

The Collaborative Goal Setting Experiences of Parents of Children with Disabilities and Occupational Therapists

Catherine Hilly

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Faculty of Health Sciences

University of Sydney

Lidcombe NSW 2141

Australia

Abstract

Collaborative goal setting between parents and therapists is considered essential to the principles of the family-centered practice philosophy. It is considered best practice to underpin family and child therapy services with family centered practice. Only recently has research evolved that examines how parents and therapists experience collaborative goal setting practice. Within the occupational therapy literature occupational therapists are encouraged to engage clients in collaborative goal setting practices yet therapists have identified that achieving this is much more difficult than it is proposed. The purpose of this research inquiry is to explore the collaborative goal setting experiences of parents who have children with disabilities, and of occupational therapists. It does so within an Australian context and from the viewpoints of parents of children of all ages and disabilities. A naturalistic inquiry was conducted that used in-depth interviews and document analysis to explore the phenomenon of collaborative goal setting experiences of parents and occupational therapists.

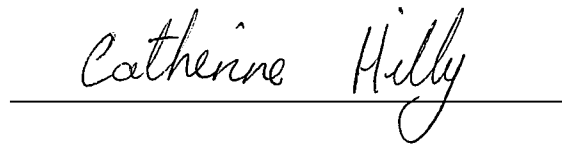
This inquiry generated five themes: “An obscure concept”: Learning to goal set; “The things we would discuss became the goals”: Goal setting experiences; “It’s just the beginning”: The impact of goal setting on families’ everyday lives and the occupational therapy process; “People vary in their life experiences”: Factors influencing goal setting experiences; and “More guidance, more direction”: How goal setting could be improved. Within these five themes the similarities and differences between parents’ and occupational therapists’ collaborative goal setting experiences were presented.

The key findings derived from this inquiry were that goal setting was experienced as a dynamic, complex process and both parents and occupational therapists had to learn how to participate in collaborative goal setting. It identified that current collaborative goal setting practices require modifications to facilitate improved active participation of parents and children with disabilities.

Statement of Authentication

This thesis is submitted to the University of Sydney in fulfillment of the requirement for the
Degree of Master of Applied Science (Occupational Therapy)

The work presented in this thesis is, to the best of my knowledge and belief, original except as
acknowledged in the text. I hereby declare that I have not submitted this material, either in
full or part, for a degree at this or any other institution.

A handwritten signature in cursive script, reading "Catherine Hilly", is written over a horizontal line.

Catherine Hilly

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Contents

Chapter 1 Introduction	1
1.1 Introduction	1
1.2 Background Information	1
1.3 Aim of the Inquiry and Inquiry Research Questions	4
1.4 Definition of Terms	5
1.5 Inquiry Assumptions	6
1.6 Significance of Inquiry	6
1.7 Scope of the Inquiry	7
1.8 Summary of the Inquiry	7
1.9 Outline of Thesis	7
Chapter 2 Review of the Literature	9
2.1 Introduction	9
2.1.1 Definition of key terms	9
2.2 History of Goal Setting Practices	10
2.3 Roles in Goal-Setting and Ownership of Goals	16
2.4 Factors Influencing Goal Setting	18
2.4.1 Clients learning to goal set	20
2.5 Collaborative Goal Setting in Family Centered Practice	21
2.6 Summary and Findings	23
Chapter 3 Methodology	25
3.1 Introduction	25
3.2 Theoretical Perspective	25
3.3 Participants	29
3.3.1 Recruitment process and gaining access	30
3.3.2 Sampling	32

3.4	Data Collection Methods	33
3.4.1	The researcher	33
3.4.2	Interviews	34
3.4.3	Review of goal setting documents in client files	35
3.4.4	Duration of data collection	35
3.5	Ethical Considerations	36
3.6	Data Analysis	36
3.6.1	Data management	36
3.7	Accuracy and Rigour of Analysis	38
3.7.1	Criterion one: Credibility	39
3.7.2	Criterion two: Transferability	41
3.7.3	Criterion three: Dependability	41
3.7.4	Criterion four: Confirmability	42
3.8	Sharing of Inquiry Using Case Study Reporting	42
3.9	Summary and Limitations of Design and Methods	43
Chapter 4	Inquiry Findings	44
4.1	Introducing the Themes and Sub-themes	44
4.2	Theme One: “An Obscure Concept”: Learning to Goal Set	45
4.2.1	“You learn as a parent”: Parents learning how to engage with and use therapists	45
4.2.2	“They just want action”: Occupational therapists’ thoughts about parents’ perspectives of goal setting	52
4.2.3	“Developing my own technique”: Occupational therapists learn to develop their own goal setting techniques	53
4.3	Theme Two: “The Things we Would Discuss Became the Goals”: The Collaborative Goal Setting Experiences of Parents and Occupational Therapists	55
4.3.1	“Goals are really open ended”: Parents’ goal setting experiences	56
4.3.2	“We kind of melded those ideas together”: The goal setting process	57
4.3.3	“Both own the goals”: Roles during goal setting and ownership of goals	60
4.3.4	“The issues that were there are different now”: Goals change	62
4.3.5	“COPM, GAS and Action Plans”: Use of goal setting tools	62

4.4	Theme Three: “It’s Just the Beginning”: The Impact of Goal Setting	65
4.4.1	“Life is busy”: The impact of goal setting on parents’ everyday lives	65
4.4.2	“Beginning of the client’s therapy life”: The impact of goal setting on the occupational therapy process	67
4.5	Theme Four: “People Vary in Their Life Experiences”: Factors Influencing Goal Setting Experiences	69
4.5.1	“The emotional aspect”: Parents’ perspectives of factors influencing their goal setting experiences	69
4.5.2	“Depends on the setting, the client and also time”: Factors of occupational therapists’ goal setting experiences	70
4.6	Theme Five: “More guidance, more direction”: How Goal Setting Could be Improved	73
4.6.1	“Reinforce with the parents”: Parents’ ideas for improving goal setting	73
4.6.2	“Take the time to goal set”: Occupational therapists’ ideas for improving goal setting	75
4.7	The Similarities and Differences of the Collaborative Goal Setting Experiences of Parents and Occupational Therapists	77
4.8	Chapter Summary	79
	Chapter 5 Discussion	82
5.1	Introduction	82
5.1.1	Goal setting involves learning	83
5.1.2	Goal setting experiences	88
5.1.3	The impact of goal setting	91
5.1.4	Factors influencing goal setting experiences	93
5.1.5	How goal setting could be improved	96
5.1.6	Goal setting is a dynamic process	100
5.2	Summary of Discussion	101
	Chapter 6 Conclusion	103
6.1	Introduction	103
6.2	Overview of the Inquiry	103

6.3	Significance of the Inquiry Findings	105
6.3.1	Implications for occupational therapy practice	105
6.3.2	Implications for policy development and management practices of child and family services	107
6.3.3	Implications for clinical training	107
6.4	Limitations of the Inquiry	108
6.4.1	Inquiry design	108
6.4.2	Sample of participants	108
6.4.3	Data gathered	109
6.5	Recommendations for Future Research and Intervention	110
6.6	Conclusion	111
	References	112

List of Tables

Table 1.1	Outline of thesis	8
Table 3.1	The application of phenomenology methodology into this inquiry	28
Table 3.2	Parent and child demographics	31
Table 3.3	Occupational therapist demographics	32
Table 3. 4	Comparison of terms to evaluate accuracy and rigour in research	39
Table 4.1	The similarities and differences of the goal setting experiences of parents and occupational therapists (OTs).....	78

List of Figures

Figure 2.1	Barclay’s model of factors influencing collaborative goal setting	19
Figure 4.1	Three types of goals desired by parents in the goal setting process	46
Figure 4.2	Summary of Theme One and sub-themes	55
Figure 4.3	Summary of Theme Two and sub-themes	65
Figure 4.4	Summary of Theme Three and sub-themes	68
Figure 4.5	Summary of Theme Four and sub-themes	73
Figure 4.6	Summary of Theme Five and sub-themes	76
Figure 4.7	Overview of Themes	81
Figure 5.1	Summary of factors influencing parents’ and occupational therapists’ collaborative goal setting experiences	94

Chapter 1

Introduction

1.1 Introduction

This research inquiry has developed out of the clinical experiences of the principal researcher while using goal setting with parents to establish service plans and to measure therapy outcomes in child and family therapy practice. Through the use of qualitative, naturalistic inquiry methods (Lincoln & Guba, 1985; Starks & Brown Trinidad, 2007; Williams, 2006), parents of children with disabilities, and occupational therapists, were interviewed about their perceptions of participating in a collaborative goal setting process. This research expands upon previous research into parent and therapist goal setting by investigating the phenomenon of parents' and occupational therapists' experiences of collaborative goal setting and describing the meanings they ascribe to it (Dyke, Buttigieg, Blackmore & Ghose, 2006; Hanna & Rodger, 2002; Hooker, 2008; Jansen Ketelaar & Vermeer, 2003; Kaiser, Braun, & Rhyner, 2005; King, Teplicky, King & Rosenbaum, 2004; King & Patterson, 2000; Leach, Cornwell, Fleming & Haines, 2010; McLaren & Rodger, 2003; Nijhuis et al., 2007, Siebes et al., 2006; Wiart, Ray, Durrah & Magill-Evans, 2010). The findings of this inquiry provide insights into how parents and occupational therapists feel that collaborative goal setting experiences can be improved, including in the areas of their roles, ownership of goals, use of specific goal setting tools and frequency of reviews.

1.2 Background Information

Within child and family therapy services, occupational therapy provision often occurs within the context of a team of health care professionals including teachers, early educators, community partners, parents and families. Collaborative goal setting with parents aims to capture the needs of the child and the family, and the priorities of other service providers in order to develop a wholistic, relevant service plan.

Not only is the use of collaborative goal setting considered pivotal to family-centered practice (King et al., 2004; Palisano, Snider & Orlin, 2004), it is an expected aspect of occupational therapy practice (Australian Association of Occupational Therapists, 2001; American

Occupational Therapy Association, 2000; Barclay, 2002; Cahill, 1998; College of Occupational Therapists, 2005). Establishing goals early in the therapeutic relationship with clients and families is thought to facilitate the evaluation of the outcome of the therapy service provided (Cusick, McIntyre, Novak, Lannin & Lowe, 2006; Law et al., 2003; Ottenbacher & Cusick, 1990). Occupational therapists, along with other human services providers, are required to document the outcomes of their intervention to demonstrate the value of their role to key stakeholders including service users, funding bodies and government agencies (Ottenbacher & Cusick, 1990; Unsworth, 2000). Goals set by families and therapists are the most commonly used outcome measures to demonstrate the impact of therapy (Cusick et al., 2006; Law et al., 2003; Novak & Cusick, 2006; Ostensjo, Oien & Fallang, 2006; Wiart et al., 2010). Involvement of families in making decisions about the nature of goals, and therefore the expected outcome of therapy, is thought to be essential to the achievement of relevant outcomes in therapy service provision (Barclay, 2002). Occupational therapists have spent significant time and effort developing specific, client-centered outcome measures and training in the utilisation of such measures to improve their collaborative goal setting skills (Cusick et al., 2006; Kielhofner et al., 1998; Law, Baptiste & Mills, 1991; Link-Melville, Baltic, Bettcher & Nelson, 2002; Ottenbacher & Cusick, 1990), and the development of such goal setting processes and measures have contributed to the place of occupational therapy in family centered practice.

Following a period of implementation of goal setting strategies within child and family services, there is now an increasing trend in occupational therapy and allied health literature to evaluate collaborative goal setting practice to ensure that it is being implemented as planned, with a client-centered focus, and the capacity to measure therapy outcomes (Cusick et al., 2006; Hurn, Kneebone & Cropley, 2006; Law et al., 1991; Leach et al., 2010; Ottenbacher & Cusick, 1990; Pollock, 1993; Wiart et al., 2010). Researchers have begun to explore therapists' and clients' perceptions about goal setting experiences including their experiences with using goal setting tools, ownership of goals set, benefits of goal setting on client autonomy and understanding of disability/illness, the role of occupational therapy and their experiences of the goal setting process (Barclay, 2002; Cahill, 1998; Carnaby, 1997; Ennals & Fossey, 2007; Leach et al., 2010; Link-Melville et al. 2002; Neistadt, 1995; Playford et al. 2000; Turner, Ownsworth, Turpin, Fleming & Griffin, 2008; Wiart et al., 2010).

It is well accepted that collaborative goal setting between parents and therapists encourages active parent participation, ownership of therapy goals and develops knowledge that enhances the quality of life for all family members (King et al, 2004). Other benefits of parent/therapist collaboration include encouragement of joint-decision making, identification of the unique needs of the family, improved parental follow-through of suggestions at home, improved participation in therapy and increased parental confidence (Jansen et al., 2003; King & Patterson, 2000; Knox, Parmenter, Atkinson, & Yazbeck, 2000; Law et. al., 2003; Mayer, Prudhomme-White, Ward & Barnaby, 2002; McLaren & Rodger, 2003; Novak & Cusick, 2006; Ostensjo et al., 2006; Wiart et al, 2010). King et al. (2004) have concluded that family-centered services, involving parents in goal setting, contributes to the effectiveness of meeting outcome expectations of children and families.

Research has explored collaboration, benefits of parental involvement in collaborative goal setting, some outcomes of parental involvement, and insights into parents' perspectives on goal setting for pre-school aged children with cerebral palsy in the context of physical and occupational therapy (Jansen et al., 2003; Ostensjo et al., 2006; Siebes et al., 2006; Wiart et al., 2010). Yet little has been found about the aspects of parental participation such as: the role of parents in collaboration; what collaborative goal setting means to parents; and how parents' experiences compare with occupational therapists' experiences.

Despite the advantages of collaborative goal setting reported in the literature, Mayer, Prudhomme-White et al., (2002) discovered that occupational therapists found it difficult to step into a parent's 'frame of reference'. Therefore, therapists did not always capture parents' needs in their goal setting.

The inclusion of parents in collaborative goal setting is based on the assumption that parents want to have an active role in their therapy services at the time that a formal goal setting process takes place (Cahill, 1998; Jansen et al., 2003). Wiart et al., (2010) found that sometimes parents preferred less responsibility for identifying goals than assumed by therapists. The level of involvement parents want to have in therapy and in goal setting is unknown, and likely to vary from situation to situation. Jansen et al., (2003) suggested that not all parents find participation in therapy beneficial and advised that therapists should be

aware of the needs of specific families as enforced parental involvement could be counter-effective for some families.

It is often assumed that by involving parents in goal setting that they are equal contributors to their child's therapy goals and significantly influence the direction that the therapy service takes for their child (Jansen et al., 2003; Ostensjo, Oien & Fallang, 2006). However it is recognised that collaborative goal setting involves complex relationships among many stakeholders, and parents' experiences of participation in this process requires further exploration (Nijhuis et al., 2007).

There appears to be a gap in knowledge within the child and family literature, and occupational therapy practice in particular, about parents' experiences of participating in collaborative goal setting with therapists. Occupational therapy literature suggests that there may be a limited understanding of what collaborative goal setting means to parents. Consequently therapists may have limited awareness and understanding about the values and possible benefits and limitations of goal setting for parents who have children with disabilities. Occupational therapists and parents may share similar or different perceptions of collaborative goal setting. Lastly, it is unknown if, or how, parents or occupational therapists would like to see collaborative goal setting practices improve.

1.3 Aim of the Inquiry and Inquiry Research Questions

The aim of this inquiry was to explore parents' and occupational therapists' experiences of collaborative goal setting. This inquiry aimed to provide occupational therapists with valuable feedback from the perceptions of its service users and service providers about collaborative goal setting, and to contribute to knowledge in the child and family literature related to the collaborative goal setting experiences between service users and providers.

The overall research question addressed by this inquiry was: "What are the collaborative goal setting experiences of parents of children with disabilities and occupational therapists?"

This inquiry specifically aimed to answer the following questions:

- What does collaborative goal setting mean to parents and occupational therapists?
- Are there similarities and differences in collaborative goal setting experiences of parents and occupational therapists?
- How do parents and occupational therapists believe collaborative goal setting could be improved?

1.4 Definition of Terms

Key terms to be explored by this inquiry are defined as follows:

Meaning – is an idea, to have a specified degree of importance (Krebs & Wilkes, 1981); is determined by theory and is understood by theoretical coherence rather than correspondence by facts (Hesse, 1980). It describes the interpretations that people have of the world (DePoy & Gitlin, 2005). In this study, the meaning of collaborative goal setting will be defined by parent and occupational therapy participants. It is used to describe the impact that collaborative goal setting has for each group.

Goal – an internal representation of desired end-states, where states are broadly constructed as outcomes, events or processes; that one wants to accomplish; and is understandable, measurable, realistic and achievable (Austin & Vancouver, 1996; Dubas, 1999). In this study, the goal refers to specific intervention outcomes that target the child or the child's situation.

Collaborative goal setting – the process of agreeing on a desirable and achievable future state and is the first step in developing a plan of action (Law et al., 2003; Playford et al., 2000). It is considered a fundamental component to therapy services (Leach et al., 2010). It is a process used by therapists to set goals together with clients where clients actively participate in the goal setting, decision making and intervention planning processes. This involves respecting the client's individual family and social circumstances, discussing scope of the therapy relationship with the client, allowing for individual differences in daily routines and providing information to enable clients to make informed choices (Purtilo & Meier, 1995). In this study collaborative goal setting is a dynamic process between parents and occupational therapists used to identify their desired futures states for their child. It is used by parents and occupational therapists to develop an action plan for therapy intervention.

Parent – the primary caregiver of the child who receives occupational therapy services. This may include biological parent, foster parent, adopted parent or grandparent. This excludes educational staff such as teachers, early educators and school counselors. The terms client, consumer and patient may be used interchangeably with the term parent when reporting on non-family-centered based therapy literature. In this study, parents were mothers of children who received occupational therapy services and participated in interviews.

Therapist – In this study, therapist refers to the primary occupational therapist employed by Therapy ACT who is responsible for establishing goals and an intervention plan with the child and family receiving occupational therapy services.

1.5 Inquiry Assumptions

For the purpose of this inquiry the following assumptions were made:

- Goal setting is influenced by a set of internal and external factors that each participant brings to the therapeutic relationship.
- Occupational therapists are familiar with the rationale and benefits for collaborative goal setting with parents, client-centered practice and also family-centered philosophy of practice.
- Occupational therapists develop their own personal style and interpretation for collaborative goal setting through their own clinical experiences.
- Parents have an understanding of their family's uniqueness and needs. They may not specifically understand their child's disability, the role of occupational therapy or the purpose/use of collaborative goal setting.

1.6 Significance of Inquiry

The significance of this inquiry is that it has explored the collaborative goal setting experiences of both parents with children with varying disabilities and ages as well as occupational therapists. It has explored a wide range of participants' experiences of collaborative goal setting including: what parents and therapists need to know before they can engage in collaborative goal setting; how participants experienced goal setting; what the

impact of the goal setting experiences were for participants; factors that influenced their goal setting experiences and participants' ideas for improving collaborative goal setting.

This inquiry has attempted to step into the frames of reference of parents by exploring the perspectives of parents about their goal setting experiences. This inquiry has provided the researcher and the readers of this report with the opportunity to reflect on current collaborative goal setting practices and consider how it may be improved to facilitate parents' and their child's increased active participation.

1.7 Scope of the Inquiry

This inquiry has expanded upon current research by investigating the collaborative goal setting experiences of parents with children of varying disabilities and ages and occupational therapists. This inquiry has occurred within an Australian context, in Canberra, where occupational therapy services to all children with developmental disabilities and delays are provided by one public therapy service and local private providers. This inquiry has interviewed five mothers of children who are currently accessing occupational therapy services or have done so within the past twelve months of the time of the interviews. Five occupational therapists delivering services within this public therapy service have been interviewed. Therapists from other disciplines such as speech pathologists, physiotherapists, psychologists or social workers have not been included in this inquiry.

1.8 Summary of the Inquiry

This inquiry interviewed five parents of children with disabilities and five occupational therapists about their collaborative goal setting experiences. Interview data was triangulated with the goal setting documents in each child's file. Data was analysed thematically using constant comparison methods and five major themes with sub-themes emerged.

1.9 Outline of Thesis

This thesis is organised into six chapters. This chapter has presented the background to this inquiry; the purpose and significance for investigating parents and occupational therapists experiences of collaborative goal setting practice; the aim of this inquiry and research questions; defined key terms and also presented its assumptions, scope and significance.

The subsequent chapters to this thesis are outlined in Table 1.1 below.

Table 1.1 *Outline of thesis*

Chapter Two	A review of the literature which addresses the major variables under study: goal setting, the development of collaborative goal setting, the benefits of goal setting, its application to family-centered practice and review of key studies of therapists' and clients' experiences of collaborative goal setting.
Chapter Three	The methodology for this inquiry is described including the theoretical underpinnings of Qualitative Research, Naturalistic Inquiry and Phenomenology. The data collection and analysis methods of participant interview, file review and constant comparison analysis is presented. Information about the participants is outlined including sampling, recruitment and gaining access. Limitations of the design and credibility and transferability are discussed.
Chapter Four	The inquiry findings are presented in text and diagrammatic forms. Five themes with sub-themes are identified and discussed. Similarities and differences experienced by parents and occupational therapists are presented throughout the chapter and summarised into a diagram at the end of the chapter.
Chapter Five	The five themes and sub-themes are discussed in relation to the existing literature on collaborative goal setting practices.
Chapter Six	An overview of the inquiry is presented and the significance of the inquiry findings is discussed. Limitations of the inquiry are presented and avenues for further investigation and intervention are outlined.

Chapter 2

Review of the Literature

2.1 Introduction

The purpose of this review is to provide background to the major variable addressed in the research: collaborative goal setting. Aspects of goal setting discussed in the review include: the development and use of collaborative goal setting in occupational therapy practice; the reported benefits of collaborative goal setting; factors influencing goal setting experiences; and the role of collaborative goal setting in family-centered practice. Studies that have investigated therapists' and clients' experiences and perspectives of participating in goal setting practice will be discussed and gaps in current knowledge will be highlighted.

Occupational therapists are taught about client-centered practice and collaborative goal setting practice as part of their undergraduate training (Law et al., 1991; Pollock, 1993). They continue to develop their goal setting skills throughout their clinical practice. Work place policies and additional training in the utilisation of goal setting tools and outcome measures are common practices in many service provision systems that adopt a family centered approach. As a professional group, it is assumed that therapists share a collective understanding of goal setting, its benefits and influences in shaping their professional role and demonstrating their accountability (Hurn et al., 2006; Ottenbacher & Cusick, 1990). Occupational therapists typically lead and modify the goal setting process to the family's needs in order to establish therapy goals and an action plan that all stakeholders work towards achieving (Law et al., 2003). Through their day to day clinical experiences, individual occupational therapists develop their own interpretation and personal style of collaborative goal setting.

