands that the client “...has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives”. Like the literature, NSW policy documents highlight the centrality of professionals providing information to help clients make informed decisions. For example, the 2000 DoCS Annual Report described empowering clients through the provision of information and resources to help facilitate informed decision-making (NSW Department of Community Services, 2000).

Research on empowerment practices with families of children with a disability has focused on identifying and defining empowering practices and exploring the outcomes of those practices (e.g., Dempsey & Dunst, 2004; Dunst et al., 1996; McIntyre, 2000; Trivette, Dunst, Boyd, & Hamby, 1996a; Trivette et al., 1996b). For example, research by Dunst, Trivette and colleagues explored the empowering

outcomes of particular helping practices (Dempsey & Dunst, 2004; Dunst et al., 1996; Trivette et al., 1996a; Trivette et al., 1996b). This series of studies began by identifying the participatory and relational components of effective family-centred helping practices (Dunst & Trivette, 1996). Participatory components included practices that were individualised, flexible and responsive to family concerns and priorities. These were practices that provide families with opportunities to be the key decision makers, with parents and professionals collaborating to achieve family identified goals. Relational components were practices typically associated with good clinical skills, such as being non-judgemental, and demonstrating empathy, respect and active listening. These conveyed beliefs about the competencies and capacities of the help-recipient.

In a series of quantitative studies with three different samples of mothers of children with a disability in the USA, Dunst, Trivette and colleagues found participatory helping practices were rated by parents as providing them with experiences consistent with empowering philosophies (Dunst et al., 1996; Trivette et al., 1996a; Trivette et al., 1996b). When these practices occurred, parents felt they had more control over the resources at hand, and identified a high degree of self-efficacy and personal control. These findings suggest that there is an increased likelihood that families will benefit from their exchange with practitioners when there is a greater emphasis on participatory practices. In contrast, a combination of both relational and participatory helping practices was recently found to significantly contribute to improved empowerment outcomes in an Australian- and USA-based study by Dempsey and Dunst (2004). Outcome-focused studies of this nature highlight the types of practices that may be empowering, however they give no indication of how professionals understand and employ these empowering practices.

Two studies do however provide some insight into how professionals understand empowerment practices (Ackerson & Harrison, 2000; Valentine, 1998). In a small qualitative study, Ackerson and Harrison (2000) examined how the meaning of empowerment is formulated by social workers at the practice level. They found empowerment was viewed as a general ideological 'lighthouse' that had motivational powers for workers rather than a well-defined practice method. There was little

consensus in the meaning of empowerment. Social workers usually focused on the meaning of empowerment at a personal level, including focusing on the individual's capacity to make decisions and act. Few participants considered empowerment in terms of broader social and environmental issues that may contribute to successful empowering outcomes for clients.

In a second study by Valentine (1998), empowerment with ten children's nurses was explored using grounded theory methods. The findings indicated that professionals possessed the theoretical knowledge and understanding to empower families, however they required further training to be able to do so. Professionals believed successful partnerships, where roles were mutually agreed upon and there was good communication, encouragement and support, enabled empowerment to occur. More junior staff however lacked the skills and behaviours to translate this theory into practice. This study also highlighted issues in the working environment such as organisational structures and culture, and staff levels as influencing professional ability to work with families in empowering ways (Valentine, 1998). No studies were identified that have explored how professionals working with families of children with a disability interpret and enact (or fail to enact) the principle of empowerment.

2.3.6 Individualising practices

Within the family-centred approach professionals are viewed as the instruments of families. Accordingly, professionals intervene with children and families as directed by families in individualised, flexible and responsive ways (Trivette et al., 1996b).

Though not expressed in these family-centred terms, NSW policy documents also direct professionals to accept, value and respect individual difference in their practice (NSW Department of Community Services, 2001c). Professionals are directed towards addressing individual needs (Disability Service Standard Number Two – Individual Needs) under the direction of the person with a disability and/or his or her family. This requires professionals to strive to understand and cater to the needs of individual children and their families (NSW Department of Ageing Disability and Home Care, 2002b). Professionals are directed to involve the child and family as an

integral part of assessing child and family needs (NSW Department of Ageing Disability and Home Care, 2002a).

Service plans to individualise service needs are advocated as a process and as a documented outcome of collaboration with families (Gallagher & Desimone, 1995; Katz & Scarpati, 1995; NSW Department of Community Services, 2001d; Watson, Townsley, & Abbot, 2002). Service plans are also a central part of the USA legislation on working with children with a disability and their families and as such, much of the literature addressing these plans arises from that country (e.g., Ackerson & Harrison, 2000; Bernheimer, Gallimore, & Weisner, 1990; Chiarello, Effgen, & Levinson, 1992; Decker, 1992; Gallagher & Desimone, 1995; Royeen, Cromack, DeGangi, Poisson, & Wietlesbach, 1996; Viscardis, 1998).

Two types of service plans dominate the literature on practice with families of children with a disability. Both the Individualised Education Plan (IEP) and Individualised Family Service Plan (IFSP) require that professionals collaborate with clients to develop plans on the basis of available assessment information, tailoring the plan to each child's special needs and including the parents (Decker, 1992). An IEP is conducted in both mainstream and special education settings and accordingly focuses on educational goals rather than family goals. A teacher drives the IEP as the primary professional with other therapy and social services included as required. In contrast, an IFSP is generally implemented in early intervention settings, and is primarily driven by the family, and thus has family needs, goals and priorities at its centre. Deal, Dunst & Trivette (1989) outlined four principles that ought to guide the IFSP process: that families and professionals must collaborate; the family must authorise services; professionals must respond to the varied needs of the family; and, the competence of the family should be promoted.

Knowledge about service plans and individualising practice largely arises from the USA and focuses on distinguishing between types of plans, or measuring their realisation in practice or outcomes of their use for children and families (e.g., Bailey et al., 1992; Decker, 1992; Gallagher & Desimone, 1995; McWilliam, Lang, Vandiviere, Angell, Collins, & Underdown, 1995; McWilliam et al., 1998).

Service plans such as IEPs and IFSPs are not mandated in Australia, although they are strongly endorsed in government and organisation policy documents as ‘best’ or ‘recommended’ practice for coordinating, planning and monitoring the services involved with a child and family (Early Intervention Coordination Project, 1994; NSW Department of Community Services, 1996, 2001d; Victorian Department of Health & Community Services, 1993). For example, NSW government policy for working with people with a disability indicates each individual should have a collaboratively developed and documented individual plan, reviewed annually in a planning meeting.

In summary, Australian and in particular NSW service policy documents, whilst not strictly proclaiming a ‘family-centred’ approach, include concepts reflecting ‘family-centredness’ as it is described in the literature. Yet research to date has largely neglected how professionals interpret these concepts and put them into practice when working with families. Where professionals have been asked to describe their understanding of these concepts (e.g., Ackerson & Harrison, 2000), there has not always been a shared understanding of what the concept means in practice. Current research on family-centred concepts in practice is chiefly concerned with whether the concepts are implemented and the outcomes of these practices for children and families. When professionals’ perceptions and experiences have been sought, these highlight barriers to implementing family-centredness including their own values, belief and skills, and the service context. Section 2.4 explores this service context, particularly with respect to predominant managerial and economic issues that inform the service context.

2.4 Managerialism and microeconomic reform in the human service context

Harbin et al. (2000) identified the considerable role the community context plays in implementing policies for working with children with a disability and their families. They highlighted factors such as government fiscal or resource constraints, or wider

health and human service reforms. Professionals working with families of children with a disability in NSW, like many of their international colleagues, work within a greater service system context largely informed by economic rationalism and managerialism (Baum, 1998; Gardner & McCoppin, 1995; Higgs & Hunt, 1999; Jones & May, 1992).

The primary tenet of economic rationalism is that free markets should determine all economic transactions (Baum, 1998). In human services, this has been associated with, for example, the privatisation or contracting out of previously public services and reductions in funding for health and welfare services (Baum, 1998).

Service systems worldwide, under persistent fiscal and regulatory pressures and within economic rationalism, have introduced private sector management techniques into public health and human services (Baum, 1998; Higgs, Neubauer, & Higgs, 1999). This has resulted in changes in human services delivery, including an increased emphasis on program budgeting and evaluation, a focus on results (particularly short term, measurable outcomes), the dissection of large bureaucracies, introduction of market style initiatives such as the separation of funding and service provision, and an increased use of external contracts (Baum, 1998).

Reforms within the public sector and the subsequent carry-over into the private sector have forced disability services to develop planning and management techniques that ensure maximum use of the available resources (NSW Disability Service Standard Number Eight – Service Management) and distribution of these in a fair and equitable manner (NSW Department of Ageing Disability and Home Care, 2002b; NSW Department of Community Services, 2001c; Spastic Centre of NSW, 2001). Individual services are responsible for developing procedures that adhere to these standards. For example, services are expected to develop procedures setting clear directions for professionals about whom they work with and how those who qualify will be prioritised based on the greatest service need (Eastern Suburbs Developmental Disability Service, 2002; NSW Department of Ageing Disability and Home Care, 2002b; NSW Department of Community Services, 1996). The major NSW provider of services has, for example, indicated that managing equitable and

efficient access to services has driven changes to central intake procedures (NSW Department of Community Services, 2001b).

Within this context of managerialism and economic rationalism, an Australian review by Kemp (2002) of services for people with disabilities over the past two decades chronicled a lack of resources and the failure of services to meet the support needs of people with disabilities and their families, despite legislation supporting equal rights for people with a disability. A lack of coordination and fragmentation of community services, continued unmet service needs, inflexible services and an inequitable service distribution were reported (Kemp, 2002).

There is also some concern in the literature that professional preparation programs in Australia may not adequately prepare human service professionals to work within this changing service context (Cummins & Baxter, 1997; Higgs & Hunt, 1999; Parmenter, 1991). Parmenter (1991) noted considerable disparity between the clinical competency-focused training of professionals working in the disability field and day-to-day challenges they now faced. A decade ago, Gardner and McCoppin (1995) explored the implication of Australian microeconomic and managerial reforms with occupational therapists, physiotherapists, speech pathologists, nurses and medical scientists. They concluded that professional training needed to be expanded from the traditional narrowly defined clinical competencies to more broadly encompass the political aspects of practice, multi-skilling, mobility between tasks and professions, and increased workforce flexibility associated with these service reforms. More recently, Higgs et al. (1999) emphasised the need to socialise students to the political, economic and social policies and issues informing practice. Like Parmenter (1991) and Gardner and McCoppin (1995), Higgs and colleagues highlighted the need to prepare professionals for their social responsibilities and roles within the political health arena rather than a focus limited only to narrowly defined clinical competencies. To date, whether these changes have occurred or how professionals interpret and understand their work with families within the broader Australian human service context has not been explored.

2.4.1 Accountability

Within an era of managerialism and microeconomic reform, professionals are increasingly directed through public policy and the principles and norms inherent in service documents and literature to be accountable for the services they provide (Dunst & Bruder, 2002; NSW Department of Ageing Disability and Home Care, 2002b; NSW Department of Community Services, 2001d; Spastic Centre of NSW, 2001). Professionals are to be held to account for the efficient use of limited resources including their time, which in turn focuses attention on outcomes (NSW Department of Community Services, 2001d). By measuring outcomes, service providers are seen to be accountable to the various stakeholders including funding bodies and managers, people with disabilities, their families, and the wider community. For example, the Spastic Centre of NSW (2001) states that they are accountable for the resources invested in them through a process of “open reporting to all stakeholders” (p. 3).

Professionals working with people with a disability and their families are also directed to be accountable for their clinical decisions. The Disability Service Standards Number Seven directs service providers to develop avenues by which service consumers “can be free to raise and have resolved, any complaints or disputes he or she may have regarding the agency or the service” (p.9). Service providers are also directed to develop and monitor professionals’ skills and knowledge to ensure they are appropriate to providing services in the current context. For example, in the case of government provided services, providers are required to focus on professional development and clinical supervision opportunities for staff (NSW Department of Community Services, 2000).

The requirement of accountability for practice approaches has driven several research studies (Dempsey & Dunst, 2004; Dunst & Bruder, 2002; Dunst et al., 1991; Dunst et al., 1996; Summers et al., 2005; Trivette et al., 1996b). In the first, Dunst, Trivette and colleagues sought to operationalise the principles, practice and program models of family-centred practice to which professionals could be accountable. They argue that without accountability family-centred approaches to practice would be an ideological ‘fad’ (Dunst, 2000). More recently, Turnbull and

colleagues explored family quality of life to measure the outcomes of services with families of children with a disability (Beach Centre on Disability, 2005; Poston, Turnbull, Park, Mannan, Marquis, & Wang, 2003; Summers et al., 2005; Turnbull, Brown, & Turnbull, 2004; Turnbull et al., 2001). Taking family-centred approaches as established core concepts of disability policy and practice, they argued that by defining and measuring family outcomes in terms of quality of life, it will be possible to measure the effectiveness of services and thus identify those producing the best outcomes for families.

On the other hand, professionals have raised their concerns regarding the implications of accountability measures within managerial-related reforms. In a discussion paper, Zebrack and Chesler (2000) asserted that social workers and other health professionals were under pressure to adapt to a new 'corporate culture' within which the goal of services is to contain costs and provide quality care through the routine monitoring of professional practices. They cited difficulties in measuring many key social work practices such as establishing therapeutic relationships in this new frame of reference, which they argue diminishes the value of these core social work skills. These authors employed specific case examples from social work practice in paediatric child oncology hospitals to illustrate their point, however similar concerns have been raised more broadly by human service professionals struggling to define and measure the relationship-oriented elements of their practice with families (Clear, 1999; Lawlor & Mattingly, 1998). In two studies Clear (1996) and Lawlor and Mattingly (1998) adopt a cultural view of practice with families and are reviewed later in Section 2.6.

2.4.2 Case management

Case management, also known as case or service coordination, is an approach to funding and organising services for people with ongoing and multiple service needs (Dunst & Bruder, 2002; Higgs et al., 1999; Jones & May, 1992; Norman, 1985). It involves a case manager, also known as a case coordinator or key worker who assumes administrative responsibilities with families including, for example, planning, identifying, coordinating and monitoring the services provided by various

professionals and services (Abbot, Townsley, & Watson, 2005; Case-Smith, 1991; Rahi, Manaras, Tuomainen, & Hundt, 2004). Professionals assuming case management responsibilities must have sound skills in communication, coordination, scheduling, mediation and conflict resolution (Case-Smith, 1991; Marcenko & Smith, 1992). According to several authors, case management is based on the assumption that by integrating and coordinating the various service programs and professionals involved with a client, a more comprehensive, flexible, efficient and cost effective array of services can be utilised and better outcomes can be achieved for children and families than would otherwise not be the case (Abbot et al., 2005; Dunst & Bruder, 2002; Higgs et al., 1999).

The literature increasingly suggests case management as a necessary component of services for families of children with a disability (Covert, 1992; Dunst & Bruder, 2002; Herman, 1997; Singer, Irvin, Irvine, Hawkins, & Cooley, 1989). Similarly, NSW government policy advocates case management as a primary feature of support services for people with a disability (NSW Department of Community Services, 1996, 2000).

Many professionals are therefore increasingly pressured by service management to alter their clinical practices to assume case management responsibilities (Abbot et al., 2005). Abbot and colleagues (2005) argue that the traditional clinical background of many professionals means they may not be prepared or able to work with this new role.

Despite being given increasing emphasis in the literature and NSW policy documents, research on case management raises questions about the extent to which professionals are adequately socialised or prepared to provide effective case management services with families of children with a disability. Investigations of case management practices have almost exclusively focused on determining the extent to which this practice is implemented by professionals and the impact of this on children and families (e.g., Dunst & Bruder, 2002; Dunst, Trivette, Gordon, & Starnes, 1993; Marcenko & Smith, 1992; Rahi et al., 2004; Sloper & Turner, 1992). Overall, these studies indicate families' do value and at times benefit from case

management practice, particularly with regards to accessing services. For example, a review paper examining the outcomes of service coordination indicated a better flow of resources, support and services, higher parent satisfaction with the provision of needed services, and improved wellbeing and quality of life within this approach (Dunst & Bruder, 2002). However families have also indicated they often do not have contact with any professional acting in a case manager role and have specified persistent unmet service needs within this approach (Marcenko & Smith, 1992; Sloper & Turner, 1992).

A recent qualitative study in the United Kingdom provides some insight into how professionals understand and experience case management responsibilities with children with a disability and their families (Abbot et al., 2005). The researchers explored the impact of case coordination or 'key worker' responsibilities within a multi-agency framework where agencies across sectors such as health, education, and disability services are encouraged to work together to better meet the needs of service users. Of the 115 professionals from the therapy, education and welfare professions that were interviewed most were positive about working in this way. They believed there was improved communication and better relationships with families and professionals and more coordinated services for families within this approach. In this study, professionals' experiences varied with regard to reconciling their clinical specialities and key worker roles. Some reported feeling positive yet others felt threatened by the role expansion or role blurring that key worker responsibility involved. This suggests that there may also be variation in how professionals interpret and react to case management responsibilities with families. To date, there has been no exploration of how professionals interpret or carry out case management responsibilities with families of children with a disability in Australia.

In sum, and it appears almost universally, human service professionals face increasing pressure to manage their services within economic constraints and a strong demand for services. There is considerable emphasis on accountability and case management practice in service policies particularly in NSW, and to a lesser extent, in the literature. In the literature, it is clear that many professionals struggle

to understand and meet the demands of these new approaches, with authors questioning the extent to which professionals are prepared to work in this practice context.

2.5 Rationale for framing practice as a cultural activity

To this point, this review has explored policy, legislation and literature to examine the concepts into which professionals may be acculturated. These concepts largely reflect the historical movements of a traditional medically framed view of practice to the more recent focus on family-centred practice within a managerial and economic rationalist service environment.

Empirical research on practice with families largely comes from the USA and provides information about the current nature of professional practice with families in two ways. First, researchers have sought to identify the characteristics or components of particular approaches, for example, defining family-centred practices, empowerment or helpful relationships (e.g., Beckman et al., 1996; Bolton, 2000; Dunst et al., 1996; Hutchfield, 1999; MacKean et al., 2005, Turnbull, et al., 2006, in press). Findings from these studies generally reflect the principles found in service policies.

Second, empirical studies have focused on how characteristics of particular approaches are applied in professionals' practice. These studies fall into one of two broad groups: those that explore outcomes and measure implementation, and those that explore professionals' experiences and understanding of their practice.

Numerous researchers have examined the extent to which particular approaches are realised in practice and the outcomes that they have for children and families (e.g., King, King, Rosenbaum, & Goffin, 1999; McIntyre, 2000; McWilliam et al., 1995; McWilliam et al., 1999; Sloper, 1999; Stewart & Neyerlin-Beale, 2000; Thompson, Lobb, Elling, Herman, Jurkiewicz, & Hulleza, 1997; Trivette et al., 1996a; Trivette et al., 1996b; Wolery, Bailey, Dunst, Schuster, McWilliam, & Trivette, 1997).

Focused as these studies are on outcome measurement, they give little indication of

what informs, facilitates or constrains the implementation of particular approaches. The inconsistent application of family-centred practice does however suggest difficulties exist in implementing this approach in daily practice.

Perhaps in an attempt to better understand what informs professionals' action in practice, researchers have also explored professionals' experiences and perspectives on working with families. Predominantly, these studies have identified practical challenges and barriers to, employing family-centred approaches or difficulties posed by particular expectations such as accountability procedures. Often these studies highlight the influence of the greater service system context, suggesting professional practice with families must be considered in terms of a broader range of contextual issues. Despite calls in the literature to consider the role of context in informing how professionals practice with families (e.g., Galvin et al., 2000; Harbin et al., 2000; Lawlor & Mattingly, 1998; McWilliam et al., 1998; Trivette et al., 1996b), researchers have neglected largely to do so.

Several studies have also explored professionals' understanding of particular practice concepts in an attempt to appreciate how this informs their work practices (e.g., Abbot et al., 2005; Ackerson & Harrison, 2000; Valentine, 1998). These studies, whilst not exclusively focused on practice with families, suggest understanding daily practice also requires considering what professionals think and believe about how they are expected to practice. However like much of the empirical research on practice with families, these studies have maintained a focus on discrete components of practice such as empowerment and case management.

What is missing from the literature is an understanding of how professionals interpret and enact the multiple concepts embedded within 'professional practice' and to which they are potentially socialised. Understanding how professionals interpret and apply the social and contextual concept of 'professional practice' with families in daily practice will potentially provide a basis for critiquing, and informing professional practice.

Adopting a view of practice as a cultural activity is developing momentum as a means of exploring how professionals understand and experience their work with families. The following section reviews the small but critical body of literature that addresses the cultural world of practice with families of children with disability.

2.6 Practice as a cultural activity

There is increasing recognition in the literature of the need to understand the world in which professionals live and make decisions about their work with families (e.g., Ahmann & Johnson, 2000; Bengtsson, 2003; Bruder, 2000; Katz & Scarpati, 1995; Lawlor & Mattingly, 1998; Mattingly, Fleming, & Gillette, 1997). In general, these authors propose clarifying the multitude of meanings, values, beliefs and assumptions that underlie and inform practice with families. Whether explicitly stated or not, as Lawlor and Mattingly (1998) note, this conforms to a cultural view of professional practice as described in the introductory chapter.

Two papers on practice with families highlight the importance of a cultural view of practice with families, though regrettably, neither explored empirically what that practice culture might be (Clear, 1999; Lawlor & Mattingly, 1998). In the earlier paper, in the USA, Lawlor & Mattingly (1998) explored the complexities of implementing family-centred practice, drawing heavily on their own ethnographic and descriptive studies with professionals and families of children with a disability. They asserted that family-centred practices are situated within cultural contexts, such as those related to biomedicine. By adopting this view, they purport that it is possible to further understand “daily dilemmas of practice” that play out in professionals’ daily work. They define these daily dilemmas as the routine events and small, persistent differences in perspective that occur spontaneously within the context of practice and which create conflict between what practitioners believe should happen and what they actually experience in practice situations (Lawlor & Mattingly, 1998). They identify a number of daily dilemmas in family-centred work practices including determining who is the client – the child or the family, turf difficulties arising in interdisciplinary collaboration, and striking the balance between being an expert and

a friend. In other words, Lawlor and Mattingly (1998) consider practice dilemmas are shaped by “the cultural world of practice” (p. 261). Specifically, they suggest that dilemmas arise from trying to reconcile the collaborative, skill-diverse and often indirect world of a family practice culture with the specialised, direct treatment and expert professional oriented culture of biomedicine. This study points to the existence and potential complexities of a family practice culture, highlighting the culture of biomedicine as one of the key cultural contexts of family-centred practice in line with the findings from the earlier review of the literature in Section 2.2.

In an Australian paper, Clear (1999) also used a cultural interpretation to contribute to understanding services for children with a disability and their families in the broader service context. Using an “ethnographic like research methodology” (Clear, 1999, p. 119), he explored the lives of parent carers of disabled children and their relationship with professionals. Like Lawlor and Mattingly (1998), he found professionals worked with families of children with a disability within a context dominated by medical and scientific rationality, which he considered incompatible with establishing caring relationships. He noted that this rationale contributed to unequal power arrangements between parents and professionals and complex parent–professional relations. Despite the hegemony of this approach, Clear also found some professionals and parents were able to establish a ‘caring culture’ characterised by more equal relationships. He argued that, by understanding how professionals’ activities are currently viewed as expert, technical and separate, a more caring culture for all may be reconstituted.

Though Clear (1999) advocates establishing a caring culture in practice with families, the findings in this paper stop short of openly exploring the array of elements that might comprise this culture. Instead, the researcher focuses on the service system, specifically its scientific and medical rationales and how they inform and constrain parent—professional relations. This consideration of the service context is an important and heretofore neglected factor in research on practice with families in Australia.

Clear's (1999) discovery that some professionals found ways of working within the constraints of these medical and scientific rationales to establish a more caring culture is also significant. Unlike the predominance of studies that adopt an a priori method to determine the extent to which a particular approach is implemented, Clear's findings suggest professionals work in different ways to negate and inform the elements guiding their practice. Identifying and exploring the array of ways professionals work could provide insight into how professionals' own actions impede or facilitate developing a more 'caring culture'.

In addition to Clear (1999) and Lawlor and Mattingly's (1998) work, three studies, all carried out within the North American context, have empirically examined a culture of practice with families of children with a disability focusing on family-centred practices in early intervention (Katz & Scarpati, 1995; Law, Hanna, King, Hurley, King, Kertoy, & Rosenbaum, 2003; McWilliam et al., 1998).

In a Canadian study, Law and colleagues quantified a family-centred service culture as a component of a larger study that sought to examine significant factors in determining parent satisfaction with a service (Law et al., 2003). The larger study involved a cross sectional survey completed by fifteen chief executive officers (CEOs), 494 randomly selected service providers and 324 randomly selected parents of children with a disability, who were linked to sixteen rehabilitation services for children in Ontario. The family-centred service culture was assessed from measurements within the CEOs responses and an aggregate of service providers' self-perceptions of the delivery of family-centred services. A composite index of a family-centred service culture was developed comprising the number of pre-determined family-centred service relevant systems and services present (e.g., service coordinator, resource centre); a count of recent changes made to make the service more family-centred (e.g., changes to information provision); a count of changes to procedures that made the service more or less family-centred (e.g., intake procedures); the CEOs beliefs about family-centred services (e.g., positive outcomes); and service providers' measures of the processes of care (e.g., treating with respect). Along with parent perceptions of family-centred services, this service culture was a principal determinant of parent satisfaction with a service.

This study by Law and colleagues (2003) highlights resources, characteristics, procedures and beliefs that comprise family-centred practice culture. In doing so, it goes beyond identifying characteristics of this approach to also describe contextual elements of the service system such as procedural changes that constitute a culture. This culture was identified quantitatively by the presence or absence of family-centred practice policies, procedures and outcomes predetermined by the researchers. It is unclear whether the preset criteria represent the professionals' 'ground up' understanding and commitment to a culture of practice with families. It therefore provides a picture of what might constitute the world in which professionals practice, but stopped short of exploring how professionals' themselves understood this world, or acted within it to bring about the services that parents equated as more satisfying.

In the second study, Katz and Scarpati (1995) adopted a cultural perspective of practice in an ethnographic investigation of early intervention services and the use of the IFSP in one state in the USA. They hypothesised that understanding the culture of these early intervention services would allow identification of aspects that encouraged or inhibited family-centred intervention. Interviews were held with nine two-parent families and an unspecified number of program staff. Focus groups were held with parents on a program advisory council. Analysis revealed patterns of meaning that produced three major cultural themes: decision making, child and family focus, and interpersonal relationships. 'Decision making' considered how families and staff were considered and expected to have input in decision making around the IFSP and how staff maintained beliefs about themselves as the primary decision makers regarding the service plan, restricting family access to information they considered 'relevant'. 'Child and family focus' referred to the staff and families' belief that the IFSP was primarily child-focused, where the professionals role is to 'fix' the child and families are expected to assist the professionals in working with the child. Prior to the IFSP however, staff perceived their role as helping families. 'Interpersonal relationships' referred to qualities and the importance of the relationship between early interventionists and families. Specifically, parents' and professionals' roles were considered to be in constant

transition, with families initially being dependent upon professionals for information and support, and becoming integral team members over time.

The elements identified provide an important insight into the early intervention culture. These highlight the co-existence of more traditional beliefs like professionals as experts, with more family-centred ones around working together with parents. Significantly, the changes in professionals' beliefs in day-to-day practice processes like the IFSP suggest the dynamic nature of the culture and variations in how beliefs are enacted in daily practice. The study however stopped short of exploring what shapes these changes and how professionals make decisions about the extent to which changes are enacted in daily practice. Articulating how professionals come to understand and enact their changing practice context, could identify barriers to the implementation of family-centred ideologies and thus provide direction for policy, education and practice recommendations to better support the realisation of family-centred approaches.

The final study, also conducted in the USA, while not specifically stating a cultural interpretation, explored the shared meaning common to a cultural view of family-centred practice (McWilliam et al., 1998). These researchers employed an instrumental case study design to identify underlying components of family-centred services. Of the six components identified, 'family orientation – opening the door' described elements of developing rapport and trust with a family that allows other elements of practice to occur. The path to opening the family orientation door was built on the other five underlying components as follows. 'Positivists – thinking the best of families' referred to maintaining optimistic and enthusiastic views of practice that included thinking positively about families without passing judgement. 'Sensitivity – in the parents' shoes' described efforts to adopt the parents' point of view in order to anticipate their feelings. 'Responsiveness – doing whatever needs to be done' involved taking an individualised and flexible approach responsive to families expressed needs and concerns. 'Friendliness – treating parents as friends' described the informal support service providers could proffer, and friendship as a foundation for frank and open interactions with families. 'Child and community skills' referred to the continued importance of child level skills and the skills

required to integrate children and families into broader community activities. The shared meanings found in these six components suggested a culture of family-centred early intervention.

In sum, more attention is being given in the literature to the cultural world in which professionals live and make decisions. To understand this cultural world requires clarifying the multiple meanings, values, beliefs and assumptions that underlie and inform daily practice with families.

2.7 Summary and reorientation to the research questions

In this review I explored the cultural world in which professionals think and act by examining state and national legislation, policy documents and the professional literature. Traditionally, framed within medical rationales, professionals are ‘experts’ working directly with the child with a disability to determine and treat the child’s and possibly the family’s needs. More recently, the family-centred approach directs professionals to work collaboratively with parents and other professionals to empower and include children with a disability and their families in mainstream community life. That said, within the broader service context, managerial and microeconomic reforms also direct professionals to coordinate services and be accountable for the quality and time and resource investment in their work with families. This is the professionals’ cultural world as depicted in legislation, policy documents and literature. A world primarily understood in the North American context due to a paucity of research studies in Australia.

The overall purpose therefore for this doctoral study on practice with families of children with a disability was two pronged. The first part was to identify and define the underlying meanings, values, beliefs and assumptions guiding professional practice with families in an Australian context from the professional perspective. That is, to explain a culture of professional practice with families. The term ‘professional practice’ is employed to encompass the multiple concepts that potentially inform daily work practice with families within the broader cultural

context of service provision. The second part was to qualitatively identify and describe how professionals instantiate this culture in their day-to-day work.

In this study I sought to advance understanding of professional practice by exposing the cultural world in which professionals live and make decisions in their work with families. Elucidating professionals' understanding of culturally acceptable practices could provide a framework for critical reflection on the way in which these practices might support families and the extent to which practitioners, policymakers and managers practices contribute to changing or sustaining these ways of working. Critical reflection of this nature could provide direction for policy, professional preparation programs and management practices to better support professionals in helping families with children with a disability.

A study adopting this cultural view of professional practice required a mechanism to illuminate and help understand the hidden production of services, focusing on understanding rather than predicting or explaining professional practice with families (Bengtsson, 2003). Cultural psychology, as outlined by Jerome Bruner provides a framework that focuses on understanding human thought and action (Bruner, 1990a). Chapter 3 outlines the Brunerian cultural conceptual framework and study method.

3 CONCEPTUAL FRAMEWORK AND STUDY METHOD

The sections of this chapter describe the conceptual framework and research methods employed in this study. In Section 3.1, the cultural psychology conceptual framework is described. Section 3.2 describes the narrative inquiry research approach and introduces and summarises data trustworthiness strategies that are incorporated in detail throughout the subsequent sections of this chapter. The sample and sampling procedures are then outlined in Section 3.3. Data collection is described in Section 3.4, including the details of the storytelling approach and design and procedures for focus groups and individual interviews. Section 3.5 describes the data analysis process and considers some of the limitation of the study and implications for the presentation of study findings.

3.1 Conceptual framework of study

This study was conceptually framed within cultural psychology, specifically within the related work of Jerome Bruner. Bruner is an internationally renowned psychologist whose writings over five decades demonstrate an evolution of ideas regarding the construction and transmission of knowledge and meaning. He has proposed cultural psychology as a means of understanding human thought and action. The concepts of meaning and situated action, culture and narrative are central in cultural psychology as understood by Bruner.

3.1.1 Meaning and situated action

Bruner proposes that human beings make sense of their knowledge and experience through two modes of thought, one paradigmatic and the other narrative (Bruner, 1986). According to Bruner, paradigmatic or logico-scientific thinking is driven by principled hypotheses and deals with identifying causes, providing provable reference and testing for empirical truth. It is in keeping with psychology's

traditional emphasis on predictability. Narrative thinking on the other hand is focused on understanding humans and their dilemmas. It deals with intentions, actions and consequences, focusing on experience and meaning. Much of Bruner's most recent works attend to narrative as the means through which individuals and cultures order experience and construct reality (Bruner, 1996a, 1997; Bruner & Kalmar, 1998; Bruner, 1996b). He frames these works within the 'new' cultural psychology (Bruner, 1986, 1990a; Bruner, 1996b).

Cultural psychology is centrally concerned with making and negotiating meaning as it influences human action. Bruner defines meaning as "a culturally mediated phenomenon that depends on the prior existence of a shared symbol system" in his seminal work *Acts of meaning* (Bruner, 1990a, p. 69) and later in *The culture of education* (Bruner, 1996b) and various papers (see for example, Bruner, 1991; Bruner, 1996a; Bruner, 1990b). In essence, according to Bruner:

The major activity of all human beings everywhere is to extract meaning from their encounters with the world. What is crucial about this process of creating meaning is that it affects what we do, what we believe and how we feel (Bruner, 1996b, p. 345).

Bruner (1990a) proposed that action, including mental activity, is given meaning by being 'situated' in a cultural setting and in the mutually interacting 'intentional states' of members of that culture. Intentional states refers to the values, beliefs, intentions, desires and commitments of the members of that cultural community.

3.1.2 Culture

Cultures, according to Bruner, are shared symbolic systems and traditionalised ways of living and working together (Bruner, 1990a, p. 11). Culture shapes human thought and action through symbolic systems such as language, rituals, myths, and literature. Cultures provide a 'cultural tool kit' or set of principles and procedures through which humans can interpret the relationships between what people do and what they mean in the ordinary conduct of life (Bruner, 1991; Bruner, 1996b).

Bruner (1990a) argues that the shared meanings of a culture express a set of principles reflecting the distinct values, beliefs and commitments of that culture. Bruner's beliefs refer to a proposition or set of propositions that are generally trusted as true, while values are generally accepted judgements of what is valuable and important in the culture's way of life. Bruner believes commitments are sufficiently organised values and beliefs. Together they locate members of a culture in their culture (Bruner, 1990a). Bruner (1990a) argues that a culture's set of principles guide actions and interactions, providing a basis for acceptable conduct and a foundation around which negotiation can take place when there is conflict between these or commitment to them.

Within Bruner's (1990a) concept of culture, all individuals within a cultural community are cultural agents because people express their opinions about and negotiate elements of their culture on a daily basis. He argues that acts and points of view can change reality if enough people actually desire, believe or do something. All individuals in the cultural community are therefore active participants in making and remaking the culture.

Bruner (1996b) asserted that the set of principles or shared meanings that comprise a culture are made public and negotiated in the stories told by its members, referring to this as the 'narrative mode of culture'. For such meaning to become apparent, members of that culture do not need to tell the same version of a story. Rather, Bruner argues that through the social processes within a culture, humans inevitably negotiate a shared meaning of the knowledge and actions they undertake or observe (Bruner, 1991).

3.1.3 Narrative

Bruner (1991) defines narratives as a conventional form for framing experience that is transmitted culturally and constrained by, for example, each individual's level of mastery, colleagues, mentors and other cultural devices. He believes that the meanings placed on most actions in a social context are constructed by what people

say about them through narrative before, during, and after, action. According to Bruner (1996b), narratives become an expression of a culture's world view in addition to being a mode of thought. People locate themselves in the world defined by their culture through narratives.

Bruner asserts that narrative trades in both human action and human intention. Thus Bruner (1990a) describes narrative as often featuring a 'dual landscape' that deals with the trouble when events and actions in the real world are incongruous with a person's conscious thought of what could or should happen. Narrative mediates between the norms evident in the culture and the more personal world of beliefs, desire and hopes. Thus, when a culture's constituent principles are violated, narratives are employed to make these deviations from the accepted norm understandable, if not acceptable (Bruner, 1991).

Building on the classical defined structures of narrative as outlined by Burke (1945) and Ricoeur (1989), Bruner with colleague Kalmar (1998) defines narrative as the interaction of seven constituent features: an *actor* who has some degree of freedom; an *act*, upon which the actor embarks; a *goal*, to whose attainment the actor is committed; *resources* to be employed in the act of reaching this goal; a *setting* within which all this occurs; *legitimacy*, where it is assumed that there is an ordinary or canonical way things should be; and, *jeopardy or trouble*, that arises when this legitimacy is challenged.

3.1.4 Assumptions underpinning this study

The starting point for this study is the assumption that professional practice with families is a cultural activity. This is based on my initial exploration detailed in the introduction chapter and the work of various authors in the literature (e.g., Ahmann & Johnson, 2000; Bengtsson, 2003; Bruder, 2000; Clear, 1999; Katz & Scarpati, 1995; Law et al., 2003; Lawlor & Mattingly, 1998; Mattingly et al., 1997; McWilliam et al., 1998). Utilising a Brunerian approach to understanding culture requires, in the case of professional practice with families of children with a disability, examining and interpreting the meaning and actions of professionals' daily

work practices. This is because; following Bruner, professionals' thoughts, actions and experiences with families can be seen as 'situated' within a cultural context and within the intentional states of the professional.

My first research question concerned the core narratives of professionals' work with families of children with a disability. Utilising Brunerian approach determines that the culturally and personally situated thoughts and actions of professionals are explained and understood through the stories they tell. The outcomes of attending to, interpreting and illuminating these stories, will be an understanding of the daily work practices of professionals working with families.

My second research question addresses the culture of professional practice with families. According to Bruner (1990a), the shared meanings of a culture as revealed through the stories of its members, express a set of principles that reflect the distinct values, beliefs and commitments fundamental to that culture. These principles, in the case of professionals in human services, would convey the culturally acceptable ways of working with families. Using Bruner's expression, these principles comprise the 'cultural tool kit' against which a professional's own values; beliefs and desires are interpreted in practice. Applying Bruner's concept of the narrative mode of culture permits learning about and understanding the culture of professional practice from the stories told by professionals.

It is anticipated that the cultural world exposed through these research questions could provide a framework for critical examination of current policy and practice with families of children with a disability. For example, how does this cultural world resemble the family-centred practices that are thought to better support families of children with a disability? Furthermore, exposing this cultural world could provide a framework for critically examining how policymakers, managers, educators and professionals' own actions contribute to creating or sustaining these ways of working. Such critical appraisals could provide direction for policies, practices and education programs that contribute to constructing a cultural world where professionals can better support families of children with a disability.

Because of the centrality of narrative to Bruner's conceptualisation of action and culture, this study required methods sensitive to uncovering the stories constructed by professionals about their practice with families. The qualitative narrative method adopted in this study is outlined below.

3.2 Research approach

Qualitative methods provide an opportunity to capture the meanings, definitions and descriptions of events essential to a Brunerian framed study, from the perspectives of those centrally involved, in this instance, the professionals themselves (Minichiello, Fulton, & Sullivan, 1999; Rodwell, 1995). Narrative inquiry is consistent with the Brunerian framework as it is a way of understanding how humans make sense of themselves and their lives within their social world (Bruner, 1990a; Gergen, 1994; McAdams, 1993; Polkinghorne, 1988; Rappaport, 1993; Ricoeur, 1989; Riessman, 1993).

The terms 'narrative' and 'story' are often used interchangeably in narrative inquiry. These terms demonstrate a belief that humans 'story' the world, making meaning of actions, events and experiences through telling stories. Stories, in other words, are centrally concerned with human action and interaction (Mishler, 1995). For the purpose of this study, the term 'story' refers to the stories that individual participants told to describe their practice with families of children with a disability. Narrative, in this study, refers to the shared stories that are an abstraction of each individual story. These shared stories in turn represent the core narratives of the cultural community. This is in keeping with narrative researchers who use the term 'community narrative' or 'cultural core narratives' when describing socio-cultural, community level narratives (Mankowski & Thomas, 2000; Olofsson, Gilje, Jacobsson, & Norberg, 1998; Rappaport, 1994; Salzer, 1998; Ylijoki, 2001). These cultural core narratives explored in the first research question are therefore distinguished from the second research question which examines professionals' stories told within the narrative mode of this culture in order to identify the key principle or shared meanings of that culture.

As suggested by Krefting (1991), numerous strategies were employed to promote the trustworthiness of this qualitative research process and product. Krefting (1991) summarised, interpreted and supplemented the work of Guba (1981), Lincoln and Guba (1985) and others to highlight four key areas of data trustworthiness and their related strategies: credibility, transferability, dependability and confirmability. Credibility refers to establishing confidence in the truth of the findings based on research design, participants and context. Credibility strategies employed in this study include for example, the use of field journals, member or ‘participant’ checking and peer examination. Transferability refers to attempts to enhance the transferability or fit of the findings to other contexts. Strategies employed in this study included a detailed description of the context and sample as provided in Chapters 2 and 3, comparisons of the sample to the population data and member checks. Dependability concerns the consistency of findings and efforts to ascribe variability to identifiable sources. Strategies employed here included for example, peer examination, code-wait-recode, and a description of analysis stages. Confirmability relates to the place of the researcher and efforts to show how and why decisions were made. Confirmability strategies employed included descriptions and examples of decision-making and triangulation of data sources.

Details of the trustworthiness strategies employed specific to this study are provided throughout the remainder of this chapter, while further reflections on these and my place in the research process are described in Section 7.2.

3.3 Sample and sampling procedures

Human service professionals working with families with school-aged children with a disability and high support needs were invited to participate in this study.

Participants worked in government or non-government agencies operating within the Northern or Eastern suburbs of Sydney, a state capital of approximately 4.5 million inhabitants in New South Wales, Australia. All of the participants dealt directly with families of children with a disability, with several participants also holding part-time team or program management responsibilities.

The University of Sydney Human Ethics Committee granted ethical approval for this study, Reference Number 98/2/53. Prior to and during data collection, participants were advised in person and in writing of the purpose of the study, the processes involved, and their right to withdraw from the study at any time without consequence. Participants received a written information sheet about the project prior to interviews and focus groups. I reiterated this information in person before obtaining written informed consent from each participant prior to interviews and focus groups. See Appendix 1 for the informed consent form and project information sheet.

3.3.1 Procedures

In my role as project manager for the ‘Supporting Families Project’², I had an ongoing affiliation with key contact people in specified geographical locations. Via these contacts, I approached six agencies to participate in the study described here. These agencies were selected to cover government and non-government services, employing professionals with various human service qualifications, providing respite and recreation, child and family therapy, and welfare assistance to families of children with a disability and high support needs. This sought to ensure that human service professionals’ cultural world was examined using maximum variation of professional backgrounds, organisation and service types within the geographical region (Rodwell, 1995).

I telephoned the key contact person in each of the six selected agencies. At this time, we identified a time and date for a focus group aligned with another scheduled meeting of agency staff such as a team meeting. Following each phone call, I forwarded an information sheet and invitation to participate in a focus group to the key contact person (Appendix 1). This person was asked to make this information

² The ‘Supporting Families Project’ was a collaborative project between the North and East Sydney region of the Spastic Centre of NSW and the Family Support and Services Project at the University of Sydney. The Australian Research Council under the Linkage Grant scheme funded the project from 1998 to 2000. The project investigated family wellbeing in families of children (aged 6 to 13) with disabilities and high support needs (Llewellyn et al., 2005; Llewellyn et al., 2003). Twenty service agencies in the North and East Sydney region referred families to the Supporting Families Project.

available to staff within their agency by posting information on noticeboards or photocopying and distributing to all staff fitting the sample criteria for this study through internal mail. Focus group participants were not required to register their participation with the key worker prior to the group, therefore no further information was available on potential participants who received the invitation but declined to participate. I made a follow-up call within two weeks of the initial call to confirm the date, time and location of the focus group.

Twenty-six participants from the six different service agencies participated in six focus groups that were conducted between February and July 2000. Focus groups were conducted in a meeting space at each respective agency, so participants in each group were known to each other as work colleagues. As some focus groups were scheduled to follow another agency meeting, I reiterated to potential participants that participation was entirely voluntary and was not a condition of their employment.

Participants in the focus groups came from different professional backgrounds, with varying qualifications and years of experience. Twenty-one of the participants were female and five were male. Five participants held diplomas as their highest level of education, twelve participants held undergraduate degrees, five had completed post-graduate diplomas or certificates, and four had completed post-graduate Masters programs. Focus group participants were employed in a variety of roles. Eight participants were employed as social workers, six as occupational therapists, five as physiotherapists, three as psychologists, two as program coordinators, and two as case managers. Overall, participants had worked in their current positions for an average of 5.4 years (range from four months to 22 years). On average, focus group participants had 9.8 years experience working with families of children with a disability (range of 1–32 years).

Following all focus groups bar one I invited participants to be part of an individual interview to follow up on issues arising from the earlier group. The one exception involved only school-based special educators who referred to different professional, historical and contextual issues informing practices to those mentioned by human service professionals in the other focus groups. Most significantly, they had limited

contact with families. The unique nature of the culture and practice of education is well noted in the literature (see for example, Bruner, 1996b). In an attempt to enhance the transferability of the findings, these were therefore not invited to participate in individual interviews (Lincoln & Guba, 1985). Of the remaining five focus groups, eighteen participants agreed to participate in an individual interview. Three of these participants had resigned and were unable to be contacted when interviews were scheduled. Focus group participants who declined to participate in individual interviews cited time constraints (n=6) and a feeling that they could not contribute additional information to that already provided (n=2) in the focus groups.

The fifteen human service professionals that participated in individual interviews came from therapy teams, assessment services, school support teams and respite and recreation services. There were three speech pathologists, three occupational therapists, two social workers, two psychologists, two physiotherapists, two with social policy qualifications majoring in disability and one community nurse. Their work experience ranged from four to twenty years. Their professional qualifications range from diplomas to professional masters. All participants were of Anglo-European background, with four noting previous employment in disability services in the United Kingdom. Two participants were males and 13 were females. Citing Guba (1981), Krefting (1991) suggests a comparison of the sample to population demographic data can enhance the transferability or applicability of the study data. The small proportion of males in this study is consistent with gender bias in human service organisations (Gardner & McCoppin, 1995). That is, only 17% of focus group participants and 13% of individual interview participants were males. As noted by Dempsey & Arthur (2002), very little is known about Australian staff working in disability services. In addition, increasing numbers of generic employment descriptions provide little information on the qualifications of human service personnel (Jones & May, 1992). This makes further reliable comparison of the sample to the population difficult. Discussions with research and clinical colleagues, and reflections on a decade of my own exposure to human service teams working in this field suggest that demographically, this sample represents a typical cross section of this population and team structures in terms of grass-roots level position,

profession, and experience. For details on individual participants see Table 1 on the following page.

Table 1: Summary of individual interview participants.

NO.	TERTIARY QUALIFICATIONS	POSITION	COMMUNITY ORGANISATION TYPE	YEAR IN CURRENT POSITION	YEARS EXPERIENCE WITH FAMILIES
1	B.A. (Social Policy)	P-T Assistant Team Manager P-T Program Coordinator	Respite & Recreation NGO	3.5	6
2	B.A. (Psych)	P-T Regional Assistant Manager – Disability P-T Psychologist	Disability Service Government	2	8
3	B.A. (Social Work)	Social Worker	Disability Service NGO	4	26
4	B.App.Sc (Speech Pathology)	Speech Pathologist	Disability Service NGO	5	5
5	Dip. (PT)	Physiotherapist	Disability Service NGO	11	11
6	B.A. (Psych) Grad.Dip. (Psych)	Psychologist	Disability Service Government	3	7
7	B.A. (Social Work) Grad.Dip. (Fam.Therapy)	P-T Social Worker P-T Case Manager	Disability Service Government	7	10
8	B.A. (Social Policy)	Program Coordinator	Respite & Recreation NGO	1	5
9	B.Science (Nursing) Dip. (Teaching)	P-T Community Registered Nurse P-T Case Manager	Disability Service Government	21 – nurse 4 – case manager	4
10	B.App.Sc (Speech Pathology)	Speech Pathologist	Disability Service - school Government	4	4
11	B.App.Sc (Speech Pathology)	P-T Speech Pathologist	Disability Service - school Government	5	7
12	Dip. (Physiotherapy)	Physiotherapist	Disability Service - school Government	13	13
13	Diploma (Occupational Therapy)	Occupational Therapist	Disability Service - school Government	5	30
14	B.App.Sc (Occupational Therapy) Masters (Occupational Therapy)	P-T Occupational Therapist P-T Team leader	Disability Service Government	8.5	8.5
15	Dip. (Occupational Therapy)	Occupational Therapist	Disability Service NGO	5	20

Key: P-T = Part time

3.4 Data Collection

Data for this study included audiotapes and transcripts of focus groups and individual interviews, literature and field notes. Hard copies of all data were stored in a locked filing cabinet. Data, field notes and literature were managed using Microsoft Word (Microsoft Corporation, 2004) and Endnote 6.0 (ISI Research Soft, 2000).

Focus group and interview data was collected adopting a storytelling approach. This storytelling approach and the design and procedures for focus groups and interviews are outlined in Sections 3.4.1, 3.4.2 and 3.4.3 respectively.

3.4.1 Storytelling

In focus groups and individual interviews I adopted a storytelling approach, also known as narrative interviewing, based on the principles suggested by Mishler (1986) and Mattingly and Lawlor (2000). Participants were invited to share stories illustrating their thoughts, feelings and actions in practice with families.

In narrative inquiry, a story is considered a specific type of discourse production where events and actions are drawn together into an organised whole by means of a temporally ordered plot (Polkinghorne, 1995). The central subject matter of the story is human action, that is, how humans act and why, and to what effect for themselves, others and their world (Polkinghorne, 1995; Ricoeur, 1989). Stories have been successfully employed as a data collection tool in numerous studies that have sought to identify and understand the experiences and practices of human service professionals, though rarely in relation to professionals practice with families of children with a disability (e.g., Hasselkus, 1998; Hasselkus & Dickie, 1994; Mattingly, 1998a, 1998b; Mattingly & Lawlor, 2000). By inviting participants to share their stories, their thoughts, actions and experiences are made publicly accessible for interpretation by the researcher.

I encouraged participants to share their stories in three ways to illustrate their practice with families. First, participants were advised of the storytelling approach on the information sheet (see Appendix 1). Second, I reinforced this verbally at the outset of each focus group and later, at the interviews. Finally, I prompted participants throughout the interview to provide examples to clarify meaning and expand the detail of their stories.

Not all comments or discussions from the focus groups or interviews were in the form of stories. Participants also made general statements or descriptions about themselves or their practice. For example, a participant commented that “... *home visits are fabulous things to do, especially if you do the home visit when the child is at home. They are absolutely invaluable*”. Although this comment revealed home visits as a valued practice activity, it gave little indication of what was valued or why about home visits. In instances where participants did not voluntarily elaborate on their broader statements, I encouraged them to tell a story that might explain the meaning behind such statements.

3.4.2 Focus groups

3.4.2.1 Design and procedures

Prior to the focus groups, I sent participants a project information sheet (Appendix 1) and an invitation that confirmed the time, date and location of the focus group. This invitation also encouraged participants to come to the focus group ready to share a ‘poor’ and a ‘good’ experience of practice with families. I used this approach as it had been successfully employed in previous narrative inquiries into the practice of human service workers. For example, in a study by Hasselkus (1998), participants were asked to relate stories of satisfying and dissatisfying experiences in dementia care in order to facilitate an understanding of what their experience of ‘doing’ occupational therapy was, in this context.

I began focus groups by reiterating the purpose and methods of the study with participants, seeking written informed consent, and reminding them of the storytelling approach that would be adopted. I confirmed that each person in the

room was willing for the focus group to be audio taped for later transcription and informed them of their right to withdraw from the group or request the tape recorder be turned off without any consequence to themselves or their employing organisation. I encouraged participants to interact throughout the focus group, inviting them to ask questions and make comments about the stories told. I did so based on Herndon's (1993) observation that focus groups promote depth and detail in data collection that can be less accessible without group interaction.

I also highlighted the confidential nature of the discussions and resulting transcripts. Participants were reminded that comments made during the focus group were confidential, for use as data in this study only, and not to be shared with others or used to make decisions about service delivery with particular families. I also noted that all data was stored in locked cabinets accessible only by those directly related with the project and any identifying information removed.

To begin a discussion, I invited participants to volunteer a good experience of working with families. The focus group continued in a free flowing way between the stories recounted and discussion of issues that the stories raised. This was facilitated by comments and questions offered by myself and other participants. On my part, questions and prompts usually served to: (i) clarify who was involved in the story and why; (ii) clarify what made it a 'good' or 'poor' experience; and, (iii) seek to encourage examples and stories to illustrate the points discussed. Participants' comments usually served to clarify or add their thoughts on the issues raised. For example, a fellow participant who had knowledge of the family in one particular story commented on how "well" the storyteller did to "get a good outcome" and build a good relationship with that family, adding more detail about the challenges that were surmounted in order to do so.

When there was agreement or disagreement between group participants about particular issues we discussed these in more detail. If participants themselves did not raise these similarities and differences, I introduced them into the discussion. For example, in one focus group a story highlighted doing whatever a professional could to keep a child at home. In contrast, another story commented on supporting the

family in coming to the realisation that the child and family might be “better off” if the child was placed out-of-home. The ensuing discussions served to clarify that although preventing placement was seen as the ideal goal in both stories, the ill health of the single mother in the latter story provided extenuating circumstances that accounted for supporting a placement decision.

Following a recursive model, I also introduced thoughts and comments from previous focus groups to facilitate further stories and discussion. Discussion primarily centred on the ‘stand out’ features that made for poor or good experiences with families. For example, I encouraged participants to share stories about ‘being family-centred’ or ‘having good relationships with families’. Focus groups continued in this way, moving between stories and discussions until each participant had shared their good and poor stories of practice or they felt issues their stories raised had already been covered.