2.1.1 Definition of key terms

Austin and Vancouver (1996) define a *goal* as “an internal representation of desired states, where states are broadly constructed as outcomes, events or processes” (p. 338). Amman (1996) clearly distinguishes between goals and objectives. She agreed with Austin and Vancouver that goals are the desired outcomes of organisations, teams and individuals

whereas objectives are the activities that facilitate the attainment of goals and allow measurement of progress. There is evidence within the literature that goals directly affect a person's focus of attention, effort, motivation and persistence, and may also affect problem-solving activities and lead to positive outcomes (Leach, Cornwell, Fleming & Haines, 2010; Locke and Latham, 1990; Theodorakis, Malliou, Papioannou, Beneca & Filactakidou, 1996). Theodorakis et al., (1996) note that goals do not affect performance alone, rather, they function in conjunction with other psychological variables that positively affect performance including self-efficacy, ability, self-satisfaction, goal level and extent to which goals are 'owned'.

“Goal setting is the process of agreeing on a desirable and achievable future state” (Playford et al., 2000, p.14). It involves establishing a goal and modifying it as necessary and is the first step in developing any plan of action (Law et al., 2003). Setting goals collaboratively fosters cooperation, enhances realistic expectations, encourages joint-decision making and helps clients develop and maintain a sense of ownership and control of their intervention. It is also seen to improve client satisfaction and individual client health and sense of well-being (McLaren & Rodger, 2003; Playford et al., 2000).

The occupational therapy literature has established the essential place of client collaboration in goal-setting in the therapy process. It has demonstrated how it enhances therapy outcomes and can be used to evaluate occupational therapy service intervention (Barclay, 2002; Cusick et al., 2006; Hurn et al., 2006; Leach, et al., 2010; McLaren & Rodger, 2003; Ottenbacher & Cusick, 1990; Turner et al., 2008). Playford et al., (2000) for example, state that goal setting in the rehabilitation field “is often tied to the assessment process which legitimately addresses pathology, impairment and disability as well as handicap and is clearly professionally owned” (p. 495).

2.2 History of Goal Setting Practices

The individualised goal setting approach to human service provision evolved from the work of Locke (1968), Locke and Latham (2002), Ryan (1970) and Kiresuk and Sherman (1968) who developed the Goal Attainment Scale (GAS). Goal setting practice developed from Locke's work which focused primarily on motivation for goal-driven behaviour within the

workplace. The GAS developed out of adult mental health practice as a standardised method for program evaluation to measure the effectiveness of individualised goals (Malec, 1999).

Prior to the use of individualised goal setting practices, programs were evaluated through the use of standardised measurement instruments. These standardised measures often failed to capture an individual's problems and ignored a person's individuality (Hurn et al., 2006). Leach et al., (2010) identified that using standardised measures provided therapists with a starting point on which to centre goal setting discussion with patients and families. However, goals that were developed from the standardised assessments tended to remain focused at the impairment level of the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2001) rather than the participation or activity levels which were generally of more concern to the client.

Since 1968 goal setting practice has evolved in both the manner in which goals are set, what they are called and also their functions. Goal setting terms have included 'goal planning', 'goal achievement', 'individual programme planning', 'individual planning process', 'individualised family service planning' and 'individual education planning' (Carnaby, 1997; Centre for Developmental Disability Studies, 2004; Decker, 1992; Hurn et al., 2006).

Goal setting practice has evolved as therapy and health care practices have changed. Under a medical model, 'patients' were initially passive recipients of therapy directed goals (Hurn et al., 2006). In this way therapists were viewed as experts and holders of knowledge for the patient's rehabilitation and goal achievement process (Cahill, 1998; Playford et al., 2000). The use of patient participation in health care became wide-spread in the 1980s when governments began to recognise the importance of the views and wishes of consumers in actively participating in their health care (Cahill, 1998). The utilisation of goal setting tools such as the Goal Attainment Scale became more widely adopted by health care professionals beyond mental health practice to facilitate patient participation in goal setting (Cusick et al., 2006; Hurn et al., 2006).

During the 1990s studies investigating the efficacy of collaborative goal setting began to appear in health care literature including occupational therapy literature (Haas, 1995; Neistadt, 1995; Purtilo & Meier, 1995). For example, Neistadt (1995) studied 269 occupational therapy directors to investigate occupational therapy assessments of clients' priorities on admission in adult physical rehabilitation facilities in the USA. She found that clients who collaborated on their treatment goals made statistically and clinically significant gains in their ability to perform self-care and community living skills. However, she also reported that the majority of occupational therapists used informal interview techniques to determine clients' priorities and that client goals obtained from these informal interviews were vague. Ottenbacher & Cusick (1990) also criticised traditional occupational therapy goal setting techniques as vague, global and without definite timeframes for achievement, often resulting in goals that were irrelevant, immeasurable and unattainable. They raised concerns about the practices of occupational therapists who set goals with little or no input from clients and significant others, indicating that without collaboration, the social and functional validity of the goals was questionable.

The evidence for the positive impact of collaborative goal setting further defined occupational therapy practices over two decades. Client-centered therapy involving the concepts of individual autonomy and choice, partnership, therapist and client responsibility, and enablement, has become central to occupational therapy philosophy and practice (Barclay, 2002; Canadian Association of Occupational Therapists, 1997; Pollock, 1993; Turner et al., 2008). Under the Australian Association of Occupational Therapists Code of Ethics, occupational therapists are required to provide clients, and others who are significant to the client situation, with autonomy by engaging them as active participants in any decision making regarding their involvement in services (AAOT, 2001 p. 3).

Since the establishment of client-centered practice, specific occupational therapy goal setting tools such as the Canadian Occupational Performance Measure (COPM) (Law et al., 1990), the Self Identified Goal Assessment (SIGA) (Link-Melville et al., 2002) and the Occupational Performance History Interview (OPHI-II) (Kielhofner et al., 1998) have been developed to evaluate occupational therapy services and determine intervention outcomes. Occupational therapists are increasingly required to demonstrate and document the outcomes of their

interventions, to demonstrate the value of their role to clients, and to receive recognition and reimbursement for their services (Ottenbacher & Cusick, 1990; Unsworth, 2000). These standard goal setting tools are thought to facilitate collaborative goal setting practices between clients and occupational therapists.

Ennals and Fossey (2007) identified that the implementation of client-centered practice by occupational therapists appeared to be more challenging than the theoretical principles suggested, particularly in mental health settings. They conducted a naturalistic inquiry within Victorian public community mental health services with four occupational therapists and six mental health consumers. They investigated how consumers and occupational therapists viewed the occupational therapy interview process using the Occupational Performance History Interview (OPHI-II) (Kielhofner et al., 1998). Specifically they aimed to explore whether occupational therapists explored and valued consumers' lived experiences of mental illness and its impact on their lives, and whether they established a genuine sense of partnership and shared direction in their work with consumers. They found that "the OPHI-II experience was generally valued by participants but therapists also felt challenged by the experience" (p. 17). They identified six themes through their study, three of which were shared by consumers and therapists: "It makes staff very uncomfortable to hear it"; "I just didn't realise how strongly she felt about it"; and "Time to talk matters" (Ennals & Fossey, 2007, p. 17). They demonstrated support for using standard consumer goal setting interviews, such as the OPHI-II, to set goals that held meaning for consumers as a means to implement client-centered occupation focused practice. Limitations in their study included a small number of participants from one Australian community mental health service only, and member-checking of only three of the six consumer participants. It is not known whether the consumer participants' experiences described in this study would be shared by other consumers. There is no documented evidence that the OPHI-II for example, has been implemented into a community-based child and family occupational therapy setting or whether this is feasible. However this study does provide some insight into the value and benefits of seeking clients' and therapists' perceptions when investigating collaborative goal setting practices in occupational therapy practice. It also supports the proposal by Nijhuis et al., (2007) that collaboration is complex.

Therapist and client experiences of collaborative goal setting are currently of topical interest in the literature. Two studies published by the journal, *Disability and Rehabilitation* in 2010 have investigated this phenomenon. Leach et al., (2010) explored therapists' perspectives of goal setting with adults in a sub-acute rehabilitation setting in Queensland. Therapists were interviewed from the disciplines of occupational therapy, physiotherapy and speech pathology using semi-structured email interview techniques. Leach et al., (2010) identified three goal setting approaches including therapist controlled, therapist led and patient focused. They categorised goal types according to International Classification of Functioning Levels (WHO, 2001) and explored barriers and facilitators to patient-centered goal setting approaches. In this study, only one therapist engaged in patient-focused goal setting practice and used the Canadian Occupational Performance Measure (COPM) to facilitate her goal setting process with her client. The authors reflected that the COPM was able to provide the therapist with structure for the goal setting process and also assisted the patient to reflect on occupation based activities in light of their acquired disability. Leach et al. also noted that patients and families needed to be oriented to the term goal and the goal setting process through education from the therapists. They reported that "ensuring a shared understanding of these terms was seen as imperative to the therapists" (p.168). Patient and family education was viewed by therapists as "integral to the goal-setting process" (p. 169) by those therapists who used therapist led or patient focused approaches to goal-setting as it enhanced the therapist-patient interactions and goals set. Leach et al. further identified some limitations with their study that were similar to those identified in the Ennals and Fossey study (2007). These included a small sample size, limitation to one facility, and that participants selected as case examples were receiving intervention from all three disciplines, indicating that the views of these participants may not have represented other patients in the unit. It is also noted that the in-depth, email communication exchange used in that study was a new phenomenon that may have resulted in lack of interpersonal relationships between parties in the interview process. However, the study does provide further insight into the challenges of facilitating client or patient centered collaborative goal setting. The authors recommended that future research could investigate the meaning behind the terminology associated with goal setting as perceived by clients and therapists.

A second contemporary study to explore the phenomenon of parents' perceptions of goal setting published by the journal *Disability and Rehabilitation* is by Wiart et al., (2010). They

explored parents' experiences with goals and goal setting by interviewing parents of pre-school aged children with cerebral palsy living in western Canada. They conducted eleven focus groups and two individual interviews with thirty-nine parents. The specific aims of their study were (1) to gain an insight into the types of goals and processes for setting occupational therapy (OT) and physiotherapy (PT) goals that are meaningful to parents, and (2) to determine if parents' experiences with OT and PT are congruent with the emphasis in the literature on functional goals and collaborative goal setting (Wiat et al., 2010 p. 249). The authors identified four themes that reflected the content of goals that were meaningful to the parents and one theme that addressed parents' experiences with the process of establishing goals. The final theme, described as "shifting roles and responsibilities in goal setting" (pp. 253-254) resonates with the clinical experiences that prompted the current study reported in this thesis. Wiat et al., (2010) reported that although the parents engaged in collaborative goal setting with therapists:

they often felt that there was a mismatch between the extent of the guidance they preferred and the input they received from therapists [and that] some parents did not feel comfortable in identifying reasonable and attainable goals, particularly when their children were young (p. 254).

Wiat et al., (2010) indicated that parents' perceptions of the level of involvement that they wanted in the goal setting process were related to the age of their child. They also identified that parents wanted to benefit from the knowledge and experience of the therapists when setting realistic goals for their children. For example one mother of a seven year old girl with a Gross Motor Functional Classification System level of V stated "please don't run around and think Mom is an expert. I live with her but I don't know what the possibilities are" (p. 254). This study was limited to parents of pre-school aged children with cerebral palsy living in Canada and cannot be generalised to all families. Only two parents participated in in-depth interviews and the authors reported that they were not able to establish a full understanding of the factors that influenced either the goals that are important to parents or their desired roles in setting goals for their children (p. 256). Although the authors described prolonged engagement with their research data, there was no evidence of member checking or triangulation of data to improve the credibility of the findings.

Although the research aims of the study by Wiart et al., (2010) are similar to those recorded in this thesis, this study has used different methodology techniques, a different sample of parents of children with varying disabilities and ages living in Canberra, Australia, and it specifically aims to explore both parents and occupational therapists' experiences of collaborative goal setting.

2.3 Roles in Goal-Setting and Ownership of Goals

Engaging clients in the goal setting process is assumed to facilitate the shared ownership of the goals between the occupational therapist and the client. Studies have described how participants in goal setting have different perceptions of goal setting ownership in any one situation, or the need to be involved in goal setting. The first is where ownership of the goal and goal setting process is perceived to lie primarily with the person providing the service to the client, such as the therapist. Playford et al., (2000) explored the views of sixteen rehabilitation staff on the ownership of goals in the rehabilitation process. They described two types of goals, those that were negotiated with clients and those that were not. They reported that the rehabilitation team assumed primary ownership of the goals when clients have to come to terms with their difficulties. Goal setting that is done primarily by team members, but understood by the client may help clients take a more direct path towards their final destination. Furthermore, they suggested that therapy owned goal setting be carried out for clients, in the absence of client capacity to effectively communicate their own needs. Goals generated by the team reportedly helped the rehabilitation team work coherently and productively (Playford et al., 2000 p. 494). The researchers stated that "the advantages of goal-setting for both teamwork and the efficacy of a unit is clear [however] the difficulties that arise centre around the perceived benefits for patients" (Playford et al., 2000 p. 494).

In instances where clients were unable to assume ownership of goals and the goal setting process, Playford et al., (2000) suggested that they be given the opportunity to assume some autonomy over goals. Playford et al., (2000) argued that "autonomy should be regarded as task-related rather than plan-related" (p. 495) and emphasised the importance of patients active participation in goal setting at some level to maintain a sense of autonomy. They presented Spriggs' (1998) work from concentration and labour camp experiences to support this proposition. Spriggs demonstrated that autonomy was possible even in situations in which long-standing assumptions are challenged or lost.

Second, the locus of control in goal setting is perceived to lie with the client, or shared equally between client and therapist. In a single-case designed study, Barclay (2002) investigated the factors that influenced the goal setting processes between an adult client following a spinal cord injury and the occupational therapist. This study demonstrated how with therapy input in the collaborative goal setting process the patient learned how to set therapy goals, resulting in the client's perception that he owned the therapy goals. By contrast the occupational therapist perceived the goals were shared by both herself and the patient. Moreover, she believed that she had ultimate responsibility in deciding what would or would not be worked on to ensure that goals set were set realistic. This raises questions about the extent to which the locus of control for establishing goals was shifted from therapist to client (Barclay, 2002).

Including clients in collaborative goal setting practice is based on the assumption that clients want to have an active role in their therapy services (Cahill, 1998; Jansen et al., 2003). Whether clients want or should have complete ownership and control for goal setting is debated. For example a study by Link-Melville et al., (2002) investigated thirty adult sub-acute medical patients' perspectives of participating in occupational therapy goal setting using the Self Identified Goals Assessment. They found that twelve patients reported that the patient should have sole responsibility for goal setting; thirteen reported that goal setting should be a joint responsibility between occupational therapist and patient and four believed that the goal setting responsibility should rest solely with the therapists.

Jansen et al., (2003) reviewed and evaluated eighteen studies published between 1980 and 2000 on the effects of parental participation in physical therapy for children with physical disabilities. They described the current belief that parents should be actively involved with therapy as equal partners in deciding goals and content for therapy for their children. This belief was reported to be based on positive effects on children's functioning as well as some limited studies investigating the effects on parents. They proposed that "parental participation may be beneficial for some parents, but not for all of them" (Jansen et al., 2003 p. 67) especially for parents who already have low coping resources. They reported a study by Miller, Gordon, Daniele & Diller (1992) which compared mothers of children with disabilities with mothers of children without disabilities. They found that thirty three percent of stressful

situations identified by mothers of children with disabilities involved interactions with medical professionals. This was more than the amount of stressful situations involving home, school or family (Miller et al., 1992). Jansen et al., (2003) advised that therapists must be aware of the needs of specific families as parental involvement may be counter-effective for some. Jansen et al., (2003) also advised that caution must be taken when drawing overall conclusions from their literature review. The studies they reviewed lacked randomisation and other controls and those studies with more rigorous research methods did not specifically question the effects of parental participation on parents.

Further investigation that specifically compares and contrasts parent's perspectives on the roles and meanings that they experience when participating in collaborative goal setting with therapists' perspectives is warranted. The studies reviewed above raise questions regarding the extent to which perceptions of clients and therapists may differ based on the capacities and needs of those in the client situation, whether the extent to which differing perceptions relates to either stages of the goal setting process, and the personal style of the therapist who is facilitating the goal setting (Barclay, 2002; Ennals & Fossey, 2007; Leach et al., 2010; Jansen et al., 2003; Link-Melville et al., 2002; Playford et al., 2000; Wiart et al., 2010).

2.4 Factors Influencing Goal Setting

Within the goal setting literature a number of factors have been identified that influence the goal-setting process. Barclay (2002) summarises her literature review on therapist and patient factors that influence goal setting and proposed a model of factors that influenced the goal setting process (see Figure 2.1). She described and hypothesised both internal, individual patient factors as well as external, therapist-patient relationship factors that influenced goal setting. Individual factors that impact on goal setting included: patient's motivation, prior beliefs about illness and past experiences of illness and chronic disability, institutionalisation and learned helplessness, patient understanding of what goals are, patient's sense of grief and ability to make a rational choice, and whether the patient perceived that the goal was relevant or realistic to them (Barclay, 2002).

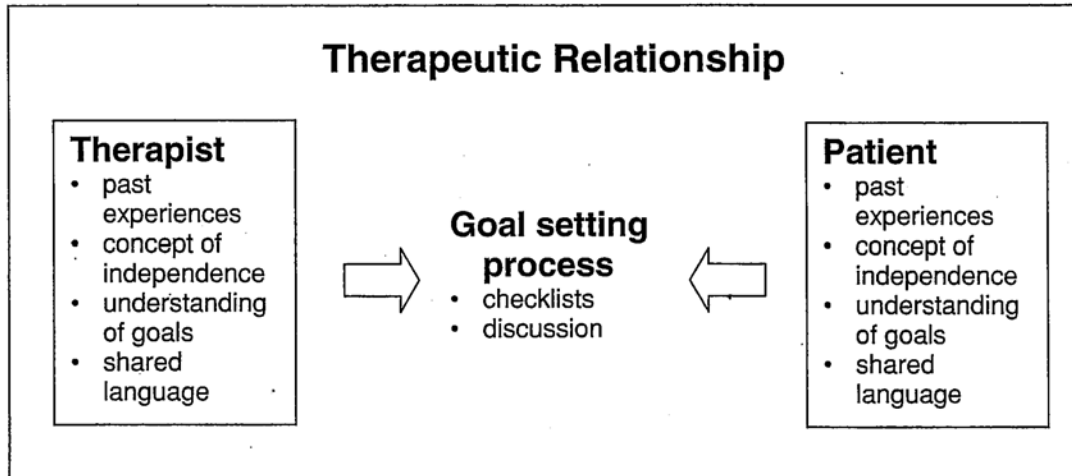


Figure 2.1 Barclay's (2002) model of factors influencing collaborative goal setting

Theodorakis et al., (1996) also discussed personal factors that influenced goal choices. These included how confident a person felt about achieving the goal; the discrepancy created by what an individual does and what they aspire to achieve; and whether goals are assigned or personally owned and levels of past performance. Other internal factors described by Maitra & Enway (2006) include the client's perceived value of participating in goal-setting, satisfaction with or benefit from occupational therapy as well as age and gender.

External factors that impact on goal setting hypothesised by Barclay (2002) were associated with the therapist-patient relationship, including the quality of the relationship and the shared language used between the therapist and patient. Ennals and Fossey (2007) also identified personal factors of the therapist such as friendliness and normality of relationship between consumer and occupational therapist as external factors impacting on collaborative goal setting. Service delivery models and service policies also impact on the collaborative goal setting processes between occupational therapists and parents. They provide the context and the service requirements for collaborative goal setting, including what documentation needs to be completed. For example, at Therapy ACT, where this study was carried out, therapists are required to establish a therapy action plan which reflects the client's and family's current priorities and this is to be reviewed at the end of the intervention cycle (Therapy ACT, 2010).

2.4.1 Clients learning to goal set

One factor which has been identified as influencing collaborative goal setting experiences is the clients' knowledge about how to participate in collaborative goal setting with therapists. In her study, Barclay (2002) learned that although the patient was familiar with goal setting terminology, such as the use of SMART goals (Specific, Measurable, Achievable, Realistic, Time frame), he still required more structure such as the use of checklists to develop his ability to identify his own goals. Through the collaborative goal setting process this patient learned about the implications of his newly acquired disability, what goals to set with his occupational therapist, and how to set and work through these goals. Barclay reported that this contrasted with the occupational therapist who had a clear idea of the likely outcomes for this client. The use of goal setting tools such as the Canadian Occupational Performance Measure, Goal Attainment Scale, Self Identified Goals Assessment or Occupational Performance History Interview may also help clients learn to goal set. It is unknown what parents or occupational therapists think about the utilisation of such tools in child and family practice, or how informal goal setting processes used by most therapists might be used to inform clients about how to develop and revise goals.

A study by Turner et al., (2008) specifically explored the extent to which goals and the ability to set goals varied over time and according to stage of recovery from an acquired brain injury (ABI). In their study, sixty people with an ABI were allocated into two groups: (i) a post-acute subgroup and (ii) a long-term subgroup. Participants completed a Self-Awareness of Deficits interview which included a goal setting component at initial assessment and again at twelve month follow up assessment. The aims of the study were to develop a framework for classifying the nature of goals identified by people with an ABI and to explore the extent to which goals and the ability to set realistic goals varied over a period of time and according to stages of recovery (Turner et al., 2008, p.98). As well as developing a classification framework of self-identified goals following an ABI, the authors found that the nature of goals changed over time as the participant's ability to set realistic goals improved over time regardless of stages of recovery of participants. This suggested that the ability to set realistic goals was influenced by factors other than the stage of recovery. They proposed that the initial focus of therapy may require enhancing self-awareness prior to goal setting in collaboration with clients in order to maximise client involvement in realistic goal setting. They identified that further research was required to explore how other factors impact on an

individual's ability to set realistic goals over time. They also suggested that a more in-depth process of inquiry that explores individuals' rationale for identifying particular goals at a given stage of recovery may assist our understanding of factors influencing goal setting.

These internal and external factors may also impact on the collaborative goal setting process for parents who have children with disabilities and occupational therapists. Barclay (2002) stated that her "study cannot be generalised to all situations where goal setting occurs between a therapist and patient" (p. 10) due to the small size of the study. Barclay's study was also limited to an adult patient in a rehabilitation setting. This client experienced a spinal cord injury where he personally lost previous occupational roles and due to life circumstances was required to re-establish roles for himself. The study presented by Turner et al., (2008) was also limited to an adult-based client population, specifically the goal setting abilities of adults following an ABI, although it tried to overcome sample size difficulties by interviewing sixty participants. Parents who have a child with a disability also go through periods of grief following diagnosis and during milestones of their child's development where family roles are changed and challenged (Dyke et al., 2006; Lovett & Haring, 2003; McLaren & Rodger, 2003). There may be other factors that impact parents and occupational therapist collaborative goal setting experiences such as the influence of other service providers including school teachers, equipment funding bodies and other therapy services. This study aims to expand on the work of Barclay (2002) and others (Ennals & Fossey, 2007; Maitra & Enway, 2006; Theodorakis et al., 1996; Turner et al., 2008; Wiart et al., 2010) to investigate the collaborative goal setting experiences of parents and occupational therapists. It also intends to explore and compare meanings that parents and occupational therapists have about their collaborative goal setting experiences and factors that may impact on their goal setting experiences.

2.5 Collaborative Goal Setting in Family Centered Practice

Within the child and family services literature there is considerable support for the use of collaborative goal setting in family-centered practice and it is considered best practice for services provision for children with disabilities (King et al., 2004; Jansen et al., 2003; Novak & Cusick, 2006; Palisano et al., 2004; Wiart et al., 2010). Collaborative goal setting is used to set goals with parents, children and therapists to develop a plan for service provision. Using this therapy service framework, parents are engaged in all aspects of the therapy

process, including collaborative goal setting, to encourage active participation, ownership and develop knowledge to enhance the quality of life for all family members (King et al., 2004; Ostensjo et al., 2006). Collaborative therapist-parent goal setting is viewed as a pivotal part of the family-centered process and has many benefits including encouraging joint-decision making between families and therapists, identifying the unique needs of the family, and improving parental follow-through of suggestions at home (King & Patterson, 2000; Knox et al., 2000; Law et. al., 2003; Mayer et al., 2002; McLaren & Rodger, 2003; Novak & Cusick, 2006). Cusick et al., (2006) recommend that researchers and therapists should be “willing to consider parents as informed experts able to contribute meaningfully to [goal setting] through identification of goal[s]” (p. 155). King et al. (2004) have concluded that family-centred services, involving parents in goal setting, are effective in meeting outcomes for children and families.

Wiat et al., (2010) specifically explored parents’ experiences of participating in goal setting with occupational therapists and physiotherapists regarding their pre-school aged children with cerebral palsy. They identified that “little is known about the types of goals that are important to parents” (p. 249) of children with cerebral palsy and that “even less is known about how parents perceive the process of goal setting with therapists” (p. 249). Children with cerebral palsy have heterogeneous disorders of movement and postures with varying levels of functional impairments. The primary goal of occupational therapy and physiotherapy intervention is to enhance the child’s functional abilities by either providing interventions to change the child, the task or the environment (Palisano, Snider & Orlin, 2004; Wiat et al., 2010). Parents in the study by Wiat et al. (2010) identified that most goals were related to their children’s happiness and being accepted and valued by others rather than improving the ways their children moved. They believed that self-initiated movement was important for their child to achieve functional independence and some parents also focused on the need to enhance on their child’s physical fitness. This was the first study to explore the types of goals set by parents of children with cerebral palsy.

Despite increasing research in the area of goal setting practice, a gap remains in the literature about parents’ and therapists’ collaborative goal setting experiences; what collaborative goal setting means to parents and occupational therapists and how they believe collaborative goal

setting could be improved. The purpose of this inquiry was to address these current gaps in knowledge.

2.6 Summary and Findings

This literature review has provided a background to the current state of knowledge about collaborative goal setting. A review of goal setting development, usage and benefits was presented along with recent research published related to participants' experiences of collaborative goal setting from the occupational therapy, adult rehabilitation and family and child practice literature. Findings that were generated from the review indicated that:

- Collaborative goal setting is seen to be an essential element of both occupational therapy and family-centered practices as it enhances therapy outcomes and can be used to measure and demonstrate the effectiveness of therapy intervention.
- Locke established the practice of collaborative goal setting in 1968. This facilitated the move away from a medical model of service provision where decisions were made for clients to the current practice of involving clients in decision making about their health care and service provision.
- Occupational therapists have been involved in developing specific tools to support therapists to engage clients in collaborative goal setting practices. However, therapists have continued to identify challenges with involving clients in collaborative goal setting practice.
- Clients have indicated that they wish to be involved in collaborative goal setting however the extent of their involvement varies and they value the input of the therapists in this process.
- There are many internal and external factors impacting on therapists' and clients' collaborative goal setting experiences.
- Clients appear to learn how to goal set by prolonged engagement in therapy and goal setting with therapists.
- Collaborative goal setting is considered best practice in child and family practice, however there is limited research available about how parents experience collaborative goal setting practices.

This literature review has identified current gaps in knowledge regarding parents' and occupational therapists' experiences of collaborative goal setting; what collaborative goal setting means to parents and occupational therapists experiences; and how they believe collaborative goal could be improved. There also remains a gap in relation to how parents who have children with disabilities experience collaborative goal setting in comparison to occupational therapists. The following chapter details the methods used in this study to attempt to address these gaps in current knowledge.

Chapter 3

Methodology

3.1 Introduction

This qualitative research inquiry developed out of clinical work experience by the principal researcher as a paediatric occupational therapist who engages in collaborative goal setting with parents as well as child and adult clients. As stated in Chapter One, this inquiry aimed to explore the experiences of collaborative goal setting of occupational therapists and parents who have children with disabilities that receive occupational therapy services, as there is currently limited literature available on this topic. The theoretical underpinnings of this inquiry stem from various qualitative research approaches and incorporates aspects of interpretivism, naturalistic inquiry and phenomenology. As the focus of this inquiry is exploratory in nature, seeking to increase understanding about parents' and occupational therapists' experiences of collaborative goal setting rather than generating or testing a theory, it relies on inductive and open-ended data collection and analysis methods. This chapter will discuss the theoretical underpinnings of this research inquiry and demonstrate the researcher's data collection and analysis methods.

3.2 Theoretical Perspective

This qualitative inquiry is framed within an interpretive theoretical approach. The epistemology is naturalistic inquiry and uses phenomenological methodology. These theoretical underpinnings have oriented the interpretation of the data collected (Bednarz, 1985; Cantrell, 2006).

Qualitative rather than quantitative research methods best support this inquiry as it aimed to explore the personal experiences of collaborative goal setting. Qualitative research is conducted when a complex, detailed understanding of an issue is required. Creswell (2007) posits that "this detail can only be established by talking directly with people...and allowing them to tell their stories unencumbered by what we expect to find or have read in the literature" (p.40). It has been used in occupational therapy research to focus on peoples' own

perspectives, views, and experiences and typically occurs in the participants' natural environment in order to capture its complex social interactions (Barclay, 2002; Dubas, 1999; Ennals & Fossey, 2007; Hooker, 2008; Link-Melville et al., 2002; Mayer et al., 2002; Whiteford, 2005). This inquiry focuses on the complex, social process of collaborative goal setting between therapists and parents of children with disabilities.

Interpretivism has been selected as one of the theoretical underpinnings for the research because the purpose of this inquiry is to explore parents' and occupational therapists' experiences of the social event of collaborative goal setting, and the meaning they ascribe to them. Interpretivism aims to understand and interpret daily experiences and social structures as well as the meanings people give to the phenomena by examining the whole phenomena through human interaction (Cantrell, 2006; Lincoln & Guba, 1985; Williams, 2006). The findings from this inquiry about participants' experiences of collaborative goal setting were developed through the social interaction between the researcher and the interviewed participants. The researcher interpreted participants' meanings about their collaborative goal setting experiences through the data collection and analysis processes. Knowledge about participants' experiences of and meanings about collaborative goal setting were generated by multiple constructions from various participants that differed across interview sites and times (Cantrell, 2006; Green, 2002; Lincoln & Guba, 1985; Neill, 2006). Interpretivism views the researcher as an active component of the inquiry through the contribution of tacit and human knowledge to understand and interpret the nuances of the multiple realities collected from the data (Cantrell, 2006; Lincoln & Guba, 1985). In this study, the primary researcher is an occupational therapist who has engaged in the process of goal setting with parents of children with disabilities. It is upon this background knowledge and experience that interpretations of participants' experiences are made.

This inquiry does not view knowledge from a positive perspective, whereby the knower and the known are independent of each other, and events are explained based on knowable facts. It does not intend to discover causal relationships, laws or make generalisations to explain reality and allow predication (Cantrell, 2006; Lincoln & Guba, 1985). Neither is this inquiry framed within critical science, as its focus is on understanding and interpretation rather than emancipation and critique of ideologies (Cantrell, 2006; Neill, 2006).

Naturalistic inquiry is a broad approach that captures the variety of other qualitative approaches such as ethnography, case study, interpretive inquiry, and phenomenology, and was developed by a range of disciplines (Williams 2006). It is a disciplined mode of inquiry conducted in natural settings, such as the usual workplace of the researcher; in natural ways by people who have natural interests in what they are studying, including practitioners, counsellors and administrators (Williams, 2006). It has been selected for this inquiry because the researcher is an occupational therapist working at Therapy ACT and participates in collaborative goal setting with parents and clients. Collaborative goal setting is part of the typical service planning process between parents who have children with disabilities that access Therapy ACT and occupational therapists (Therapy ACT, 2010) and is therefore a natural phenomenon for parents and occupational therapists. Through collaborative goal setting experiences with clients, the researcher has developed a desire to understand what parents' and other colleagues' experiences of goal setting are, and what meanings they attribute to this phenomenon.

Phenomenology is the particular methodology underpinning this inquiry, as it aimed to study the phenomenon of collaborative goal setting experiences by several parents and occupational therapists (Creswell, 2007; McCaslin & Wilson Scott, 2003). A phenomenologist assumes that human experience makes sense to those who live it and that human experience can be consciously expressed (Dukes, 1984). In this study, the researcher reduced data gathered from semi-structured interviews and textual records of goal setting documents in client files to describe the shared experiences of several informants, creating a central meaning, or "essence" of the goal setting experience. Starks and Brown Trinidad (2007) asserted that "phenomenology contributes to a deeper understanding of lived experiences by exposing taken-for-granted assumptions about these ways of knowing" (p. 1371). This inquiry is viewed as a phenomenological study as it seeks to explore the shared everyday clinical experience (i.e. the phenomenon) of collaborative goal setting from the perspectives of several parents and occupational therapists. Knowledge derived about goal setting experiences was subjective and gained through the embodied perception from the parents and occupational therapists that were interviewed. The knowledge found was described as "what" and "how" the participants experienced collaborative goal setting (Starks & Brown Trinidad, 2007).

Discourse analysis was not selected as this inquiry did not seek to explore how language used by participants shaped and reflected their goal setting experiences (Starks & Brown Trinidad, 2007). Instead it aimed to seek the core commonality and structure of participants' collaborative goal setting experiences. Neither was grounded theory selected to guide the study, as it was not the intention of this inquiry to develop an explanatory theory about collaborative goal setting practices (Starks & Brown Trinidad, 2007).

Table 3.1 below has been adapted from Figure 1 in Starks and Brown Trinidad 2007 (p. 1373) and summarises the application of phenomenological inquiry to this study.

Table 3.1 *The application of phenomenology methodology into this inquiry*

Philosophy	Collaborative goal setting experiences are a perceived reality shared by participants with common features between participants.
Goal of inquiry	To describe the meaning of the lived experience of the phenomenon of collaborative goal setting of parents and occupational therapists.
Methodology	What is the lived experience of the phenomenon of collaborative goal setting experiences of parents who have children with disabilities and occupational therapists?
research question	
Sampling	Those parents and occupational therapists that have recently experienced collaborative goal setting. Purposive sampling techniques used.
Data collection	Participants described their collaborative goal setting experiences. The researcher probed for details and clarity. Client files were reviewed to triangulate goal setting documents with interview data.

Analytic methods	Identified descriptions of the phenomenon of collaborative goal setting experiences; clustered units into discrete categories; taken together these described the “essence” of core commonality and structure of the collaborative goal setting experiences.
Audience	Therapists, therapy service managers and researchers who need to understand the lived experiences of collaborative goal setting experiences of parents who have children with disabilities and occupational therapists.
Product	A thematic description of the “essences” and structures of the lived experiences of collaborative goal setting.

3.3 Participants

Occupational therapists working with children and families at Therapy ACT, and parents who have accessed occupational therapists for their child/ren at Therapy ACT within twelve months of the time of recruitment were invited to participate in this research inquiry. It was assumed that these participants had engaged in collaborative goal setting in accordance with Therapy ACT family and person focused practice policy (Therapy ACT 2010).

The criteria for inclusion in this inquiry were that participants:

- Had the ability to provide written and informed consent.
- Consented to being interviewed and tape recorded.
- Had the ability to communicate at a level that allowed active participation in interviews in the English language or through the assistance of an interpreter.
- *Parent participants:* had a child or children that had accessed occupational therapy through Therapy ACT within 12 months of being interviewed or was currently receiving an occupational therapy service. Had not received a service from the principal investigator within 24 months of the time of interviews
- *Occupational Therapist participants:* Currently worked with children and families at Therapy ACT.

3.3.1 Recruitment process and gaining access

Interested parents and occupational therapists who met the inclusion criteria volunteered to become involved in the inquiry. Advertisements (see Appendix 1) were placed in waiting rooms at Therapy ACT sites and in the Early Childhood Association Australia ACT branch newsletter.

Letters inviting parents to participate were sent by the researcher once parents had contacted the researcher to express an interest in participating in this inquiry. Service data bases and client files were utilised to ensure that parents met the inclusion criteria and to retrieve goal setting documents.

Gaining access to occupational therapy participants occurred through contact with occupational therapist participants via the Senior Occupational Therapist at Therapy ACT who sent a generic, email invitation to all occupational therapists who fulfilled the inclusion criteria. Those invited were informed by the Senior Occupational Therapists that their treatment at Therapy ACT would not be influenced at all by their decision to participate in this research study or not. This eliminated possible coercion of junior staff to which the researcher provides professional support during the usual professional role and minimised coercion by the Senior Occupational Therapist to junior staff.

Potential parent and occupational therapist participants were provided with information about the purpose of the inquiry, their rights, and complaints/concerns mechanisms prior to participating in this inquiry (see Appendix 2).

3.3.1.1 Parent participants

Five parents from a total of seven volunteers were recruited from a varying range of family backgrounds, professional experiences and had children with varying ages and disabilities. Due to time constraints to complete this inquiry, two parents could not be interviewed. Only mothers, rather than fathers or other family members, elected to participate in this inquiry. Those parent participants who volunteered to participate in the study and met the inclusion criteria were selected to participate. The following table (Table 3.2) summarises the demographic data of parent participants (i.e. mothers) and their children.

Table 3.2 Parent and child demographics

Parent's pseudonym	Parent's occupation	Child's pseudonym	Child's diagnosis	Child's age	Who lives at home
Mary	Clinical psychologist/ Mum	Josie	Developmental Coordination Disorder	6 yr 9 mo	Mum, Dad older brother and Josie
Lyn	Engineer/Mum	Craig	Dyspraxia	4 yr 5 mo	Mum, Dad, younger brother and Craig
Keiko	Home mum	Tommiko	Neuronal Migration Disorder	2 yr 7 mo	Mum, Dad and Tommiko
Marie	Journalist/Mum	Abigail	Autism Spectrum Disorder (ASD)	6 yr 10 mo	Mum, Dad and two children
		Max	ASD	3 yr 10 mos	
Margaret	Teacher/ Mum	Lucy	Down syndrome	11 yr	Mum and Lucy

3.3.1.2 Occupational therapist participants

Five occupational therapists were recruited for this inquiry who all worked in child therapy services at Therapy ACT. A total of five occupational therapists volunteered to participate in this inquiry and all met the inclusion criteria so were selected. Table 3.3 provides information about the amount of experience each therapist had and what age-based therapy team they were employed in at the time of interview.

Table 3.3 Occupational therapist demographics

Therapist's pseudonym	Aged-based therapy team	Years of clinical experience	Years of experience in child and family services	Length of time at Therapy ACT
Peter	School Age	5 years	2.5 years	2.5 years
Carol	Early Childhood	15 years	7 years	2.5 years
Jane	School Age (high school students only)	2.5 years	2.5 years	2.5 years
Ann	Equipment Services Team	25 years	25 years	20 years
Michael	School Age	7 years	7 years	5 years

3.3.2 Sampling

Purposive sampling was employed to increase the range and scope of the data exposed and the likelihood that a full array of multiple realities was uncovered, and to obtain detailed data about participants' goal setting experiences (DePoy & Gitlin, 2005; Green, 2002; Lincoln & Guba, 1985). For example, Margaret was specifically invited to participate as she had a daughter in upper primary school and prior to her inclusion most parents represented early childhood and early school aged children.

3.4 Data Collection Methods

A range of data collection instruments and procedures were utilised, including semi-structured in-depth interviews with participants, and the collection of textual records of goal setting documents from file reviews. Participant observation data, using video or one way mirrors, were not collected due to the invasive nature of observation and also time limitations of the researcher. It is not common practice for an outsider to observe a goal setting interaction, therefore observation would have created an unnatural situation that may have influenced the way the goal setting process between therapists and parents was experienced.

3.4.1 The researcher

The researcher was used as the primary data gathering tool, or as Lincoln and Guba (1985) describe, a “human instrument” (p. 39). As a data gathering instrument, the researcher was required to be a “sensitive homing device” (Lincoln & Guba, 1985 p. 224) to negotiate meanings and interpretations of the data collected (Lincoln & Guba, 1985). It is recognised that the researcher had knowledge about collaborative goal setting practices, and understanding of the goal setting culture with clients within this work context to direct data collection and shape interpretations of the findings (Lincoln & Guba, 1985).

The researcher conducted all participant interviews and reviewed client files. The researcher had over nine years of clinical experience within family and child services. Six years of that work experience occurred at Therapy ACT. The researcher had personal as well as clinical experiences interacting with families who had children with disabilities. The researcher has a cousin with autism and she made this known to some parents during interviews to facilitate information sharing and the development of rapport. The researcher also had her own recently acquired medical diagnosis and was familiar and sensitive to parent’s experiences of grief and loss when hearing of their child’s diagnoses and learning about their implications for their lives. The researcher had engaged parents, children, and adult clients in collaborative goal setting practices throughout her work experience and had utilised goal setting tools such as the Canadian Occupational Performance Measure (COPM), the Goal Attainment Scale (GAS), SMART goals (specific, measurable, achievable, realistic timeframe), as well as therapy action plans and Individual Family Service Plans (IFSP). The researcher had also received further training on the utilisation and selection of outcome measures in clinical practice. The researcher has participated in other research studies into family-centered

practice and the use of outcome measures. This research was triggered by the researcher's interest in how therapists interact with parents of children with disabilities and her strong desire to hear about parents' experiences of their interactions with occupational therapists and how family-centered practices can be strengthened. It is a hallmark of naturalistic inquiry that the researcher has an understanding of the context and background of the subjects of interest, in this case collaborative goal setting (Lincoln & Guba, 1985). In this inquiry the researcher's background and experiences contributed to her tacit understanding of collaborative goal setting which enabled her to interpret the perspectives of parents and occupational therapists collaborative goal setting experiences.

3.4.2 Interviews

Most data was collected from semi-structured in-depth interviews with participants. Interviewing is frequently used in qualitative health research because it is least intrusive and interviews occur typically between health providers and clients in daily practice (Starks & Brown Trinidad, 2007). Interviewing parents and occupational therapists in their natural environments is routine practice for the principal researcher when goal setting with parents and when supervising and mentoring occupational therapists. In this inquiry, the researcher presented herself as the listener and asked participants to give accounts of their experiences of collaborative goal setting. The researcher established rapport with participants by outlining her purpose of the interview as one of gathering information about current collaborative goal setting practices, rather than making judgments about participants' responses. Prior to commencing audio-taping, participants were informed of their rights as volunteer participants and written consent was obtained. Participants were reminded that they could terminate the interview at any time and that the researcher would write notes during the interview. Throughout the interview the researcher reflected back to participants about her interpretations of what was discussed and the notes that she took.

Semi-structured interviews were used to draw out participants' experiences of the phenomenon under investigation (Starks & Brown Trinidad, 2007). An interview guide was developed by the researcher and examined by the research team and local Human Research Ethics committees before use (see Appendix 3). Although the wording of this guide was not altered throughout the interview process, some questions were left out or expanded depending on the information provided by the participant during the course of each interview.

Typically interviews were conducted in natural settings within the environment in which goal setting occurred such as the therapy and home sites. Most interviews with parents and therapists were conducted at Therapy ACT clinic sites, however two parent interviews occurred within the parent's homes. Participants were invited to hold interviews at a time and location convenient to them. Interviews lasted approximately one hour. The shortest lasted about forty minutes and the longest about one and a half hours. All interviews occurred within the day, during typical business hours.

All interviews were audio-taped to record an accurate account of the interview including the recollection of the conversation, pauses and overlaps (Silverman, 2005). These audio-tapes were later transcribed by the principal researcher verbatim. Data developed from audio-tapes facilitated the focus of the actual details of the social aspect of collaborative goal setting (Silverman, 2005). Audio-taping also enabled the researcher to be responsive to participants during the interview using non-verbal communication, thus facilitating the establishment of rapport, rather than being preoccupied with taking detailed notes.

3.4.3 Review of goal setting documents in client files

Textual records including the actual documents produced by the goal setting process in client files were reviewed. The purpose of this review was to examine the context and background on which the goal setting experiences between occupational therapists and parents occurred as well as what written documentation of the goals were provided to parents. These data sources detailed the "who, what, when and where" aspects of the context for goal setting, which was used to further define and refine subsequent data collection (DePoy & Gitlin, 2005).

Employing both textual data and interviews with parents and occupational therapists allowed data to be triangulated, thus contributing to the credibility and rigour of this inquiry design (Lincoln & Guba, 1985; Williams, 2006).

3.4.4 Duration of data collection

The length of time spent on data collection was impacted by the timeframe of the researcher's candidature to complete her Masters by Research Degree. Although data saturation was not achieved, the core elements of the phenomenon of parents' and occupational therapists' collaborative goal setting experiences was uncovered within the data collected (DePoy &

Gitlin, 2005; Starks & Brown Trinidad, 2007). Starks and Brown Trinidad (2007), state that typically, data from small numbers of participants is sufficient for a phenomenology study to unearth the core elements of the phenomenon under investigation.

3.5 Ethical Considerations

This inquiry was undertaken as a research project for the researcher's Masters by Research Degree through The University of Sydney. Ethics approval by the Human Research Ethics Committees at The University of Sydney and the ACT Department of Housing, Disability and Community Services was obtained prior to the recruitment of participants (see Appendices 4 & 5). Participants volunteered to participate in this inquiry. They were informed of their rights for participation and consent was obtained before data collection occurred (see Appendix 6). Data collected from the field, including signed consent forms, interview notes, tapes, and copies of goal setting documents in client files, was temporarily stored and transported in a locked brief case. Data was stored at the researcher's workplace in a locked filing cabinet. At the completion of this thesis, data was transferred at The University of Sydney for long-term storage. Only the research team had access to the data collected. Staff and clients of Therapy ACT did not have access to the data collected. Confidentiality was maintained in reports and verbal presentation of research findings by the use of pseudonyms for parents, children and occupational therapists. The researcher did not disclose the names or identities of research participants to work colleagues or clients.

3.6 Data Analysis

Throughout the data gathering process, data were analysed inductively to look for emergent patterns that would guide subsequent data collected using specific case selection techniques (DePoy & Gitlin, 2005; Lincoln & Guba, 1985; Patton, 1990). The purpose of data analysis was to identify the essence of the personal experiences of collaborative goal setting from the interviews of research participants and textual data. A composite description of the phenomenon of the collaborative goal setting experiences of parents and occupational therapists has been written in the subsequent chapters of this thesis to give the reader the essence of the phenomenon of the collaborative goal setting experiences of participants.