Immediately following each focus group I wrote field notes about emerging themes and possible issues for further investigation. Field notes are further explained in Section 3.4.4. I transcribed each focus group, removing all identifying information from the transcript concerning participants, families and locations. All dialogue and other outstanding features of the conversation were included, such as interjections (e.g., *hmm*), pauses, associated actions (e.g., putting finger to lips in whispering gesture, hands gesturing inverted commas when certain words like ‘empowerment’ or ‘family-centred’ were used) and voice modulation (emphasis, whispering, etc). The importance of these features of the conversation in narrative analysis is described in Section 3.5.1. I sent these transcripts to each person involved in the focus group. Participants were invited to review the transcript and contact me if they felt the interview did not reflect their experiences, or they wished to correct, confirm, refute or make any additional comments to those listed in the transcript. Member checks by participants at this stage, serve to help ensure the transferability of the data (Lincoln & Guba, 1985). I sent a reminder note regarding review to each participant two weeks after the transcripts were sent. Seven participants contacted me to confirm that they were happy with the content of the transcript. When no alternative comments were received, no changes were made to focus group transcripts.

3.4.3 Individual interviews

3.4.3.1 Design and procedures

Interviews adopted a conversational style. I developed an interview guide of several broad questions and probes about professional practice with families of children with a disability. Riessman (1993) argues that the value of open-ended questions is that these produce narrative accounts. These questions and associated probes are listed in Figure 1.

Questions were designed to identify and understand what the participants were doing in their practice with families. The initial, open-ended question about how work was going, while often useful for leading participants into storytelling mode, did not always capture the day-to-day thoughts and actions of participants. Inviting participants to share the story of a ‘typical day’ was employed as an additional prompt, in case a participant had difficulty storying his or her daily practice from the opening question. Inviting participants to share stories of a ‘typical day’ has been successfully employed to capture stories of daily activities (see, for example, Segal & Frank, 1998). As participants described practice activities in their typical days, I wrote notes on these for subsequent prompts to further storytelling.

Participants were encouraged to share stories about each of the activities they described in their practice with families. For example, I said: “You talked about doing home visits with families. Could you tell me a little more about that or a time when you have done a home visit with a family?” I used probes derived from Bruner’s seven constituent features of narrative as described in Section 3.1.3, to clarify the features of the ensuing stories (Amsterdam & Bruner, 2000; Bruner & Kalmar, 1998). Bruner suggests stories are framed to answer questions such as these. The probe questions, with the features of narrative (italicised) were: What *actions* were described? Who or what *actors* were involved? What *goal* he or she was seeking to attain? What *resources* were employed? In what *setting* did this action occur? What is typical or *legitimate* practice in this situation? What *trouble* may have existed when this legitimacy was discarded or challenged? Following a

recursive model, I introduced thoughts and comments from previous interviews to facilitate further stories and discussion about professional practice.

Figure 1: Interview guide for individual interviews

1. You have been working with families of children with a disability here as *(position)* for *(number)* years now. *(from demographic information sheet)*
How is that going?
2. Bearing in mind that I am trying to understand what you do with families, I wonder can you tell me the story of a typical day and some of the things you might do?
Probe for and within stories to illustrate:
 - a. Acts – Can you tell me more about what __ involves doing?
 - b. Actors – Can you tell me about who was involved in this?
 - c. Goal – What were you trying to achieve/your reasons for doing this?
 - d. Resources – What resources were employed in this action?
 - e. Setting – Where and when did this take place?
 - f. Legitimacy – Can you tell me how you feel you/he/she should have acted? Did this differ from how they acted and why?
 - g. Trouble – What trouble may have existed in doing this?

All individual interviews were conducted in a private space at the participant's workplace. I began interviews by reiterating the purpose and processes involved in the individual interview as described in the information sheet. I confirmed consent to audiotape the interview with each of the participants and I reminded them of their right to cease the interview, request the tape be switched off, or comments to be excluded from the interview data. Each participant completed an informed consent form (see Appendix 1) and a demographic information sheet (see Appendix 2) at the outset of the interview.

The individual interviews with the fifteen volunteers were undertaken over eleven months between June 2000 and May 2001. Interviews ranged from one to two and a half hours each. All participants were interviewed in person at least once, with two

participants being interviewed twice due to time constraints on the day of the original interview.

Following these interviews, participants were sent a copy of the draft transcript and preliminary notes on analysis and were invited to comment. With one exception, participants indicated they were satisfied with the transcript. This participant indicated sections of the transcript that she would like removed. She noted that though “all the comments were true” she did not want these comments included in the study. Three sections of the transcript pertaining to actions where she defied organisational policies were subsequently removed and excluded from analysis.

3.4.4 Field notes

Three field note files were kept as outlined by Minichiello, Aroni, Timewell & Alexander (1990). These files were a transcript file, a personal log and an analytical log. The transcript file included transcripts of each focus group and interview, notes on the setting, people present, and any special considerations that might have affected the interview (e.g., interruptions, group dynamics, the proximity of the interview to school holidays and the associated pressure to find respite or vacation care places, etc). According to Minichiello et al. (1990) the personal log includes descriptions and reflective notes about the people involved, the setting and methodological issues, and the analytical log includes a detailed analysis of the questions asked during interviews and ideas and questions that emerge as the study progresses. I chose to combine the personal and analytical logs for convenience because of the intertwined nature of analysis and personal reflections. Entries in this combined personal and analytical log therefore included reflections on the dissertation process, methodological, theoretical and analytical comments including options, suggestions, observations and decisions made in the research process. Information about the nature of emerging narratives and themes were recorded along with notes concerning relevant literature. This combined log also included difficulties that arose during interviews and analysis.

3.5 Data Analysis

Data analysis took two forms relevant to the two research questions. Narrative analysis was employed to address the first research question, which is, identifying the cultural core narratives of professional practice with families. Analysis of narratives was employed to explore the second research question, thus explicating the culture of professional practice with families and how these narratives shape and are shaped by professional practice.

Polkinghorne (1995) clarifies the difference between narrative analysis and analysis of narratives. Narrative analysis follows the logic of Bruner's narrative mode of thought. In narrative analysis the researcher collects descriptions of thoughts and experiences and configures them by means of a plot into a story narrative. The purpose is to produce stories or narratives that provide a framework against which disconnected data elements come together in an explanatory way. Alternatively, analysis of narratives adopts paradigmatic reasoning, employing inductive analysis procedures like those outlined by Strauss and Corbin (1990) to derive concepts from the data. In analysis of narratives, the researcher seeks to analyse collected stories and identify concepts and their inter-relationships that hold true across these stories. Alternatively, As Polkinghorne (1995) noted "analysis of narratives moves from stories to common elements, and narrative analysis moves from common elements to stories" (p. 12).

I began by using narratives analysis to address the first research question. This is outlined in Section 3.5.1. The stories identified by this process were subsequently utilised in the analysis of narratives process employed to address the second research question, that is, to elucidate the culture of professional practice with families. This process is outlined in Section 3.5.2.

3.5.1 Identifying the cultural core narratives of professional practice with families

There are many and varied methods of narrative analysis (e.g., Mishler, 1995; Murray, 2000; Polkinghorne, 1995; Riessman, 1993), yet each is centrally concerned with how the protagonist interprets things (Bruner, 1990a; Riessman, 1993). It is the

researcher's task in narrative analysis to interpret those interpretations (Riessman, 1993). In this study, analysis of the transcripts from focus groups and interviews was conducted adopting what is often termed a 'plot-structure' approach. Within this approach, plot lines are compared across a series of accounts, with the researcher searching for similarities and differences in how the stories unfold (Chase, 2005; Polkinghorne, 1995; Riessman, 1993). Narratives were developed using a hermeneutic circle mode of interpretation of texts, involving the to-and-fro recursive movement between the data, the parts of the narrative and the emerging narratives (Polkinghorne, 1995).

Analysis took place in five stages. The first stage involved identifying the stories from the interview and focus group texts. The second stage involved reviewing the stories and identifying their plot structure. In the third stage, key features of the stories were identified. The fourth stage involved exploring variations in these stories in terms of plot structure and key features. In this stage, the shared stories were revealed through patterns across stories. In the fifth and final stage, having identified the narratives, I explored conditions shaping how these narratives were told. These stages are outlined below.

The first task in this narrative analysis involved identifying the segments of the data that took storied form. Stories are recognisable by their structure and content. They have a beginning, middle and end and space of time in which the protagonists' actions play out (Amsterdam & Bruner, 2000; Brown & Kreps, 1993; Polkinghorne, 1995; Ricoeur, 1989).

Riessman (1993) suggests looking for entrance and exit talk, as defined by Jefferson (1979), can assist in identifying text that takes a narrative form. In this study, entrance talk included comments like "*Now I am thinking of this family where there was...*" or "*for example there was a situation with this family*". A statement indicating the significance or relevance of the story often prefaced the story. For example, a psychologist began her story stating "*Personally and professionally it is a very difficult situation when you have an insight into what services are available, and then have to pass that on to families*". She subsequently recounted the details,

setting and circumstances in which she advised families to publicly complain in order to get services that she was unable to offer. She closed or 'exited' the story by restating the relevance of the story: "*So I guess that being 'in between' can be a real dilemma*". A complete transcript of this story can be found in Appendix 4.

I reviewed interview and focus groups transcripts, bracketing narrative data. A total of 163 stories of professional practice with families were identified from focus group and interview data in this first stage of analysis. Each was a story told about a practice situation an individual professional had encountered. Practice situations often revolved around a particular task or activity such as discharging a family, providing information, prescribing a wheelchair, or going on a home visit.

A separate file was developed to contain the transcript for each story. Close and repeated listening of the audiotapes was undertaken for each story and transcripts were refined as required. Riessman (1993) suggests this re-transcription allows for analysis of the spoken and unspoken features of the discourse such as pauses and interruptions that may help distinguish the emerging narratives. For example, changes were made to the transcript after review of the tapes to indicate when the dialogue that was whispered had not been noted on the draft transcript.

In the second stage of analysis, these stories were examined for a "skeleton" structure against which the plots of stories could be compared. Textual analysis across these stories revealed that each story unfolded in a three stage, temporally ordered plot. That is, professionals oriented to, acted within, and evaluated their actions in any given situation. In the first stage, individuals *oriented* to and indeed oriented the listener to the situation. They talked about things they would like to do and how committed they were to this. They also compared this personal account to actions they 'ought', or felt expected to do, to help families. They described how they felt about possible tensions between what they would like to do and what they ought to do, often reflecting on the professional and personal resources they could employ. In the second stage, individuals *acted* to deal with the situation. They described how they decided, organised and carried out their actions and why. In the third stage, individuals *evaluated* their actions. They reflected on the implications of

their actions for themselves and others, often framing their experiences as positive or negative.

To illustrate plot structure, an occupational therapist's story about writing an application for the technical aide to facilitate a child's inclusion in the local mainstream school is presented below and a full transcript presented in Appendix 4. She oriented to the situation this way:

Increasingly we are being taught to focus on the good things and that sort of stuff, but when you are doing things like writing a lot of those submissions and that you have to focus on the negative, it is all negative, negative, negative. That poses a real dilemma for you. If you don't write it negatively, then you don't get the money.

She went on to describe and explain her decision to write the report focusing on the negatives about the child's condition:

I know it is quite distressing that anything for money has to be this real sob story about how things are just going in this downwards spiral where there is no solution and everything is just gloom and doom. But sometime you have to write that way. You just have to [said with emphasis] to get the help.

She then evaluated the possible implications of writing the report in a negative way for the parent and their child and the expectation that she should focus on the strengths and positives in the family's situation:

It goes against a lot of the philosophies when we are working with people with disabilities trying to look at how positive things are and how they should be valued and the things that they can offer society and all this kind of stuff. Suddenly it is like 'no!' They [the child] are very devalued in those families. Parents see copies of these reports and one says their child has achieved all these things, and the submission for funding says that they are not doing very

well at all, and then dealing with the fall out from that. I suppose we keep reinforcing for families that things aren't going well.

In the third stage of identifying the narratives of professional practice with families, I sought to identify critical features of the stories. Identifying critical features in the narrative is described as an important part of identifying narratives in narrative analysis (See for example, Mishler, 1995; Polkinghorne, 1995; Riessman, 1993). Riessman (1993) suggests looking for underlying propositions or features that help the stories make sense rather than simply reading for content. At this stage, I proposed and tested numerous possible defining features in my field notes, including for example: (i) Are the stories founded in different conceptual sources of trouble, such as clashing expectations within the culture, a clash between a personal and cultural expectation of practice, or a clash between family and professional culture? (ii) Does experience always feature in the story told? (iii) Are all stories founded only in response to changing service structures and policies, and if so how do these responses differ? On review of the data, the inconsistency of these across stories indicated these were not defining features of the narratives. As an example, this process of identifying and testing propositions is illustrated below using the proposition of helping as an interpretive framework.

'Helping' was identified as a critical feature of stories of professional practice with families. It provided a framework against which professionals interpreted how they potentially could or were able to help families by their actions. Overt comments like *"how does that help them"*, *"I get a real buzz from helping them"*, and *"you just can't put things into place to help them"*, first alerted me to the proposition that helping was central in stories of practice. On returning to the text, I found other words like supporting, assisting and improving the situation were employed synonymously in describing how they interpreted practice. These words were employed by professionals to interpret practice at each stage of their stories. For example, in referring to the number of service plans she was supposed to be involved in, a social worker questioned *"Like do they [IEPs] even help?"*. Describing what motivated her decision to spend considerable time with a family building rapport, a community nurse stated *"it is about helping them feel confident"*. Evaluating his

decision to visit a family outside of work hours so that a father could be involved in therapy, a psychologist noted “*It’s okay, as long as it helped him feel involved. As long as that helped support the family*”. While all used helping to interpret their work with families, the extent to which participants felt they could and did help families varied across the stories. This finding was critical in distinguishing the emerging narratives in stage four of this narrative analysis.

In the fourth stage of narrative analysis, I explored variations in how stories were told within this plot structure and across the key features. The aim of this stage of analysis was to explore patterns in how the stories were told. The question here was: are there shared stories or cultural core narratives in this cultural community? And if so, what are these cultural core narratives? Story plots were compared and contrasted using a cross-story analysis.

I began by outlining a draft plot of possible narratives. To organise data for this analysis, I reviewed each story and grouped those that appeared to be similar. This resulted in four groups of stories and a fifth group which I was unable to clearly place in one of the other four groups at this stage. Then, using the three-stage narrative structure of *orient*, *action* and *evaluate* as a framework, I coded the stories in each group based on key characteristics of that story. I entered each coded characteristic into an analysis table under orientation, action, and evaluation. I then reviewed this table, comparing the listed characteristics and referring back to the stories to confirm the intended meaning. This facilitated removal of duplicates and the refining of characteristics in each stage of the plot. Each story in each group was then re-read to see how it ‘fitted’ the draft plots. I repeated this process with the other three groups of stories resulting in four draft narrative plots. I then compared and contrasted the fifth group of stories to other stories and the four draft plots. These stories provided information to refine the four draft plots. Furthermore, they provided a means of checking the dependability of the four emerging plots (Chase, 2005). Ultimately, each story in this fifth group was represented in these draft plots. The result of this process was four draft plots.

The interpretive framework of helping differentiated the four draft plots. For example, one had a resounding characteristic of ‘not helping’ families, while another reflected a hope that ‘any help is better than no help at all’. The varied perspectives on and experiences of helping were therefore included in the draft plots. Ultimately, four draft-plots for the cultural core narratives were established through this comparative analysis. At this stage, I termed the draft plots ‘flow’, ‘cross-current’, ‘battle’ and ‘drown’.

With the draft plots in place, I began testing and further refining the narratives. Propositions were posed and tested as the narratives or patterns in the stories were developed and refined. Essentially this analysis questioned if these plots represented the only stories told in this data. I reviewed each story to determine whether each fitted one, several, or none of the narrative plots. This further clarified final details of the plots as characteristics of stories that ‘didn’t quite fit’ were examined. This process of checking for inconsistencies in the data and interpretation serves to enhance the coherence and credibility of the findings (Krefting, 1991). By way of example, I considered at this point whether the draft ‘flow’ narrative was characterised by the professional being ‘okay’ with the help and the context in which it was provided. The excerpt from the story below (represented in full in Appendix 4), indicates the practitioner was personally okay with the help provided, however the story was still founded in a challenge to an expectation of how they should help – that is, hands on assistance with families.

I found it very hard, when we had some of these changes to a consultative approach, giving up some of the hands on. But then I thought ‘maybe I can give the best in a different way,’ not copping out and not doing it, because I would feel very bad if I couldn’t give of something. So I think that is what it is. I look at, you know, so instead of maybe feeling upset and thinking like ‘this is the end’ or something, I say to myself ‘this is an obstacle. Go back to that thing that I have always set up for myself. What do I do?’ Well I either give up and I am a failure, or how do I do it? I go round it, over it, under it, through it, one way or the other.’ So I think that is basically it. So it is to say ‘be flexible.’ Is there another way of giving towards them instead of hands on. Is there a better way of doing it to help these children and families?

Other stories that initially seemed to indicate participants were content with both the help and the context, on closer inspection, were told retrospectively or with a qualifying statement or both. For example, a speech pathologist suggested in an individual interview that *“Before, I used to get frustrated that they wouldn’t follow through on the suggestions or home programs, whereas nowadays I have learned and I don’t have the time or energy for that stress...”* Analysis of stories that initially seemed like inconsistencies in the data eventually highlighted that each story, though told differently, was founded in trouble, even when participants were content with the help provided. In retrospect, this is consistent with narrative theory, which suggests that all narratives are founded in some form of trouble or challenge to expectations (Bruner, 1990).

Triangulation of data sources is suggested as another means of enhancing the credibility and confirmability of qualitative research (e.g., Chase, 2005; Lincoln & Guba, 1985; Krefting, 1991; Rodwell, 1995). Triangulation involves the same issues being investigated in a number of ways to elucidate whether evidence exists to support a particular finding (Minichiello, Fulton et al., 1999). During narrative analysis, I compared if and how the stories were told within and between focus groups and individual interviews. Each focus group and individual interview contained stories reflecting one or more of each of the conceptual narratives and each story was represented by one of the four narratives, thus enhancing the credibility of the data. Not surprisingly, this triangulation process also highlighted variations in how the narratives were adopted across the data, suggesting a need to consider the conditions under which they might be adopted. This occurred in the fifth stage of analysis.

One final process was employed in refining and checking the emerging narratives accurately reflected professionals’ experiences. Lincoln and Guba (1985) suggests two processes of member checking and peer examination to enhance the credibility of research findings. Four professionals were invited to review the narratives. Three were study participants and thus provided ‘member checks’ of the narratives. Lincoln and Guba (1985) suggest however that member checks can be difficult for

informants particularly in recognising their own stories and therefore suggest a higher conceptual analysis. I invited three participants that I considered had been quite reflective in their interviews, and who had provided thoughtful, critical feedback on earlier drafts or transcripts. Individual interview participants 12 and 15 were experienced practitioners from government and non-government providers. The other participant who received this draft was unfortunately unable to provide detailed feedback due to health issues. These member checks were supplemented with a peer examination, which Lincoln and Guba (1985) suggest promotes more reflexive analysis and testing of hypotheses. A peer with qualitative research experience and nine years experience with families of children with a disability was also invited to review the narratives. In addition, the narratives were taken to a qualitative research graduate forum where doctoral and master colleagues and experienced qualitative researchers provided feedback. For member checks and peer examinations, I invited them to think about each narrative individually, to compare the narratives, and to consider how these narratives reflected their own experience of practice with families of school-aged children with a disability. They raised a number of issues that sent me back to the data and served to further clarify the narratives. For example, at this stage, what would become the '*making it work*' narrative stated the individual actually did both what they wanted to do to help families and what they thought they were expected to do. The question was posed: Did they have to do both? If they did not, did that make the story more in line with another narrative? In returning to the data, I found they did not need to do both. Rather, the defining feature of the narrative was their drive to ensure they worked in line with their personal vision of helping families, quietly working out ways to do this, and if necessary, to "get away with it". One common strategy they employed to hide their own personally valued practices was, at times, also doing what they "ought to do".

Four narratives resulted from this movement between narratives and data. I called these: *making it work*, *having to fight*, *hopeless struggle* and *making the best of it*. With the four narratives identified, in the fifth stage of analysis I explored the conditions that informed these narratives. Searching the stories corresponding with each cultural core narrative identified the conditions. Conditions identified included, for example, time of year, changes in service policies, interactions with colleagues,

interactions with managers and policymakers and the personal circumstances of the professionals such as their commitments outside work or experience. The four cultural core narratives of professional practice with families are presented and discussed in Chapter 4.

3.5.1.1 Implications and limitations

In this section, possible limitations of the analytical techniques chosen to identify the narratives of professional practice with families are explored noting the implications for the subsequent presentation and interpretation of these narratives in Chapter's 4 and 7.

Researchers have argued both for and against data analysis that involves data collected from both focus groups and individual interviews. Adopting the standpoint of some narrative researchers that the 'context of the telling' is crucial to the story told and subsequent analysis and interpretation (e.g., Riessman, 1993), it might be assumed that focus groups produce different stories and therefore cannot be combined with individual interviews. In this study however, I have suggested that both focus group interview and individuals provide access to the cultural core narratives and negotiated understanding of culturally acceptable practice. My reflections on the implications of this are detailed in Section 7.2.

As stated previously, there are much debated approaches to narrative inquiry. Though widely used, there are limitations to the 'plot structure' approach as employed in this study. Riessman (1993), suggests that this plot structure approach often employed in life history research is more consistent with traditional qualitative studies, placing more emphasis on general themes than that which can be learned from the specifics of how a story is told. A closer contextual and textual analysis focused more on 'how' the stories are told may possibly reveal different meanings and narratives. Some issues of context were considered here, such as the timing of the interviews, whether a focus group or individual interview, the life situation of the participant, and their connectedness to management. A discourse analysis may also have 'told a different story'. For example, my analytic log contains questions, not amendable to answering in a plot structure analysis, about how and when participants

shifted from general stories about practice to specific client ones, from talking about their actions in terms of “I” versus “we”, and between current and past stories.

The approach adopted in this study in part reflects traditional identity studies within a life history approach, where researchers often seek to uncover and interpret narratives present within an individual or community (Chase, 1995). To do so, the researcher adopts an authoritative voice in analysis and representation of the narratives. Like Chase (2005), I believed that my task was to “...make visible and audible taken-for-granted practices, processes and structural and cultural features of our everyday social worlds” (p. 664).

Some researchers suggest that when an authoritative voice is adopted, the researcher should include extensive quotations to support interpretations (e.g., Riessman, 1993). Though offered in Chapter 3 and the Appendices, lengthy quotations are not included in the presentation of findings in Chapters 4 and 5. This decision was made to ensure quotes from individual practitioners did not distract from the community level presentation of shared cultural understandings and conceptual narratives.

3.5.2 Identifying the culture of professional practice with families

The second aim of this study was to explain the culture of professional practice with families. Bruner (1996b) asserts that a culture depicts the ordinary way of doing things. When there is an exception to the ordinary, members of that cultural community will tell a story that explicates what they should ordinarily do and explains how their actions fit with this. Within this narrative mode of culture, it was assumed the stories participants told about their practice therefore depict their understanding of culturally acceptable or ordinary ways of working with families. By analysing these stories, it is therefore possible to elucidate the culture of professional practice with families.

For the purpose of identifying the culture of professional practice with families I re-analysed the 163 stories collected through the focus group and interview process. These stories were originally identified in the first stage of identifying the narratives of professional practice as described in Section 3.5.1. Analysis to identify the culture

of professional practice with families followed the inductive analysis procedures outlined by Strauss and colleagues (Strauss, 1987; Strauss & Corbin, 1990).

Analysis began with open coding of undifferentiated data into categories. In open coding, codes are applied to each denoted unit of meaning in the empirical data (Strauss & Corbin, 1990). Each sentence and then paragraph in each story was read, re-read and coded for these units of meaning.

Open coding resulted in 41 'concepts' of professional practice with families. Strauss and Corbin (1990) described concepts as a collection of characteristics and attributes, and the characteristics and attributes of a concept as 'properties'. Though analysis continued to follow the processes outlined by Strauss and Corbin (1990), these concepts are hereafter called 'principles' to be consistent with the Brunerian framework which focused analysis towards the shared meaning or set of principles comprising a culture. At this stage principles included, for example, financial accountability, clinical accountability, advocacy, community inclusion, collaboration, maintaining family relationships, open communication, bandaid, information giving, preventing out-of-home placement, helping family wellbeing, vocation/calling, hands-on treatment/'direct is best' documentary evidence, resource constraints, wholeness-child in family, respect, crisis responsive, keeping the peace, family as centrepiece, professional distance, uniqueness of each family, gate keeping, strengths focus, normalisation of experience, judgement calls, interpretive/bridging role and consultancy.

To cluster and refine these principles, I employed the process known as constant comparative analysis. Constant comparative analysis requires comparing and contrasting principles (concepts) to ensure each is mutually exclusive and internally consistent (Strauss, 1987). I re-read the coded data pertaining to each principle and explored and documented the properties of that principle, the way these were conveyed to professionals, their implications for practice, and possible consequences of this practice. This was coded in a table for each principle. An example of an analysis table developed for the 'interpreting and conveying information' code is shown in Table 2 on the following page. This process of identifying the properties,

communication, implications for action and potential consequences was repeated with each of the principles identified in open coding.

Throughout this constant comparative process, several principles were merged. For example, the principle of preventing out-of-home placement was combined with maintaining family relationships. On the surface, the titles implied different principles: the location of the child in the family home and the quality or integrity of family relationships. On closer analysis of the text however both principles were about keeping the child at home rather than seeking out-of-home placement. The original 41 principles of practice with families were reduced to 32 by this process.

Table 2: Example of principle analysis table

<p>Principle: Interpreting and exchanging information</p>
<p>Properties:</p> <ul style="list-style-type: none"> ○ Who they interpreted for – between families and the service system ○ What they interpreted – information (about, for example, family service needs, priorities, service policies and procedures, service availability) ○ Why they interpreted – some affinity/knowledge/connection with both families and service system
<p>Implications for practice:</p> <ul style="list-style-type: none"> ○ Keep informed of family circumstances via positive relationships ○ Keep informed about service parameters via documentation and contact with managers. ○ Listening to family service needs and priorities and conveying translating these into language and concepts recognised and valued by the system (e.g., writing funding applications) ‘technical jargon’ in reports to families ○ Attending to information from the service system (including assessments) and removing technical jargon when informing families of the same
<p>Conveyed:</p> <ul style="list-style-type: none"> ○ Service policies requiring them to make local service interpretations of state legislations or service policies ○ Past experiences of successful communications with families and the service system that involved the respective removal or insertion of ‘technical jargon’ ○ In-services to professionals about changing service policies and implications for families
<p>Potential consequences:</p> <ul style="list-style-type: none"> ○ Crisis of allegiance – to the system or the family? ○ “Piggy in the middle” – caught between service system and family with no power to change the conditions you relate to others ○ Inability to adequately understand or represent family concerns

At this stage, the process of exploring potential connections between the principles began. Strauss and Corbin (1990) suggest working towards the identification of a core principle around which all other principles can be integrated and related. Identification of a core category is usually achieved by systematically relating a principle to all other principles until the core principle is identified. In this study however, there was no one core principle. Rather, related principles were grouped to represent components of the culture of professional practice with families. For example, the component of “being objective” in professional practice with families was composed of principles about maintaining a professional distance, making decisions based on facts and evidence and ‘bracketing’ personal emotions. On initial grouping, 33 principles were grouped into 10 components of the culture of professional practice with families. These ten components and their constituent principles occurred in varying frequency across the stories. For example, since helping was the primary interpretive employed in professionals’ stories, helping or a constituent principle featured in some form in each story analysed. Other principles and components, such as those representing ‘inclusive practice’ featured in each individual interview and focus group, but with less frequency across stories.