3.6.1 Data management

Interview data were collected on audio-tapes and transcribed verbatim. Other textual data, including consent forms and interview notes were kept in a folder and referred to during data

analysis. Photocopies were made of pertinent client goal setting documents, such as therapy action plans, therapy and medical reports that described the context for goal setting. These documents were also stored in the folder with the consent forms and locked up in a filing cabinet within the researcher's workplace. There were 124 pages of transcription. Example of a transcript files can be seen in Appendices 7a and 7b. The transcript of each interview ranged in length from five to twenty five A4 typed pages. Word processing was used with Microsoft Word and facilitated data storage, duplication and analysis. Data was coded manually using margin notes and coloured highlighters on multiple text copies.

3.6.1.1 Data analysis techniques used

The analysis technique of content analysis was employed using Lincoln and Guba's (1985) constant comparative method to process the data rather than Glaser and Strauss's grounded theory analysis (1967) which aims to derive theory. This inquiry intended to explore the social phenomenon of collaborative goal setting from the perspectives of parents and occupational therapists rather than generate and test hypotheses. Significant statements from participants were grouped into larger units of information called "meaning units" or themes and a description was written about "what" and "how" collaborative goal setting occurred for participants (Moustakas, 1994).

At each stage of the data analysis, data were used to analyse the subsequent data, and earlier data remained in use throughout the analysis. This provided continuous development of the data to its successive stage where the analysis stopped (Lincoln & Guba, 1985). Data analysis occurred within a "continuously developing process" (Lincoln & Guba, 1985 p. 340) where each stage of the process guided the next throughout the inquiry.

The first step was to collect units of information which were "chunks of meaning" that evolved from the data itself (Marshall, 1981). This involved scanning the data line by line to highlight different meaning chunks. These units of data were then used to build up provisional categories of ideas that related to the same content (Lincoln & Guba, 1985). Units were categorised on tacit, intuitive grounds using a "look-alike" and "feel-alike" approach (Lincoln & Guba, 1985). Units were linked into categories on "whether the contents were essentially similar" (Lincoln & Guba, 1985 p. 347). Each category was given a title that included direct quotes from participants, and a rule for inclusion of units into that category

was developed. A miscellaneous category was established for units that did not seem to fit. This process was continued with all the data until it had been exhausted.

The entire category set was reviewed and miscellaneous data were then either re-categorised or discarded from the data. The categories were also reviewed for overlap and some categories were merged together (Lincoln & Guba, 1985). Then the categories were examined for possible relationships among them including the similarities and differences between the goal setting experiences of parents and occupational therapists. The refinement of categories resulted in quotation banks of verbatim quotes from participants with the development of five themes and several sub-themes (see Appendix 8 for an example of a quotation bank). Analysis ceased when the data sources were exhausted and the categories were saturated.

A final review of the entire category set occurred to develop a member checking summary document (see Appendix 9). When developing the member checking summary the researcher ensured that she represented the wide range of participants' experiences rather than simply reconstructing the average response. This summary was sent to all participants. Two parent and two occupational therapy participants responded to this by mail and email. All confirmed that the findings were a true reflection of their experiences. Following feedback from the member checking, the sub-theme of “*‘she’s not the expert’: expectations of therapists, child and parents*” was dissolved into the other two sub-themes within theme four “*‘people vary in their life experiences’: factors influencing participants’ goal setting experiences*”. The participants' responses to this member checking process have been integrated into the inquiry findings and discussion chapters of this thesis.

3.7 Accuracy and Rigour of Analysis

Research findings in naturalistic inquiry consist of tacit knowledge from the participant and emerge within the dynamic interview process between the participant and the researcher, as the human instrument (Lincoln & Guba, 1985). Therefore this inquiry was not concerned with the generalisability or external validity of findings, but rather the primary focus was to obtain a comprehensive and truthful representation of the phenomenon of participant's collaborative goal setting experiences (DePoy & Gitlin, 2005).

The evaluation of the accuracy and rigour of the data analysis for this inquiry was based on four criteria proposed by Lincoln and Guba (1985). Table 3.4 outlines these four criteria with their conventional terms and compares them to the similar constructs used within a Positive paradigm. How this inquiry met each of these four criteria will be discussed below.

Table 3. 4 *Comparison of terms to evaluate accuracy and rigour in research*

Naturalistic term	Conventional term	Positivist term
Credibility	Truth value	Internal validity
Transferability	Applicability	External validity
Dependability	Consistency	Reliability
Confirmability	Neutrality	Objectivity

3.7.1 Criterion one: Credibility

Credibility is used to evaluate how credible the inquiry findings are that have been developed throughout this inquiry and to determine the confidence in the “truth” of the findings (Lincoln & Guba, 1985). This inquiry used the techniques of prolonged engagement, triangulation and member checking to ensure its credibility.

3.7.1.1 Prolonged engagement

As the researcher worked at Therapy ACT and was regularly engaged in collaborative goal setting experiences herself with parents and clients, she had spent sufficient, prolonged time in the field to become oriented to the setting, learn the culture of collaborative goal setting and to build trust with parent and occupational therapist participants (Lincoln & Guba, 1985). The researcher was known to all the occupational therapist participants and had provided services to Margaret and Lucy more than four years ago, therefore had established a trusting relationship with them. Tommiko was invited to participate through encouragement from her primary occupational therapist and Lyn had met the researcher at an external information session during the recruitment process. These mechanisms provided opportunities to build trust between the participants and the researcher. Participants were invited to spend as much

time as they wanted talking to the researcher about their collaborative goal setting experiences. Participants were also given opportunities to discuss final thoughts or additional ideas that were not facilitated by the interview guide. Prolonged engagement facilitated credibility of the findings as participants felt comfortable with the researcher and were more likely to provide truthful accounts of their collaborative goal setting experiences (Lincoln & Guba, 1985).

3.7.1.2 Triangulation

The phenomenon of collaborative goal setting experience was triangulated by interviewing parents and occupational therapists and reviewing textual records of goal setting documents in client files. The goal setting experiences of parents were checked against the experiences of the occupational therapists as well as the goal setting documents in their child's files. This enabled the researcher to validate particular themes by examining how the themes were experienced as similar or different between the parents and occupational therapists (DePoy & Gitlin, 2005; Lincoln & Guba, 1985). The goal setting documents also validated the parents' experiences and recall of their experiences of collaborative goal setting events. Triangulation supported the credibility of this inquiry through its collection of "evidence" about the truth of the collaborative goal setting experiences from three sources of data: parents; therapists and goal setting documents (Lincoln & Guba, 1985).

3.7.1.3 Member checking

The technique of member checking was employed by the researcher to check the accuracy and truthfulness of themes and sub-themes that evolved through the interviews with participants and subsequent data analysis. Lincoln and Guba (1985) reported that member checking "is the most crucial technique for establishing credibility" (p. 314) as participants must be given the opportunity to react to the researcher's interpretation of their information. Data were initially analysed into five major themes with multiple sub-themes. These data were summarised into a five page document (see Appendix 9) and sent to all interview participants. Feedback was obtained from two parents and two occupational therapists. All participants reported that the summary was an accurate description of their experiences and identified sections within it that they had contributed to. Formal member checking provided participants with the opportunity to give an assessment of the researcher's overall adequacy in constructing the findings and to confirm individual data points (Lincoln & Guba, 1985).

Member checking was also used informally throughout the interview process by the researcher to check that information was supplied as the participant intended it to be; to provide an opportunity for the participant to immediately correct errors; and to clarify any misinterpretations (Lincoln & Guba, 1985).

3.7.2 Criterion two: Transferability

Transferability is used to determine whether the generated themes from this inquiry may have application to other contexts or with other participants. This was achieved through the use of thick descriptions of participant experiences, dialogues with the researcher, emic categories and context for the interviews within this thesis (Green, 2002; Lincoln & Guba, 1985; Williams, 2006). This methodology chapter has provided descriptions of participants in tabulated forms to describe who the participants were and from what experiences they based their information that they provided to the researcher. Purposeful sampling was included, such as by inviting Margaret to participate in this inquiry to tell of her eleven years experience of engagement in therapy. This aimed to obtain the widest possible range of information for inclusion. Also the wide inclusion criteria for participating in this inquiry for any parent of a child who had accessed or was accessing occupational therapy, aimed to capture as many participants as possible from a wide variety of backgrounds. This methodology chapter provided thick descriptions about how participants were recruited; where participants were interviewed; the time of day they were interviewed; and the duration of interviews.

3.7.3 Criterion three: Dependability

Dependability examines the extent to which the inquiry findings could be repeated if the inquiry was replicated with the same or similar participants in the same or similar context (Lincoln & Guba, 1985). Dependability examines both the inquiry process as well as the product from the inquiry. This methodology chapter has provided detailed information about the inquiry process. It has specified how data was obtained, kept and analysed. This enables this inquiry to be repeated. All interviews have been audio-taped and transcribed verbatim which provide an accurate account of what participants said (sample transcripts of participants' interviews with the researcher's coding and memos is provided in Appendices 7a and 7b). The members were also provided with a summary of data to confirm the accuracy of the researcher's interpretation of their information which also supports the accuracy of the inquiry themes and sub-themes generated.

3.7.4 Criterion four: Confirmability

Confirmability is used to determine to what extent the inquiry findings are based on the participant's information and conditions of the inquiry rather than the biases, motivations, interests or perspective of the researcher (Lincoln & Guba, 1985). Confirmability was demonstrated by referencing the findings from this inquiry back to the literature on collaborative goal setting and family centered practices as presented in the discussion chapter of this thesis (Williams, 2006); through the use of participants' words to describe the themes and sub-themes; and also through the use of triangulation of data from three different sources.

Despite the measures taken to ensure accuracy and rigour of analysis, it is unlikely that repeating this inquiry would produce the exact same themes and sub-themes, as they have evolved from the tacit knowledge of the participants and have been drawn out by the researcher as a human instrument through a dynamic interview process with each participant on a particular day, time and location (Lincoln & Guba, 1985). It is unlikely that even if this inquiry was repeated with the same participants and same researcher that the information would be the same as the interview process itself has heightened the awareness of concepts around collaborative goal setting for participants. However, all measures have been taken by the researcher to ensure rigour of analysis which has been demonstrated by prolonged engagement in the field; interviewing multiple participants who agreed on the themes and sub-themes that evolved from all interviews; reviewing textual, client goal setting documents; and comparing findings to the literature.

3.8 Sharing of Inquiry Using Case Study Reporting

The phenomenon of the collaborative goal setting experiences of parents of children with disabilities and occupational therapists is presented in subsequent chapters of this thesis. The representation of the experiences of participants is told through a phenomenological approach using a case report rather than scientific or technical report because it supports a description of the multiple experiences that were encountered over a range of inquiry sites and participants (Green, 2002; Lincoln & Guba, 1985). A case example of one parent's experiences was presented at the Early Childhood Intervention Australia Conference in Canberra in May 2010 (Hilly, 2010). It is anticipated that the findings from this inquiry will be presented to colleagues at Therapy ACT and possibly at future occupational therapy conferences and publications.

3.9 Summary and Limitations of Design and Methods

The focus of this inquiry and its theoretical basis has been presented. The proposed focus of this inquiry was to explore parents' and occupational therapists' collaborative goal setting experiences. The data collected throughout the inquiry was idiographic and the outcomes are tentative in their application (Lincoln & Guba, 1985). The transferability of the inquiry findings remains in the hands of the researcher and the audience to build on to their own prior and tacit knowledge about collaborative goal setting. It is anticipated that the reader of this inquiry will come away with a feeling that they understand better what it is like for parents and occupational therapists to experience collaborative goal setting (Polkinghorne, 1989). The following chapter presents the data collected, analysed and synthesised into five major themes with sub-themes. The essence of the collaborative goal setting experiences of parents and occupational therapists are presented.

Chapter 4

Inquiry Findings

The purpose of this inquiry was to explore the goal setting experiences of parents of children with disabilities and occupational therapists. It specifically intended to capture the meanings participants attributed to their collaborative goal setting experiences, explore similarities and differences in the collaborative goal setting experiences of parents and occupational therapists, and to investigate how participants believe goal setting could be improved.

Analysis of parent and occupational therapist interviews and review of file goal setting documents resulted in five major themes, each with their own sub-themes. In this chapter, the themes will be introduced, described, and illustrated using participant quotes in *italics*.

Pseudonyms have been used to protect the confidentiality and anonymity of the participants. Throughout the chapter similarities and differences of parents and occupational therapists' experiences of collaborative goal setting are presented and discussed within each major theme and sub-theme. The key similarities and differences between parents' and occupational therapists' experiences are summarised in Table 4.1.

4.1 Introducing the Themes and Sub-themes

Five key themes emerged from parent interviews and occupational therapist interviews as well as client goal setting documents have been combined to develop each theme. They have been labeled using key representative quotes from participants. The five key themes are:

Theme One: "An obscure concept": Learning to goal set

Theme Two: "The things we would discuss became the goals": Goal setting experiences

Theme Three: "It's just the beginning": The impact of goal setting on families' everyday lives and the occupational therapy process

Theme Four: "People vary in their life experiences": Factors influencing goal setting experiences

Theme Five: "More guidance, more direction": How goal setting could be improved

Each theme also consists of two or more sub-themes. These sub-themes are designed to clarify and further explore each theme. An overview of the five themes and their sub-themes is summarised at the end of this chapter in Figure 4.7

4.2 Theme One: “An Obscure Concept”: Learning to Goal Set

The first theme “An obscure concept”: Learning to Goal Set, described the importance of learning how to set goals before parent and occupational therapist participants could engage in collaborative goal setting. One sub-theme emerged from parent data and was labeled: “You learn as a parent”. It described how parents learn to engage with and use therapy input. Two additional sub-themes were discussed by occupational therapist participants and labeled “They just want action”, which described therapists’ thoughts about parents’ perspectives, and “Developing my own technique”, which described how occupational therapists learned to develop their own goal setting techniques. Each sub-theme will be described and outlined using quotes from participants in this section. A summary of this theme and the following sub-themes is presented at the end of this discussion in Figure 4.2.

4.2.1 “You learn as a parent”: Parents learning how to engage with and use therapists

Parents described many things that they needed to learn to effectively engage with therapists in collaborative goal setting. The data from parent and therapist interviews and goal setting documents indicate that when parents first access therapy services they go through a learning process which focuses on gaining knowledge about their child’s disability and development, what therapy is, how to set goals, how to live with their child, and how to access and utilise therapy services when required. The learning process that parents described is conceptualised in Figure 4.1, which illustrates three types of goals that occur in the goal setting process. The bottom level of the figure refers to goals that are parent focused, and targets their desire to obtain knowledge, particularly information about their child’s disability and what it means relative to future development. It appears that goal setting around this parent need should probably occur before collaborative goal setting processes are directed towards more specific goals which focus on parent/child needs or the child’s needs. Upon this knowledge base, parents described how they needed to set goals that assisted them to learn how to help their child, how to adjust to life with a child who has a disability, and how they can use therapy when they require it. The final level of goals described is conceptualised as child-focused

goals, which are directed towards developing particular skills and outcomes for the child. While this third type of goal is most commonly the focus of collaborative goal setting, the parents in this study indicated that there were knowledge related goals that they needed to set with therapists before they felt able to engage in genuine goal setting collaboration with therapists around child management issues. It appeared that ‘the getting of knowledge’ may sub-serve two functions. First, it gives parents the knowledge about disability, the impact of disability, and the place of therapy in their lives that is needed for realistic goal setting. Second, this knowledge base may function to place parents and therapists on a more ‘equal information footing’, which may contribute to knowledge sharing and genuine collaboration in a child focused goal setting process. The sub-themes outlined below in this section use parent’s words to illustrate this finding.

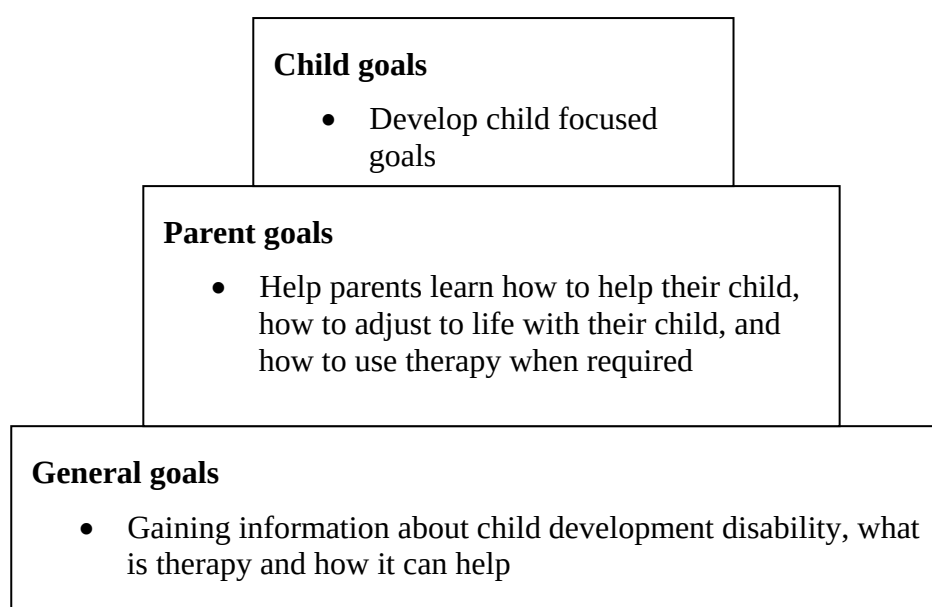


Figure 4.1 Three types of goals that are desired by parents in the goal setting process

4.2.1.1 “First identify where deficiencies are”: Gaining knowledge about their child’s disability, difficulties, diagnosis and prognosis

All five parents talked about the process that they went through and were going through to learn about their child’s disability and its impact. Parents required information about their child’s diagnosis, development, prognosis and how to help their child before they felt they could engage in genuine collaborative goal setting. This was the first level of goals and goal

setting featured in Figure 4.1. Some children had a clear diagnosis at birth, such as Down syndrome, whereas other children were much older before they were given a diagnosis. For example, Mary recalled the diagnostic history of her daughter *“For quite a while it was unclear how disabled she was. She didn’t have any specific syndrome... it wasn’t clear whether she would be...intellectually disabled even sort of to a moderate level”* (Mary).

Most parents went through a process of comparing their child’s development with typical development and sought assistance from therapists about how to make this comparison. They also valued therapists’ expertise as being able to support their child’s development. The following three parents provided examples of seeking information about their child’s development before they could engage in goal setting. *“First identify where deficiencies are ...and where my child falls behind his age group”* (Lyn); *“At the beginning I was a bit tense because I felt under pressure ...I was expecting her [to be] a bit better and I was comparing her to other children”* (Keiko). *“In the area of her of not knowing how to help her development in those areas has been, I ‘spose the biggest kind of area that I felt supported in”* (Margaret).

Like the parents, occupational therapists also identified that when parents of young children first entered the service they often needed information about disability and child development before they could set goals. Carol said *“often parents with babies ... or particularly with the younger aged children don’t have any specific areas of concerns, such as a client of three months with cerebral palsy, but she just wants to know about general development”*.

Over time, parents learned about the implications of their child’s development and diagnosis and as a result, felt they were ready to learn how to help their child. This appeared to be the second level of goal setting figured in Figure 4.1. For example, one mother described her understanding of the impact of autism on her children’s development, stating *“I know that my children’s development is spiky and uneven and I know what that means in terms of autism”* (Marie). She further demonstrated how she engaged in purposeful learning opportunities so that she could better help her children reporting *“I went to a workshop this year... it helped me realise that there was stuff that I was doing without actually realising it that was working really well”* (Marie).

These examples demonstrate that parents require particular support from therapists in order to learn how to set different types of goals. They need help to learn about their child's diagnosis, developmental level and the implications of these before they can learn how to help their children.

4.2.1.2 “I have to do the therapy”: Learning what therapy is without clear goals

Mary and Lyn both referred to the concept of “*doing therapy*” for their children without really understanding why they were doing what they were doing. This indicated that parents did not have a clear understanding of what goals had been established for their children and it was likely that goals were established without their active participation. Mary reported that “*the connection between those activities and an outcome isn’t clear and linear*” and Lyn said “*all they do is just make you go through these activities and try and find something that is interesting for him.*”

File reviews of Josie’s and Craig’s goal setting documents also supported their mothers’ lack of clarity around therapy goals. Mary’s daughter, Josie’s file consisted of two parts. Only one developed therapy action plan was found across the two files. This plan was established in 2004 and indicated joint occupational therapy, speech pathology and physiotherapy. It did not specify any intervention goals. Josie had also seen a private occupational therapist in 2008, one year before she started kindergarten. The reason for referral was to develop a programme to help prepare her for school; however no goals were documented within this report.

Lyn’s son Craig had a therapy action plan completed by a speech pathologist at the commencement of his speech pathology intervention however no occupational therapy goals were documented on this action plan or in any subsequent action plans or goal setting tools. One home programme document specified a broad goal which was “*Craig will copy more pre-writing shapes and develop visual-motor coordination skills*”. Lyn in particular noted the lack of clarity and measurement around her goal setting experiences. Her comments are consistent with this file review.

Parents did not differentiate between occupational therapy and other disciplines such as physiotherapy or speech pathology. They saw “therapy” as one and the same without having a clear understanding of the different roles that the different disciplines played or what the therapy goals aimed to achieve. They hoped that what they were doing would be beneficial and identified that their child needed *“a lot of stimulation”* (Keiko). Marie described the importance of being involved in goal setting to understand why the therapists made the recommendations that were made. She identified that if she did not know where she was going and why, then she was disinclined to do any therapy. She said *“I have no idea of what we are doing and why. Where are we going? Why are we going?...If I don’t have direction...I am disinclined”* (Marie).

Margaret had a clearer understanding of the benefits and purpose of *“therapy”* for her daughter. She identified the value in practice with her daughter, Lucy, and understood the impact of practice and therapy on Lucy’s abilities. She stated *“I see when we don’t practice it’s easy for her to slip back”* (Margaret).

This sub-theme indicated that parents need to build knowledge about what therapy was and how it could benefit their child before they could engage fully with therapists, follow through home programmes and actively participate in collaborative goal setting. Understanding what therapy was also contributed to development of a level of foundation knowledge about diagnosis and disability that parents in this study felt was needed before they could engage in more specific child focused goal setting.

4.2.1.3 “They don’t know what they want”: Learning what goals are and learning to goal set

Therapists articulated similar views about what needed to be in place before child-focused goals and goal setting could become a collaborative process. Peter, for example, identified that often parents *“don’t know what they want”* when they first met him because they did not have a good understanding of their child’s developmental level, how occupational therapy could help their child, or even how to set goals. When their children were young, parents indicated that they did not see clear, specific goals, however as their child became older they could see what goals could be set and how they could be articulated. Mary explains this learning process as follows *“Early development is ... you’re working on ...sensory*

processing, you're not working on specific skills but as they get older you can work on specific skills that adults recognise more and can see more as a goal".

Marie also described her particular learning process to set goals when she stated *"It takes ...a while ... to understand that those small... goals are actually worthwhile for a start...and it is worthwhile pursuing them"*.

Parents struggled with goals being *"implicit not explicit"* (Mary) and *"not very black and white"* (Lyn) which hindered their ability to learn to goal set. They found it *"hard to judge"* (Lyn) when their child had achieved the goal. Keiko reported that she *"hadn't really set goals much yet"*. Two parents observed that they did not focus on the goals in the same way as the therapists did. Mary reported *"when you're not a therapist seeing them [the goals] as important is kind of difficult at times"* and Lyn stated that *"I'm focusing on the activities that I look at even though the occupational therapist has written just the goals. I can't say that I have focused on them"*. Implicit, unclear therapy goals were perceived by the parents in this study when they were at the stage of learning how to engage in collaborative goal setting with therapists.

Occupational therapists also reported observations that parents did not always know how to goal set. They felt that parents did not always have *"those skills to set goals"* (Peter), *"don't know what their goals are"* (Ann) and were in many cases *"guided"* (Carol) by them to *"identify the important issue"* (Carol) for goal setting. Carol described having a driving role in the goal setting process to help families learn to set goals and identified that families learn to set goals when they are *"in the system a bit longer"*. Jane also stated, *"the actual setting of the goals, I suppose, is driven by me. So families don't know what to do, what goals are first off, and they just want to get on with it"*.

Peter identified that parents often did not *"have a good understanding of what OT is"* or why they had been referred to occupational therapy, which resulted in the therapist having to take a more information-provider role before he could engage the parent in goal setting. This is further identified when he stated:

I think some parents come in and it's usually a new parent, that goes 'I don't know why I'm here' or 'I've been told by the school that I need to come but I don't know why', and I think that that's sometimes can be a little bit of another role for the therapist to actually say - well look, I'm actually sorry - but your child is delayed (Peter).

Both parents and occupational therapist identified that parents did not always know how to goal set with therapists initially. While occupational therapists saw that they had a driving role in goal setting to facilitate parent's learning about how to set goals, parents appeared to need information and support from therapists to establish a general understanding of their child and occupational therapy services first, before they could learn how to help their child and ultimately set the child-focused goals which were the focus of occupational therapists and therapy.

4.2.1.4 Learn how to live with their child

Collaborative goal setting and prolonged engagement with therapy facilitated parents' understandings and abilities of learning how to live with their child. Parents identified that over time they learned how to live with their child and that everything had "*gotten easier*" (Mary). They learned how far to push their child's development, how to get support and resources, and what to expect from therapy. This in turn impacted on their ability to engage in collaborative goal setting as parents had a better understanding of the needs of their child and family and how therapy could support them.

Lyn described her understanding about how far she could push her child:

Sometimes if I want him to achieve something and he just can't because of the dyspraxia he can't do it I know I get very frustrated...but I mean that would only be if you took the goals to the extreme if you pushed him too quickly and you wanted to achieve it too early. Those sorts of things could sort of be detrimental (Lyn).

Marie commented on her ability to get the resources that she needed to help manage her children. She said "*I'm pretty good at ... getting support and resources*".

This process of parents learning to live with their child was supported by parents' engagement in therapy and collaborative goal setting. Parents described this learning as a crucial aspect of learning to be a parent of a child with a disability.

4.2.1.5 Learning how to use therapy as required

Another learning task for parents was learning how to use therapeutic strategies when they required them, rather than feeling they have to “do therapy” without any clearly defined goals. Only one of the five mothers interviewed (Mary), indicated that she was able to do this successfully. She described how she actively controlled her engagement in therapy and the extent to which she collaborated in goal setting with therapists. Mary discussed how she wanted to be a parent and not a “therapy parent”, when she said that “*at the end of the day you just want to be a parent anyway and not be the therapist*”. She also described a cycle of purposeful engagement/non-engagement in therapy, and how she gave herself and her daughter permission to have breaks from therapy to experience just being a family. She said:

So there's a rhythm to energy and attention to therapy...To make appointments, to ... really pay attention to it and then a break. And then just kind of let it ride and so whatever we do we do. And those cycles at different points in the cycle the goals are different (laughs). At one point it is sort of resting the system and having fun and enjoying each other and at another point it is...doing the therapy and pushing through difficulties (Mary).

Mary demonstrated that she was able to independently identify when she required further involvement from therapists and was in control of her family and her daughter's access to therapy, and therefore was the ‘driver’ of the goal setting process. Mary demonstrated that she had learned how to goal set with therapists and could focus on the final tier of “child focused” goals and goal setting levels featured in Figure 4.1, when she chose to.

4.2.2 “They just want action”: Occupational therapists’ thoughts about parents’ perspectives of goal setting

Occupational therapists reported that when parents came to therapy they often “just want action” (Carol) and do not expect to set goals. The occupational therapists were aware of the many emotional aspects of the parents who brought their child to therapy such as feeling “pressured” and “overwhelmed” (Jane) and how this impacted on their goal setting.

Occupational therapists observed that each parent's ability to set goals and the extent they desired to be involved in the collaborative process varied. Jane reported *"It can be overwhelming, I think, ...the whole goal setting process... other families I think, just take it on and they love it"*.

Like the parents who were interviewed, the occupational therapists also identified that parents' experiences, understanding and valuing of goal setting differed to their own. Ann stated:

I think it probably, at most, would be a target or a direction of where they're going. Like an aim, or purpose that something's happening. I would say is what they would probably more see it as so much vaguer or general (Ann).

Michael talked about the benefits gained by parents being involved in goal setting. He commented:

I think some parents have found it quite a strange thing to go through initially but have ... have found it quite beneficial because they can see what exactly where their children's goals...and what areas of life it was affecting... their lives and what they needed to improve upon (Michael).

Despite discussing the benefits of collaborative goal setting, Michael suspected that the majority of the parents he saw preferred him to set the goals and drive the intervention rather than do this collaboratively. He said:

I still get the feeling that ...most clients that I deal with and families and parents still have that very old medical [model] in mind, and they kind of see the therapist as someone who sets the goals or drives intervention (Michael).

4.2.3 "Developing my own technique": Occupational therapists learn to develop their own goal setting techniques

Similar to the learning process described by parent participants, the occupational therapist participants also discussed how they learned to develop their own goal setting techniques. However, aspects of the therapists' learning were different to that of the parents.

Occupational therapists had knowledge of disability, child development and clinical experience about the impact of disability on a child's occupational performance. They had been taught how to set goals as part of their under-graduate training, had access to goal setting tools, and participated in goal setting more frequently than parents. While they had the background knowledge to assist with goal setting, they described how they had to develop their own goal setting techniques and skills for engaging parents in the collaborative goal setting process. Peter identified that he was still developing and finding a "*comfort zone*" in engaging parents in collaborative goal setting. Carol was a more experienced therapist who did not put too much emphasis on goal setting and viewed it only as "*a starting point*" to therapy and she reported feeling comfortable with how she was goal setting with families. The therapists described how they developed systems for engaging in goal setting and reviewing goals. Some used more formal processes than others. For example, Ann described her system in this way "*I used to keep a folder with all my [therapy] action plans so I just checked them regularly to see where everyone was up to*". Peter described that having a more formal goal setting system enabled him "*to review goals and review [therapy] action plans more efficiently*".

Whereas Michael sometimes used less formal methods which he described as:

If there hasn't been any sort of formal goal setting or collaborative goal setting with the family even in my progress notes, I always write a little plan of action which are a few goals and what I need to do.

In summary, both the occupational therapists and the parents in this study described how they went through a personal process of learning to set goals. While parents had to learn about their child, about disability, what they could achieve within the therapy context, and then articulate what they wanted, therapists had to learn to develop their own systems and techniques to engage parents in collaboration. Figure 4.2 summarises Theme One: “An obscure concept”: Learning to goal set.

Theme One: “An obscure concept”: Learning to goal set

- “You learn as a parent”: Parents learning how to engage and use therapists
- “First identify where deficiencies are”: Gain knowledge about their child’s disability, difficulties, diagnosis and prognosis
- “I have to do the therapy”: Learn what therapy is without clear goals
- “They don’t know what they want”: Learn what goals are and learn to goal set
- “Learn how to live with their child”
- “Learn how to use therapy as required”
- “They just want action”: Occupational therapists’ thoughts about parents’ perspectives
- “Developing my own technique”: Occupational therapists learn to develop

Figure 4.2 – Summary of Theme One and sub-themes

4.3 Theme Two: “The Things we Would Discuss Became the Goals”: The Collaborative Goal Setting Experiences of Parents and Occupational Therapists

This second theme presents how parents and occupational therapists in this study experienced collaborative goal setting. Some aspects of parents’ and occupational therapists’ experiences of collaborative goal setting were similar. Both reported a general discussion and sharing of ideas as common parts of the goal setting process. However their experiences differed in their understanding of ownership of goals and their recall of how the goal setting was structured

through the use of specific tools (refer to Table 4.1 at end of chapter). There were six sub-themes that emerged from the data about how participants experienced goal setting. These were: parents' experiences; the actual goal setting process; roles of goal setting and ownership of goals; goals changed; and the use of goal setting tools. These are described below and a summary is presented at the end of this discussion in Figure 4.3.

4.3.1 “Goals are really open ended”: Parents' goal setting experiences

Parents identified that goal setting was largely *“mixed in with everything else”* (Mary) and was not a clearly defined event. For example, Lyn reflected on her goal setting process and stated *“I can't say that it is something that I have actually sat down and thought that this is the goal that I have to achieve”*. Mary reported that *“goal setting hasn't been done in a discreet, clear way where you can notice the impacts of it as an event”*. Parents also spoke about the types of goals set as *“tiny goals”* (Marie), *“really open ended”* (Marie) and targeting *“jobs and tasks”* (Mary) rather than specific skills or measurable goals where they would be able to see a change in their child.

Parents described goal setting and goal review experiences with therapists where their needs were met and were not met. Mary recalled a positive goal setting experience that she had with a private speech pathologist. She valued that the therapist had chosen one of her specific areas of concern about her daughter, discussed the reasons why this needed to be addressed and provided her with direct advice about how to address it. She reported:

One therapy experience that really did stand out was when I went to a [private] speech therapist... and she set goals and prioritised in a way that no-body else had ever done and God I loved it...She just said, this was a priority, it was dribbling...She said this is really important we have to address this. Other children won't like it, it will socially isolate her, all that, and you need to do these intensive exercises...you need to do them this often, you need to build up. So she was very directive and ...the thing that she picked as a priority happened to be something that I really cared about. And it did bother me, so I was really on board (Mary).

Mary wanted her goal setting experiences with occupational therapists to be as positive as the experience she had with the private speech pathologist. She wanted direction from therapists

and for therapists to select goals that were highly motivating and meaningful to her. Margaret similarly recalled positive experiences from goal setting with therapists. She said *“we always came away with our page of suggestions...I could stick them up and be reminded of what to do...I’ve still got one stuck on my kitchen wall”* (Margaret).

These experiences contrasted with another parent’s experience of an occupational therapy review in which Lyn reported not being provided with enough direction or support. She stated:

When I had the review it was more like just a few more ideas like you can try this, you can try that. But still - just generally doing most of the same thing. I probably wanted it to be a bit more tailored, a bit more focused (Lyn).

These stories indicated that the parents in this inquiry wanted well identified processes and to set more specific goals and goal setting processes with therapists than what they had experienced.

4.3.2 “We kind of melded those ideas together”: The goal setting process

Both parents and occupational therapists described the goal setting process as just *“a discussion”* (Lyn, Peter, Jane) where they *“shared ideas”* (Margaret, Jane) and developed a therapy action plan rather than as a formal goal setting event. Lyn described her impression of goal setting as:

Even when we have had the meetings it hasn’t sort of been a big thing. Like this is the goal, it is more just talking about where he fits and what I can do to help rather than setting the goals. It was more of just a discussion (Lyn).

Margaret recalled the goal setting process with a therapist as follows. *“He had some ideas from what he had seen with her as well as I had my own ideas...and we kind of melded those together”*. She identified that goals were reviewed during therapy sessions rather than at specific review meetings. In regards to goal reviews she stated *“so you’re kind of reviewing them as you go”*.

Occupational therapists reported that goals were set by multi-disciplinary teams as well as between a parents and the occupational therapist. Carol described the multidisciplinary goal setting experience as:

We get some background from the family, we find out what the priorities are at the time, we do our observations, we go away for five minutes as a team to talk about...our different observations, who is able to be involved and at what kind of time. And then we come back and we talk to the family about feedback from our observations. And then we prioritise from that. And then we say what we could offer (Carol).

Jane also talked about setting goals within a multidisciplinary team and commented that the “multi-disciplinary [goal setting process] has worked really well... even if we have completely separate goals it has worked well”.

Some therapists described their goal setting experiences as a process of asking families about their main concerns, assessing the child and then proceeding to more formal goal setting using the Canadian Occupational Performance Measure (COPM) and/or therapy action plans, whereas other therapists used a more informal goal setting approach. Ann described her formal process using the COPM as follows:

I usually start off by asking ‘what are their main concerns to find out the issues that they have?’ That’s not setting goals but it’s a starting point. ...I usually also outline with the family what’s going to happen, what the process is going to be. So for how the assessment process might go and basically indicate a certain point in that will be for planning together and setting goals together. So it’s sort of, hopefully in their heads that that’s where we’re going to end up at the beginning. So then I would ...gather information through that whole assessment process with the family involved ...and then I’ve actually found having some sort of structure assists a lot with the goal setting. So, in particular I guess I’ve experienced using the COPM (Ann).

This was a similar approach used by Peter who reported:

I use ... an initial phone consult or an even face to face consult to ask them what they’re doing, how they’re doing, and nearly even like a modified COPM like an informal

assessment just to run through the basics and ask them about the basic activities of daily living. And get an idea of what they can and can't do. And then sort of pick different bits... [I] talk to the parent and identify rough needs and then ... I assess the child, and then I slightly review the goals (Peter).

Carol talked about using the first assessment appointment as an introduction to therapy services and how she then arranged a subsequent appointment to establish goals. She reported that she set goals with families informally using a therapy action plan, and recognised that children and families had “*had enough*” by the end of an initial assessment and that “*often at the end people just want to get out of the door*” (Carol).

Most participants viewed the goal setting discussion as a positive process. Margaret described the discussion as “*kind of a mutual thing*” where she shared her ideas with her therapist. She found it beneficial to share ideas “‘*cause ... you don't think of everything*” (Margaret). Ann found it useful to contain the client's range of goals and issues. She informed the interviewer:

Often, especially for complicated cases, you might start here, all sorts of things crop up and it's useful to come back to the goals and say that actually these are the ones that we agreed on ... I can think of cases where for a particular family it has been extremely useful to help what your doing contained. And that sometimes the best thing to do is to re-visit the goal setting (Ann).

Two parents described some negative aspects of their goal setting experiences. Mary found that she did not remember to do all the things recommended and said “*many things are offered... and then you go away and see which ones you manage to do and you might do a little bit of that. That one becomes, you know, more normal part of things but this one you forget*” (Mary).

Similarly, another parent found her goal setting experience frustrating when she was not provided with any resources to implement the goals established. Marie reported:

Well often you get in a room and the bleeding obvious is pointed out to you... So they're pointing out stuff to you that (a) you already know or (b) you've already seen...You have a goal setting session with the therapist and they give you tips and suggestions but you don't get any resources to implement whatever it is that they are telling you to do (Marie).

On the whole, both therapists and parents found their collaborative goal setting experiences to be positive, however a few negative comments were made by parents about some of their experiences. Goals were set informally during discussion between parents and therapists and reviewed in the same informal manner.

4.3.3 “Both own the goals”: Roles during goal setting and ownership of goals

Most parents perceived that they took an active, “*driving role*” in the goal setting process because they saw it as themselves who owned the goals. Mary, Marie and Margaret demonstrated this when they said: “*I’m a very much a driver in therapy...I take such an active role*” (Mary), “*I was the one who was driving it*” (Marie), “*I think it’s me... who probably owns them [the goals] most of the time*” (Margaret).

Some occupational therapists agreed with parents that parents were directing the goal setting process, including Jane who reported “*I try and let it be family or client driven but take on that overarching leadership role*” and Ann who said “*some parents are probably more actively directing*”.

In contrast, other occupational therapists felt that they were the ones that were driving the goal setting process. Peter recalled that “*quite often I feel as though I’m dictating the goals or setting the goals for them as opposed to ...them actually prescribing the goals to me*”. Similarly Michael reported:

I probably tend to direct it a bit more ...I guess, it’s the time thing again, you’ve got your hour ... we’ve spent a bit of time talking about background and what not and goals and then we get to our action plan. It’s the writing as well. You’ve written all of this stuff

down on your triplicate notes. You then have to summarise it again onto your COPM and your action plan and literally I'm writing down actions towards the end of the session and saying this is how I think would be the best way to go about it (Michael).

Parents viewed the occupational therapist's role as providing "guidance", "reassurance" and "support" (Lyn). Occupational therapists viewed their role as providing information to parents about disability and child development (Peter and Ann); providing parents with "permission to push their child" (Peter); actually writing the goals (Carol, Ann and Michael), "prompting families [to set goals] using the COPM" (Jane); and as a "listening role" (Ann and Michael).

Carol saw the roles of parents to "accept the goals and the plan to get there" whereas other occupational therapists viewed the parents roles as to "provide information and advice from their point of view" (Ann) and to "tell their story" (Michael).

Some parents and occupational therapists agreed that parents should own the goals because they were about their child and their family and the occupational therapist's role was just to support them. Jane, who held this belief said:

They're the ones that have referred for a particular problem so I think it's their goal to own, theirs to achieve even if most of the actions are done by us... I've got a few families who definitely see it that way (Jane).

However, other occupational therapists felt that both parties should own the goals. Ann said "I think you both own the goals because you both contributed to them" and Michael said "I'm a little bit responsible in... the ... scheme of things and they're responsible in the scheme of things. I see it as an equal responsibility".

In summary, therapists and parents agreed that parents should have an information providing role and therapists should have a supportive and listening role. However, therapists and parents differed on who drove the goal setting process and who should own the goals. Parents

felt that they drove the process and owned the goals, but therapists felt that at times they were the drivers of the goal setting process and ownership of goals was a shared responsibility.

4.3.4 “The issues that were there are different now”: Goals change

Both parents and occupational therapists observed that the goals which had been set changed before they were formally reviewed. Marie reported that *“the issues that were there four months ago are different to the issues that [will be] are there four months from now”*. She identified that she moved on from the goals that were initially set with the occupational therapist even though the therapist still looked back at the goals when they contacted her to review them.

The occupational therapists also recognised that therapy goals changed. Jane observed this when she said *“some goals haven’t been achieved and they continue, or some goals go away because the issue isn’t current anymore”*.

Occupational therapists accepted this as part of the therapy process and tended to adjust their intervention plans accordingly. However Carol identified that sometimes she had to set limits around families changing goals so that they could manage to do one thing at a time. She reported:

And if they’re changing the goals all the time...we’re not necessarily going to write a new action plan. Sometimes...you do have to put limits on it...so we do one thing at a time rather than trying to do everything (Carol).

Both parents and occupational therapists observed that goals often changed before they were reviewed by therapists. Therapists’ narratives indicated that while some were able to easily adjust to this change, some felt they had to set limits around how much goals could be changed.

4.3.5 “COPM, GAS and Action Plans”: Use of goal setting tools

This sub-theme emerged from the occupational therapy participants’ data only. When the researcher showed the parents templates for goal setting tools such as the Canadian Occupational Performance Measure (COPM), the Goal Attainment Scale (GAS) and therapy

action plan, some parents recalled previously seeing and using therapy action plans only. Keiko was one of these parents. Tommiko, her daughter had three action plans in her file. These action plans were reviewed annually by the multi-disciplinary team and commenced in 2007 at Tommiko's initial assessment. Occupational therapy goals were established in each plan although not always documented in measurable terms. They included: *"to develop swiping and grasp", "supportive seating options," "deliberate reaching", "assist [Tommiko] to learn to sit", "develop her hand and play skills (cause and effect), grasp and release"*.

Therapists, on the other hand, valued the use of tools to structure their goal setting processes and to introduce their role to new families and to facilitate reviews of goals. One of the five therapists reported that she did not tend to use goal setting tools, other than therapy action plans, as she felt that it put families through more *"hoops"* and that they detracted from her doing *"action"* (Carol).

Peter discussed his experiences with using the COPM and GAS as follows:

And I always love a COPM... it does take a lot more time to sit down because it is such a global assessment that you often pick out ten thousand things and then slowly break them down and then prioritise them. Instead with GAS, you usually have parents who are a bit more driven and actually go that 'this is my goal and this is where I want to come' and they have actually identified it quite easily (Peter).

He reported feeling frustrated with therapy action plans because they did not record client progress, only achievement as a yes or no response.

Jane also used the COPM and modified the therapy action plan to include a rating scale similar to that on the COPM. She reported:

I have been using the Canadian Occupational Performance Measure to find out the full gamete of all their concerns - a really holistic approach...I was using it quite frequently with the new clients to me...I did use it with some of my ongoing clients but in a more brief way in that I got the measurement done but not the whole interview...so we pretty much did the measurement for each of our goals on our action plan (Jane).

Michael also discussed using the COPM to establish a collaborative goal setting process with clients because he thought it was “*a very nice, easy way to explain occupational therapy...and it really addresses all the areas that we’re looking to*”. He also felt that documenting a COPM or action plan enabled the family to see “*the major issues for their children and how it impacts on their family*”.

Four out of the five occupational therapists reported experience in and regular use of goal setting tools such as the COPM and the GAS. They discussed benefits in using the tools to explain occupational therapy to parents and to provide a means for measuring progress of goal attainment.

Parents, therapists and goal setting documents all indicated that the goal setting process between parents and therapists varied considerably. The first policy at this therapy service on Family and Person Focused Practice was established in 2005 by the Senior Manager that documented that therapists were to establish a therapy action plan. This policy has subsequently been reviewed in 2007 and 2010 (Therapy ACT, 2010). Despite the existence of this policy, staff adherence to the establishment and review of therapy action plans has not been consistent even though all five occupational therapists interviewed during this inquiry indicated that they did establish therapy action plans. No other goal setting tools were found in the five files reviewed. This could be explained by the fact that some of the parents interviewed did not experience collaborative goal setting with any of the five occupational therapists interviewed. Occasionally goals were documented in home programmes rather than as therapy action plans or other goal setting tools such as a Canadian Occupational Performance Measure interview form. The file reviews demonstrate consistency with the parent’s experiences of goal setting and their reports around lack of goal explicitness and the unclear goal setting events.

Figure 4.3 summarises Theme Two: “The things we would discuss became the goals”: The goal setting experiences of parents and occupational therapists.