Systematically relating these principles further clarified and refined the components and their constituent principles. For example, at this point I considered merging two principles: ‘family as crucial team member’ (working together) and ‘family as key decision makers’ (empowerment). As I reviewed the data relating to these principles, it became clear ‘family as a team member’ was about the structure of formal and informal teams and the importance of inviting families to be a part of this collaboration. It did not define what parents’ role might be within this team. Alternatively, ‘families as key decision makers’ focused more on the process of ensuring family decisions were encouraged and recognised as directing practice.

Systematically relating these 32 principles identified relationships between some components of this culture. For example, the principles comprising the ‘positive relationships’ component were frequently highlighted in stories representing the principles of ‘working together’ component. Other components appeared to be mutually exclusive, such as those relating to ‘practice as bandaid’.

I sought feedback on these draft cultural components from several study participants and research colleagues as suggested by Lincoln and Guba (1985). I first invited three of the individual interview participants to offer comments on this draft. Each participant received a printed copy of the draft components and principles and was asked to comment in writing in a meeting with the researcher or both. Each participant had been involved in an individual interview and focus group. The participants, identified as individual interview participant numbers 3, 11 and 14 in Table 1, Section 3.3.1, were selected based on their availability to review the drafts, and to represent maximum diversity within the sample in terms of service types (government and non-government), profession and position (a social worker, speech therapist and occupational therapist/team leader), years experience with families (26, 7 and 8.5 respectively) and employing organisation. Unfortunately, due to the resignation of both participants from the respite and recreation organisation, it was not possible to contact and therefore include a fourth reviewer from this service type. Participant reviewers were invited to comment on whether these components represented their understanding of culturally acceptable practices, that is, ways they felt they ought to work with families. They were also asked to provide any general feedback about, the clarity of wording or similarity of components. Each commented that the components represented how they “ought to practice”, however they emphasised that this often contrasted with how they personally “did or would like to practice”. Minor changes were made to some components based on feedback and the subsequent return to the data. For example, it was suggested that the principle of a safe ‘professional distance’ equated with that of ‘bracketing personal emotions’. Returning to the data confirmed this comment and thus these two were merged into the ‘professional distance’ principle in the objective component. Other changes were made to wording of certain components including for example changing one component from ‘bridging’ to ‘mediation’.

To further enhance the credibility and dependability of the findings I undertook peer examination of the components as suggested by Lincoln and Guba (1985). I presented these refined components of the culture of professional practice to a group of peers with qualitative research experience in a study seminar for qualitative

researchers. Participants included fellow doctoral research students at various stages of study and several academic staff with qualitative research experience. I posed questions and invited their critique, particularly of what I considered ‘tricky’ decisions within the analysis process. For example, at that point two components referred to principles about out-of-home placement. In ‘helping’, an overall aim of services was preventing out-of-home placement. In the ‘bandaid’ practice theme and driven by this ultimate aim, professionals prioritised service distribution to families at immediate risk of out-of-home placement. My peers challenged me to return to the data and determine if it was the crisis or the out-of-home placement that was central in this component. Based on review of that data, I determined that the immediacy of need rather than out-of-home placement was key. Reflecting the interrelated nature of components of professional practice, the threat of imminent out-of-home placement was a prominent crisis (bandaid theme) which professional practice ultimately aimed to prevent (helping theme). There were however other factors that produced this crisis such as “noisy families”. The ‘bandaid’ component of practice thus was refocused towards crisis.

Through this consultation and constant comparative analysis, the data were ultimately grouped into ten cultural components representing 32 principles of professional practice with families. These are: (i) *helping*, (ii) *positive relationships*, (iii) *working together*, (iv) *individualised practice*, (v) *empowering practice*, (vi) *inclusive practice*, (vii) *practice as a bandaid*, (viii) *mediation*, (ix) *“It’s a business”*, and (x) *objective practice*. Each component of professional practice comprised subcategories pertaining to the principles underlying practice with families. These cultural components are presented and discussed in Chapter 5 and summarised in Table 4 in Appendix 3.

4 CULTURAL CORE NARRATIVES OF PROFESSIONAL PRACTICE WITH FAMILIES

This is the first of two chapters in which the findings of this study are presented and discussed. This chapter addresses and interprets findings in relation to the first research question, outlining the cultural core narratives professionals employ to explain their daily work with families of children with a disability. In Chapter 5 the culture of professional practice with families is presented and discussed to address the second research question.

Four cultural core narratives of professional practice with families of children with a disability were identified in this study. These are titled: *making it work*, *having to fight*, *hopeless struggle* and *making the best of it*. Each narrative is named using a phrase from the participant story that most strongly represented the essence of the narrative.

The four narratives are conceptual abstractions grounded in professionals' stories about practice. They represent the fundamental narratives that professionals work amidst as members of this cultural community. Each narrative is hypothetically available to all professionals to describe their work with families in a practice situation. Individual professionals may work in different narratives concurrently (e.g., in different venues or with different families) or sequentially (e.g., moving from one task to another). Circumstances that inform the narratives assumed in a practice situation are described Section 4.5 following the narratives.

The narratives are framed by and focused on the notion of helping families. In each narrative, professionals questioned the extent to which practices helped to improve the health, development or wellbeing of the child with a disability, the caregiving family, or both.

The narratives served to explain and legitimise professionals' actions to themselves and others. In doing so, these narratives reflect the professionals' own vision of how to help families. Each narrative also reflects how actions correspond with culturally accepted practices. The culture of professional practice presented in Chapter 5 outlines what professionals understand to be culturally acceptable ways of working with families.

In Sections 4.1 to 4.4 each narrative is described and then illustrated by a corresponding story from a participant. The first two narratives – *making it work* and *having to fight* narratives reflect different approaches to enacting the professional's desire to challenge the policies and conditions he or she considers inappropriate to helping families. The *hopeless struggle* and *making the best of it* narratives that follow present different levels of concern about feeling less inclined or able to challenge these conditions.

Section 4.5 examines the circumstances that inform how professionals take up these narratives in individual practice situations. Potential implications of the narratives for professionals, their practice world and families are considered in Section 4.6.

4.1 Making it work

In the *making it work* narrative the professional secretly goes about helping families in ways he or she believes are important in spite of their organisational context. In this narrative, the professionals' personal views are paramount, and policies and conditions in opposition to these are obstacles that need to be worked around. They believe their skills are best employed to help families in line with this personal vision. Professionals in this narrative are confident in their abilities and secure in their conviction that others value them.

In the *making it work* narrative, professionals prefer to draw as little attention to their daily practice as possible. They may need to do tasks that they consider objectionable

or that are not in line with their views about helping families to ensure they are left alone.

In this narrative, professionals maintain a positive and hopeful frame of reference: they feel they help families and quietly challenge undesirable policies and conditions. Though these professionals are reprimanded for circumventing organisationally determined policies and practices, they may become even more covert to achieve the goals with families that they regard as important. Margaret's story provides an example of a *making it work* narrative.

Margaret is a shrewd and determined occupational therapist, often working 'under the radar' of her boss, bending rules and going around any barriers to help families as she sees fit. She considers Departmental pressure to discharge families after they have received their time limited (10 weeks) or issue limited (e.g., wheelchair prescription) 'unit of service' can adversely affect her ability to help families with ongoing support needs. Margaret is confident however that she can still help families despite these constraints. She acknowledges that to avoid overloading staff, families must be discharged. However she believes that maintaining contact with some families with ongoing needs is more helpful and less taxing on professionals' limited time and facilitates a more efficient response by preventing time being wasted in "getting to know families all over again". She doesn't mind "bending the rules a little bit to keep that contact happening" if it allows her to help families better. Sometimes she discharges the family and addresses their service needs "off the record" by not recording her work on the statistics of service sheets. She also discharges other families she does not believe need ongoing help. Her managers have noticed her reluctance to discharge families and she has been reprimanded repeatedly concerning this. She is not overly concerned about these reprimands, listening, and then working out new ways to continue contact with families "on the quiet". She is confident that her extensive experience and expertise are too valued by the organisation for any serious consequences to occur. Moreover, if the situation was to change and she could not continue her current practices, she is confident she will find "the right next

step” where she can do so elsewhere. She feels satisfied that she is helping families to the best of her ability.

4.2 Having to fight

In contrast to the secretive or ‘underground’ nature of the *making it work* narrative, the *having to fight* narrative openly challenges policies and conditions considered unjust and in conflict with the professional’s individual vision for supporting families. Professionals in the *having to fight* narrative are confident in their skills and knowledge, viewing themselves as crusaders and developing a ‘plan of attack’ on behalf of families to change policies or conditions that they see as constraining their efforts to help families.

These professionals challenge policymakers and their supervisors by directly opposing ‘offending’ policies and conditions. They also indirectly challenge the status quo by ‘lighting the fire’ of rebellion in others including families and their colleagues. In the *having to fight* narrative, professionals openly ‘push to the limit’ their’s and others’ skills, resources, constraints and expectations. They anticipate being reprimanded and draw some satisfaction that by association, their ‘cause’ has been noticed.

In this narrative, professionals often feel it is their battle alone, at least at the outset. Yet they are optimistic that change can occur, acknowledging however that the battle will be ongoing. In this narrative, whether the situation is resolved or not, professionals feel justified in their personal vision for helping families, and retain their anger and frustration which motivates them to fight, regardless of personal or professional consequences.

Karen’s story described below provides an example of the openly combative stance of the *having to fight* narrative.

Karen is a social worker, determined, outspoken, prepared to fight and lead others, even if it means upsetting the boss. She feels concerned that the shift to consultancy and tertiary models of services delivery with reduced direct contact hours does not support families appropriately. She feels it is hypocritical and dishonest to perpetuate an approach that she considers ill conceived and an ineffective use of her skills. To support and empower families, she therefore “works the system”, often working in ways that are not sanctioned. Despite being directed by management to pacify families, she encourages them to “make some noise” and gives them information on how to do so. She tells families they will not receive the required level of support unless they are noisy, as noisy families are more likely to be assessed as ‘in-crisis’ and therefore get the service they need. Her commitment to this fight is reaffirmed, as more and more families are “cottoning on to the idea” of manipulating the system to fight for the services they need. She thinks pressure is being brought to bear on policy makers and managers as an increased proportion of families present, perhaps unnecessarily, as ‘in crisis’, and others request details of how to make noise via official channels. She feels vindicated because families are fighting for and getting the help they need and the wrongful reduction in therapy services is being challenged.

4.3 Hopeless struggle

Like the *having to fight* narrative, in the *hopeless struggle* narrative professionals are concerned about their ability to help families within policies and conditions that they consider ineffective and ill informed. In contrast though, professionals in the *hopeless struggle* narrative despair at their inability to change the conditions to which they are subjected. Their own vision of working with families is completely overwhelmed and they hold no hope that they can help families within this situation. In this narrative, professionals are concerned that their skills and resources are inadequate to the task or wasted within existing policies and conditions.

This narrative is about professionals quietly and despondently doing what they are told to do to help families. Complaints to those with power to change the situation

barely feature: these are considered pointless with consequences to be avoided such as prompting reprimands or exposing a professional or personal weakness. In this narrative, energy is directed towards ‘surviving’ the situation. Surviving requires professionals to limit their emotional investment in families and service outcomes, treating their work as a job to earn money. Despite occasional mutterings to like-minded colleagues, professionals in this narrative largely feel alone and powerless.

On reflection, the professionals in this narrative are disappointed with themselves and their inability to help families. They construe any feedback from others about their efforts as a complaint, criticism, or ill informed affirmation of practices that do not help families. Lisa’s story below provides an example of the *hopeless struggle narrative*.

Lisa is despondent, drowning in expectations she feels unable to fulfil and despairing that her efforts can in any way help families. The “new issue, new referral” intake policy at her workplace directs Lisa to work with families to resolve only the issue identified on referral before discharging them. Within this practice, most families experience multiple and ongoing re-referral, which results in long waits for services and their being allocated to the “next available” service provider with a caseload vacancy. Lisa despairs at how this devalues existing relationships with families, but feels she has no choice but to comply with this policy. She is distressed and frustrated as families she has worked with before who required her specialised gastrointestinal feeding skills are instead getting services from comparatively inexperienced and unknown therapists. Believing she cannot change the situation, she continues to work in line with this service policy, feeling her capacity to support families is severely restricted and her time and skills are wasted. When these policies were first implemented, Lisa quietly vented her frustrations and concerns to her colleagues and team manager to no effect. Nowadays, she “throws her hands up in the air in despair” and says nothing beyond the occasional “quiet whimpering” to like-minded colleagues. She sometimes reminisces about the “good old days” when she could work directly with families and utilise her skills, however she finds reality quickly makes these “dreams all come crashing down in the end”.

4.4 *Making the best of it*

Like the *hopeless struggle*, in the *making the best of it* narrative professionals feel they lack the skills or opportunities to change the official conditions and policies informing their practice. Yet the *making the best of it* narrative is one of pragmatism in which the professional accepts without concern that these policies and conditions take priority over the professional's better judgement. Instead, they react and adjust their practice to take into account the policies enforced by their organisations.

In this narrative, professionals believe that those 'in control' are decent and good and have the best interests of children, families and their workers at heart. Hence the *making the best of it* narrative reflects hope that doing what they are directed to do will affect families positively.

The *making the best of it* narrative may include talk of working 'outside' service policies however this is not reflected in action. Actions are justified as doing what is expected by their organisation. Here, professionals look for positive and personally satisfying elements in their actions. They may also seek reassurance and guidance from others including colleagues, mentors, managers, and families. In this narrative, professionals are firm in the belief that they have done their best within the existing conditions and policies, even when they do not agree with these, to help families in some way. Matthew's story illustrates the *making the best of it* narrative.

Matthew is easygoing, adapting to and making the most of whatever opportunities and tasks are presented by his job. He accepts that he is expected to take part in individualised service plan meetings and associated documentation. Matthew acknowledges that these are ideally aimed at individualising support and empowering families. However, he thinks two key issues challenge this aim. First, the extensive number of professionals involved in each service and the number of service plans each professional must be involved in create an impossible workload. To offer individualised service within this context, Matthews explains "you would do nothing but service plans and meetings" at the "expense of providing an actual

service”. Second, he thinks that the standard format for service plans and meetings makes for prescriptive and generalised rather than individualised practice. Despite these flaws in service plans, Matthew has faith that they fundamentally support children and families and believes they are better than the alternative of no plan at all. He is confident that by using service plans as directed, he can contribute to helping empower families and provide them with some services relevant to their individual needs. He remains mindful however of not becoming overly prescriptive or repetitive in the large number of plans to which he contributes.

4.5 Circumstances that inform the narratives adopted

As noted previously, each narrative is theoretically available to all professionals to describe their work with families in a practice situation. However certain circumstances may contribute to an individual being more likely to adopt a particular narrative. The circumstances identified here do not serve to predict which narrative will be related. Rather, in keeping with Bruner’s narrative way of thinking, circumstances are highlighted from an analysis of participants’ stories that may help understand the narratives adopted in particular practice situations.

In his published work, Bruner does not speak directly to the concept of community narratives as presented in this thesis. Within the narrative mode of culture, he argues that through their stories, members of a cultural community can express the narrative or shared meanings of their culture. Through storytelling, he suggests that individuals ‘try on’ possible stories for fit with their identity and commitments (Bruner, 1990a; Bruner, 1996b). Within the narrative mode of thought, Bruner suggests that a person’s character, setting and actions are regularly combined differently in constructing a person’s life or ‘narrative identity.’ He argues that characterising the story or narrative goes beyond simple consideration of the character or personality, to considerations of circumstances and setting (Bruner, 1986).

Participants' stories highlighted several circumstances that potentially influenced which cultural core narrative a participant adopted in a given situation including personal life circumstances, interactions with colleagues, managers and policy makers, changes in the service policies and the time of year. These are addressed in turn.

Professionals' personal circumstances potentially inform the cultural core narrative adopted. The *having to fight* and *making it work* narratives were characterised by professionals having the time and energy to devise and execute a plan to help families outside the dictates of policy and conditions. In contrast, the *hopeless struggle* narrative describes professionals whose energy and opportunities are committed only to surviving the situation. In the *making the best of it* narrative, professionals do whatever they have the time and energy available for within what they are told to do and the time and resources available. Professionals varyingly described circumstances that informed the time, energy and headspace they had available for their work with families. Life outside work potentially informed the narrative adopted. Having young children, or being a caregiver for a person with special needs, for example, limited the time and opportunity professionals had for greater work flexibility. For example, a participant who needed to pick her children up after school was unable to do after hours home visits. Alternatively, having grown children or no caregiving responsibilities allowed comparatively more time, energy and flexibility in some practice situations. In this study, professionals rarely mentioned discussing work situations with family or friends. Like women in caring occupations in a study by Kardos et al. (2001), professionals were more likely to discuss work concerns with colleagues.

Professionals' interactions with colleagues and supervisors may also inform the narrative told. Clear (1999) describes peer support and supervision systems as the 'caring culture' necessary for professionals working with children with a disability and their families to carry out their work. Yet *hopeless struggle* and *having to fight* narratives portray professionals' battles and struggles as largely a solo one. It is possible if additional interaction with colleagues and supervisors existed, where there are opportunities for talking through actions, seeking reinforcement, learning from

more experienced colleagues, and consequently building confidence in their skills, that another cultural core narrative may be adopted.

Professionals' interactions with managers and policy-makers may also inform the narrative told. Workplaces where managers and policy-makers invite and respond to professionals' priorities and concerns potentially encourage understanding and ownership of policies and conditions directing practice. In the *making it work* and *hopeless struggle* narratives, professionals barely interact with, and indeed sometimes avoid managers and policy-makers, believing that decisions are made and enforced by these people independent of professional involvement. In contrast, in the *having to fight* narrative, professionals believe they can and should relate to managers and policy-makers about their practice, however most often this is in a hostile way. In the *making the best of it* narrative, professionals may not feel they can inform policies and conditions. There is however a sense they can question and understand the reasoning behind policies and conditions and they feel encouraged that by deferring to these, they can indeed help families.

Changes in policies and conditions of practice may also influence which narrative professionals adopt. To varying degrees across the narratives, professionals considered they could help families within changes to the policies and conditions shaping their practice. For example, system reform based on government policy had implications for the way professionals were directed to work with families. Professionals traditionally accustomed to providing direct intervention with families were now directed to work as consultants and case managers. The *making it work*, *having to fight* and *hopeless struggle* narratives told of the varying ways that respectively professionals worked around, against, or unhappily within these new roles they considered would not benefit families. In contrast, the *making the best of it* narrative was the only cultural core narrative that encompasses professionals' belief that they can help families by working as directed by policies and conditions even when this includes primarily a case management approach.

The time of year may also have shaped the narratives constructed. Around school holiday time, professionals experienced increased pressure from desperate families

pleading for assistance in caring for their child in the holiday period. For example, families requested assistance with accessing respite hours or home therapy sessions to replace school-based care and therapy. Professionals talked about families desperately “threatening to dump their child at respite” unless they received the assistance they required. The *making it work* and *having to fight* narratives reflected the subsequent pressure to “somehow work something out” to help families at this particular time.

4.6 Implications of the narratives

In this section I explore possible implications of the narratives in order to better understand the nature of professional practice. In the first instance, the implications of these narratives for professionals are considered, including discussion about how these might contribute to a personal narrative. Second, the implications for culturally acceptable ways of working are explored. This section concludes with consideration of the implications for families.

One implication of the narratives is the extent the professional’s desire to ‘help’ families is fulfilled. In each narrative, professionals framed and evaluated their actions in accordance to how they helped families. This is not surprising given the professionals in this study belong to what are colloquially called ‘the helping professions’. Literature suggests that when professionals help others it can personally motivate and satisfy their own need to help and places them in a validated and empowering position in society (Bengtsson, 2003; Bolton, 2000; Dempsey & Arthur, 2002; Devereaux, 1984; Gartner & Riessman, 1993; Hasselkus & Dickie, 1994). If through their narratives, professionals evaluate their actions as unhelpful, this therefore has implications for their motivation in future practice situations.

In each narrative, professionals variously assessed the extent to which they could help others, and therefore potentially the satisfaction they could draw from their daily practice. In *making it work* and *making the best of it* narratives, professionals were basically satisfied with the help they provided. Perhaps however, the

sustainability of the dual, underground practice in the *making it work* narrative order to help families is questionable. In the *having to fight* narrative, professionals were not always satisfied with the help that they provided directly, but they drew some personal and perhaps compensatory satisfaction from the fight to provide help as they felt they should. In the *hopeless struggle* narrative, professionals ultimately felt unhelpful to families, and the narrative reflected their corresponding sense of despair.

The narratives have implications for the expectations professionals' experience. The narratives, through the actions they convey and the explanations they offered, served to position professionals as affirming or undermining particular expectations of their practice. Narratives can thus potentially prompt professionals to negotiate new, or affirm existing ways of working with families. This provides some insight into how professionals contribute to or impede cultural transformations in practice through their daily actions.

The expectation that professionals reduce direct contact with children and families and work in more consultancy and case management roles is used here to illustrate the implications of each narrative for expectations of practice. In the *making the best of it* and *hopeless struggle* narratives, professionals were more likely to work in line with expectations, whether they personally agreed with them or not. In these narratives, professionals reduced their direct contact with children and families, attempted to explain or legitimise the reasoning for this change, and to varying degrees began trying to adapt to and assist families within their new roles and responsibilities. This potentially contributes to affirming the shift to consultancy and case management approaches to working with families.

In the *having to fight* narrative, the professionals' intent was to publicly and explicitly challenge or undermine how they were expected to practice. By openly challenging the offending expectation, professionals in this narrative hoped to start a dialogue that would cause these expected practices to be renegotiated. In this narrative, professionals openly challenged the withdrawal of direct contact services by, for example, encouraging families to complain about the changes, openly

continuing to offer direct therapy and declining any new positions or responsibilities potentially aligned with this shift. This undermined the shift to consultancy and case management services and potentially maintained the expectation that direct services will be available.

In the *making it work* narrative, the underground nature of some work with families suggested that professionals tend not to openly challenge an acceptable practice. Yet professionals also engaged sometimes in a dual practice, doing both what they personally wanted to do and what was culturally expected. Therefore in the *making it work* narrative, professionals potentially both reinforce and undermine how they should practice with families. In this narrative a professional might appear to be working as a case manager and consultant, thus be affirming transformation to this approach. He or she may however also quietly undermine it by continuing, for example, to work with families directly outside of work hours without recording or reporting this work.

An exhaustive exploration of the implications of these narratives for families requires asking the families themselves, an activity which was beyond the scope of this study. However, it is possible to consider the implications of these narratives for families based on professionals' perceptions of how families were helped. As noted previously, the extent to which actions helped families both framed and focused the narratives.

In the present study, the degree to which practice 'helped' families varied across the four cultural core narratives. The *making it work* narrative described working out a way to help families to the professionals' satisfaction, even if it meant quietly going around or against what they were expected to do. In the *making the best of it* narrative, professionals believed that by doing as directed by others they could help families. The *having to fight* narrative of professional practice involved fighting to help families as professionals felt they should by openly challenging practices they did not believe helped families. The *hopeless struggle* narrative suggests professionals believe that families cannot be helped within constraints of the conditions or service system.

There are obvious limitations to basing the implications for families on professionals' perceptions alone. First, professionals based their evaluations of helping on their own perceptions of family needs and what could be helpful to families in the situation. Second, this perspective does not consider if families interpreted the associated actions as helpful. It does not consider if and how this represents what families felt was needed or helpful in the situation. For example, a participant described *making it work* by providing respite for a family, who in reality were strongly and repeatedly requesting a more permanent out-of-home placement option that had been arranged after considerable counselling. In her evaluation, she 'made it work' by keeping the child at home and providing the family with the helpful break she felt they needed. The implication for this family was potentially a continued unmet service need. The extent to which professionals and families agree on what is helpful or supportive varies in the literature, further highlighting the need to explore the implication for and relevance of these narratives from the family perspective in the future (e.g., Baxter, 1989; Beckman et al., 1996; Clear, 1999; Herman & Marcenko, 1997; MacKean et al., 2005; McKenzie, 1994; Rahi et al., 2004).

5 THE CULTURE OF PROFESSIONAL PRACTICE WITH FAMILIES

According to Bruner (1990a), there is a two-way relationship between an individual's thoughts and actions and the cultural context in which they are situated. Applied in this context, this presupposes that professionals' thoughts and actions within each narrative have the potential to both inform and be informed by the cultural context in which they occur.

This chapter therefore presents the culture or shared meanings of this cultural community of professionals working with families of children with a disability. As members of this culture of professional practice with families, participants' stories portrayed these shared meanings. Reflecting this, participants own words, descriptions and examples are used throughout this chapter to describe this culture.

The culture of professional practice with families derived from this study can be thought of as being composed of ten components. These are: (i) *helping*, (ii) *fostering positive relationships*, (iii) *working together*, (iv) *empowering practice*, (v) *inclusive practice*, (vi) *individualised practice*, (vii) "*it's a business*", (viii) *objective practice*, (ix) *practice as a bandaid*, and, (x) *mediation*. These titles were drawn from participants' stories.

Within each of these cultural components, I identified a set of shared meanings, or in Brunerian terms, principles of professional practice with families reflecting the shared values, beliefs and commitments of this cultural community (Bruner, 1990a). Borrowing from Bruner, these cultural components form a 'cultural tool kit' employed to interpret professionals' intentions in their work with families. They convey what these participants understood to be culturally acceptable ways of working with families. Following Bruner, they therefore do not necessarily reflect individual's intentions and values. In other words, individuals may (and do) hold

different views about what should happen in professional practice from what they identify as culturally acceptable ways of working.

The cultural components that comprise this culture of professional practice with families are outlined in Section 5.1. Section 5.2 discusses these components in the context of the literature and policy and practice documents. Section 5.3 draws on these cultural components to illustrate ways in which the culture of professional practice is constructed and conveyed.

5.1 Components

5.1.1 Helping

You are idealistic and wanting to do everything to help... after all, that's what it's all about... But the thing is you can't lose that... you have to preserve that light and that fire... It embodies the philosophy behind your work. It does. It has to. Otherwise, this work is hard and you give up. You would get burnt out or you wouldn't care. So you have got to preserve that fire, that drive to get the best that you can for these people.

This participant's comment illustrates the underlying belief that the 'core business' and goal of practice is to help children with a disability and their families. This is reflected in the professionals' narratives as described in Chapter 4, which are framed and focused on the notion of helping. Participants described helping in terms of whom they helped, how they did so, and why.

Participants described the inter-relationship between helping a child with a disability and helping their family. The family unit is their client, and therefore focusing help on the child or on other family members is viewed as helping the entire family unit. Whether adopting a child-focus or family-focused approach, the professionals in this study believed they could help the family and the child. For example, accessing respite time for a child, providing mobility programs for the child, and teaching a

mother back care techniques were described as helping a family to be healthy and stay together.