Theme Two: “The things we would discuss became the goals”: The goal setting experiences of parents and occupational therapists

- “Goals are often really open ended”: Parents’ goal setting experiences
- “We kind of melded those ideas together”: The goal setting process
- “Both own the goals”: Roles within the goal setting process and ownership of goals
- “The issues that were there are different now”: Goals change

Figure 4.3 – Summary of Theme Two and sub-themes

4.4 Theme Three: “It’s Just the Beginning”: The Impact of Goal Setting

Both parents and occupational therapists valued participating in collaborative goal setting, however for each group it had a different impact. This third theme addresses the impact of collaborative goal setting on parents and occupational therapists. Parents indicated that goal setting impacted on their families’ lives in ways that included how they interacted with their child and therapists, how they balanced everyday living with carrying out therapy interventions at home, and some described the emotional impact of goal setting. The occupational therapists described how goal setting impacted on their therapeutic relationships with families including how it helped prioritise family and therapy goals, and how it facilitated their case management. Both parents’ and occupational therapists’ perspectives are discussed in this section. Theme Three with sub-themes is summarised at the end of this section by Figure 4.4.

4.4.1 “Life is busy”: The impact of goal setting on parents’ everyday lives

Parents described “*busy lives*” (Margaret) and having limited time to carry out therapy programmes at home with their child amongst all of their other family responsibilities. All five parents described benefits of goal setting, suggesting that it was motivating and that it reminded them about what they needed to focus on with their child. Parents noted the value of documents obtained during the goal setting process. For example, Mary reported that “*the*

piece of paper actually sort of anchors you” and Margaret recalled that “we always came away with our page of suggestions...I could stick them up and be reminded of what to do...I’ve still got one stuck on my kitchen wall”.

Several parents described the benefits of using goals to witness their child’s achievements. Lyn described this benefit, reporting, *“when you’ve got a child with special needs and you’re trying to deal with a lot of different areas I think it is very comforting ...at least to know that you are getting somewhere”*. Keiko also valued Tommiko’s goal achievements despite small achievements noted. She reported that *“goal setting is better than nothing because Tommiko tries to reach even little by little”* and also commented that *“every time she [achieves] a goal I am happy”*. Margaret also discussed how she valued seeing small improvements in her daughter, stating:

At least the parent can see that there’s some improvement...with a child with a disability often they can only be the tiniest amounts but every little bit is important...and that’s where the goal setting is really helpful to a parent (Margaret).

Only one parent participant raised negative impacts of goal setting. Marie commented that goal setting added to her workload, was *“guilt inducing”*, put her *“under pressure”* and that *“it just adds to the burden of what you’ve got”*. However she also reported some benefits of goal setting including that it gave her a relationship with someone outside her family who knew her son, helped *“spur”* her on, and gave her *“some context for what is happening to you”*.

Parents described the impact of goal setting on their children. For example, Margaret reported that *“for Lucy it meant that she probably got opportunity to practice things we wouldn’t have thought to do necessarily”*. She also commented that it was *“fun to do [the activities] together”*. Lyn illustrated how goal setting facilitated Craig’s communication with his father. She stated that *“Craig usually has something to show his Dad ...so I guess that provides an avenue of communication between the two of them”*.

Despite having busy lives, the parents generally reported benefits from their participation in collaborative goal setting such as using the goals to remind them of what they needed to be doing with their children, having a relationship with a therapist and seeing improvement in their children.

4.4.2 “Beginning of the client’s therapy life”: The impact of goal setting on the occupational therapy process

Goal setting was viewed by occupational therapists as the beginning of the therapy process and a way to develop a therapeutic relationship with families. Ann and Michael discussed how collaborative goal setting facilitated their relationships with parents. Ann stated, *“in terms of developing rapport and the follow up of your intervention, I guess collaborative goal setting is about ensuring that happens. That, their primary issues are kept primary”*.

Michael reported that

It’s the beginning, it’s the initial part, of the clients life as being part of therapy too so if that hasn’t really been identified or addressed very well then perhaps it has the flow on affect, then perhaps therapy doesn’t go as well (Michael).

Jane and Ann both discussed the benefits of finding out what the family actually wanted rather than imposing goals on them. Jane reported *“it’s been really good in finding out what the family really wants to work on and not what the OT thinks that they should work on”*.

Similarly, Ann reported:

The advantages are that you’re not assuming you know what the family want. You’re actually giving them permission to say what is important to them and it also lets you... have input from a professional point of view (Ann).

All therapists described goal setting as a communication tool to ensure families and therapists had a common direction and purpose. They also reinforced its purpose in helping to prioritise family concerns and allocate therapy resources to each family. Carol and Ann provide examples of how therapists used goal setting as a communication tool. Carol stated that *“it gives them... a common plan... a direction and then contact details of everyone involved”*. Ann recalled that *“you end up with a very clear set of priorities of things that you want to*

work on with the family”. Furthermore, Carol highlighted what she viewed as the professional benefits of collaborative goal setting. She said:

It provides a means of accountability to ... management or to ...new staff ...or the child transfers to another team then they can see the history of what priorities have been there in the past or how long that they have been working on the same thing and maybe it needs a change (Carol).

Therapists described the benefits of collaborative goal setting on their workload management and indicated that it reminded them of where they were in their plans with clients, or informing new therapists taking over their caseloads. As Jane explained, “*it makes it easier for me to follow. You’ve got it all written there what you do so it’s ...certainly easy for me to follow or somebody else to pick up if needed*”.

Ann discussed the added benefit of preventing her from feeling overloaded by many actions required for each client. She reported that “*it keeps me focused; it keeps me targeted and helps prevent getting overloaded from getting overwhelmed by the range of things you can do with a client*”.

This section discussed how the impact of collaborative goal setting differed for parents and occupational therapists. Figure 4.4 below summarises Theme Three: “It’s just the beginning”: The impact of goal setting on parents and occupational therapists.

Theme Three: “It’s just the beginning”: The impact of goal setting

- “Life is busy”: The impact on goal setting on parents’ everyday lives
- “Beginning of the client’s therapy life”: The impact of goal setting on the occupational therapy process

Figure 4.4 – Summary of Theme Three and sub-themes

4.5 Theme Four: “People Vary in Their Life Experiences”: Factors Influencing Goal Setting Experiences

Parents and occupational therapists discussed a range of factors that influenced their goal setting experiences.

4.5.1 “The emotional aspect”: Parents’ perspectives of factors influencing their goal setting experiences

Parents discussed internal factors influencing their goal setting experiences, including their own personality traits; the emotional struggle of living with a child who has a disability, and worry about their child’s future. Several parents identified how their own personality traits influenced their experiences, including being “*assertive and having a little dose of perfectionism*” (Mary); being a “*fairly forthright person*” (Marie); being “*a fairly practical person*” (Margaret) and “*not too shy about holding back*” (Margaret).

Despite reporting confidence in her ability to advocate for Josie, Mary reported that she did “*struggle with [feeling] I’m not doing enough*”. This was a common emotional reaction among the parents, particularly voiced by Marie who stated “*the emotional aspect of what is happening ...you are dealing constantly with the reality that your child may never develop at all ... [you have to] live with an enormous emotional and psychic, and spiritual burden*”. Lyn described worrying about her son’s future as influencing her goal setting experiences. She stated, “*it’s mainly the disability he has - the dyspraxia - and my fear or obsession with him having problems with literacy*”.

The parents interviewed also described external factors that influenced their goal setting experiences such as the “*support from people around [them]*” (Marie); many changes in therapists; the relationship with their child’s therapist; and their child’s and their own readiness to set goals. Two parents commented on the impact of changing therapists on their goal setting experiences. For example, Marie reported “*I can’t tell you the number of therapists I have had here for each kid in each discipline. Chopping and changing...so the goals get lost*”. Similarly, Margaret recalled “*changing [therapists]...for a while there it seemed like every other week...I found it hard because you had to start all over with someone again*”. Margaret went on to stress the importance of having a stable relationship with her

child's therapist which enabled her to share information for more effective goal setting. She reported that *"the more I get to know someone the more I'm likely to share with them"*.

Marie identified the importance of both her and Max being ready to address the goals set by others. She provided an example where an Early Intervention Team had suggested she start toilet training her son. She had identified that both she and Max were not ready to take on this task, and so she communicated this to the team. When recalling this event to the interviewer, she became tearful and recounted how this event taught her to advocate for her child, helping her to realise that she was the key player in her goal setting experiences. She reported, *"I will tell them whether the kid's ready or not and I will tell them whether the family is ready for what they're asking"*.

4.5.2 "Depends on the setting, the client and also time": Factors of occupational therapists' goal setting experiences

The occupational therapists identified many factors which influenced their goal setting experiences. These factors have been grouped into the sub-themes of family, child, therapist and external factors. Each sub-theme is described below.

4.5.2.1 Family factors

Therapists discussed both parental factors as well as other family factors such as number of children in the family and parents' previous experiences with child development; whether parents had done any research into their child's disability, length of time families had been *"in the system"* which influenced their understanding of what was therapy, goal setting and their child's disability (Peter, Carol), a family's understanding of their child's disability and implications for the future, *"mental health issues"* of parents and their ability *"to plan ahead and make task lists"* (Jane), parents *"stage of grief and loss"* (Ann), family readiness and *"willingness"* to actively engage in goal setting (Michael), and *"whether parents re-engaged again after... intervention"* (Ann). Jane had experienced different families with different levels of understanding of their child's future needs, and she felt this had influenced her goal setting experiences. She reported that *"it depends on where the family is...I think of some families really understand the disability and understand where they are going and understand what will pop up in the future and other families just have no idea"*.

4.5.2.2 Child factors

Therapists also described child factors that influenced their experiences. These included the age group and stage of life of the child. Carol discussed that families of younger children often did not identify goals. She reported *“parents with babies...or particularly the younger aged children don’t have any specific areas of concern... for some, the older children who attend for handwriting or pencil grip you might be more specific in goals”*.

Ann discussed the issue around Duty of Care and how sometimes therapists were challenged with focusing on goals that impacted on the health and safety of the child even though these goals may have differed from the parent’s goals. She reported how she overcame this challenge in her goal setting experiences:

I know that there has often been a debate around ... family concerns, issues, goals versus what you professionally may feel is a priority and what if the two don’t meet and what to do about duty of care.... I guess, I still think in the long run, if you address what the, if you do it collaboratively and you address the family’s concern, you can always come back to those critical issues (Ann).

4.5.2.3 Therapist factors

Therapists identified their own factors that influenced goal setting including preparing for goal setting and developing their own goal setting technique. Peter explained:

I’m still finding my own way of setting goals and my own way of empowering a goal setting discussion... I get in there and I am very solution focused that person will present a problem and I will present a solution (Peter).

Like the parents, therapists also identified the influence of their own personality traits, as Jane stated *“I’m kind of organised, strategic type personality anyway so it works for me”*.

Carol also identified that further training and knowledge influenced her goal setting as it gave her other things to try with clients.

4.5.2.4 External factors

All therapists raised external factors that influenced their goal setting. These included having time to goal set and develop a relationship with the family, and the service model. For example Ann was working within an equipment prescription team and described that she had a “*very specific and narrow*” job and “*in the current position, doing equipment prescription using COPM doesn’t fit with the model*”. Jane discussed why she had to develop therapy action plans with clients. She said “*we have to set these goals and work out an action plan...as a government service we need to get specific things on paper*”.

Staffing, waiting lists and the influence of colleagues’ goal priorities also influenced the occupational therapists goal setting experiences. Peter discussed his experience of the influence of his colleagues’ goal priorities, “*other disciplines...can be quite forceful in their goal setting and they may actually just dictate a goal and then that just happens like that as well*”.

Jane discussed that she was setting multidisciplinary goals with a new speech pathologist to get through their waiting list as this enabled her to close clients from occupational therapy once families accepted that they would remain open in the system for speech pathology.

The child’s school setting was also discussed by several therapists as influencing their goal setting experiences. This included issues around Occupational Health and Safety and Individual Learning Plans, teachers having their input and whether goal setting occurred at school, home or in the therapy environment (Peter, Carol, Jane, Michael).

Therapists identified more factors influencing their goal setting experiences than the parents did. The factors raised by the therapists can be grouped into sub-themes of family, child, therapist and external factors.

Figure 4.5 summarises Theme Four and sub-themes.

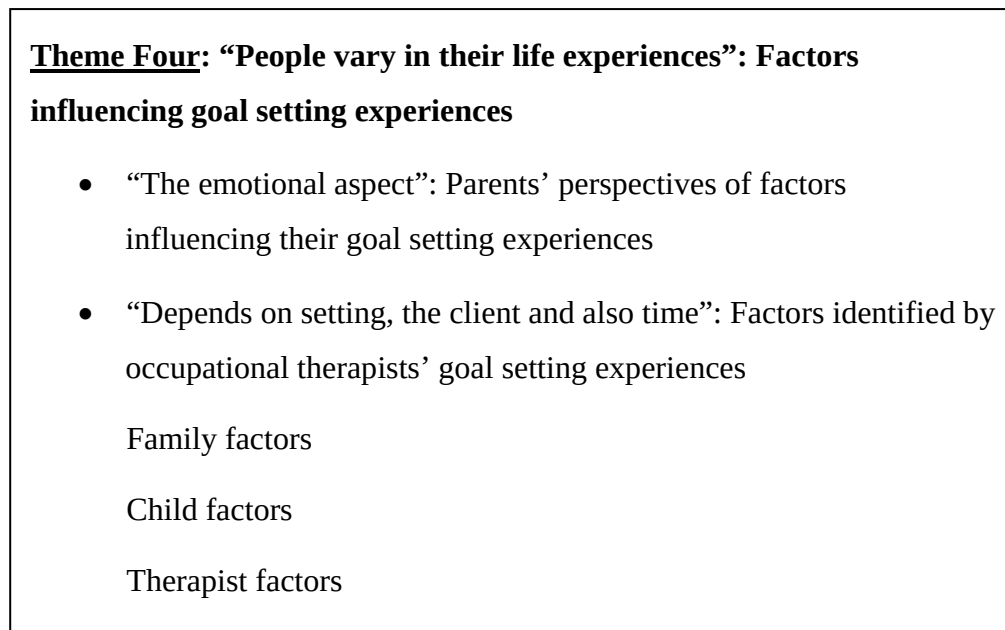


Figure 4.5 – Summary of Theme Four and sub-themes

4.6 Theme Five: “More guidance, more direction”: How Goal Setting Could be Improved

Throughout the interviews parents and occupational therapists provided ideas about how the collaborative goal setting process could be improved. This final theme discusses both perspectives.

4.6.1 “Reinforce with the parents”: Parents’ ideas for improving goal setting

Parents wanted goals to be “*more explicit*” (Mary) with “*steps*” (Mary, Lyn) for achieving the goals, “*timeframes*” (Lyn) and “*difficulty levels*” (Lyn). They wanted therapists to reinforce that their interventions with their children were useful and to explain the ‘how’ and ‘why’ as Marie and Mary discussed:

I’ll tell you, what makes a big difference is when the therapist sees you in your own environment with the child and actually points out what has been done. They see your little routines with your kids... they say ‘you see how you’re doing that? That’s great! I’m going to write that down...What you’re doing there is great! And the reasons why it’s working is because’ (Marie).

You've got to be saying – look, of course, in the end we want your child to be able to tie their own shoelaces or whatever but we don't know how quickly that will happen. It's better if we improve the base skills along the way...The therapist needs to reinforce with the parent that, oh, the fact that we've improved this, that's great that will help them get to blah (Mary).

They valued having input from the therapist rather than attempting to construct goals independently. Mary discussed the value of the therapist's input into the goal setting process. She said:

You don't want to leave out the therapist's knowledge because I know that I could fear that with my driving everything, there won't be any room for therapists to say 'hey - you forgot about this – or - actually this would be really good, have you thought about it?'(Mary).

Parents also discussed including their child more in the goal setting process or at least making the goals more child-focused based on their child's interests. Lyn suggested using a “*chart or pictures...so that [child] could understand as well*”. Mary had not considered involving Josie, who was school-aged, in the goal setting process until she participated in this research interview and was asked about Josie's role in goal setting. She thought that it would be a good idea to include Josie in future goal setting discussions and advised therapists to:

Ask the child... if the child is not able to express verbally, or be asked directly, what do you notice they have a particular passion for trying to learn, like, so how can we infer what the child's goals might be? (Mary).

Margaret was also interested in including Lucy, who was twelve years old, more in goal setting but required help in communicating this to Lucy who had an intellectual disability associated with Down syndrome. She stated that “*it would be nice to see her more involved... if someone could teach me I'd be happy to learn*” (Margaret).

Marie also advised that she wanted “*practical, concrete information*” and she said “*no don't give me anything to read. You know I'm here, tell me what I need to know, break it down for*

me right now". She described feeling overwhelmed and was overloaded by having two children with autism. She was not in a position to read a lot of information. She preferred to have direct advice that was broken down into manageable steps.

Lyn generally wanted *"more guidance...and a little bit more direction"* as she did not feel confident without regular support from therapists. She felt that having a more formal goal setting process including *"a timeframe to review those goals"* such as *"once a term"* would be useful to help her see whether Craig had *"achieved them and which are the main focus areas"*.

The parents interviewed provided a range of strategies to improve collaborative goal setting. These included making the event more structured, with a formal review process and providing more practical information than they had previously received from therapists. Involving their child in the collaborative process was also of interest to parents even though most had not previously considered this.

4.6.2 "Take the time to goal set": Occupational therapists' ideas for improving goal setting

Carol was happy with her goal setting process, however the other four therapists identified strategies to improve it. Therapists felt that setting goals within a multi-disciplinary team rather than as a single discipline was most useful (Peter, Carol and Jane), particularly to coordinate services and to *"prevent less duplication"* (Carol).

Some therapists felt that using a goal setting tool such as the Goal Attainment Scale (GAS) or the Canadian Occupational Performance Measure (COPM) would help structure the goal setting process and provide a means for recording and evaluating client progress. Peter and Michael both discussed how they would like to use goal setting tools:

I think ...using a tool ... that's flexible enough like GAS to actually design goals that are unique because I think that is the challenge with our client bases that everyone is so unique that it is hard to set individual goals. And I like with the GAS - it is actually recordable over time (Peter).

In my ideal world of goal setting I would be doing a COPM first... identifying what those...two, three, four or five goals are and then I would love to do GAS goals and draw all of those up (Michael).

While Carol and Ann discussed the importance of structuring goals and using a language that parents could understand to facilitate parent's participation in goal setting, Peter disclosed that he needed *"more guidance and more...structure as to how to empower parents and give them permission to break down...big goals"*. Generally, therapists suggested structuring their time to include goal setting and reviews; limiting their caseload numbers and client diversity so that they could adequately take time to goal set with families (Peter, Jane, Ann, Michael).

In summary, the occupational therapists, along with parents discussed strategies to improve the collaborative goal setting process. There were some differing opinions amongst them as to the benefits of using goal setting tools however four out of the five did have a preference for using such tools. Therapists also discussed the benefits of setting goals as a multi-disciplinary therapy team. Figure 4.6 summarises Theme Five and sub-themes below.

Theme Five: "More guidance, more direction": How goal setting could be improved

- "Reinforce with the parents": Parents ideas for improving goal setting
- "Take the time to goal set": Occupational therapists' ideas for improving goal setting

Figure 4.6 Summary of Theme Five and sub-themes

4.7 The Similarities and Differences of the Collaborative Goal Setting Experiences of Parents and Occupational Therapists

Throughout this data analysis, the similarities and differences of the goal setting experiences of parents and occupational therapists were investigated. Each theme has been reviewed specifically to investigate the similarities and differences in the participants' experiences. Theme One identified that both parents and therapists had to learn how to engage in collaborative goal setting however what they learned differed. Theme Two demonstrated that both parents and therapists experienced goal setting as a general discussion and sharing of ideas, felt that therapy goals changed before reviews, and identified similar roles that each party engaged in during the process. However, parents identified that goals set were open ended and did not recall the use of specific goal setting tools. Therapists and parents also differed on their perceptions about who owned the goals. Parents believed that they owned the goals while and therapists believed that the ownership was shared (Theme Two). Both parents and therapists identified many factors that influenced their goal setting experiences (Theme Four), however therapists identified a wider range of factors than parents. Lastly, in Theme Five, parents and occupational therapists identified different strategies to improve collaborative goal setting processes. For example, therapists identified the use of specific, measurable, goal setting tools. Table 4.1 summarises the similarities and differences of parents and occupational therapists experiences across each of the five themes.

Table 4.1 *The similarities and differences of the goal setting experiences of parents and occupational therapists (OTs)*

Theme	Similarities	Differences
Theme One: Learning to goal set	Both have to learn how to set goals	More frequently set goals (OTs) More to learn (parents)
Theme Two: Goal setting experiences	General discussion and sharing of ideas Goals changed Roles in process	Open ended goals (parents) Use of tools (OTs) Ownership
Theme Three: The impact of goal setting	A reminder Develop relationship More than one person thinking Narrows down Communication tool Educates families	Adds to workload (parents) Workload management tool (OTs) See child's progress (parents)
Theme Four: Factors influencing the goal setting experiences	Both identified parental, family, child, OT and external factors	More factors identified by OTs than parents
Theme Five: How goal setting could be improved	Both identified ways goal setting could be improved	Different ideas raised by OTs and parents

4.8 Chapter Summary

The findings generated by this inquiry have been presented in this chapter. They demonstrated that both parents and occupational therapists learn to actively engage in collaborative goal setting. Parents' learning about goals and goal setting occurred in relation to three types of goals that they want targeted by goal setting processes with therapists. These were general goals, parent goals and child goals. Findings suggested that goal setting around helping parents acquire knowledge about their child's disability, development, prognosis and the role of therapy should occur before collaborative goals setting processes are directed towards more specific goals which focus on parent/child needs or the child's needs. Occupational therapists had to learn to develop their own goal setting techniques to facilitate active parent engagement in collaboration.

Parents described open-ended goals that lacked clarity. They did not recall specific goal setting events with therapists, rather, that these discussions were "*melled*" into their child's therapy process. Both parents and occupational therapists identified that the therapy goals changed more frequently than they were reviewed. Only therapists discussed using specific goal setting tools yet some parents did identify therapy action plans. Therapists had varying responses towards the goal setting tools however generally they were positive about using them. The occupational therapists reported that the goal setting tools enabled them to measure goal attainment, introduce their role to families and structure their goal setting processes with families.

The impact of collaborative goal setting was experienced differently by parents and occupational therapists. Parents found goal setting beneficial because it helped motivate them to do therapy with their child at home, reminded them what they had to do in amongst their "*busy lives*", enabled them to monitor their child's progress and facilitated a relationship with their child's therapist. One mother (Marie) noted negative impacts of collaborative goal setting including that she found it "*guilt inducing*" and "*added to the burden*" of her existing roles and responsibilities.

Occupational therapists described collaborative goal setting as the “*beginning of the therapy process*” and reported that it helped to foster a therapeutic relationship with clients.

Therapists used goal setting as a communication tool to prioritise family and therapy needs and allocate therapy resources. They also used it as a case management tool to manage their busy caseloads.

Parents and occupational therapists identified a wide range of factors that influenced their collaborative goal setting experiences. These ranged from personal factors such as emotional readiness and personality, to external factors including changes of therapists, service model, time, and the influence of other agencies such as school. The factors identified by occupational therapists could be categorised into child, family, occupational therapist and external factors.

Both parents and occupational therapists identified strategies for improving their collaborative goal setting experiences. Parents requested more explicit goals with steps and timeframes for goal achievement. They valued the professional input of the therapists. They wanted practical concrete information and also wanted to be able to include their children in the goal setting discussion. Occupational therapists discussed the benefits of setting goals as a multi-disciplinary team rather than as a single profession with families. They wanted to use goal setting tools more consistently and routinely allocate time for goal setting and reviews.

Figure 4.7 is a diagrammatic summary of all themes and sub-themes that portray the goal setting experiences of parents who have children with disabilities and occupational therapists. In the following chapter the inquiry findings will be discussed in relation to the existing literature.

Figure 4.7: Overview of Themes that Describe Collaborative Goal Setting Experiences from the Perspective of Parents and Occupational Therapists



Chapter 5

Discussion

5.1 Introduction

Collaborative goal setting in child and family occupational therapy practice is a dynamic process between parents of children with disabilities who require occupational therapy services and occupational therapists (King et al., 2004; Novak & Cusick, 2006; Palisano, et al., 2004; Wiart et al., 2010). This process involves the discussion, education and agreement about a desirable and achievable future state for the child and family. Its purpose is to educate families about their child's disability and development, how occupational therapists can support families and children, and to develop a plan of action for occupational therapy involvement (Law et al, 2004; Playford et al., 2000). Collaborative goal setting is a complex process influenced by a wide range of factors (Holliday, Ballinger & Playford, 2007; King, Tucker, Baldwin & La Porta, 2006; Nijhuis et al., 2007; Oien, Fallang & Ostensjo, 2009; Ostensjo, Oien & Fallang, 2008; Wiart et al., 2010) in which parents' and occupational therapists' priorities and goals are discussed and negotiated to form a therapy action plan (Holliday et al., 2007).

The purpose of this inquiry was to explore the collaborative goal setting experiences of parents of children with disabilities and occupational therapists living and working in Canberra, Australia. Qualitative methods of data analysis led to the development of five themes with several sub-themes that described the phenomenon of collaborative goal setting as experienced by parents of children with disabilities and occupational therapists.

This inquiry specifically aimed to answer the following questions:

- What does collaborative goal setting mean to parents and occupational therapists?
- Are there similarities and differences in collaborative goal setting experiences of parents and occupational therapists?
- How do parents and occupational therapists believe collaborative goal setting could be improved?

The focus of this chapter is to discuss the key findings that have evolved from this inquiry in relation to existing literature. The following key findings will be addressed: goal setting is a learning process for both parents and occupational therapists; there were similarities and differences in how parents and occupational therapists experienced collaborative goal setting; the impact of collaborative goal setting was experienced differently by parents and occupational therapists; many factors influenced the collaborative goal setting experiences; both parents and occupational therapists felt goal setting could be improved and goal setting was a dynamic process.

5.1.1 Goal setting involves learning

A major finding of this inquiry was that both parents of children with disabilities and occupational therapists went through a learning process in order to engage and participate in collaborative goal setting. As identified in Chapter Four, parents had much to learn before they felt they could contribute meaningfully to goal setting with therapists. Three types of goals that occur in the goal setting process between parents and occupational therapists were conceptualised by Figure 4.1. Both parents and occupational therapists discussed their experiences of learning to set goals. This is consistent with findings from other research in the child and family field as well as adult rehabilitation settings (Barclay, 2002; Holliday et al., 2007; Leach et al., 2010; Mayer et al., 2002; Oien et al., 2009; Ostensjo et al., 2008; Turner et al., 2008).

Mayer et al., (2002) interviewed nine occupational therapists about how they contributed to the parent-child relationship with families that they worked with. All participants reported an educational role with families and that “at times they had to help families understand diagnoses and reports from various professionals” (Mayer et al., 2002 p. 416). They found it useful to provide families with information about the functional implications of the medical reports and diagnoses which provided a different perspective to the other professionals and helped established their professional contribution (p. 416). They also described their role as helping parents learn to interpret the behaviours of their child as a way to help parents respond to their child more appropriately. It can be hypothesised that participants in the Mayer et al study were supporting parents at the general and parent goal setting levels conceptualised in Figure 4.1 in this study.

A study by Oien et al., (2009) also demonstrated the usefulness for developing shared knowledge that parents experienced from learning about their child through joint observations with the child's therapists. In that study, parents and service providers of thirteen preschoolers with cerebral palsy participated in focus group interviews. The purpose of the study was to explore parents' and professionals' perceptions of setting and implementing goals within a family-centered rehabilitation programme. Findings suggested that the professionals viewed their role as a leadership role in supporting parental competence and understanding about their children (Oien et al., 2009), indicating that they targeted the general level of goals featured in Figure 4.1 of this inquiry.

In another study by the same authors, Ostensjo et al., (2008) interviewed parents and service providers of thirteen preschool children with cerebral palsy through participation in two-step focus group interviews. Participants were interviewed after goal setting, implementation of a three month home programme and after their child's ten day involvement in a rehabilitation unit and again after a goal setting review and a further five month home programme. The authors found that during the second goal implementation period, parents increased the number of play-related goals for their children (Ostensjo et al., 2008). They hypothesised that this change in identification of goals was based on parents' prior experiences in implementing and achieving previous goals in the home environment, and also from the observations and discussions with staff at the rehabilitation unit. This demonstrated that these parents learned to set goals through their engagement and active participation in therapy with their children. This is a similar finding to that of the present inquiry that is supported by Theme One "An obscure concept": Learning to goal set.

Holliday et al., (2007) explored patients' perspectives of goal setting in neurological rehabilitation. In this study participants described difficulties in understanding their disability, and the impact of this difficulty to set goals. An example of this was provided by Neil who reported "it was difficult to set the goals because I didn't know what I could achieve" (p. 393). The authors reported that Neil was reluctant to suggest goals because of "lack of predictability of the disease course" (p. 393). The authors suggested that in order to improve collaborative goal setting, there are "particular tasks that need to be completed before

successful goal setting can occur” (p. 394). These tasks include initially clarifying the nature of goals in the setting and their role in the therapy process; discussion of the disability and prognosis in relationship to the specific diagnosis; determining the clients’ prior experiences of goal setting; clarifying the expectations of client involvement and allocating time for goal setting (Holliday et al., 2007 p. 394). Again, similar views were expressed by the parents and/or therapists in the current inquiry.

As discussed in Chapter Two, the studies by Turner et al., (2008) and Barclay (2002) demonstrated that patients in acquired brain injury and spinal rehabilitation settings go through a learning process about understanding their disability, how to live with this disability and their ability to set goals with support from engagement with therapists in collaborative goal setting. Turner et al., (2008) also supported the notion by Holliday et al., (2009) that clients initially need to be provided with information “to enhance their self-awareness prior to developing meaningful therapy goals” (Turner et al., 2008 p. 105). From her pioneering work on exploring client perspectives of goal setting with an occupational therapist, Barclay (2002) also raised the issue about “whether it is important for patients to be educated regarding what goals are, and the important features of goals, when they first start working with their therapist” (p. 11). Similarly, Leach et al., (2010) demonstrated the importance of educating clients prior to participation in collaborative goal setting. They interviewed multi-disciplinary therapists who provided intervention to patients in a sub-acute rehabilitation setting following a stroke. The authors identified that the degree of patient centeredness in the goal setting approaches was influenced by the need to “orient the patient and family to the term goal and the goal-setting process” (Leach et al., 2010 p. 168). They recommended that therapists need to ensure a shared understanding of the terms goal and goal-setting, with clients before engagement in goal-setting and that patient and family education is integral to the goal setting process.

Similar to the findings of this inquiry, these studies demonstrated that parents and clients must develop self-awareness of their own and their child’s disability, and its implications for everyday living and future functioning, prior to being able to participate in collaborative goal setting with occupational therapists. Novak & Cusick (2006) stated that “parents need knowledge and skills that are relevant to setting goals” to participate in collaborative goal

setting (p. 10). By engagement in collaborative goal setting with therapists, parents learn how to goal set and learn more about their child's disability and future possibilities. Having education about how to goal set prior to this engagement is required. Therapists need to address general goals such as provide information about the child's disability, child development and therapy first before helping parents address parent goals that focus on how parents can help their child and how they can adjust to their life with their child. Furthermore, parent goals need to be addressed before parents can consider child focused goals, such as goals around specific skills that the child needs to develop (see Figure 4.1). While the current inquiry has added to the body of evidence that supports this early stage of goal setting, it has also highlighted that therapists may not always provide the guidance parents need to set specific and measurable goals, or to learn how to articulate desired goals.

Glaser's (1996) model for the development of competence can be used as a theoretical model to support the finding in this inquiry that parents need to set goals on the three levels in Figure 4.1, and to explain parents' process of developing competence in setting goals at each level. He described three phases to develop competence. Initially learning involves a significant amount of external environmental support, and as competence is attained there is an increasing amount of internalised self-regulation that controls a person's ability to engage in the learned task. When children first access therapy services, parents often require a higher level of external support from therapists to learn about their child's diagnosis, developmental level and how therapy can support them. During the course of engagement with therapists, parents transition from requiring a lot of external support to an "apprenticeship" phase (Glaser, 1996 p. 305). At this phase therapists reduce the support and offer guided practice, fostering self-monitoring through the provision of home programmes and therapy reviews. Less direct contact is provided during this phase. Parents eventually learn to self-regulate where they have control and understanding of their child and know how to utilise occupational therapy as required. During this phase, parents make selective use of external supports (i.e. therapists) for specific issues such as for prescription of a new wheelchair or supporting their child's transition to high school. Competence is developed when parents are able to predict the future needs of their child, feel that they have control of their child and family situation and can continue to learn about their child and live with their child without external support. The role of the occupational therapist is that of a teacher or a coach by

providing assisted practice and feedback when needed, and fading support when parents begin to manage their ongoing living situations themselves.

There is currently a move towards coaching families to help parents develop this competence. Recently at the Early Childhood Intervention Conference Australia (May 2010), two key note speakers presented papers on how they are changing the focus of early intervention therapy from child-centered practice towards supporting the responsiveness of families (Luscombe, 2010; Mahoney, 2010). The goals in both of these approaches were to support families learn how to respond to their child and manage everyday living with their disabled child.

In this study, occupational therapists also identified that they had to learn how to set goals as well as parents. In particular, therapists acknowledged that they had to develop their own style to engage parents in collaborative goal setting. This finding has not been identified in previous occupational therapy research reviewed for this thesis. A similar finding was reported in a study by Wohlin Wottrich, Stenstrom, Engardt, Tham & von Koch (2004), in which physiotherapists identified that they did not know how to set goals, despite wanting to involve patients in a goal setting process (p. 1203). While the study by Ennals and Fossey (2007) outlined in Chapter Two demonstrated that occupational therapists felt “challenged by the experience” (p. 17) of using a formal goal setting instrument with clients, there was no report that the therapists had to additionally learn to develop their own goal setting style as did the occupational therapists in this present inquiry.

In 2005 McClain recommended that educators “should train students in the use of formal tools to establish collaborative goals” (p. 59). Occupational therapists are taught at undergraduate level how to engage clients in collaborative goal setting and have a suite of goal setting tools available to facilitate this process such as the Canadian Occupational Performance Measure (COPM) (Law et al., 1998), and the Goal Attainment Scale (GAS) (Kiresuk & Sherman, 1968). However, this inquiry has demonstrated that therapists find learning to apply these tools in clinical practice and engaging parents in collaborative goal setting challenging. Possible reasons for this may include the following. First, therapists often continue a caseload from a previous therapist who has not established a formal goal setting routine with clients. Second, therapists do not always allocate sufficient time to

discuss goals with parents (Holliday et al., 2007). Third, as found in this study, parents often are perceived to “*just want action*”, and therapists feel that engaging in goal setting puts parents through “*more hoops*” before commencing therapy. Fourth, perhaps experience plays a role in the level of comfort about setting goals. Two of the five occupational therapists interviewed had less than three years’ experience. Therapists with more long-term experience may have developed more ability through tacit knowledge to support parents’ understanding and may be in a better position to assist parents in learning about their child’s disability and future options.

5.1.2 Goal setting experiences

Some of the parents’ experiences of collaborative goal setting found in this study are similar to parents’ and clients’ experiences reported in other studies. These included the use of goal setting tools, their role, ownership of goals and the phenomenon of goals changing over time (Link Melville et al., 2002; Holliday et al., 2007; Oien et al., 2009; Wiart et al., 2010).

In this inquiry parents did not experience goal setting as a clearly defined event and as a result, felt that goals were not explicit. This made it difficult for parents to develop competence in understanding their child’s disability and utilise therapy as required. For example, the parents in this inquiry reported that goal setting was “*mixed in with everything*”, and were unable to identify the use of goal setting tools, such as the Canadian Occupational Performance Measure or Goal Attainment Scale during their goal setting experiences with therapists, despite therapists reporting that they used these tools. This was a similar finding to the parents’ experiences reported in the study conducted by Wiart et al., (2010) where they interviewed parents in focus groups about their goal setting experiences. They reported that “parents did not talk about using standardised goal setting processes with therapists” (p. 254). The lack of clarity around the goal setting event and the different values that parents placed on goal setting compared to therapists, may account for this discrepancy between parents and therapists in the identification of using goal setting tools. If parents cannot see a clearly defined goal setting event and do not have a paper record that can be used as a reference point in future goal review appointments, it would be difficult for parents to recall the use of specific goal setting tools, and indeed, to recall specific goals that may have been set.

The parents in the study by Wiart et al, (2010) reportedly benefited from the therapists' knowledge and experiences in goal setting. This finding found resonance in the data from parents in this current inquiry, who reported that they "*don't think of everything*" and were worried about missing things without the benefit of the therapist's knowledge. Again, Glaser's (1996) model of developing competence supports the concept that parents initially require coaching and external support from therapists to facilitate their learning about their child and how to use therapy when required.

The parents and occupational therapists in this current inquiry identified that the therapy goals changed sometimes more frequently than they were reviewed. Link-Melville et al., (2002) also identified that goals and perceptions on goal achievement evolved dynamically over time (p. 657). One factor influencing goals changing was the child's life stage such as entering school. As reported in the findings, one parent described how her daughter's transition to school shifted her focus of therapy goals. Parents in the Wiart et al., (2010) study also identified that the focus for therapy shifted once their children entered school and they became involved with Individual Learning Plans (ILP). They also reported that parents recognised that their child's involvement in the goal setting process would change as they became older and were able to identify their own school-related goals (p. 254). In a study by Ostensjo et al., (2008) the Canadian Occupational Performance Measure (COPM) and Goal Attainment Scale (GAS) were used in combination with a nine-month rehabilitation programme for preschoolers with cerebral palsy. This study showed that the priorities of goals using the COPM and GAS changed over time. The reasons for goals changing were varied. A key feature was that parents learned how to set goals and how to identify their own needs and goals, they could generalise this skill across age and occupational context, and medical type of service provision.

Parents in this inquiry viewed themselves as "*drivers*" of the goal setting process and ultimate owners of the therapy goals. This contrasted with therapists who reported that they sometimes had to drive the goal setting process and viewed goals as being equally owned by the families and themselves. The therapists viewed their role as being to write down the goals for parents using their knowledge of goal setting terminology. Oien et al., (2009) also reported in their study that parents were the drivers of goal setting and owned the goals.

Parents in their study felt that goals should be based on their needs and preferences however like this present inquiry, these parents also valued professional input and supervision (p. 561). Although the parents in the study by Oien et al., (2009) had preschool aged children which differed in this present inquiry where the ages of children ranged from two years of age to twelve years, the findings in this present inquiry were similar. In the Oien et al., (2009) study the professionals took on a “leading position” (p. 563) with parents and viewed the goal setting process as a “partnership” (p.563). Parents provided information about the child’s problems, interest and learning opportunities at home, while therapists provided knowledge about how to make goals task specific and scaled them down into small steps (Oien et al., 2009). The view of the professionals in their study was also shared by the occupational therapists interviewed during this inquiry. Leach et al., (2010) reported that despite the development of client-centered practice current practice is largely therapist driven (p. 160) which was a view shared by the occupational therapists in this inquiry.

How much parents and clients want to be involved in the goal setting process is an individualised experience (Jansen et al., 2003; Link-Melville et al., 2002; Oien et al., 2010; Wiart et al., 2010). In this present inquiry, all five parents interviewed valued engagement in collaborative goal setting with therapists. Four of the five mothers indicated their role as drivers and owners of the process. One mother was still in the early stages of understanding her child’s disability and the implications for this (Keiko). She reported feeling comfortable and happy with her involvement with therapists and did not identify that she wanted to take on a more driving role (Keiko). These parental experiences supported the research of others about their views of the roles that they took on in collaborative goal setting with therapists (Jansen et al., 2003; Link-Melville et al., 2002; Oien et al., 2010; Wiart et al., 2010).

The collaborative goal setting experiences of parents and occupational therapists in this present inquiry were similar to the experiences of parents and therapists in other research in regards to the use of goal setting tools, their roles, ownership of goals and the changing nature of goals (Jansen et al., 2003; Link-Melville et al., 2002; Holliday et al., 2007; Oien et al., 2009; Ostensjo et al., 2008; Wiart et al., 2010). Most research has focused on parents’ and clients’ perceptions about their experiences of collaborative goal setting. This is the first inquiry to explore the collaborative goal setting experiences of both occupational therapists

and parents within an Australian context for service provision to children from birth to eighteen years of age of all disabilities. Further research is required to investigate how parents and therapists respond to more structured, clearly defined goal setting events where therapists provide parents with information about goals and the goal setting process.

5.1.3 The impact of goal setting

Similar to the wide body of evidence surrounding the benefits of client engagement in collaborative goal setting practice, the parents and occupational therapists in this inquiry valued their participation in collaborative goal setting (Barclay, 2002; Leach et al., 2010; McClain, 2005; Mayer et al., 2002; McLaren & Rodger, 2003; Novak & Cusick, 2006; Turner et al., 2008; Wiart et al., 2010; Wohlin Wottrich et al., 2004). As outlined in Chapter Four, the impact of goal setting practice for parents and the occupational therapists differed.

Parents identified having busy lives and used goal setting to establish a relationship with therapists; motivate themselves and their children in participating in therapy activities; see their child's progress; and help to focus and remind them of what they needed to be doing with their children. Marie described the emotional impact and great sense of guilt that she experienced from goal setting. These experiences were echoed by the parents in the study by Wiart et al., (2010) where parents identified that they couldn't "do it all" (p. 253) and that there wasn't enough time to do everything that needed to be done during the day. In the study by Wiart et al., (2010) there was a mother of a ten year old girl who described her expectation of doing the therapy created "another source of really intense guilt" (p. 253). Parents in this current inquiry raised concerns about having to do the therapy too and the emotional burden that they experienced because of this. Although overall the impact of goal setting was perceived by parents as positive, it did add to parents' sense of burden and time pressures from trying to implement the identified therapy goals in amongst their busy lives. These findings emphasise both the importance of considering families in the broader context of their lives when collaboratively goal setting with them, and recognising the potential impact of the goal-setting process itself.

Functions of the collaborative goal setting process included: to define the therapists' role, reason for involvement with the family and the child, and to establish a family-therapy action

plan for therapist's engagement. Another was to establish a partnership with the family in deciding how therapy services for their child would be provided and to move away from the former child-centered approach where professionals told parents what to do (Novak & Cusick, 2006). The views of the occupational therapists interviewed in this inquiry about the impact of goal setting were consistent with the literature (Leach et al., 2010; Link-Melville et al., 2002; McClain, 2005; McLaren & Rodger, 2003; Novak & Cusick, 2006). The therapists interviewed saw the impact of collaborative goal setting as a "*starting point*" to therapy; an opportunity to educate families about their role and what services they could offer; and to hear the families' stories. Therapists used goal setting to develop therapeutic relationships with families and as a communication tool to ensure they had a common direction and purpose with families. They found it was a useful means to prioritise family and therapy concerns and actions.

Consistent with family centered philosophy, the occupational therapists in this inquiry valued the benefits of engagement of parents in their goal setting practices as a means of understanding the child's needs within the context of the family's needs. In the study by Mayer et al., (2002) the occupational therapists believed that parents knew their child best and what services would best meet their family's needs. One therapist in that study reported having difficulty stepping into the frame of reference of the parents. Therapists in this current inquiry did not identify difficulties stepping into the frame of references of parents but did identify challenges in developing their own goal setting techniques to most effectively engage parents in collaboration.

A unique experience of the therapists interviewed in this inquiry was that goal setting was seen as an effective case management tool to keep track of their overall client workloads. Therapists described using action plans as a means for remembering what to follow up on with each client and focusing their reviews with clients. Ann described keeping a separate folder of all her action plans as a prompt for following up on actions agreed to. This perspective has not been found in the literature about therapist's perspectives to date. This theme evolved during this inquiry as therapists were given permission to take time to reflect on their goal setting experiences. Typically the therapist's work day is busy and therapists described having large and varied caseloads to manage competing work demands. In light of

this, it is not surprising that therapists found goal setting as a useful caseload management tool.

Overall the impact of goal setting as described by parents and occupational therapists interviewed in this inquiry was consistent with the literature. A key finding of this inquiry was the difference of the impact of collaborative goal setting as reported by parents and occupational therapists. This inquiry may help facilitate occupational therapists' understanding of the impact of collaborative goal setting when engaging parents who have busy lives.

5.1.4 Factors influencing goal setting experiences

The participants in this inquiry identified a wide variety of factors influencing their collaborative goal setting experiences. These factors can be grouped into child, family, occupational therapist and external factors (refer to Figure 5.1 on following page).