Participants believed they could best help families by directly assessing child and family needs and providing hands-on treatment to the child or family by, for example, activities as diverse as teaching children to walk or counselling parents. They described being prepared to work in this way through their education and past experience. They also hoped they could provide supplementary, indirect help by supporting others like teachers, scout leaders, and sports groups to support the children and their families.

Helping families was also talked about as maintaining the health and development of the child and family and ultimately supporting families staying together, rather than seeking alternative care arrangements. Within the constraints of available resources, participants therefore do “whatever is needed” to help families keep their child at home. For example, a social worker identified the extra help that was needed in the home to enable a mother to continue caring for her child, and subsequently sought funding and services to ensure the respite hours, home care, counselling and hoists requested were provided.

These professionals felt helping support children and families in need could or had also helped satisfy their own innate desire to help others. The day-to-day provision of help in itself or notable improvements in child and family functioning constituted a reward for their efforts.

Professional practice with families also involved a sequential process of helping activities. Thus, participants described conducting intake meetings that were used to establish each family’s need for help and to broadly determine if family needs corresponded with the support the agency was able to provide. These meetings were guided by agency intake protocols that governed the service the agency could provide. Successful negotiation of the intake procedures served as an entry point for families to receive the help that these professionals provided within the constraints of their agency’s services. An initial assessment involved these professionals

determining the exact nature of the help needed. For example, a child may need speech therapy, a family home may need an access ramp or the family may require counselling or access to respite services. A service plan was then developed for each family to match the support available to the needs identified. The meetings involved in each service plan provided an opportunity for those involved to negotiate this help. The ensuing documented service plan acted as a written helping contract between professional and families. Professional practice and family outcomes were evaluated against this contract.

5.1.2 Positive relationships

It is about building relationships with them... trying to build relationships with families so that they begin to trust you and trust that you are going to be following through on what you say you are going to follow through on and things like that.

Professional practice with families included establishing and maintaining positive relationships. Positive relationships began with an effort to build rapport. Participants believed this was best achieved in early face-to-face interactions that enabled them to talk with others and observe their reactions. A positive relationship was seen to be characterised by distinct features including friendly, open communication, trust, respect and commitment to helping families.

Participants talked about open communication within relationships as a crucial source of information in identifying and monitoring family needs and thus providing responsive services. They described open-communication as a two-way flow of information that keeps families and professionals informed about the resources and constraints, needs and priorities of each other. For example, when a mother felt comfortable enough to express her guilt about using respite services to a social worker, the social worker was able to provide the appropriate psychological and practical support in dealing with this guilt and finding a respite home that felt “right” to this mother.

Participants believed their daily interactions with families ought to be based on respect. Respecting families involved the professional reserving judgement or disapproval about family decisions and priorities even when they think these may not be in the best interest of the family. For example, an occupational therapist described supporting and acknowledging a family's decision that they were "not ready" to consider a wheelchair for their child's mobility around home.

Participants talked about building a family's trust and confidence as a part of a good relationship. They felt they ought to earn the trust and confidence of a family, demonstrating their skills and commitment by, for example, following through on proposed interventions. Within the context of trusting relationships, professionals could help families to deal with challenges often associated with raising children with a disability. For example, a psychologist "planted the seed" about accessing family counselling to discuss the possibility of out-of-home placement. A trusting relationship ensured that her suggestion was perceived as potentially helping the family rather than judging the all too evident fractured family relationships.

Participants thought practice could involve friendly relationships where they demonstrate a genuine interest in and knowledge of the family outside of their immediate service-based relationship. Though not 'best friends' this does mean these professionals are willing to chat informally with families, for example, about work or holidays, and will enquire about families no longer on their caseload.

5.1.3 Working together

I mean obviously, collaborative consultation is the essence of it all ... the structure is certainly there for the sharing of the information and the support for families and, you know, the contact with other agencies.

Participants believed that their practice should involve working together as part of a collaborative team to better improve and maintain the health and wellbeing of families of children with a disability. Working together involves professionals interacting with others, sharing information, expertise and experiences that can help

focus and address a diversity of family needs. Working together can involve formal procedures such as service plans or informally consulting with colleagues and families in order, for example, to seek information, advice or support.

Participants thought that ‘truly working together’ was about collaboration rather than simply about being identified as a part of a group or team of people. Collaboration involves developing and working towards a shared vision of the goals of support for each family, and through collaboration, a clearer picture of family needs, and more efficient, effective and responsive means to addressing them is possible. Thus, collaboration was valued as a means of reducing the likelihood of overlap or gaps in service delivery. In this context of collaboration, families were regarded as the centrepiece of the collaborative team. Family concerns and priorities needed to inform the services provided.

5.1.4 Individualised practice

You react with every family differently, depending on the response that you get from the family themselves.

My participants considered that at the core of professional practice was the need for ‘individualising’ practice. They believed that they had to identify and value the uniqueness of each family’s circumstances and consider this in the subsequent design and implementation of support. This ‘individualising’ involved building a positive relationship and working together with families to clarify, for example, family needs, strengths, concerns, learning styles, and priorities.

These professionals believed that service plans could provide a framework through which they could individualise their practice. Ideally, these plans involved professionals meeting with each individual family and other service providers to devise and monitor service needs and document the goals and steps involved in providing the services. Professionals would ideally be involved therefore in every family’s planning meeting, however this was not viewed as a practical use of their limited time and resources. This suggests that though participants shared a belief that

culturally acceptable practice was always individualised, they did not necessarily share a vision of how to individualise practice.

5.1.5 Empowering practice

That is the most important thing – empowering parents to make the decisions.

Professional practice, according to the participants in this study, should aim to empower or ‘help families to help themselves’ by developing their knowledge, confidence and skills in directing services and caring for their child. The professionals talked about empowering families by providing information and encouraging decision-making.

According to these professionals, information is central to empowering practice. They thought that by providing information and advice, families were better prepared with knowledge, confidence, skills and resources to make informed choices and improve control of their circumstances. They also thought they ought to offer families choices, providing a variety of information.

The professionals also talked about empowering communities, including, for example, informing and encouraging school communities and local councils to consider disability and access issues. They thought that informing and encouraging communities helps to develop their capacity to provide opportunities to include and support people with disabilities and their families within mainstream society. For example, an occupational therapist described providing information and advice to a school and local vacation care program to help them include children with a disability and worked with the local council in establishing a ‘disability awareness’ festival.

5.1.6 Inclusive practices

We are supposed to be about working towards this idea of people with disabilities being a part of your local community and being accepted as part of the local community.

My participants reported inclusion of children with a disability and their families in mainstream society as an overall goal of professional practice with families. Practice was thought of as helping normalise the community living experiences of people with disabilities and their families by empowering families and communities.

The professionals sought to include children with a disability and their families by helping them develop skills and confidence to enable them to participate in mainstream programs or settings. For example, providing a family with information about a setting or inclusive opportunity, preparing a child to meet the requirements of that setting, such as independent dressing, or applying for funding to support the child's inclusion in the setting.

Inclusive practice should also help prepare communities to facilitate opportunities for people with disabilities and their families. Socially, preparing communities involved challenging assumptions and providing information about disability to increase community understanding and acceptance by, for example, providing opportunities for specialist disability and mainstream schools to share in community events. At a political level, my participants reported lobbying for improved integration and opportunities for people with disabilities by, for example, petitioning governments for program funding. Another requirement of professional practice was to prepare the physical environment to support people with disabilities and their families participating in everyday community activities, by designing wheelchair assessable playgrounds.

5.1.7 Practice as a bandaid

Sometimes it is just a bandaid effect. I mean we had three parents in one week say that they are going to leave their children with us, and it is a matter

of us going there and meeting with the family ... and it is a lot of, well we almost felt like we are grovelling to her just to “keep her at home” and we are saying this is what we can realistically put in place in the home ... and that kind of has like a temporary short term affect, whereas in 6 months time, we haven't really dealt with it because I mean there are a lot of issues ... So in 6 months time, we will probably get another phone call, and our little meeting that we have with her might not work next time.

The culture of professional practice with families of children with a disability as reported by the professionals in this study was permeated by a reactive, crisis-oriented, short-term approach that the professionals attribute to the overwhelming demand for the limited services available.

Within this demand for services, these professionals decide which families or needs most urgently qualify for services. Families must demonstrate the immediacy or urgency of their service need in order to move from a waiting list to receiving a service. In principle, this is the only need that is addressed before the professional discharges the family, focusing their attention on the next most urgent family or need. Practice can therefore involve encouraging families to express the seriousness of their needs and to explore consequences should these not be met, for example, by placing their child out-of-home. Participants felt that as a result of these demands there is a pattern of continuously working with families that are in or reporting an immediate crisis.

My participants thought this bandaid, quick-fix approach was a pervasive but fundamentally flawed means of supporting families. With short term, quick-fixes families were often re-referred for previously 'patched' issues or referred for issues that would not have arisen were the professionals afforded the time to work with families on more long term or preventative approaches.

5.1.8 Mediation

There are many people who don't understand that while you are treading this path fairly carefully with clients, that you are actually preventing them from going to the Minister or the CEO. That happens when; say that person complains to the CEO. I mean all hell breaks loose. People, managers stop in their jobs for days on end and asking how are we going to deal with this family. We are in crisis!'... Everybody is making threats and you are the bunny in the middle!

The professionals in this study thought they should act as intermediaries between families and 'the system', helping to prevent and resolve conflict and discrepancies around expectations of services. They described themselves as uniquely positioned to have some affiliation with, and knowledge of both the families they served and the service system that employed them.

Negotiating realistic expectations of services requires the professionals to have information about the resources, constraints and priorities of families and the service system. Through positive relationships with families, professionals identify family concerns and priorities and forward these, on the families' behalf, to the service system. Similarly, participants felt they should explain policies and procedures to families. However, they reported often not feeling involved in and informed enough about policies and procedures to do so.

The participants reported often interpreting the information they relayed to suit the intended family or system audience. They believed this meant that the information would be better understood and have a greater impact in service negotiations. So when forwarding a parent's request or concern to a service, the professional might translate this request to reflect, for example, the cost containment priority of a service by stressing the cost effectiveness of a family's requests. Participants also interpreted information from the system to families, removing professional jargon and summarising lengthy service policies.

The participants felt that they were expected to placate families, keeping families' concerns and complaints out of the public arena and ultimately avoiding 'bad press'. This meant they prioritising working with families with the potential to be the loudest in the public arena.

5.1.9 'It's a business'

Health and community services now are businesses, and the people at the top are businesspersons. They are not people oriented. The policies are coming from central office, and most of those people have never worked out in the field. They wouldn't have any idea of the issues involved, and I think that is reflected in the policies that are coming out that we are supposed to follow.

The professionals in this study considered that practice with families should involve a business approach. Words reflecting a corporate management or business approach were recurrent in their stories of practice using terms such as, the core business, contracts, cost and investments in practice.

The professionals thought their practice with families had become finance driven, with services operating within a chronic shortfall of funds and resources. They felt pressured to minimise cost and contribute to securing funds for their work with families. Services and professionals tender for limited government funding for programs and equipment, so participants felt the "competition" for limited funds was strong and could undermine attempts to collaborate with other agencies. As a consequence of this competition for limited resources, participants felt they often had to inflate the service need to ensure the urgency and worthiness of their application was demonstrated. This was discussed earlier in Section 5.1.7 where professional practice was thought of as a bandaid. Professionals also often needed to be creative and find alternative funding sources to help meet child and family needs, including for example, asking community clubs to purchase equipment on a family's behalf.

The professionals in this study reasoned that the high demand for their services meant that services needed to be rationed. They interpreted the shift to consultancy

models of service delivery and increasing case management responsibilities as the system's efforts to ration services. Within this model, each professional has more families on their caseload, but spends less time working with them directly and more time supporting others like teachers to help children and families. In this way, the professionals' expertise is rationed.

With regard to ongoing professional development, participants felt that practice ought to involve participating in programs such as supervision sessions, case conferences and education sessions that were aimed at developing and maintaining the quality of practice with families. The believed experienced clinicians should share their expertise, help develop newer graduates' skills, and monitor the quality of the services provided to children and families. Newer graduates could seek advice and reassurance from more experienced colleagues about what to do with particular clients and in specific situations.

The participants talked about measuring and being accountable for time and resources invested in their daily practice. They felt they are accountable to management through statistics of service that involve recording and labelling specific units of time (e.g., 15 minute blocks) with an observable and measurable pre-determined classification, for example, report writing, assessments, education sessions, team meetings. These statistical categories directed professionals to pursue activities and outcomes that were valued by management and exclude others not so highly valued. Current reporting criteria essentially excluded and thus negated much of what professionals did and valued in their practice with families. For example, time spent building rapport could not be recorded, nor could the outcome of family empowerment or family confidence and trust in the professional.

Notwithstanding these concerns, participants valued keeping written records as evidence of what they do and why. They document their daily decisions, actions and reasoning in, for example, service plans, statistics of service, progress notes, and client reports. They are also legally bound to report some practices, such as concerns about child abuse or neglect under the NSW Children and Young Persons (Care and Protection) Act (1998). Documenting practice provides evidence against which

professionals can be held accountable by funding bodies, managers and families for the time and money invested in their services. Records of their actions, decisions and rationales can also serve as evidence should professionals' practice be legally questioned. Though they valued record keeping, participants believed that such documentation can be excessive, duplicated and an undue drain on limited resources, especially time, that could otherwise be channelled towards working directly with children and families. For example, a program manager told a story of reformatting an annual report with identical information to meet requirements of three different groups to which his program was accountable.

5.1.10 Objective practice

We try to make it as objective as possible. Because if we are subjective, then how are we going to make it a fair system, especially if there are five different subjective experiences in the room!

The professionals in this study considered that objective practice is critical to their own wellbeing and to the fair distribution of services to families. They described objectivity as refraining from allowing their personal feelings and preferences from informing their practice decisions. Not surprisingly therefore, participants reported deferring to service policies and legal guidelines to guide impartial decisions in practice about, for example, which families receive services, when, how and why, or what constitutes a reportable child abuse or neglect concern.

The participants equated objectivity with an element of "professional distance" that advises against becoming too personally involved or emotionally invested in the lives of their clients. Maintaining a professional distance can help minimise stress and stop professionals becoming emotionally 'burnt out' when they cannot help families as they would like. Objective practice therefore involves them confining their interactions with families to working hours around issues related to the service needs of the child and family. This belief presents a contrast with the friendly interactions professionals equated with positive relationships with families as discussed in Section 5.1.2. Participants described dealing with this paradox by

distinguishing friendly interactions as talking abstractly about non-service related issues in a ‘friendly way’ but not actually getting involved in, or meeting with families outside of service concerns.

5.2 Cultural components in the context of literature and policy documents

In the *helping* component, professionals’ beliefs about who they help reflect the ongoing debate in the literature about who is the focus and who benefits – the child, the family or both. Several researchers have noted that professionals’ primary focus is on helping the child with a disability (Katz & Scarpati, 1995; McWilliam et al., 1998). That said, Katz and Scarpati (1995) reported professionals and families believed that whilst the IFSP was aimed at improving the child’s development, it possibly indirectly influenced the family. In a study by McWilliam et al. (1998), early interventionists more confidently asserted their beliefs that by helping the child they also helped families to function. In my study, there was an additional belief, that is, that helping families helps children, suggesting an interdependence of child and family service needs. Interpreted within the context of less allowable time for direct treatment of children with a disability (NSW Ageing and Disability Department, 2000a), this finding may reflect participants hope that they are still helping children, albeit indirectly, by working with their families. This interweaving of child and family interventions also reflects assumptions about family-centred practices identified by Bailey and colleagues in the USA over a decade ago (Bailey et al., 1992). In that study professionals assumed that children and families are inextricably intertwined in such a way that intervention with one influences the other, whether intentional or not.

The belief that the most appropriate help is provided through direct intervention is reflected in the literature and professional preparation in the USA. Lawlor and Mattingly (1998) referred to professionals valuing direct practice as ‘real work’ noting this described the types of treatments that professionals had been trained to provide through their formal education. According to Whitehead et al. (1998)

professional training still mainly directs professionals to provide direct assistance to their clients. Yet as Jones and May (1992) noted over a decade ago, that in the shift towards managerialism and economic rationalism, 'real work' oriented training may lead professionals to hold unrealistic expectations of the nature of their actual real world practice (Jones and May, 1992). Without information available about the focus of professional preparation programs in Australia it is not possible to determine whether the participants in this study were confronted by similar unrealistic expectations to those of their North American colleagues.

At a personal level, the participants' beliefs that helping others meets their own desire to help others is well corroborated in the literature (e.g., Bengtsson, 2003; Bolton, 2000; Dempsey & Arthur, 2002; Devereaux, 1984; Hasselkus & Dickie, 1994). For example, writing about the "exhilaration" of helping others in occupational therapy practice, (Devereaux, 1984) stated "The process of helping others helps one self: it is satisfying, therapeutic and curative" (p. 79). Gartner and Riessman (1993) further specified these benefits noting that if helpers feel they are playing an active and needed role in society, it can increase their social status, and can lead to feelings of empowerment and a sense of control (Gartner & Riessman, 1993). According to Schön (1991), professionals' desires and beliefs about relationships with clients can also be a source of meaning, self-education and renewal for the professionals themselves.

At a broader system level, the participants' personal beliefs about helping potentially conflict with the standards they are required to uphold. As employees of NSW disability services, they are held accountable to the Ninth NSW Disability Service Standard that is ideologically founded in a commitment to maintaining family relationships. In contrast, participants believed doing "whatever is needed" to ensure families keep their child at home was as much, if not more about the lack of alternative care options available as it was about the ideological importance of maintaining family relationships.

The *positive relationship* component evident in this study reflects the characteristics and value placed on relationships in both service policy documents and the literature.

Good relationships with families have been repeatedly associated with determining family needs and providing more responsive services (e.g., Beckman et al., 1996; McWilliam et al., 1998; Turnbull, Turnbull, Erwin, & Soodak, 2006, in press).

The characteristics of positive relationships described by participants fit neatly with those espoused in the literature. Parents of children with a disability have identified that helpful services involve professionals demonstrating a genuine interest in the child and family, sharing information with families, answering their questions and inviting the families' viewpoints (Baxter, 1989; McKenzie, 1994). Similarly, the qualities of open communication, non-judgemental approach, and respect identified by participants are consistent with attributes of family-centred practices and with the visions and values of the government departments that fund and provide disability services (Dunst, 2000; Hutchfield, 1999; McWilliam et al., 1998; NSW Department of Ageing Disability and Home Care, 2002b; NSW Department of Community Services, 2001c; Turnbull et al., 2000b).

Friendly relationships with families suggested by participants are also espoused in the literature (e.g., Allen & Potten, 1999; Clear, 1999; Katz & Scarpati, 1995; Lawlor & Mattingly, 1998; McWilliam, Tocci, & Sideris, 1997; Singer et al., 1989; Thompson, 1998). In an Australian study (Clear, 1996) noted that the personal quality of the relationship, where families feel professionals 'step outside' their professional self in a gesture of personal identification is a sign of a genuine, collaborative partnership between professional and parents.

Collaborating with colleagues as well as with families also appears in the literature as it did in this study under the component *working together*. Working together with colleagues is part of what (Clear, 1999) described as the 'caring culture' necessary to carry out caring practices with families of children with a disability. According to Munford and Sander's (1999) advice and questioning that resulted from working with colleagues prompted the reflective practices that best support families.

Actively including families as the most valued members of service teams is frequently found in the literature as a central component of practice (e.g., Bruder,

2000; Case-Smith, 1991; McWilliam et al., 1995; Viscardis, 1998). However, empirical studies suggest that families are often far from active, valued components of professional practice. Clear (1999) found that it was rare for parents' real interests to be heard by professionals. He argued that the disciplinary identification in professional processes devalued families' role in teams, because parents were neither expert professionals nor were they expected to know how to address the child's identified needs. Similarly, a Canadian study by MacKean et al. (2005) questioned the reality of collaborative working relationships with parents, suggesting in practice what often evolved was a transference of responsibility to parents rather than a true collaboration. The participants in this study clearly valued collaborative relationships with families, however the extent to which they were enacted could not be determined.

Individualised practice is identified as a central element of good practice with families in service policy, professional guidelines, empirical research and by the participants in this study (NSW Department of Ageing Disability and Home Care, 2002b; NSW Department of Community Services, 2001c). It is widely endorsed within the family-centred practice approach (Dunst, 2002; McWilliam et al., 1998; Summers et al., 2005; Trivette et al., 1996b).

Controversial however is the use of service plans. At a cultural level, participants focused on the value of services plans in individualising practice. In contrast, the literature focuses more directly on the types of plans and how they are differentiated (e.g., Bailey et al., 1992; Decker, 1992; Gallagher & Desimone, 1995; McWilliam et al., 1995; McWilliam et al., 1998).

The challenge appears to be how to individualise services that need to be provided on a 'mass quantity' basis and which are therefore often standardised and subject to the principles of managerialism and economic rationalism such as cost efficiency (Lawlor & Mattingly, 1998; Lipsky, 1980; Zebrack & Chesler, 2000). This challenge is shared by human service professionals in many studies (e.g., Katz & Scarpati, 1995; Lipsky, 1980; McWilliam et al., 1995; Zebrack & Chesler, 2000).

In the literature and practice guidelines, empowerment is often defined abstractly as an intangible vision or goal rather than a well-defined way to practice (Ackerson & Harrison, 2000; Bradley, 2000). In this study, participants talked about *empowering practice* empowerment as a goal of their work, however they also talked about what they did in their efforts to empower families. Specifically, they described their belief in the centrality of family control and decision-making, and the centrality of sharing information. These beliefs are consistent with the participatory helping practices associated with empowering philosophies in practice with families of children with a disability (Dempsey & Dunst, 2004; Dunst et al., 1996; Trivette et al., 1996b; Trivette, Dunst, & Hamby, 1996c). For example, parents have identified a greater sense of personal control and control over resources when professionals provide them with opportunities to be the key decision makers, and when parents and professionals collaborate to achieve family identified goals (Trivette et al., 1996c).

Participants' beliefs about *inclusive practice* reflect the changes in how inclusion has been perceived from being physically integrated to inclusion as a full member of the community (Bradley, 2000). Participants' actions and beliefs reflected attempts to combat barriers to inclusion identified in the literature including fear, lack of physical accessibility to programs and community, lack of opportunities for integrated social activities, and a lack of skills and knowledge in the community on disability and how to include families (Covert, 1992; Harbin et al., 2000).

The cultural component of practice as a *bandaid* demonstrates professionals' concern with the problems associated with obtaining needed services. The pervasiveness of this bandaid practice philosophy in Australia is suggested by similar findings by Kemp (2002). In a study of service use by people with disabilities Kemp (2002) found that to obtain services, people with disabilities needed to similarly emphasise their problems and difficulties. Kemp (2002) further argued that this meant that people with disabilities are pressured to conform to stereotype-based expectations of disabled people that are held by professionals and enforced by service structures. For participants in this study, this was reflected in their belief that families needed to present as being unable to cope with caring for their child at home in order to obtain services. This reinforces the negatively framed knowledge of caring for a child with

a disability that dominates the literature (e.g., Baine, McDonald, Wilgosh, & Mellon, 1993; Dyson, 1993; Herman & Marcenko, 1997; Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dulap, Robbins, & Plienis, 1992; Larson, 1998; Quine & Pahl, 1991).

Mediation is central in much of human service work. Zebrack et al. (2000), for example, studied mediation with childhood cancer survivors and suggested that there is a conflict of interest when serving in multiple roles: as an advocate for clients; mediator between clients and the system; and, a representative of the health care system. From a cultural perspective, Lawlor and Mattingly (1998) described professionals' dilemmas communicating within two cultures in family-centred paediatric occupational therapy services; the culture of biomedicine and family cultures. The conflict within the culture evident in this study is demonstrated, for example, by participants feeling that they should empower and motivate families to speak out and at the same time placate families through mediation. This latter conciliatory role was also identified in a Danish study with families of children with a disability (Bengtsson, 2003). In that study, it was the parents who identified professionals as conciliators between parents and the system; noting however that professionals were often not able to help families in this role to the extent they mistrusted information even when provided through a conciliatory caseworker.

Professionals have variously been labelled in human services literature as 'cultural bridges', 'cultural brokers' and mediators', describing their role as moving between the social world of their clients and that of the service system (Bengtsson, 2003; Hanlon, 2001; Weiner, 1991; Witkin & Harrison, 2001). A study by Hanlon (2001) differentiated between the 'brokering' and 'bridging' positions in professional practice. Buffering described professional practice as being bound by the organisation and its principles. Professionals essentially protected the organisation and their subsequent practices from challenges or change by confining their activities and justifications to those specifically tied to that organisation. On the other hand, bridging involves an extended sense of place where professional practices link them to and across different organisations and their guidelines. In the present study, regardless of whether participants were brokering within organisations or more

commonly bridging across the system, the valued component of mediation involved negotiating, interpreting and ‘peacekeeping’.

The ‘*it’s a business*’ cultural component revealed by this study reflects the challenges and difficulties associated with the business approach that are well documented in the literature (e.g., Ackerson & Harrison, 2000; Clear, 1999; Dunst & Bruder, 2002; Lawlor & Mattingly, 1998). Patterson and Hovey (2000) identified managed care and cost containment strategies as barriers to the overall implementation of family-centred care with children with special health care needs. Zebrack and Chesler (2000) focused specifically on how the managerialism and economic rationalism objectives diminished the value and importance of the therapeutic relationship that social workers build with families, because psychosocial support cannot be quantified within managerialism and economic rationalism objectives.

Several authors have explored the consequences of business-like reporting mechanisms for professionals and their practices. Lipsky (1980) argued that the reporting mechanisms employed by bureaucracies tend to shape the behaviour of workers to reflect the sanctions and incentives implicit in what is measured. This suggests that within these reporting and measuring procedures, the less measurable, but often more personally satisfying elements of practice such as building relationships with families, begins to diminish in the daily practice of professionals. The long term implications of this are highlighted in a narrative description of therapists’ lives by White (1997) who found that the formalisation of practice into discrete, measurable units led professionals to ‘thin’ descriptions and conclusions about the value of their work. His suggestion that this in turn leads to professionals feeling despair, fatigue and burnout which in turn contributes to high staff turnover has been corroborated in literature on turnover in the helping professions (Hall & Hall, 2002).

Participants’ specific concerns over the burden of excessive paperwork is corroborated in empirical studies from Australia (Litchfield & MacDougall, 2002) and the USA (Rothman, 1994), and is acknowledged as a concern by NSW DoCS

(NSW Department of Community Services, 2001d). Documenting a response to concerns in the human service sector about increased costs and reporting associated with accountability, the NSW DoCS stated a need to “... act to ensure we strike the balance between required accountability/reporting requirements and not overburdening service providers” (NSW Department of Community Services, 2001d, p. 27). It is unclear in these policy documents or from the participants in this study what achieving this balance would entail.

The cultural component of *objective practice* highlights the paradox between friendly, positive relationships with families at the same time as maintaining an objective professional distance. Clear (1999) suggested that parents understand this paradox however they appreciate those who personally identify with the family, viewing this as a sign of a genuine parent–professional partnership.

A study by Bolton (2000) provides some insight into the possibility of the co-existence of professional distance and a friendly relationship. They found that although nurses believed their emotional investments in their clients caused the most anxiety and stress in their work, this investment was also the greatest potential source of job satisfaction. Nurses therefore sought to maintain a professional demeanour but highly valued the freedom to emotionally invest beyond the ‘professional’ caring role.

Service policy documents demand that professionals impartially and objectively manage the distribution of limited time and service resources (NSW Department of Ageing Disability and Home Care, 2002b). Similarly, the importance of objectivity is reinforced by education in human services (Clear, 1999; Jones & May, 1992). Yet the likelihood that this contributes to what professionals believe is objective decisions and fair distribution of services is challenged in an Australian study on disability services (Kemp, 2002). Kemp found that decisions about service provision and distribution were more likely to favour clients who conformed to service criteria or professionals’ own expectations of what a ‘worthy’ recipient of services would be. In reality then, professionals’ decisions and actions are not necessarily objective or

fair, a statement supported by participants concerns about the bandaid approach described previously in Section 5.1.7.

5.3 Constructing and conveying the culture

The ten components of the culture of professional practice are conveyed, constructed and validated through professionals' interactions with others and participation in formal procedures or rituals, activities and the setting itself.

Participants' interactions with families informed their understanding of professional practice. For example, addressing the long-term service needs of many families contributes to developing friendly relationships with families where professionals become interested and invest in families' lives beyond their service needs.

Participants' interactions with colleagues and managers contributed to generating, reinforcing and conveying their understanding of culturally acceptable ways of working with families. Informally talking with colleagues, reasoning through decisions and sharing experiences and concerns, provided opportunities to negotiate shared understanding of practice.

Interactions around and participation in formal procedures or practice 'rituals' such as team meetings, case conferences, intake meetings and staff development or training sessions also contributed to participants' understanding of professional practice. For example, team meetings and case conferences provided a structure for interactions and working together with colleagues while workplace supervision structures managed and maintained the quality of services. Training sessions and team meetings often served as points where organisational policies and more tacit guidelines for practice were shared and discussed. For example, training sessions about legal issues highlight the importance of documentation and evidence, while the 'bandaid' nature of practice may have been constructed through intake meetings, case conferences and supervision sessions that convey pressure to work only with families in immediate crisis.

Organisational and system directives appeared to prompt formal and informal interactions and activities. These include legislative imperatives such as the Commonwealth and NSW State Disability Services Acts of 1986 and 1993 respectively; funding assessment packages (NSW Ageing and Disability Department, 1999, 2000a) and mission and value statements (e.g. NSW Department of Ageing Disability and Home Care, 2002b, 2003; NSW Department of Community Services, 2001c). Documents explicitly directed participants to the practices that are valued by 'the system'. As noted previously, for example, the Disability Service Standards and accompanying manuals directed professionals to maintain family relationships and encourage integration of people with disabilities and their families into mainstream communities.

Features of the setting itself also played a part in the construction of culturally acceptable ways of working with families. For example, the community-based location of services validates the importance of inclusion, while the place of the professional as a 'go-between' for families and the service system contributes to their understanding of their mediation role.

6 FAMILY-CENTRED APPROACHES AND THE CULTURAL UNDERSTANDING OF PROFESSIONAL PRACTICE

In this chapter, I consider how the new understanding of professional practice derived from this study relates to family-centred approaches as it is documented in the literature. Although the intent of this thesis was not to explore the implementation of family-centred approaches, the findings provide a framework for examining the realisation of this practice approach.

The chapter addresses two key points. The first, addressed in Section 6.1 is concerned with exploring how professionals, as illustrated by the participants in this study, have been acculturated to family-centred practice. The second, addressed in Section 6.2 is concerned with exploring how the culture of professional practice as explored in this study may provide new insight into the implementation of family-centred approaches in daily practice.

6.1 Family-centred approaches in professional practice

The culture of professional practice with families as illuminated in this study suggests that participants were acculturated to working with families in family-centred ways. Culturally acceptable practices as evident in five cultural components reflect features of the family-centred ideology as defined in a review paper by Dunst (2002). Specifically, treating families with dignity and respect is represented in *positive relationships*. Adopting individualised, flexible and responsive practices equates with *individualised* practices while sharing information so that families can be empowered to make informed decisions features in the *empowering* component. Engaging in parent–professional collaborations and partnerships is represented in *working together* and mobilising supports and resources necessary to support the child and family features in the *inclusion* component. More broadly, the ten

components are not dissimilar to features of family-centred cultures in early intervention studies in the USA (Katz & Scarpati, 1995; Law et al., 2003; McWilliam et al., 1998). For example, the value of a sound relationship between professionals and families as a foundation for other components of practice has been highlighted in these studies as in the *positive relationships* components in this study.

The similarity between the ten components and the literature suggests there has been a cultural shift towards more family-centred practices in at least one group of human service professionals in Australia. Earlier, Dunst and colleagues identified the slow filtering of family-centred principles from policy to practice level as a significant contributor to the implementation lag (Dunst et al., 1991). More recently, Bruder (2000) suggested professionals did not understand family-centred approaches. These studies however are not founded in Australian practice.

The findings from this study suggest that family-centred components of practice are being constructed and conveyed. Service policies, training and interactions with families were highlighted in participants' stories as conveying family-centred approaches. As indicated in Section 2.3, NSW service policies and procedures though not specifically using the term 'family-centred' reflect the features and intentions of this approach to working with families. For example, participants described multi-disciplinary team structures and policies endorsing service plans directing their attention to the importance of *working together* with other professionals and the family to meet child and family needs.

Many participants also described attending 'family-centred' in-service workshops where they discussed with colleagues and facilitators what this approach could or should mean in their daily practice. It is unclear from participants' stories to what extent, if any, their pre-service training contributed to their understanding or use of the family-centred approach. Hypothesising this contribution is complicated by the dearth of research on human service professional preparation programs in Australia. However international research suggests that such programs typically result in professionals' ill prepared to work in family-centred ways (Bailey et al., 1992; Bailey et al., 1991).

Participants valued the opportunity to build a relationship with families and work together, believing this to be the best source of information to ensure services are useful and utilised. This was particularly evident in the lament about reduced opportunities to interact directly with children and families occasioned by the policy shift to consultancy services. Families themselves contributed to socialising professionals to more family-centred principles by, for example, working together with professionals and requesting and demanding information and responsibility for decision making in service delivery.

Despite the cultural understanding of family-centred approaches evident in this study, acculturation to other practice approaches was also evident. Participants also distinguished their work with families as ‘professional’. The ‘professional’ components reflect a business oriented and a traditional medical approach to practice.

6.2 Realising family-centred approaches in practice

There is strong representation in the literature of inconsistent actualisation of family-centred principles in practice (see, for example, Bailey et al., 1992; Dunst, 2002; Mahoney, O'Sullivan, & Dennebaum, 1990; McWilliam et al., 1999; Sokoly & Dokecki, 1992; Wolery et al., 1997). The findings from this study however challenge suggestions such as those made by Bruder (2000) that professionals do not understand family-centred principles.

Rather, the cultural understanding of professional practice gained from this study suggests there are obstacles or roadblocks to substantiating family-centred approaches in daily practice. Identifying and understanding these obstacles within a cultural framework potentially opens avenues for professionals to employ family-centred approaches.

In this section I outline the barriers to the implementation of family-centred approaches. First, by discussing the business-oriented and traditional features in the

cultural understanding of professional practice. Second, I discuss competing philosophies within this cultural world and the implications for implementing family-centred practice. Third, I consider the implications of the cultural core narratives for understanding family-centred practices.

The ‘professional’ elements of the cultural understanding of professional reflect both traditional medically framed practices as well as the systemic shift toward managerialism and economic rationalism. The latter included *helping* as a routine, sequential process of service entry, prioritising, assessment, planning, provision and evaluation; and the *business* of managing the quality of services through, accountability for funding, clinical decisions and resources with a need to meet and contain the cost of providing services. In their cultural world as depicted in this study, professionals also remain socialised to a more traditional medical approach. That is, believing direct interaction between the therapist and client is superior along with maintaining a professional distance from the client.

The existence of competing acceptable practices within the professionals’ cultural world suggests family-centred approaches will continue to be challenged by embedded or more strongly imposed principles guiding practice. Participants explained and legitimised practices that were not family-centred by referring to these competing, though still culturally acceptable ways of working with families. For example, one participant’s story interprets the bandaid approach as justified when there is little time and therefore this approach is not working to empower families or their communities. Another participant’s story explained his practice of working only with the child by reference to the inter-dependence of helping the child and family. In other words, he was helping the family by helping the child despite the lack of family involvement. In both these examples, culturally acceptable ways of working with families were employed to justify not implementing more family-centred principles.

Cultural components reflecting non family-centred ways of working were explained by imposed policy and procedures particularly those reflecting managerial and economic rationalisation. Professionals were provided with detailed operationalised

processes about how they ought to work, including, for example, intake and discharge procedures, and collection of service type statistics. Professionals were held accountable to these processes. Issues such as service accreditation, employment opportunities and service funding were often contingent on complying and accountability to these policies and practices. For example, organisations and their professional employees are accountable under the Disability Services Act (NSW) and the Disability Service Standards by the process of DADHC assessments and audits for ongoing funding and accreditation (NSW Ageing and Disability Department, 1998, 1999, 2000a).

Competing with imposed processes constraints, the family-centred principles usually considered 'best practice' and evident in service system policies did not have a similar accountability function (e.g., New South Wales International Year of the Family Secretariat, 1994; NSW Ageing and Disability Department, 1998; NSW Department of Ageing Disability and Home Care, 2002a, 2002b; NSW Department of Community Services, 1996, 2001c). The question remains: would operationalising family-centred principles in policies and procedures facilitate implementation? For example, one participant suggested that detailing processes involved such as information provision and building relationships may help validate the value of empowerment within existing calls for accountability.

Developing more family-centred policies and procedures may not necessarily lead to working in family-centred ways. A pertinent example comes from the findings in relation to service plans as a tool for individualising practice. Services plans theoretically offer structures for professionals to provide individualised and collaboratively developed support to families. However participants understood that implementation of service plans involved processing families in a routine and standardised manner. One example of accountability that was given was that a parent could sit through a service plan meeting, the 'box' for family involvement could then be 'ticked'. There was no consideration given to the extent to which families were involved, included or empowered in this process. Similarly, Katz and Scarpati (1995) found no shared understanding of the IFSP process and thus, no corresponding cultural shift in the early intervention culture.

The cultural core narratives of professional practice identified in this study provide insight into the cultural world of current professional practice for human service professionals. Returning to the conceptual framework for the study, Bruner (1990a) believes that acts and points of view can change reality. That is, if enough people want something to happen, then it will most likely happen. The implications of this belief are that if enough professionals adopt narratives in that support family-centred principles, then more family-centred principles will become substantiated in practice. Conversely, if a commitment to the more traditional practice elements is retained in the narratives adopted, these will remain substantiated in daily practice.

This Brunerian perspective suggests that, to acculturate, implement and substantiate family-centred principles as pre-eminent in practice with families will require: (i) support to professionals to achieve their family-centred desires, (ii) re-training or re-acculturation to minimise the impact of the embedded traditional medical approach; and (iii) reorientation of service policies and procedures to legitimise equally business rationalisation approaches with family-centred approaches, requiring equal accountability mechanisms to support equal validity.

The narratives also highlight the importance of professionals developing a vision of how they can help families in family-centred ways within the existing context. Professionals employed helping as their primary interpretive framework. When an individual could not envision how to help families by employing a family-centred approach, then they adopted a narrative to reflect their stance as supporting or undermining this approach. The understanding of family-centred ways of working by professionals in this study suggests they are ideally primed to change their cultural world to reflect, in far greater proportion, the ideal components of the family-centred approach espoused in the literature.

In sum, the culturally framed understanding of professional practice with families derived in this study identifies roadblocks along the path toward family-centred approaches in daily practice. In particular, the cultural shift towards accountability in managed care was highlighted as posing a practical barrier to family-centred services

in practice. At a more theoretical level, competing philosophies within the professionals' cultural world were also identified as a barrier to family-centred practice. Finally, cultural core narratives were identified as a means through which family-centred practice could be affirmed or undermined.

7 SUMMARY AND CONCLUSIONS

7.1 The study in review

In this study I investigated the nature of professional practice with families of children with a disability from the perspective of human service professionals in NSW, Australia. My overall purpose and intention in examining professional practice with families from a cultural perspective was to expose the cultural world in which professionals think and act.

This study took an investigative approach to exploring and understanding the world in which professionals live and make decisions about their practice with families as suggested by several authors (e.g., Ahmann & Johnson, 2000; Bengtsson, 2003; Bruder, 2000; Katz & Scarpati, 1995; Lawlor & Mattingly, 1998; Mattingly et al., 1997).

Jerome Bruner's writings on cultural psychology were used to frame this study. In line with Bruner's concepts of narrative mode of thought and narrative mode of culture, I assumed the narratives professionals related, provided access to what they thought, felt and did in their daily practice and what they understood to be culturally acceptable ways of working with families. I employed narrative methods of data collection and analysis to gather and interpret these stories. Four conceptual cultural core narratives that described and explained professionals' work practices were identified through narrative analysis. Analysis of narratives was employed to identify ten cultural components that comprise this culture of professional practice with families.

Identifying, exposing and naming the dimensions of professional practice with families provides insight into what forms, and in turn is informed by professionals' daily work practices. It provides a framework for reappraising the family-centred approach that literature and policy promote. This study has implications for

designing human service policy and management practices, professional education, and professional practice. Before exploring these, I offer some reflections on the research process.

7.2 Reflections on the research process

Much has been written on the importance of recording and acknowledging personal reflections in the research process (Chenail, 1995; Koch, 1998; Merriam, 1988; Minichiello et al., 1999). I have already described how my early reflections led to the reconceptualisation of this study framed within a Brunerian cultural psychology framework. I now add my reflections on completing this study, with particular reference to the narrative data collection and analysis process and the implications of the Brunerian cultural conceptual framework.

Overall, participants appeared to value the storytelling approach to data collection. Despite busy schedules, many reported feeling happy and even grateful for the opportunity to ‘tell the stories’ of their experiences around practice with families. The significance of this becomes more evident when realising that participants were rarely consulted or represented in the government or organisational policies and procedures. Despite participants’ readiness to share their stories, several challenges emerged during data collection.

My own experiences as an occupational therapist with families of children with a disability posed some challenges. Participants occasionally assumed I had some familiarity with situations they described, essentially considering me to be a part of, in Brunerian terms, their cultural community. There were advantages and disadvantages to this assumed familiarity. Viewing me as a colleague seemed to make conversation free flowing and open. Assuming I had some understanding, stories were seemingly less interrupted by the need to explain or a fear of judgement of the actions the stories portrayed. Participants readily shared stories, perhaps surprising given the somewhat clandestine nature of the *making it work* narrative and

the sense of quiet despondency that characterised the *hopeless struggle* narrative. The assumed familiarity and understanding may have contributed to this.

As a researcher, my challenge was to vigilantly check rather than assume participants' meanings of the various situations and terms they described. Though I may have had my own knowledge or experience, my task was to identify and interpret their understanding of these situations and terms. The strategy I employed in walking this 'tightrope' was to prompt participants to further explain terms and situations irrespective of my prior knowledge.

Despite the readiness with which participants shared their stories, it is likely that participants did at times 'check' or control the narrative they shared in interviews and in focus groups. Issues including for example, the depth or honesty of the relationship with other focus group participants, the presence of more senior clinicians, or the fear of being identified from the interview text could have influenced the stories told. This probable curbing of the stories shared publicly amongst members of the social or cultural community is well acknowledged in the literature (e.g., Chase, 2005; Guba & Lincoln, 2005; Gubrium & Holstein, 1998). I feel confident however that the joint focus groups and individual interview techniques employed for collecting stories in this study, while having limitations (detailed in Section 3.5.1.1), captured the range of community level narratives that existed.

A major challenge in narrative inquiry involves capturing the meaning in the data (Goodfellow, 1997; Koch, 1998; Riessman, 1993). Narratives researchers suggest that meaning and interpretation can lie not just with dialogue but also in other features including the cultural, social and institutional context and features of the conversations such as gestures, silences, and interjections (e.g., Chase, 2005; Riessman, 1993). On reflection, while I acknowledged and prepared for these more conversational elements in data collection, I did not truly appreciate it until I was in the throes of narrative analysis. Reading transcribed dialogue where the individual said "so of course, I happily trot off to all the IEP meetings" implies the individual did indeed go as expected to each meeting. However a transcript that noted the

sarcasm in her voice and the exaggerated ‘wink’ as she said this relayed a different action and meaning. It conveyed she did not go or intend to go to the IEP meeting for every child on her caseload. Rather, she selectively attended, but wanted others to think she was going as expected. This type of feature of the conversation helped distinguish the ‘under the radar’ type actions and intentions of the *making it work* narrative from a *making the best of it* narrative, where professionals were more inclined to do what they felt was expected of them.

Despite my best efforts to record these non-dialogue features, capturing all gestures with only an audiotape presents a challenge. There are times when, for example, I was caught up in the conversation and did not note the counter number on the audio recorder next to my field note comments. I relied on my memory to locate these field notes in the appropriate stories. Now sitting on ‘the other side’ of a narrative inquiry, I suspect that an audiovisual record would be a simpler and more accurate record for data collection and analysis.

Data analysis in this study involved a challenging movement between what Bruner terms paradigmatic and narrative thinking. The analysis of narratives method employed to inductively derive the cultural components from professionals’ stories challenged me to avoid presuppositions contained in the research literature and concentrate on drawing the units of meaning from the data. The shared meanings, or ten components of the culture of professional practice do not of course predict professionals practice, nor do they necessarily reflect the personal intentions and beliefs of individual practitioners about how they would like to work with families. This is strongly supported by the variations in how professionals’ instantiate these components in daily practice as exposed by the four cultural core narratives. This, I believe, adds weight to Bruner’s (1996a) assertion that the use of narrative and paradigmatic thinking assists more beyond prediction to understanding.

The Brunerian cultural psychological framework and the narrative methods provided a valuable means to illuminate the ‘hidden’ cultural world of practice with families. Essentially, professional practice with families was exposed as narrative. That is, within the narrative mode of culture, culturally appropriate practices were conveyed

in the stories professionals told in and about their practice. Professionals employed cultural core narratives to help make their daily work practices understandable within this cultural context.

Mattingly and colleagues (1997) also described practice as narrative, or the playing out of stories. In their view, practice is considered an interaction between the professional and the client, rather than the simple employment of technical skills such as assessing a child's joint range of motion or the family home for wheelchair access. The 'story' of an interaction with a client forms part of the broader life story of that client. The findings in my study I believe build and expand on this notion of practice as narrative. From my perspective, professional practice with families becomes a culturally negotiated phenomenon, where the meanings of practice are learned and negotiated through the stories professionals tell in their interactions with families, colleagues and managers, and through participation in, for example, procedures such as team meetings and service plans. Each story potentially forms part of the personal narrative of the professional, the family and the others with whom they interact.

7.3 The relevance of this cultural world to other circumstances

The question is: can the cultural world of professionals working with families of children with a disability in Sydney, Australia reflect the cultural world of other settings? For example, there are shared elements of this cultural interpretation across disciplines, geography, client groups, and program types. In this section I hypothesise the robustness of the cultural interpretation of practice identified in this study.

When considered in the context of the literature, the cultural interpretation of professional practice with families identified in this study appears remarkably robust. As noted in Section 6.1, the three previous cultural interpretations of practice with families that I am aware of are echoed in professionals' practice with families (Katz & Scarpati, 1995; Law et al., 2003; McWilliam et al., 1998). However, these cultural

interpretations did not consider the broader practice context. To consider the proposed strength of the broader conceptualisation of professional practice requires consideration of the literature more generally. The prevalence of concerns about the more business-like elements of practice and the continued experience of traditional medically framed practices is reported across varied settings, professions and countries, therefore suggesting robustness of the broader conceptualisation of professional practice identified in this study.

Two explanations are hypothesised for the potential robustness of this cultural interpretation in other settings: shared systemic conditions and ideologies and similar professional preparation programs. The conditions and ideologies prevalent in the culture of professional practice with families are global issues. Service systems worldwide, under persistent fiscal and regulatory pressures and within economic rationalism, have introduced private sector management techniques into public health and human services (Baum, 1998; Higgs et al., 1999). Similarly, the shifts from traditional medical and scientifically driven practices towards normalisation of experience for people with a disability and the subsequent introduction of more client or family-centred practices is well documented, particularly across Europe, North America and Australia (Bradley, 2000; Cummins & Baxter, 1997; Wolfensberger, 1983). Professionals, at least in the developed world, are therefore constructing the shared meaning of their practice amidst the same basic conditions and ideologies. Though as Bruner (1996b) suggests, the mode of discourse employed to construct meaning may vary in different contexts, the meaning constructed and transmitted is remarkable similar in this instance.

To the best of my knowledge, no study until now has identified narratives describing professionals' daily work practice with families. How these narratives hold true across other practices and contexts therefore requires further investigation. If one assumes, based on the arguments above that the cultural context of practice remains more or less similar across settings, then it is possible that the cultural core narratives also hold true. What may vary however are the circumstances and settings that inform how professionals adopt these narratives in their daily practice. For example, a rural therapist or sole therapist may have fewer opportunities to interact with

colleagues and managers and therefore, by circumstances, be more inclined to adopt the solo-oriented *having to fight* or *hopeless struggle* narratives.

In sum, while the potential robustness of the cultural understanding of professional practice identified in this study is hypothesised here, further research is needed to investigate its relevance in other settings, place, time and geographical location.

7.4 Recommendations

7.4.1 Education

Professional preparation programs need to help professionals to develop skills and knowledge to work with families and communities in collaborative, individualised, empowering and inclusive ways, and to identify and manage challenges to their implementation if family-centred approaches are to be firmly embedded in the cultural world of professional practice. Family involvement in the planning, implementation and evaluation of pre-service and in-service training for professionals is increasingly endorsed as a means of supporting the development of these skills (see, for example, Itzhaky & Schwartz, 2000; Jivanjee & Friesen, 1997; Niemeyer & Proctor, 1995; Turnbull, Blue-Banning, Turbiville, & Park, 2000a; Whitehead et al., 1998). Education programs that encompass practical activities and opportunities to interact directly with families or participate in family-informed curricula present opportunities for professionals to develop and refine skills in, for example, building collaborative relationships with families. Niemeyer and Proctor (1995) add that this also helps professionals develop insight into the family and community context in which interventions are situated, thus potentially contributing to designing more responsive and effective support for families.

As a requirement of the respective professional bodies, most professional preparations programs for human services professionals encompass a practical or fieldwork component (Gardner & McCoppin, 1995). Fieldwork placements where students and professionals are placed with families provide practical opportunities to

develop skills and confidence to build relationships and work together with families of children with a disability to empower and include them in mainstream community life. Families have indicated their support for and belief in the value of professionals undertaking fieldwork placements with them in order to develop their communication skills and understanding of children and family needs (Niemeyer & Proctor, 1995).

The cultural component of *working together* also highlighted the importance of professionals developing skills in inter-disciplinary collaboration. Doing so requires, for example, inter-disciplinary units of study to become integral parts of university curricula and service-based continuing professional development opportunities to be provided around interdisciplinary teams. According to Jivanjee and Friesen (1997), incorporating inter-disciplinary components into pre-service and in-service training provides practical opportunities for professionals to develop these skills and build professional networks for sharing expertise and information. Team learning is also a critical part of the lifelong learning communities that Bruder (2000) argues are necessary to effectively prepare professionals to work with families.

Professional preparation programs must play a role in acculturating professionals to their roles and responsibilities within a managerial and economic rationalist service context and by association, supporting professionals in finding meaning in and a vision for helping families within this context. Higgs and Hunt (1999) suggests that preparation programs must groom professionals for interactions with the political, economic and social responsibilities and issues in practice. In a shift from curricula typically centred on treatment oriented clinical competencies, programs must include components that ready professionals for tasks such as accessing and accounting for funding, advocating and lobbying government and others with and on behalf of families and case management responsibilities.

7.4.2 Policy and practice

In addition to educating professionals on working with families, the service context, including policies and procedures, must support the application and development of

skills for working with families in more empowering, individualised, inclusive and collaborative ways to achieve the desired policy imperatives of family-centredness.

As noted in Section 2.1.2, in NSW service agencies receiving government funding are currently accountable via the NSW Disability Service Standards and the NSW Disability Services Act (1993) to provide empowering, individualised, inclusive and collaborative services with families of children with a disability (NSW Ageing and Disability Department, 1998, 1999, 2000a). Though guided by these standards, professionals such as the participants in this study are not directly accountable to these standards in their daily practice. As the current Standards In Action Manual notes, policies are not operationalised in such a way as to provide a checklist for professionals and agencies to inform full conformity with the Standards (NSW Ageing and Disability Department, 1998).

Extending and applying the Disability Service Standards as a framework for performance management and performance indicators for human service professionals would contribute to measuring and thereby valuing and reinforcing the application of the more process-oriented elements of working with families. Consider for example, the Fifth Disability Service Standard – Participation and Integration. Section 5.2 of this Standard states that “Services are provided in a way that facilitates the integration and participation of the each person with a disability in the community, at times and in ways similar to other members of society” (NSW Ageing and Disability Department, 1998, p. 4–5). Measures need to be developed that can operationalise and measure how professionals provide these services.

Participants in this study were often socialised to working with families through their interactions with colleagues and managers. They valued these interactions believing they helped develop and refine their skills, knowledge and commitment to working with families. Munford and Sanders (1999) also suggested service structures that support opportunities for interaction with colleagues enhances the quality of support for families by prompting reflective practice and building peer support networks. These findings challenge managers to provide opportunities for professionals to interact formally and informally with colleagues, managers and more experienced

clinicians. Ensuring space and time for more informal interactions can be facilitated by, for example, ensuring staff have ready access to a meeting or staff room, and may also be promoted by shared office space. Policies and procedures that direct more formal interactions, such as programming regular team meetings and supervision sessions could also facilitate this interaction. Within these sessions, managers and senior clinicians have opportunities to support professionals in developing an appreciation of how they can help families by minimising professional-centred, direct-therapy practices and including more family-centred approaches within emerging roles such as case managers. Supervision also needs to go beyond a typical focus on clinical competencies, to support elements of practice common to all human service professionals working with families, such as negotiating demands for accountability in the wider service context.

Literature suggests that reflection is integral to quality services in the health professions and specifically to practice with families (Mattingly, 1991; Munford & Sanders, 1999; Schön, 1991). Employing Brunerian terms, the understanding of professional practice in this study could be used in supervision sessions or informally as a 'cultural tool kit' to promote reflection on practice by members of this cultural community. This cultural tool kit could be used to facilitate awareness of individual active roles in constructing, sustaining or potentially transforming their practice culture. Critical reflection on the cultural components requires professionals to consider if and how this culture enables them to help families. Reflection on the cultural core narratives could provide a frame to individual practitioners to reflect on the narratives they adopt and how they contribute to supporting or undermining particular expectations of their practice. Finally, by identifying patterns in the narratives adopted, individuals and service managers can potentially identify and act on issues like burnout that have serious implications for the professionals and the families they serve.

Finally, within service policies and conditions demanding accountability, there is a need to expand existing accountability measures to encompass the process-oriented, social, relational and participatory elements of professional practice with families, such as measuring the relational processes involved as well as the outcomes of

empowering families and communities. Doing so requires further research as outlined below.

7.4.3 Future research

In this section, I put forward some key areas for further investigation arising from this study that examined how professionals interpreted and enacted the diverse and contextual concept of professional practice. Specifically, I recommend examining the cross-cultural relevance of these findings, exploring other key perspectives within this cultural community, and examining the implications of this cultural world for professionals and the institutional structures supporting it.

Further exploration of the cross-cultural validity of the cultural world of professional practice identified in this study is needed. The question of whether other cultural communities representing, for example, professionals representing different settings or levels of managerial responsibility, different client groups or from different geographical locations warrants further investigation within a similar cultural framework. The cross-cultural weight of professionals' cultural world would further focus on how professionals are acculturated to and prepared for movement between, for example, settings and professional specialties or shifts into more senior management or supervisor roles.

NSW human service professionals' stories, including their experiences and interactions with families were the focus of the cultural study outlined in this thesis. The cultural understanding of professional practice with families subsequently derived provides only one part of the puzzle. Understanding how professional practice informs and is informed by others involved in the service system potentially provides insight into pathways for change. Two perspectives thought to be critical are considered below: that of families and of educators involved in human service preparation programs.

The family perspective, in an era where family-centred practices ideally provide a structure for quality services, is fundamental. Research that examines the meaning,

values, beliefs and assumptions that families hold about the cultural world of professional practice is needed. Consider for example, parents much reported desire for direct therapy services for the child with a disability (e.g., McWilliam et al., 1995; Thompson, 1998; Wehman & Gilkerson, 1999). Given participants in this study shared this belief, it is possible that professionals contribute to socialising families to this and other beliefs and expectations about services. This in turn has implications for families, for example, when a reduction in direct therapy services through case management and consultative practices leaves families concerned about the loss of a direct service adversely effects their child's development. Culturally framed research into families' understanding of, and actions in professional practice could provide a foundation for critically examining use and expectations of services. This in turn has implications for how services are designed and promoted to families. To date, family perceptions of services have predominately explored parent satisfaction with and use of services and in more paradigmatic ways focused on prediction.

Research into how human service professional preparation programs contribute to socialising beginning practitioners to the cultural world of professional practice with families is also needed. What beliefs, values and assumptions do, academics, for example, hold about practice with families, or the program managers responsible for coordinating the ongoing professional development and support of their staff? How then do their culturally situated actions contribute to sustaining these expectations of practice and socialising human service professionals to work with families? Similarly, how do service managers and policymakers understand professional practice with families and how does this contribute to their actions and interactions with human service professionals? Research of this nature may uncover pathways that contribute to, for example, the persistence of traditional child-focused practices or conversely pathways opening up possibilities for family-centred approaches.

Developing empirically grounded institutional processes that legitimise both family-centred and business-like principles is timely. This includes identifying mechanisms to operationalise, measure and account for the seemingly less measurable elements such as empowerment and for the processes involved in, for example, case

management or empowering mainstream community services. Framed within the NSW Disability Service Standards, which already hold agencies accountable, research that seeks to operationalise these standards at a practice level potentially could provide a framework for performance indicators.

Research exploring how the cultural core narratives identified in this study are developed, maintained or potentially altered over time is also needed. This study provided a point of time reference to a cultural world and the cultural core narratives contained within. This could also involve critical reflection on the narratives that professionals live out and how these may be sustained by, for example, institutions like universities and the service organisations that prepare and employ human service professionals to work with families. Research of this nature would provide a framework for renewed consideration of issues known to inform experiences of both providing and receiving quality services for families of children with a disability. For example, feelings of despair, fatigue and burnout contribute to high turnover in helping professionals' professions (Hall & Hall, 2002), which in turn influence the nature and quality of families experiences of and satisfaction with services (Thompson, 1998). Identifying, for example, what practices and processes contribute to adoption and sustaining over time *hopeless struggle* narratives could point to either system or individual determinants or a combination of both, which, if appropriately counteracted, could remove the potential for burnout and lack of service efficacy.

7.5 Final words

This thesis began with my family's story of their interactions with professionals around my own health and development as a child. That story was the start of my own journey – attempting to understand what influences professionals' thoughts, actions and interactions with families of children with a disability. This thesis marks a critical point along that continuing journey.

And so the journey continues. These findings challenge me, amongst others, to use this new understanding of professional practices as a foundation to critically appraise and potentially transform existing practices, as we strive to construct a cultural reality that better supports the health and development of children and families in the future.

REFERENCES

- Abbot, D., Townsley, R., & Watson, D. (2005). Multi-agency working in services for disabled children: What impact does it have on professionals? *Health and Social Care in the Community*, *13*(2), 155–163.
- Ackerson, B. J., & Harrison, W. D. (2000). Practitioners' perceptions of empowerment. *Families in Society: The Journal of Contemporary Human Services*, *81*(3), 238–244.
- Agosta, J., & Melda, K. (1995). Supporting families who provide care at home for children with disabilities (Families of children and adolescents with special needs). *Exceptional Children*, *62*(3), 271–283.
- Ahmann, E., & Johnson, B. (2000). Family-centred care: Facing the new millennium. *Paediatric Nursing*, *26*(1).
- Allen, J., & Potten, J. (1999). Quality in the provision of family support services. *National Child Protection Clearing House Newsletter*, *7*(1), 1–4.
- Allen, R. I., & Petr, C. G. (1998). Rethinking family-centred practice. *American Journal of Orthopsychiatry*, *68*(1), 4–15.
- Amsterdam, A. G., & Bruner, J. (2000). *Minding the law*. Cambridge, Mass: Harvard University Press.
- Australian Institute of Family Studies. (1994). *New South Wales facts on families*. Sydney, NSW: Social Policy Directorate.
- Bailey, D. B., Buysse, V., Edmondson, R., & Smith, T. M. (1992). Creating family-centred services in early intervention: Perceptions of professionals in four states. *Exceptional Children*, *58*(4), 298–309.
- Bailey, D. B., Palsha, S. A., & Simeonsson, R. J. (1991). Professional skills, concerns, and perceived importance of work with families in early intervention. *Exceptional Children*, *58*(2), 156–165.
- Bailey, D. B., Simeonsson, R. J., Yoder, D., & Huntington, G. S. (1990). Infant personnel preparation across eight disciplines: An integrative analysis. *Exceptional Children*, *57*, 26–35.
- Baine, D., McDonald, L., Wilgosh, L., & Mellon, S. (1993). Stress experiences by families of older adolescents or young adults with severe disability. *Australia*

- and *New Zealand Journal of Developmental Disabilities*, 18(3), 177–188.
- Baum, F. (1998). *The new public health: An Australian perspective*. Melbourne: Oxford University Press.
- Baxter, C. (1989). Parent-perceived attitudes of professionals: Failure of professionals to meet family needs. *Disability, Handicap and Society*, 10, 127–140.
- Bazyk, S. (1989). Changes in attitudes and beliefs regarding parent participation and home programs: An update. *American Journal of Occupational Therapy*, 43(723–728).
- Beach Centre on Disability. (2005). *Beach Centre Family Quality of Life Scale User's Manual*. Lawrence, Kansas: University of Kansas.
- Beckman, P. J., Frank, N., & Newcomb, S. (1996). Qualities and skills for communicating with families. In P. J. Beckman (Ed.), *Strategies for working with families of young children with disabilities* (pp. 31–47). Baltimore: Paul H. Brookes.
- Bengtsson, S. (2003). Overcoming goal displacement in social service provision. *Scandinavian Journal of Disability Research (SJDR)*, 5(3), 262–280.
- Bernheimer, L. P., Gallimore, R., & Weisner, T. S. (1990). Ecocultural theory as a context for the Individual Family Service Plan. *Journal of Early Intervention*, 14(3), 219–233.
- Bolton, S. C. (2000). Who cares? Offering emotion work as a ‘gift’ in the nursing labour process. *Journal of Advanced Nursing*, 32(3), 580–586.
- Bradley, V. J. (1992). Overview of the family support movement. In V. J. Bradley, J. Knoll & J. M. Agosta (Eds.), *Emerging issues in family support* (Vol. 18, pp. 1–8). Washington, DC: American Association on Mental Retardation.
- Bradley, V. J. (2000). Changes in services and supports for people with developmental disabilities: New changes to established practice. *Health and Social Work*, 25(3), 191–200.
- Brown, M. H., & Kreps, G. L. (1993). Narrative analysis and organisational development. In S. L. Herndon & G. L. Kreps (Eds.), *Qualitative research: Applications in organisational communication* (pp. 47–61). New Jersey: Hampton Press, Inc.
- Bruder, M. B. (2000). Family-centered early intervention: Clarifying our values for

- the new millennium. *Topics in Early Childhood Special Education*, 20(2), 105–116, 122.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, Massachusetts: Harvard University Press.
- Bruner, J. (1990a). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Bruner, J. (1991). The narrative construction of reality. *Critical Inquiry*, 18, 1–21.
- Bruner, J. (1996a). Frames for thinking: Ways of making meaning. In D. R. Olson & N. Torrance (Eds.), *Modes of thought: Explorations in culture and cognition*. (pp. 93–105). New York, NY, USA: Cambridge University Press.
- Bruner, J. (1997). A narrative model of self-construction. In J. G. Snodgrass & R. L. Thompson (Eds.), *The self across psychology: Self-recognition, self-awareness, and the self concept*. *Annals of the New York Academy of Sciences*, Vol. 818. (pp. 145–161). New York, NY, USA: New York Academy of Sciences.
- Bruner, J., & Kalmar, D. A. (1998). Narrative and metanarrative in the construction of Self. In M. D. Ferrari & R. J. Sternberg (Eds.), *Self-awareness: Its nature and development*. (pp. 308–331). New York, NY, USA: The Guilford Press.
- Bruner, J. S. (1990b). Culture and human development: A new look. *Human Development*, 33(6), 344–355.
- Bruner, J. S. (1996b). *The culture of education*. Cambridge, MA, USA: Harvard University Press.
- Burke, K. (1945). *The grammar of motives*. New York: Prentice Hall.
- Case-Smith, J. (1991). The family perspective. In N. Dunn (Ed.), *Paediatric occupational therapy practice: Facilitating effective service provision* (pp. 319–331). Thorofare, New Jersey: Slack.
- Chase, S. E. (2005). Narrative inquiry: Multiple lenses, approaches, voices. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks: SAGE Publications.
- Chenail, R. J. (1995). Presenting qualitative data. *The Qualitative Report*, 2(3), 1–7.
- Chiarello, L., Effgen, S., & Levinson, M. (1992). Parent–professional partnership in evaluation and development of individualized family service plans. *Paediatric Physical Therapy*, 4(2), 64–69.
- Children and Young Persons (Care and Protection) Act (NSW), (1998).

- Clear, M. (1996). *Public policy, personal reality: Disablement and a research for caring culture*. Unpublished doctoral, University of Western Sydney, Hawkesbury, Richmond.
- Clear, M. (1999). Caring culture and the politics of parent/professional relations. *Australian Journal of Social Issues*, 34, 119–129.
- Covert, S. B. (1992). Supporting families. In J. Nisbet (Ed.), *Natural supports in school, at work, and in the community for people with severe disabilities* (pp. 121–163). Baltimore, Maryland: Paul H. Brookes, Publishing Co.
- Cummins, R. A., & Baxter, C. (1997). The influence of disability and service delivery on quality of life within families. *International Journal of Practical Approaches to Disability*, 21(3), 2–8.
- Deal, A., Dunst, C. J., & Trivette, C. M. (1989). A flexible and functional approach to developing individualised family service plans. *Infants and Young Children*, 1, 32–43.
- Decker, B. (1992). A comparison of the individualized education plan and the individualized family service plan. *American Journal of Occupational Therapy*, 46(3), 247–252.
- Dempsey, I., & Arthur, M. (2002). Support staff in a sample of Australian community-based services for people with a disability: Career intentions, personal characteristics and professional development needs. *Journal of Intellectual and Developmental Disability*, 27(3), 2001–2214.
- Dempsey, I., & Dunst, C. J. (2004). Helpgiving styles and parent empowerment in families with a young child with a disability. *Journal of Intellectual and Developmental Disability*, 29(1), 40–51.
- Devereaux, E. B. (1984). Occupational therapy's challenge: The caring relationships. *American Journal of Occupational Therapy*, 38(12), 791–978.
- Dinnebeil, L. A., Hale, L., & Rule, S. (1999). Early intervention program practices that support collaboration. *Topics in Early Childhood Special Education*, 19(4), 225–235.
- Disability Services Act (Cwth), (1986).
- Disability Services Act (NSW), (1993).
- Donnellan, A. M., & Mirenda, P. L. (1984). Issues related to professional involvement with families of individuals with autism and other severe

- handicaps. *Journal of the Association for Persons with Severe Handicaps*, 9 (Spring), 16– 25.
- Dunst, C. J. (1990). Family support principles: Checklists for program builders and practitioners. In *Family systems intervention monograph* (Vol. 2, No. 5). Morganton, North Carolina: Family, Infant and Preschool Program, Western Carolina Centre.
- Dunst, C. J. (2000). Revisiting “rethinking early intervention”. *Topics in Early Childhood Special Education*, 20(2), 95–104.
- Dunst, C. J. (2002). Family-centered practices: Birth through high school. *Journal of Special Education*, 36(3), 139–147.
- Dunst, C. J., & Bruder, M. B. (2002). Valued outcomes of service coordination, early intervention, and natural environments. *Exceptional Children*, 68(3), 361–375.
- Dunst, C. J., Johanson, C., Trivette, C. M., & Hamby, D. (1991). Family oriented early intervention policies and practices: Family-centred or not? *Exceptional Children*, 58(2), 115–121.
- Dunst, C. J., & Trivette, C. M. (1996). Empowering, effective helpgiving practices and family-centred care. *Pediatric Nursing*, 22(4), 334–343.
- Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering families*. Cambridge, MA: Brookline.
- Dunst, C. J., Trivette, C. M., Gordon, N. J., & Starnes, A. L. (1993). Family-centred case management practices: Characteristics and consequences. In G. H. S. Singer & L. E. Powers (Eds.), *Families, disability and empowerment: Active coping skills and strategies for family interventions* (pp. 89–118). Baltimore, Maryland: Paul H. Brookes.
- Dunst, C. J., Trivette, C. M., & Hamby, D. W. (1996). Measuring the helpgiving practices of human services program practitioners. *Human Relations*, 49(6), 815–835.
- Dunst, C. J., Trivette, C. M., Starnes, A. L., Hamby, D. W., & Gordon, N. J. (1993). *Building and evaluating family support initiatives: A national study of programs for persons with developmental disabilities*. Baltimore: Paul H. Brookes Publishing Company.
- Dyson, L. L. (1993). Response to the presence of a child with disabilities: Parental

- stress and family functioning over time. *American Journal on Mental Retardation*, 98(2), 207–218.
- Early Intervention Coordination Project. (1994). *Proposed forward directions: Community consultation paper*. Sydney: Social Policy Directorate, NSW Department of Community Services.
- Eastern Suburbs Developmental Disability Service. (2002). Intake protocol and procedures within the central intake system. In N. D. o. C. Services (Ed.), *Local level policy*. Sydney: Unpublished procedures.
- Gallagher, J., & Desimone, L. (1995). Lessons learned from implementation of the IEP: Applications to the IFSP. *Topics in Early Childhood Special Education*, 15(3), 353–378.
- Gallimore, R., & Coots, J. (1996). Classrooms are just another cultural activity. In D. L. Speece & B. K. Keogh (Eds.), *Research on classroom ecologies: Implications for inclusion of children with learning disabilities* (pp. 229–250). New Jersey: Lawrence Erlbaum Associates.
- Galvin, E., Boyers, L., Schwartz, P. K., Jones, M. W., Mooney, P., Warwick, J., et al. (2000). Challenging the precepts of family-centred care: Testing a philosophy. *Paediatric Nursing*, 26(6), 625–645.
- Gardner, H., & McCoppin, B. (1995). Struggle for survival by health therapists, nurses and medical scientists. In H. Gardner (Ed.), *The politics of health: The Australian experience* (2nd ed., pp. 371–427). Melbourne: Churchill Livingstone.
- Gartner, A., & Riessman, F. (1993). Making sure helping helps. *Social Policy*(3), 35–36.
- Gergen, K. J. (1994). Mind, text and society: Self-memory in social context. In U. Neisser & R. Fivush (Eds.), *The remembering self: Construction and accuracy in the self-narrative* (pp. 78–104). Cambridge, MA: Cambridge University Press.
- Goodfellow, J. (1997). Narrative enquiry: Musings, methodologies and merits. In J. Higgs (Ed.), *Qualitative research: Discourse on methodologies* (pp. 61–74). Sydney: Hampton Press.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Resources Information Center Annual Review Paper*, 29, 75-91.

- Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks: SAGE Publications.
- Gubrium, J. F., & Holstein, J. A. (1998). Narrative practice and the coherence of personal stories. *The Sociological Quarterly*, 39(1), 163-188.
- Hall, P. S., & Hall, N. D. (2002). Hiring and retraining direct-care staff: After fifty years of research, what do we know? *Mental Retardation*, 40(3), 201–211.
- Hanlon, N. T. (2001). Sense of place, organisational context and the strategic management of publicly funded hospitals. *Health Policy*, 58, 151–173.
- Hannerman, R., & Blacher, J. (1998). Predicting placement in families who have children with severe handicaps: A longitudinal analysis. *American Journal on Mental Retardation*, 102(4), 392–408.
- Harbin, G. L., McWilliam, R. A., & Gallagher, J. (2000). Services for young children with disabilities and their families. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (2nd ed., pp. 387–415). New York: Cambridge University Press.
- Hasselkus, B. (1998). Occupation and well-being in dementia: The experience of day-care staff. *The American Journal of Occupational Therapy*, 52(6), 423–434.
- Hasselkus, B. R., & Dickie, V. A. (1994). Doing occupational therapy: Dimensions of satisfaction and dissatisfaction. *American Journal of Occupational Therapy*, 48(2), 145–154.
- Herman, S. E. (1997). Exploring the link between service quality and outcomes: Parent's assessments of family support programs. *Evaluation Review*, 21(3), 388–404.
- Herman, S. E., & Marcenko, M. O. (1997). Perceptions of services and resources as mediators of depression among parents of children with developmental disabilities. *Mental Retardation*, 35(6), 458–467.
- Herndon, S. L. (1993). Using focus group interviews for preliminary investigation. In S. L. Herndon & G. L. Kreps (Eds.), *Qualitative research: Applications in organisational communication* (pp. 39–45). New Jersey: Hampton Press, Inc.
- Higgs, C., Neubauer, D., & Higgs, J. (1999). The changing health care context: globalisation and social ecology. In J. Higgs & H. Edwards (Eds.), *Educating*

- beginning practitioners: Challenges for health professional education* (pp. 30–37). Oxford: Butterworth-Heinemann.
- Higgs, J., & Hunt, A. (1999). Rethinking the beginning practitioner: Introducing the ‘interactional professional’. In J. Higgs & H. Edwards (Eds.), *Educating beginning practitioners: Challenges for health professional education* (pp. 10–18). Oxford: Butterworth-Heinemann.
- Humphry, R., Gonzales, S., & Taylor, E. (1993). Family involvement in practice: Issues and attitudes. *American Journal of Occupational Therapy*, 47(7), 583–593.
- Hutchfield, K. (1999). Family centred care: A concept analysis. *Journal of Advanced Nursing*, 29(5), 1178–1187.
- ISI Research Soft. (2000). Endnote (Version 6.0). Berkeley, CA: ISI Research Soft.
- Itzhaky, H., & Schwartz, C. (2000). Empowerment of parents of children with disabilities: the effect of community and personal variables. *Journal of Family Social Work*, 5(1), 21–36.
- Jefferson, G. (1979). Sequential aspects of storytelling in conversation. In J. Schenkein (Ed.), *Studies in the organisation of conversational interaction* (pp. 219–248). New York: Academic Press.
- Jivanjee, P. R., & Friesen, B. J. (1997). Shared expertise: Family participation in interprofessional training. *Journal of Emotional & Behavioural Disorders*, 5(4), 205–211.
- Johnson, B. H. (2000). Family-centred care: Four decades of progress. *Family, Systems and Health*, 18(2), 137–156.
- Jones, A., & May, J. (1992). *Working in human service organisations: A critical introduction*. Melbourne: Longman Cheshire.
- Kardos, S. M., Moore-Johnson, S., Peske, H. G., Kauffman, D., & Liu, E. (2001). Counting on colleagues: New teachers encounter the professional cultures of their schools. *Educational Administration Quarterly*, 37(2), 250–290.
- Katz, L., & Scarpati, S. (1995). A cultural interpretation of early intervention services and the IFSP: Parent and professionals perceptions of their roles and responsibilities. *Infant-Toddler Intervention: The Transdisciplinary Journal*, 5(2), 177–191.
- Kemp, L. (2002). Why are some people's needs unmet? *Disability and Society*, 17(2),

205–218.

- King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: Linking process with outcome. *Journal of Pediatric Psychology, 24*(1), 41–53.
- Kirshbaum, M. (2000). A disability culture perspective on early intervention with parents with physical or cognitive disabilities and their infants. *Infants & Young Children, 13*(2), 9–20.
- Koch, T. (1998). Story-telling: Is it really research? *Journal of Advanced Nursing, 28*(6), 1182–1190.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dulap, G., Robbins, F. R., et al. (1992). Consistent stress profiles in mothers of children with autism. *Journal of autism and developmental disorders, 22*(2), 205–216.
- Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy, 45*(3), 214–222.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science Medicine, 47*(7), 865–875.
- Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., et al. (2003). Factors effecting family centred delivery for children with disabilities. *Child: Care, Health and Development, 29*(5), 357–366.
- Lawlor, M. C., & Mattingly, C. F. (1998). The complexities embedded in family-centred care. *American Journal of Occupational Therapy, 52*(4), 259–299.
- Leiter, V. (2004). Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities. *Social Science Medicine, 58*(4), 837–849.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: SAGE Publications.
- Linfoot, K. (1998). Early childhood special education: Recent trends in service delivery. *Early Edition, 6*(2), 12–25.
- Lipsky, M. (1980). *Street-level bureaucracy: Dilemmas of the individual in public services*. New York: Russell Sage Foundation.
- Litchfield, R., & MacDougall, C. (2002). Professional issues for physiotherapists in family-centred and community based settings. *Australian Journal of Physiotherapy, 48*(2), 105–112.

- Llewellyn, G., McConnell, D., Thompson, K., & Whybrow, S. (2005). Out-of-home placement of school-aged children with a disability and high support needs. *Journal of Applied Research in Intellectual Disabilities, 18*(1–6).
- Llewellyn, G., Thompson, K., & Whybrow, S. (2004). Activism as a mothering occupation. In S. A. Esdaile & J. A. Olson (Eds.), *Mothering occupations: Challenge, agency, and participation* (pp. 282–305). Philadelphia: FA Davis.
- Llewellyn, G., Thompson, K., Whybrow, S., McConnell, D., Bratel, J., Coles, D., et al. (2003). *Supporting families: Averting out-of-home placement for children with high support needs*. (ARC Linkage Final Report). Sydney: University of Sydney.
- 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*(1), 74–85.
- Mahoney, G., O'Sullivan, P., & Dennebaum, J. (1990). A national study of mothers' perceptions of family-focused early intervention. *Journal of Early Intervention, 14*(2), 133–146.
- Mahoney, G., O'Sullivan, P., & Fors, S. (1989). The family practices of service providers for young handicapped children. *Infant Mental Health Journal, 10*(2), 75–83.
- Mankowski, E. S., & Thomas, E. (2000). The relationship between personal and collective identity: A narrative analysis of a campus ministry community. *Journal of Community Psychology, 28*(5), 517–528.
- Marcenko, M. O., & Smith, L. K. (1992). The impact of a family centred case management approach. *Social Work in Health Care, 17*(1), 87–100.
- Marshall, M., Sheaff, R., Rogers, A., Campbell, S., Halliweel, S., Pickard, S., et al. (2002). A qualitative study of the cultural changes in primary care organisations needed to implement clinical governance. *British Journal of General Practice, 52*, 641–645.
- Mattingly, C. (1991). Narrative reflections on practical actions. In D. A. Schön (Ed.), *The reflective turn: Case studies in and on practice* (pp. 235–257). New York: Teachers College Press.
- Mattingly, C. (1998a). *Healing dramas and clinical plots: The narrative structure of experience*. Cambridge: Cambridge University Press.

- Mattingly, C. (1998b). In search of the good: Narrative reasoning in clinical practice. *Medical Anthropology Quarterly*, 12(3), 272–297.
- Mattingly, C., Fleming, M. H., & Gillette, N. (1997). Narrative explorations in the tacit dimensions: Bringing language to clinical practice. *Nordiske Udkast*, 1, 65–77.
- Mattingly, C., & Lawlor, M. (2000). Learning from stories: Narrative interviewing in cross-cultural research. *Scandinavian Journal of Occupational Therapy*, 7, 4–14.
- McAdams, D. P. (1993). *The stories we live by: Personal myths and the making of the self*. New York: Guilford Press.
- McIntyre, C. L. (2000). *The role of competency-enhancing helping practices in parental adaptation for families of children with special needs*. Unpublished PhD, The University of Texas, Austin.
- McKenzie, S. (1994). Parents of young children with disabilities: Their perspectives of generic children's services and service professionals. *Australian Journal of Early Childhood*, 19(4), 12–17.
- McWilliam, P. J., Lang, L., Vandiviere, P., Angell, R., Collins, L., & Underdown, G. (1995). Satisfaction and struggles: Family perceptions of early intervention services. *Journal of Early Intervention*, 19(1), 43–60.
- McWilliam, R. A. (1996). Service delivery issues in center-based early intervention. In R. A. McWilliam (Ed.), *Rethinking pull-out services in early intervention: A professional resource* (pp. 3–25). Baltimore, US: Paul H. Brookes.
- McWilliam, R. A., Maxwell, K. L., & Sloper, K. M. (1999). Beyond "involvement": Are elementary schools ready to be family-centered? *School Psychology Review*, 28(3), 378–394.
- McWilliam, R. A., Tocci, L., & Harbin, G. L. (1998). Family-centred services: Service providers discourse and behaviour. *Topics in Early Childhood Special Education*, 18(4), 206–226.
- McWilliam, R. A., Tocci, L., & Sideris, J. (1997). *Case study interpretations of family-service provider relationship – Services for young children with disabilities: An ecological perspective*. Chapel Hill, NC: Early Childhood Research Unity, University of North Carolina.
- Merriam, S. B. (1988). *Case study research in education: A qualitative approach*.

- San Francisco: Jossey-Bass Publishers.
- Microsoft Corporation. (1999). *Encarta World English Dictionary*. Retrieved June 15th, 2005, from <http://uk.encarta.msn.com>
- Microsoft Corporation. (2004). Microsoft Word for Mac (Version 11.0) [Word Processing]: Microsoft.
- Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1990). *In-depth interviewing: Researching people*. Melbourne: Longman Cheshire.
- Minichiello, V., Fulton, G., & Sullivan, G. (1999). An introduction to health research. In V. Minichiello, G. Sullivan, K. Greenwood & R. Axford (Eds.), *Handbook for research methods in health sciences* (pp. 36–56). Sydney: Addison Wesley Longman.
- Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge: Harvard University Press.
- Mishler, E. G. (1995). Models of narrative analysis: A typology. *Journal of Narrative & Life History*, 5(2), 87–123.
- Munford, R., & Sanders, J. (1999). *Supporting Families*. Palmerston North, New Zealand: Dunmore Press.
- Murray, M. (2000). Levels of narrative analysis in psychology. *Journal of Health Psychology*, 5(3), 337–347.
- New South Wales International Year of the Family Secretariat. (1994). *Valuing the family*. Sydney: NSW Government, Social Policy Directorate.
- Niemeyer, J. A., & Proctor, R. (1995). Facilitating family-centred competencies in early intervention. *Infant-Toddler Intervention: The Transdisciplinary Journal*, 5(4), 315–324.
- Norman, A. J. (1985). Applying theory to practice: The impact of organisational structures on programs and providers. In M. Weil & J. M. Karls (Eds.), *Case management in human service practice* (pp. 72–93). San Francisco: Jossey-Bass.
- NSW Ageing and Disability Department. (1998). *Standards In Action Manual* (Manual). Sydney: NSW Ageing and Disability Department.
- NSW Ageing and Disability Department. (1999). Self assessment package for non-government service providers. Sydney: NSW Ageing and Disability Department.

- NSW Ageing and Disability Department. (2000a). Community Self Assessment Package. Sydney: NSW Ageing and Disability Department.
- NSW Ageing and Disability Department. (2000b). Early Childhood Intervention Coordination Program. In NSW Department of Community Services, NSW Department of Education and Training, NSW Health & Non-government organisations (Eds.) (p. 2). Sydney: NSW Ageing and Disability Department.
- NSW Department of Ageing Disability and Home Care. (2002a). *Living in the community – Putting children first: A policy for supporting children and young people with a disability and their families in NSW*. Sydney: NSW Department of Ageing, Disability and Home Care.
- NSW Department of Ageing Disability and Home Care. (2002b). *Strategic directions*. Retrieved 19/01/03, 2003, from www.dadhc.nsw.gov.au/strategicdirections.htm
- NSW Department of Ageing Disability and Home Care. (2003). DADHC services. Sydney: DADHC.
- NSW Department of Community Services. (1996). *Policies for working with people with disabilities* (2nd ed.). Sydney: NSW Department of Community Services.
- NSW Department of Community Services. (2000). *Annual Report 99–00* (Annual report). Sydney: NSW Department of Community Services.
- NSW Department of Community Services. (2001a). *Fact sheet 1: What the Department of Community Services does*. Sydney: NSW Department of Community Services.
- NSW Department of Community Services. (2001b, January 2001). *Fact sheet 5: DoCS' transformation: Making the difference*. Retrieved 16.06.01, 2001, from www.community.nsw.gov.au
- NSW Department of Community Services. (2001c). *Our visions and values*. Retrieved 28/02/02, 2002, from www.nsw.community.gov.au/vision.htm
- NSW Department of Community Services. (2001d). Purchasing, a partnership model: Position paper. In Partnership and Communities Directorate (Ed.) (pp. 31). Sydney: NSW Department of Community Services.
- NSW Department of Education and Training. (1997). *Enrolment of Students in NSW Government Schools: A Summary and Consolidation of Policy*. Sydney:

- NSW Department of Education and Training.
- NSW State Government. (2001). Media Release: New NSW Department of Ageing, Disability & Home Care. Sydney.
- Olofsson, B., Gilje, F., Jacobsson, L., & Norberg, A. (1998). Nurses' narratives about using coercion in psychiatric care. *Journal of Advanced Nursing*, 28(1), 45–53.
- Parmenter, T. R. (1991). Has social policy left research behind? *Australia and New Zealand Journal of Developmental Disabilities*, 17, 1–6.
- Patterson, J. M., & Hovey, D. L. (2000). Family-centred care for children with special needs: Rhetoric of reality. *Family, Systems and Health*, 18(2), 237–251.
- Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. New York: State University of New York Press.
- Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. *Qualitative studies in education*, 8(1), 5–23.
- Polmanteer, K., & Turbiville, V. (2000). Family-responsive Individualised family service plans for speech pathologists. *Language, Speech and Hearing Services in Schools*, 31, 4–14.
- Poston, D. J., Turnbull, A. P., Park, C., Mannan, H., Marquis, J., & Wang, M. (2003). Family quality of life: A qualitative inquiry. *Mental Retardation*, 41, 313–328.
- Quine, L., & Pahl, J. (1991). Stress and coping in mothers caring for a child with severe learning difficulties: A test of Lazarus' transaction model of coping. *Journal of Community and Applied Social Psychology*, 1, 57–70.
- Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. (2004). Meeting the needs of parents around the time of diagnosis of disability among their children: evaluation of a novel program for information, support, and liaison by key workers. *Pediatrics*, 114(4).
- Rappaport, J. (1993). Narrative studies, personal stories, and identity transformation in the mutual help context. *Journal of Applied Behavioural Science*, 29(2), 239–256.
- Rappaport, J. (1994). Community narratives and personal stories: An introduction to five studies of cross level relationships: Unpublished manuscript.

- Ricoeur, P. (1989). *Time and narrative* (K. McLaughlin & D. Pellauer, Trans. Vol. 1–3). Chicago: University of Chicago Press.
- Riessman, C. K. (1993). *Narrative analysis*. Thousand Oaks: SAGE Publications.
- Roberts, R. N., Rule, S., & Innocenti, M. S. (1998). *Strengthening the family—professional partnership in services for young children*. Baltimore, MD, USA: Paul H. Brookes Publishing Co.
- Rodgers, S., & Brown, G. T. (2004). *A comparison of paediatric occupational therapy curricula between Australia, New Zealand and Canada: Summary of survey findings* (Summary of survey findings). Brisbane: University of Queensland.
- Rodwell, M. K. (1995). Constructivist research: A qualitative approach. In P. J. Pecora, M. W. Fraser, K. E. Nelson, J. McCroskey & W. Meezan (Eds.), *Evaluating family-based services* (pp. 191–214). New York: Aldine De Gruyter.
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family centred service: A conceptual framework and research review. *Physical & Occupational Therapy in Pediatrics, 18*, 1–20.
- Rothman, J. (1994). Community and organisation issues. In *Practice with highly vulnerable clients: Case management and community based services* (pp. 255–281). New Jersey: Prentice Hall.
- Royeen, C. B., Cromack, T., DeGangi, G., Poisson, S., & Wietlesbach. (1996). Measuring parent and professional attitudes about the individualised family service plan: A preliminary report. *The Occupational Therapy Journal of Research, 26*(2), 111–127.
- Salzer, M. S. (1998). Narrative approach to assessing interactions between society, community, and person. *Journal of Community Psychology, 26*(6), 569–580.
- Schön, D. A. (1991). *The reflective practitioner: How professionals think in action*. London: Arena.
- Segal, R., & Frank, G. (1998). The extraordinary construction of ordinary experience: Scheduling daily life in families with children with attention deficit hyperactivity disorder. *Scandinavian Journal of Occupational Therapy, 5*, 141–147.
- Singer, G. H. S., Irvin, L. K., Irvine, B., Hawkins, N., & Cooley, E. (1989).

- Evaluation of community-based support services for families of persons with developmental disabilities. *Journal of the Association for Persons with Severe Handicaps*, 14(4), 312–323.
- Singer, G. H. S., & Powers, L. E. (Eds.). (1993). *Families, disability, and empowerment*. Baltimore: Paul H Brookes.
- Singh, N. N. (1995). In search of unity: Some thoughts on family–professional relationships in service delivery systems. *Journal of Child & Family Studies*, 4(1), 3–18.
- Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25(2), 85–99.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with a severe physical disability. *Child: Care, Health and Development*, 18, 259–282.
- Sokoly, M. M., & Dokecki, P. R. (1992). Ethical perspectives on family-centered early intervention. *Infants & Young Children*, 4(4), 23–32.
- Spastic Centre of NSW. (2001). *Annual report*. Sydney: The Spastic Centre of NSW.
- Stebnicki, M. A. (2000). Stress and grief reactions among rehabilitation professionals: Dealing effectively with empathy fatigue. *Journal of Rehabilitation*(1), 23–29.
- Stewart, S., & Neyerlin-Beale, J. (2000). The impact of community paediatric occupational therapy on children with disabilities and their carers. *British Journal of Occupational Therapy*, 63(8), 373–379.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. New York: Cambridge University Press.
- Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research*. Newbury park, CA: Sage Publications.
- Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., et al. (2005). Conceptualising and measuring family quality of life. *Journal of Intellectual Disability Research*, 49, 10.
- Thompson, K. M. (1998). Early intervention services in daily family life: Mothers' perceptions of 'ideal' versus 'actual' service provision. *Occupational Therapy International*, 5(3), 206–222.
- Thompson, L., Lobb, C., Elling, R., Herman, S., Jurkiewicz, T., & Hulleza, C.

- (1997). Pathways to family empowerment: Effects of family-centredness delivery of early intervention services. *Exceptional Children*, 64(1), 99–113.
- Trivette, C. M., Dunst, C. J., Boyd, K., & Hamby, D. W. (1996a). Family-oriented program models, helpgiving practices, and parental control appraisals. *Exceptional Children*, 62(3), 237–248.
- Trivette, C. M., Dunst, C. J., & Hamby, D. (1996b). Characteristics and consequences of helpgiving practices in contrasting human services programs. *American Journal of Community Psychology*, 24(2), 273–293.
- Trivette, C. M., Dunst, C. J., & Hamby, D. W. (1996c). Factors associated with perceived control appraisals in a family-centred early intervention program. *Journal of Early Intervention*, 20(2), 165–160.
- Turnbull, A. P., Blue-Banning, M., Turbiville, V., & Park, J. (2000a). From parent education to partnership education: A call for a transformed focus. *Topics in Early Childhood Special Education*, 19(3), 164–172.
- Turnbull, A. P., Brown, I., & Turnbull, H. R. (Eds.). (2004). *Families and people with mental retardation and quality of life: International perspectives*. Washington, DC: American Association on Mental Retardation.
- Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000b). Evolution of family-professional partnerships: Collective empowerment as the model for the early Twenty-first Century. In J. P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (2nd ed., pp. 630–650). New York: Cambridge University Press.
- Turnbull, A. P., Turnbull, R., Erwin, E., & Soodak, L. (2006, in press). *Families, professionals and exceptionality: Positive outcomes through partnerships and trust*. Upper Saddle River, New Jersey: Merrill/Prentice Hall.
- Turnbull, H. R., Beegle, G., & Stowe, M. J. (2001). The core concepts of disability policy affecting families who have children with disabilities. *Journal of Disability Policy Studies*, 12, 133–143.
- Valentine, F. (1998). Empowerment: Family-centred care. *Paediatric Nursing*, 10(1), 24–27.
- Vandiver, V. L. (2004). Families with a cause. *PsycCRITIQUES 2004*, [np] *American Psychological Assn, US*.
- Victorian Department of Health & Community Services. (1993). *Early intervention:*

- Supporting families in rural Victoria*. Melbourne: Victorian Government Department of Health and Community Services.
- Viscardis, L. (1998). The family-centred approach to providing services: a parent perspective. *Physical & Occupational Therapy in Pediatrics, 18*(1), 41–53.
- Watson, D., Townsley, R., & Abbot, D. (2002). Exploring multi-agency working in services to children with complex health care needs and their families. *Journal of Clinical Nursing, 11*, 367–375.
- Wehman, T., & Gilkerson, L. (1999). Parents of young children with special needs speak out: perceptions of early intervention services. *Infant-Toddler Intervention: Transdisciplinary Journal, 9*(2), 137–167.
- Weiner, C. L. (1991). Arenas and careers: The complex interweaving of personal and organisational destiny. In D. R. Maines (Ed.), *Social organisation and social processes: Essays in honour of Anselm Strauss* (pp. 175–188). Hawthorn, New York: Aldine De Gruyter.
- White, M. (1997). *Narratives of therapists' lives*. Adelaide: Dulwich Centre Publications.
- Whitehead, A., Jesien, G., & Ulbanski, B. K. (1998). Trends in professional education: Weaving parents into the fabric of early intervention interdisciplinary training: how to integrate and support family involvement in training. *Infants and Young Children, 10*(3), 44–53.
- Witkin, S. L., & Harrison, W. D. (2001). Editorial: Whose evidence and for what purpose? *Social Work, 46*(4), 293–296.
- Wolery, M., Bailey, D. B., Dunst, C. J., Schuster, J., McWilliam, R. A., & Trivette, C. M. (1997). *Early Childhood Follow-through Research Institute Year 2 progress report*. Chapel Hill: Frank Porter Graham Child Development Centre, University of North Carolina.
- Wolfensberger, W. (1983). *Normalisation-based guidance, education and supports for families of handicapped people*. Downsview, Canada: National Institute on Mental Retardation.
- Ylijoki, O.-H. (2001). Master's thesis writing from a narrative approach. *Studies in Higher Education, 26*(1), 21–34.

Zebrack, B. J., & Chesler, M. A. (2000). Managed care: The new context for social work in health care – Implications for survivors of childhood cancer. *Social Work in Health Care*, 31(2), 89–103.

APPENDICES

Appendix 1: Information Sheet & Consent form

The University of Sydney
Faculty of Health Sciences
School of Occupation & Leisure Sciences

Cumberland Campus
East Parade/PO Box 170
LIDCOMBE NSW 1825
Phone: 02 9351 9723
Fax: 02 9351 9166

PROJECT INFORMATION SHEET

Understanding helping professionals' work with families of children with a disability.

Thank you for agreeing to participate in individual interviews in relation to my project about service providers working with families of children with a disability and high support needs. This study is focused on understanding how service providers work with families of children with a disability. It is anticipated that a better understanding of service provider occupations will provide for recommendations in future practice, education and research.

The project involves identifying what service providers are doing when working with families of children with a disability and high support needs and how this is influenced and informed by their greater service context. This is occurring in two stages. In the first stage, service providers will be invited to share and discuss good and poor experiences of working with families in focus groups. The second stage involves individual interviews to further explore your daily work practices with families of children with a disability. I will be encouraging you to share stories about your experiences with families.

Interviews and focus groups will take place in a mutually convenient location and take approximately 1–1.5 hours of your time on each occasion. I would like to audiotape the interviews for later transcription and analysis. All data will be confidential and accessed only by those directly related to the project. All information will be reported anonymously. None of the information discussed will be

directly available to service agencies, funding sources or families. Following focus groups and interviews, you will receive a copy of the transcript. At your discretion, I will clarify, add or remove information from this transcript.

Participation in the research project is entirely voluntary. You are not expected to participate in this project as a requirement of your employment. As a participant, you would be free to withdraw at any time without consequence for yourself or your organisation.

I trust that this information sheet explain the project to you, however, if you require any further information, please do not hesitate to contact me at the address and/or telephone number listed below. Should you have any concerns or complaints about the project, please contact the Executive Officer of the Human Ethics Committee, The University of Sydney on (02) 9351 4811.

Kirsty Thompson

CONSENT FORM

Understanding helping professionals' work with families of children with a disability.

I, _____ (full name)

Have read the information sheet pertaining to the project 'understanding helping professionals' work with families of children with a disability.

I understand what is required of me and that any information I provide will be treated confidentially and reported anonymously.

I acknowledge that I can withdraw from participation at any stage without consequence to myself, or any family or agency to which I am linked. I am aware that should I have any concerns or queries regarding this project that I can contact the researcher at 02 93519723. I am also aware that should I have any concerns or complaints about the project, I can contact the Executive Officer of the Human Ethics Committee, the University of Sydney on (02) 935194811.

Signed:

Witnessed:

Date:

Date:

Appendix 2: Demographic information sheet

The University of Sydney
Faculty of Health Sciences
School of Occupation & Leisure Sciences

Cumberland Campus
East Parade/PO Box 170
LIDCOMBE NSW 1825
Phone: 02 9351 9723
Fax: 02 9351 9166

Code No ____

DEMOGRAPHIC INFORMATION

Understanding helping professionals' work with families of children with a disability.

Please indicate in the space below:

Title of your current position:
Years/months experience in current position:
Years/months experience working with families of children with a disability:
Type of community organisation (e.g., Government/Non-government, Disability)
Any qualifications you hold that relate to your current work with children with a disability and their families:

Appendix 3: Final analysis tables for core narratives and culture of professional practice with families

Table 3: Analysis table distinguishing narratives of professional practice with families

Plot stage Narrative	Making it work	Having to fight	Hopeless struggle	Making the best of it
Orient	<ul style="list-style-type: none"> * Confident in skills and that they are valued * Professional may be comparatively free of personal family or financial commitments * Committed to and motivated by personal vision of helping families * May draw some motivation from challenge of ‘getting away with it’ 	<ul style="list-style-type: none"> * Steadfastly committed to personal vision of how to support families * Feel compelled to fight to change other ‘unjust’ expectations of their practice * Confident in own skills, knowledge or ability rally these for the ‘fight’ 	<ul style="list-style-type: none"> * Believe skills and resources inadequate or inappropriate to change and/or meet existing expectations * Own vision of practice completely overwhelmed by how others direct them to practice * No faith/belief practising as directed will help families * May have comparatively more pressing personal or financial responsibilities 	<ul style="list-style-type: none"> * Pragmatism – directed by others (most forcefully imposed, usually policies and condition of the system), even if it is against their better judgement * Confident can adapt skills to whatever expected of them * Have faith in those that direct their practice
Action	<ul style="list-style-type: none"> * Quietly do what they want. Try not to explain to others what they do * May or many not do what expected to do 	<ul style="list-style-type: none"> * Openly act and explain their actions as contrary to expectations * Motivated by desire to change expectations and/or draw attention to expectations as unacceptable practice guidelines. This reaffirmed when their contrary actions are noticed and potentially accepted. * Draw some energy from the fight * May feel battle is a solo one 	<ul style="list-style-type: none"> * Quietly practice – don’t believe complaints would be heard or would make a difference * Go through the motions, with emphasis on surviving, and doing what they are told * May seek reassurance from others that what they are doing is acceptable, but don’t believe this themselves * Feel alone 	<ul style="list-style-type: none"> * Do what others expect of them * Search for personally satisfying aspects in what they do * Explain practice by adherence to how they felt expected to practice

Plot stage Narrative	Making it work	Having to fight	Hopeless struggle	Making the best of it
Evaluate	<ul style="list-style-type: none"> * Positively frame experiences * Done best; Child/family helped; and/or 'got away' with doing what they wanted 	<ul style="list-style-type: none"> * Positively frame actions as just and right, but are cynical the fight will need to continue * Look to see if others attended to the issue or changed practice because of their actions. Perceive the reprimands they receive as satisfying confirmation of their actions 	<ul style="list-style-type: none"> * Negatively frame whole experience * Disappointed in their efforts and the outcome * Don't believe they have helped families * Interpret all feedback as reinforcing hopelessness of situation 	<ul style="list-style-type: none"> * Positively frame situation, believing they have done their best within opportunities defined for them * Believe any help for family is better than no help at all.
Helping framework	<ul style="list-style-type: none"> * Believe they can and will quietly find some way of helping families to their personal satisfaction 	<ul style="list-style-type: none"> * Fight to help families as they feel they should and to change practice expectation they don't believe can help families 	<ul style="list-style-type: none"> * Can't see how they can or did help 	<ul style="list-style-type: none"> * Hopeful and believe they can help by doing what others tell them

Table 4: Components and principles of the culture of professional practice with families

Cultural component	Principles
Helping	<ul style="list-style-type: none"> – Interdependence of child and family support – Direct hands-on help is best – Satisfying a personal desire to help – Aims to preventing out-of-home placement – Aims to improve/maintain health and functioning of child and family – Involves following a helping process
Positive relationships	<ul style="list-style-type: none"> – Open communication – Trust and respect – Integrity & commitment – Friendly interactions
Working together	<ul style="list-style-type: none"> – Collaboration with family and colleagues – Sharing information, skills and knowledge – Family as crucial team member – Developing shared goals/vision for practice
Individualised practice	<ul style="list-style-type: none"> – Recognising unique service needs and priorities – Flexibility and responding to individual needs
Empowering practice	<ul style="list-style-type: none"> – Families as key decision makers – Providing information and teaching skills
Inclusive practice	<ul style="list-style-type: none"> – Normalising community living experience – Empowering families and communities to develop inclusive opportunities
Professional practice with families as a bandaid	<ul style="list-style-type: none"> – Crisis represents service worthiness – Short term, quick-fixes
Professional practice with families as mediation	<ul style="list-style-type: none"> – Interpreting and exchanging information – Negotiating expectations – Placating families
It's a business	<ul style="list-style-type: none"> – Rationing services – Measuring and accounting for daily practices – Quality control mechanisms – Finance driven conditions – Documenting evidence
Objective practice	<ul style="list-style-type: none"> – Maintaining a 'professional distance' – Impartial decisions guided by policy, facts and evidence

Appendix 4: Transcripts of stories employed to illustrate analysis

KEY		
R:	-	indicates the participant is speaking.
I:	-	indicates my responses and questions during the interview
[]	-	indicates cross-reference the researcher included in the transcript for clarity and ease during analysis
<i>(italics)</i> -		indicates any outstanding features of conversation

In Section 3.5.1, examples of entrance and exit talk were provided to illustrate how they helped identified stories data. The example provided was drawn from a story told by a psychologist in an individual interview. The full transcript of the story is provided below.

Story #104, from interview with participant #6

BEGIN STORY #104:

R: Personally and professionally it is a very difficult situation when you have an insight into what services are available, and then have to pass that on to families. Sometimes you say to families, like they will ask us to do stuff and we will just say 'there is nothing. Okay we will put in a submission, but it is going to take a long time to go through the processes. We personally think you should ring the minister direct. You didn't hear it from us, but this is what we think you should do and if you don't cry out, if you just keep quiet, then you are not going to get the support. You have really got to do this.' So often we are doing stuff I guess that where we are not following our Department Code of Ethics, we are breaching it a little, but we are trying to be supportive to the family. So the family are like 'Okay.' And now a lot of families are like cottoning on and saying like 'we are just letting you know that we are going to ring the minister, so you will probably get a phone call' and we are like 'do it.' Or they might say 'so you know of a name in DADHC who we can ring about this' and we will say 'you didn't hear it from us, but such and such, and here is the number' (laughing)

I: Sounds like it happens a bit?

R: Yeah. So I guess that being ‘in between’ can be a real dilemma
END STORY #104

In Section 3.5.1, a story was employed to illustrate the plot structure of the emerging narratives. It was part of a larger discussion about efforts to facilitate inclusion that featured a number of distinct stories. The transcript of this story (no. 62), told by an occupational therapist in an individual interview about the tasks of writing submissions for services or funding, is provided below.

Story #62, from interview with participant #14

BEGIN STORY #62:

R: Another thing when we were talking about mainstreaming and getting that aid time for that child to get into their local school. That is increasingly people are being taught to focus on the good things and that sort of stuff, but when you are doing things like writing a lot of those submissions and that you have to focus on the negative. It (*2 second pause*), well it is all negative, negative, negative. That poses a real dilemma for you. If you don’t write it negatively (*leaves off*)

I: Yes?

R: Then you don’t get the money. I know it is quite distressing that anything for money has to be this real sob story about how things are just going in this downwards spiral where there is no solution and everything is just gloom and doom. But sometimes you have to write that way. You just have *to* (*with emphasis*) to get the help. It goes against a lot of the philosophies when we are working with people with disabilities trying to look at how positive things are and how they should be valued and the things that they can offer society and all this kind of stuff. Suddenly it is like ‘no!’ They [the child] are very devalued in those families too.

I: I guess it is a hard thing to juggle (*leaves off as R begins again*)

R: Exactly. Parents see copies of these reports and one says their child had achieved all these things, and the submission for funding says that they are not doing very well at all, and then dealing with the fall out from that. I suppose to keep reinforcing for families that things aren’t going well.

I: Okay. Yeah.

END STORY #62.

In Section 3.5.1, an excerpt from a story was used to illustrate how propositions were tested to refine the narratives in the fourth stage of narrative analysis. Story #86 was told by a physiotherapist and reflected what would later become a '*making the best of it*' narrative. It was employed to illustrate the (eventually unsubstantiated) proposition that there were some stories where professionals were content with the context and the help they were able to provide.

Story 86 from interview participant #6

BEGIN STORY #86

I found it very hard, when we had some of these changes to a consultative approach, giving up some of the hands on. But then I thought 'maybe I can give the best in a different way,' not copping out and not doing it, because I would feel very bad if I couldn't give of something. So I think that is what it is. I look at, you know, so instead of maybe feeling upset and thinking like 'this is the end' or something, I say to myself 'this is an obstacle. Go back to that thing that I have always set up for myself. What do I do?' Well I either give up and I am a failure, or how do I do it? I go round it, over it, under it, through it, one way or the other.' So I think that is basically it. So it is to say 'be flexible.' Is there another way of giving towards them instead of hands on. Is there a better way of doing it to help these children and families.

I: Okay, yeah.

R: Like good information. Good telephone counseling and being available. I think that is what is best. What I did when we changed, when we would be on the phone I would go through and negotiate with them. I think it is negotiation instead of just counseling. I would say 'I am only a phone call away. Please remember that. This is my telephone number, this is the fax, and this is voice mail. Just leave a little message even if it is only a telephone number of who you are, and I will ring you back. Gradually, I think they come to realise. It is like 'oh Judy, you are probably busy but I need to ask you about this. Sorry'' and this sort of thing. And then I would ring either

that day or the next day. I always, that's why I put down my voice mail. If I have no specific time, and then I think, what's on the voice mail, who didn't I see. Do you know what I mean. Gradually, I think that I have built up a trust with them that (names self) is not on site for those people, but they know that she is still available. I have left my telephone numbers for them at work and we have forms that we set up from school age programs. And the referral forms, I mean we say to the staff, please write that in and fax it through to us. And if there is nothing that we can do on site, then we will either take it away or get the parents to come in. So what we are doing now, where possible, if it means that it is a wheelchair, then the parents can bring it in. Like collect their child after school, bring it in and we will repair it here or we will adjust it here. And actually, the parents (leaves off)

I: So it sounds like it is about getting them to understand the changes as well?

R: Yes. Absolutely. So it is a gradual thing. So over the last 12 or 18 months now, it is using our own personal ways of dealing with things, not letting down the families, but managing them in the best way possible. And information you might think is not doing hands on, but you say 'look I am available. If you want to come here, ring up and bring your child. I am available if you want to take them out.' Like it is saying 'can you take 2 hours off work, bring them in at 8 o'clock in the morning and I will attend to you here, and then you drop them off and go on to work. It's amazing, gradually, over time, people are getting used to it. But it has been persistent and I think that the main thing is saying 'I am available, you will have to contact me as well as I contact you. You either have to put it in writing what you want or ring up here and say I need something done, we have put it on form here' like I take down the exact intake what they say and bring up at the next meeting. I say to them (the parents) that we have a meeting not this Thursday but next Thursday, it will probably have to wait until then, because it has to be put through our program, but it will get done. If there is anything else urgent in the mean time, then we will, like I will give them some ideas over the phone that they can do in the mean time. So that is what we do. So I think the telephone, being available and voicemail saying please leave a message and I will get back to you. I think the people trust it, because they

knew me so well there (at the school site). The other clients have never had it any other way, so they think that that is the way that it is. So we make them decide is it really a full team, or is it just physio? And a lot of them will say 'oh it is just physio,' and then you can get it done quick to help out.

END STORY #