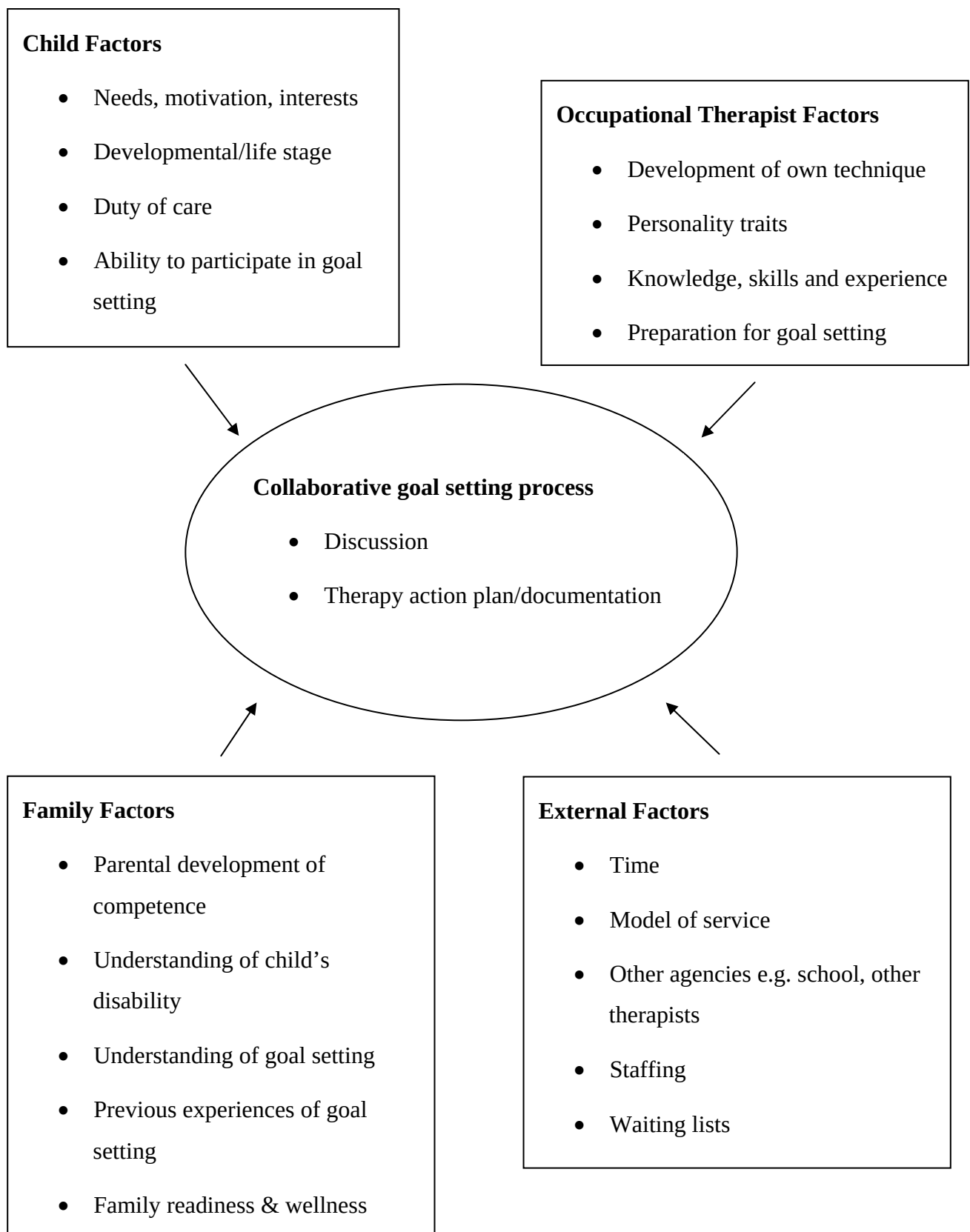


Figure 5.1 Summary of factors influencing parents' and occupational therapists' collaborative goal setting experiences

These factors reflected factors that have been described by participants in other research studies that have investigated collaborative goal setting from the viewpoints of therapists, clients and parents (Barclay, 2002; Ennals & Fossey, 2007; Holliday, et al., 2007; Oien et al., 2009; Leach et al., 2010; Wiart et al., 2010; Wohlin Wottrich et al., 2004). For example, in the study by Wiart et al., (2010) parents identified that the age of their child influenced their involvement in goal setting. The authors found that “parents did not feel comfortable identifying reasonable and attainable goals, particularly when their children were very young” (Wiart et al., 2010 p. 254). This was a theme identified by the occupational therapists in this present inquiry. For example, Carol reported that “*parents with babies....or particularly the younger aged children don’t have any specific areas of concern*”. The parents interviewed in this inquiry also identified that the age of their child influenced their goal setting experiences. Mary discussed being able to set more task specific goals once her daughter entered school, rather than when she first accessed therapy services as an infant.

Goal clarity and whether goals were broken down into small steps was another factor voiced by parents in this present inquiry which was similar to a theme identified by Oien et al., (2008). Parents in this present inquiry identified that goals were often implicit and they wanted more specific steps about how to help their child achieve the goal. Oien et al., (2008) reported that both parents and service providers valued goals formulated in small and achievable steps and that clear goals increased their engagement in the goal implementation (p. 562).

Barclay (2002) represented factors influencing the goal setting process between an adult client in a spinal rehabilitation setting and the therapist (see figure 2.1). She identified a range of factors influencing the goal setting process including: culture of the rehabilitation environment and service delivery model; nature of the relationship between the therapist and the client; use of goal setting tools such as Canadian Occupational Performance Measure, Goal Attainment Scale and SMART (specific, measurable, achievable, relevant and time frame) goals to structure the process; the client’s prior beliefs about illness; and his initial limited understanding of his disability and potential for goal achievement (Barclay, 2002, pp. 10-11). All of these factors were identified by the parent and occupational therapist participants in this present inquiry.

Additional factors influencing the collaborative goal setting experience of the participants from this inquiry shared by other research participants include the quality of the relationship between the therapist and client (Ennals & Fossey, 2007; Holliday et al., 2007); clients' understandings of goal setting (Barclay, 2002; Leach et al., 2010; Holliday et al., 2007; organisational structure and changes (Barclay, 2002; Wohlin Wottrich et al., 2004) and therapist time to goal set with clients (Holliday et al., 2007; Leach et al., 2010).

Unlike the research of the goal setting experiences of adults and therapists in the adult rehabilitation and community mental health settings where goals are directly set by the service recipient with therapists (Barclay, 2002; Ennals & Fossey, 2007; Holliday et al., 2007; Leach et al., 2010; Wohlin Wottrich et al., 2004), the goals set by parents and occupational therapists in this inquiry were set on behalf of the child and family to reflect all needs of the children, parents and families. The extra dimension of considering the child's needs as well as the family's whole context is a unique experience of parents and therapists which adds complexity to collaborative goal setting in family and child therapy settings (Ostensjo et al., 2008). This can be seen diagrammatically by comparing an earlier diagram by Barclay (2002) (figure 2.1) to a diagrammatic representation of the factors that influenced the goal setting experiences of participants in this inquiry (figure 5.1).

Similar to other research that has investigated clients' and therapists' experiences of collaborative goal setting a wide, varying range of factors influencing these experiences have transpired during this inquiry. Goal setting in the child and family field appears to be more complex than goal setting directly with service recipients who are able to engage in goal setting about themselves. This appears to be due to multiple factors influencing the goal setting process including family, child, parental factors and external factors.

5.1.5 How goal setting could be improved

The parents and occupational therapists interviewed in this inquiry presented ideas about how their goal setting experiences could be improved. The strategies identified by participants in this inquiry compliment those strategies recommended by authors of other research into

collaborative goal setting practice (Holliday et al., 2007; Leach et al., 2010; McClain, 2005; Oien et al., 2009; Ostensjo et al., 2006; Wiart et al., 2010).

The parents in this inquiry discussed strategies to make the goal setting process more explicit including having time frames, difficulty levels and scheduled reviews of the goals set. They expressed their need to be given steps for achieving the goals by the therapists. This is consistent with the study by Oien et al., (2009) who also found that parents increased their engagement in implementation of the goals when they were broken down into steps by service providers and had clear goals. The parents in the study by Oien et al., (2009) described what useful goals looked like and reported that they were “observable, contextualized, written, visible for everybody involved with the child, and set within a given timeframe” (p. 562). In an earlier poster presented by Ostensjo et al., (2006) at the 18th annual meeting of the European Academy of Childhood Disability they reported that “parents stressed the importance of making the goals concrete” (p.29). This was also identified by parents in the present inquiry.

Parents in this present inquiry discussed the value of having the therapist suggest goals as part of the goal setting process rather than leaving the goal formulation to the parents alone. This finding is consistent with the findings by Wiart et al., (2010) who also reported that parents valued from the knowledge and prior experience of therapists in contributing to the formulation of goals.

The parents in the study by Wiart et al., (2010) and this present inquiry touched on the role of the child in the goal setting process. The authors identified that the child’s role in goal setting would likely change as they became older and could identify school related issues (Wiart et al., p. 254). Mary discussed that she would like to include Josie in future goal setting events and recommended that in order to improve goal setting, children should be included or at least parents and therapists should infer what the child’s goals might be (Mary). There is a growing body of research into the inclusion of children in the goal setting process and goal setting tools are being developed to support this inclusion (Mandich, Polatajko, Miller, & Baum., 2004; Missiuna & Pollock, 2000; Polatajko & Mandich, 2004). However the child’s active participation in collaborative goal setting is limited by their cognitive and language

abilities (Missiuna, Pollock, Law, Walter & Cavey, 2006). Mary's idea of trying to infer what the child's goals might be may be a useful strategy for goal setting with children and adults with disabilities who are unable identify their own goals.

Unlike other research, parents in this inquiry identified the need for practical information and actual resources to help them implement goals with their children at home. Marie particularly raised this issue as she has two children with autism and expressed her need for additional resources and support. She reported feeling "*overwhelmed*" by goal setting and greatly burdened by living with two children with disabilities. Her perspectives may be unique to parents with more than one child in the family with a disability. Further research into the perspectives of parents with more than one child with a disability and what resources parents require to implement goals into their home settings could be explored.

The occupational therapists identified a different range of strategies to improve collaborative goal setting to the parents interviewed. They reported that setting goals as a multi-disciplinary team rather than between a parent and an occupational therapist was most useful. Researchers within the early intervention setting have investigated the most effective and collaborative service delivery approach for families with children with multiple and complex needs (Davies, 2005; Davies, Luscombe & Harrison, 2006; Carpenter & Egerton, 2005; Limbrick, 2005). This research indicates trans-disciplinary service delivery models that utilise a key worker to coordinate services and set goals with families is the most effective approach (Davies, 2005). The Team Around the Child service delivery model is a concept developed by Limbrick (2005) in England that applies a trans-disciplinary model to the coordination of interventions for young children who have complex needs and required intervention of services from a number of practitioners. No research to date has been found outside of the early intervention literature that has utilised the Team Around the Child model for children across early childhood and school age service teams. The utilisation effectiveness of multi- or trans-disciplinary goal setting is an area that requires further exploration.

Some therapists felt that using a goal setting tool such as the Goal Attainment Scale (GAS) or Canadian Occupational Performance Measure (COPM) helped to structure the goal setting

process. The use of more formalised goal setting processes and using tools is supported by other researchers in the field of collaborative goal setting (Barclay, 2002; Cusick et al., 2006; Ennals & Fossey, 2007; Link Melville et al., 2002; McClain, 2005; McLaren & Rodger, 2003; Novak & Cusick, 2006). However this inquiry has identified some challenges around using tools including that therapists need to learn how and when to use them and develop their own goal setting technique with parents; therapists need to schedule in goal setting reviews; some therapists do not feel that using a goal setting tool is beneficial and actually creates more hoops for parents to jump through before receiving intervention. Research into the routine administration of goal setting tools, such as the COPM within a geriatric rehabilitation unit has begun (Colquhoun, Letts, Law, MacDermind & Edwards, 2010). The use of goal setting tools such as the COPM and GAS is being used routinely in research within the child and family field (Cusick et al., 2006; Novak & Cusick, 2006; Ostensjo et al., 2008). However more research is required to specifically investigate the use and impact of using more formalised goal setting procedures within a child and family setting and the use of tools such as the COPM and GAS in everyday practice. Further research could also investigate what impact the use of goal setting tools has on parents' experiences of goal setting and to what extent routine use of goal setting tools has on client outcomes within the child and family setting.

Therapists in this inquiry discussed the importance of allowing time for goal setting with parents and suggested reducing caseload numbers. Other authors also identified the importance of the goal setting process on client outcomes and therefore recommend that time should be allocated for this (Holliday et al., 2007; Leach et al., 2010). Baker, Marshak, Rice & Zimmerman (2001) recommend that by involving client participation in collaborative goal setting from the start of the therapy process it does not become a time-consuming activity further into the process such as when evaluating the goals. Caseload numbers may not be able to be reduced within the model of the therapy service delivery, but encouraging therapists to understand and value the importance for allocating time to collaboratively goal set with families could support their increased engagement in, and routine practice of collaborative goal setting with parents and children.

Parents and occupational therapists both suggested a range of strategies to improve their engagement in collaborative goal setting that are consistent with the literature. It is vital to improve parents' participation in collaborative goal setting so that they can develop competence in the everyday and life long management of their disabled children. Therapists need to routinely engage parents and children in more formal goal setting processes, including goal setting reviews, so that they develop their own skills in engaging families in collaborative goal setting. This will ultimately improve the efficacy of parents' goal setting experiences.

5.1.6 Goal setting is a dynamic process

Collaborative goal setting in child and family occupational therapy practice is a complex, dynamic process that attempts to address the “multiple, changing and intertwined needs of many individuals” (King et al., 2006 p. 47). This includes the needs of the child, the parents, other family members, and community members such as teachers or childcare workers as well as therapy service delivery needs. As discussed elsewhere in this chapter, involving multiple people and services in the goal setting experience add to the complex nature of collaborative goal setting.

Oien et al., (2009) recognise that goal setting in child and family practice may be more complex than it has previously been portrayed. One of the reasons for this complexity is the changing nature of goals that was identified by participants in this inquiry and has been found in other research (Link Melville et al., 2002; Ostensjo et al., 2008; Wiart et al, 2010). This inquiry demonstrated that collaborative goal setting typically occurs at a specific time and place between a parent and therapists despite whether parents could recall their goal setting experiences as clearly defined events or not. At this particular time and place, parents discussed issues that were current and a therapy action plan was in most cases developed. Therapists developed home and school programmes and planned other direct interventions based on the goals and action plans established. At a later point in time, therapists reviewed those goals and action plans with parents. Despite having goals and action plans developed, parents continued to live with their child in between therapy interventions and reviews and did not always find these therapy plans and goals relevant. Marie identified that often her goals would change in between therapist reviews. She recalled that goals were established at specific points in time however she did not find this helpful when her children and her family

situation changed more frequently than these therapy reviews. This is a constant and inherent dilemma experienced by parents and therapists when collaborative goal setting. Unless therapists live with the family and are able to adjust goals as family or child circumstances change, the therapy goals established at a specific point in time may not always be the most current or meaningful for parents. Therefore it is a necessary task of therapists to support parents in developing competence for the lifelong management of their disabled children which includes helping parents to learn to contact therapists as required, such as when child or family circumstances change.

Another contributing factor towards the complex nature of collaborative goal setting was that parents learn to become more active participants in goal setting the more they do it with therapists. This factor was discussed earlier in this discussion. As parents become more active participants in goal setting the nature of the goal setting experience for parents and therapists change.

This inquiry, as consistent with other research, has demonstrated that the nature of collaborative goal setting is “interactive and ongoing” (Ostensjo et al., 2008 p. 257). The functions of collaborative goal setting were to direct the course of occupational therapy intervention for a finite period and to support parents in learning to direct their own services for their child and family as well as to acquire a sense of control and competence for the lifelong management of their disabled child (King et al., 2006).

5.2 Summary of Discussion

This chapter has presented and discussed the essential elements of the phenomenon of the collaborative goal setting experiences of parents’ who have children with disabilities and occupational therapists. The findings discussed were connected to the function of collaborative goal setting and therapists’ role in this process. This was to support parents to develop competence for living with their disabled children and learn to access and utilise therapy services as required. The key findings in this inquiry included: goal setting was a learning process for both parents and occupational therapists; there were similarities and differences in how parents and occupational therapists experienced collaborative goal setting; the impact of collaborative goal setting was experienced differently by parents and

occupational therapists; many factors influenced the collaborative goal setting experiences; both parents and occupational therapists felt goal setting could be improved and goal setting was a dynamic process. In the following chapter an overview of the inquiry will be reiterated and limitations and significance of the inquiry will be discussed along with recommendations for further research and intervention.

Chapter 6

Conclusion

6.1 Introduction

This chapter presents an overview of the inquiry and outlines the significance of these findings for clinical practice, policy development and clinical training for occupational therapists involved in collaborative goal setting with families and children with disabilities. The limitations of this inquiry and recommendations for future research and clinical practice will also be presented.

6.2 Overview of the Inquiry

This inquiry evolved from the researcher's experiences in the work environment where she was involved in collaborative goal setting with parents of children with disabilities and also supported junior staff to develop skills to engage parents collaboratively. A variation in the use of goal setting tools and practices was observed by the researcher. The need to explore parents' and occupational therapists' experiences of collaborative goal setting was identified through these clinical observations as well as through a review of the literature into collaborative goal setting. This research had not previously been conducted in an Australian context with parents of children with varying disabilities and aged from early childhood to school age.

The aim of this inquiry was to explore the collaborative goal setting experiences of parents of children with disabilities and occupational therapists. The specific research questions for this inquiry were:

- What does collaborative goal setting mean to parents and occupational therapists?
- Are there similarities and/or differences in collaborative goal setting experiences of parents and occupational therapists?
- How do parents and occupational therapists believe collaborative goal setting could be improved?

The literature reviewed revealed that understanding participants' experiences of collaborative goal setting has begun to be more recently explored as clinicians and researchers alike have identified that it may be more complex than initially believed (Barclay, 2002; Ennals & Fossey, 2007; Holliday et al., 2007; Jansen et al., 2003; King et al., 2006; Leach et al., 2010; Link-Melville et al., 2002; Maitra & Ernway, 2006; Oien et al., 2009; Ostensjo et al., 2008; Playford et al., 2000; Turner et al., 2008; Wiart et al., 2010). This research has occurred in occupational therapy adult rehabilitation and mental health settings as well as within the child and family context. However there was no research found within an Australian, child and family sector that explored both parents and occupational therapists goal setting experiences; what goal setting may mean to participants; whether there were similarities and differences in how goal setting was experienced; or how participants believed that goal setting could be improved.

This inquiry employed qualitative, phenomenology methodology and the research methods of in-depth interviews and document analysis. These were framed within a naturalistic inquiry paradigm. This methodology was selected to explore the complex, social phenomenon of collaborative goal setting from the perspectives of parents and occupational therapists. This naturalistic inquiry was conducted by the researcher in her workplace and utilised natural methods of client and therapist interviews as well as file reviews of goal setting documents. All interviews were audio-taped and transcribed. Data from interviews and file reviews were analysed thematically using constant comparison analysis techniques. Five major themes emerged:

- “An obscure concept”: Learning to goal set
- “The things we would discuss became the goals”: The goal setting experiences
- “It’s just the beginning”: The impact of goal setting on families’ everyday lives and the occupational therapy process
- “People vary in their life experiences”: Factors that influenced goal setting experiences
- “More guidance, more direction”: How goal setting could be improved.

These themes with their sub-themes were discussed in detail in relation to the findings of this inquiry and the existing literature. Participants have been informed of these inquiry findings. The results from this inquiry are currently being utilised to re-develop collaborative goal setting processes within the researcher's workplace. The researcher intends to present the findings to her work colleagues and the wider occupational therapy community, such as at a National Occupational Therapy conference, in the near future.

6.3 Significance of the Inquiry Findings

This inquiry has supported an earlier notion that collaborative goal setting in child and family practice is complex and indicates that it requires much learning for both clinicians and parents alike. The functions of collaborative goal setting are to establish a therapeutic relationship between therapist and parent; to determine a course of action for therapists, parents and others; and to support parents in developing competence in learning how to live with their child and utilise therapy services as required. This inquiry has demonstrated that goal setting is a dynamic process that is broadly discussed by parents and therapists. Goal setting can be conceptualised as addressing three levels of goal types which include general goals, parents' goals and child goals, and that they need to be addressed in order. Goal setting is not perceived by parents as a clearly established event. There is much variation in how goal setting is currently undertaken between therapists. Goal setting is valued quite differently between parents and therapists. Many factors influenced participant's goal setting experiences most notably was the notion of parents' understandings of their child's disability and expectations. Both parents and occupational therapists have identified many strategies to improve the current collaborative goal setting practices.

The findings gained from this inquiry have implications for improving the collaborative goal setting process between parents, children and occupational therapists. The findings are significant to the clinical practice, policy development and clinical training of occupational therapists and other therapy disciplines.

6.3.1 Implications for occupational therapy practice

Collaborative goal setting in child and family practice is considered pivotal to the establishment of a family-centered framework (King et al., 2004; Palisano et al., 2004). Engaging clients in collaborative goal setting is an ethical requirement of the Australian

Association of Occupational Therapists (2001), the American Occupational Therapy Association (2000) and the College of Occupational Therapists (2005). This inquiry has demonstrated that parents do value their participation in collaborative goal setting with therapists despite a variation in how much they want to participate. The findings serve to remind occupational therapists that they are required to engage families in collaborative goal setting and also that parents do value participating in goal setting. Collaborative goal setting is difficult to achieve effectively and requires therapists to develop their own techniques to engage parents in the process and to allocate time to goal set and review the goals with families.

The findings support occupational therapists considering themselves as “coaches” (Glaser, 1996; Luscombe, 2010; Mahoney, 2010) and using the collaborative goal setting process to help parents develop competence for the long-term management of their children. There are certain tasks that therapists need to address before parents can successfully and actively engage with them in genuine collaborative goal setting. These tasks include: initial clarification of the nature of goals in the setting and their role in the therapy process; discussion about the child’s development, disability and prognosis in relationship to the specific diagnosis; determination of the parents’ prior experiences of goal setting; clarification of the expectations of the parent’s and child’s involvement and allocation of time for goal setting and reviews (Holliday et al., 2007). The goal setting process itself may help support parents in learning about their child, what is therapy, how to goal set and to become competent participants in subsequent goal setting events.

Occupational therapists should consider the possible engagement of the child in collaborative goal setting, particularly for school aged children who have language and cognitive abilities to participate. For children who are unable to actively participate in goal setting, therapists should consider the child’s desires, interests and motivations when goal setting with parents. Child-focused goal setting tools have been created to involve children actively in collaborative goal setting. These tools include the Perceived Efficacy and Goal setting System (PEGS) (Missiuna et al., 2006) and the Paediatric Activity Card Sort (PACS) (Mandich et al., 2004). The utilisation of such tools should be considered in clinical practice to support therapist’s active engagement of children in goal setting.

The findings suggest that collaborative goal setting needs to be a clearly established event with scheduled subsequent reviews. Parents require clear, specific, explicit goals that have time frames, a measurement component and steps so that they know how to achieve the goal. Documenting goals in parent-friendly, clear language with scheduled review dates may assist parent's understanding and recall of goals established. The use of goal setting tools such as the Canadian Occupational Performance Measure (COPM) or Goal Attainment Scale (GAS) could be considered by therapists to use routinely to ensure parent involvement in goal setting. Further investigation of the use of the COPM and GAS in child and family practice is needed.

6.3.2 Implications for policy development and management practices of child and family services

Service managers and policy developers need to allow therapists time to establish and review goals collaboratively with parents and families. Family centered philosophy policies should reflect that goal setting is a shared, collaborative process whereby parents can choose how much involvement they would like to have in the process. Service managers need to support staff in their development of their own goal setting techniques. They could consider implementing routine use of goal setting tools to assist therapists achieve clinical competence for collaborative goal setting practices. Consideration should also be given to the utilisation of more trans-disciplinary service delivery models such as the Team Around the Child which supports more cohesive and collaborative goal setting between parents and multiple service providers (Luscombe, 2010; Davies, 2007). The application of this type of service model to school aged and adult disability services needs further empirical exploration.

6.3.3 Implications for clinical training

As supported by McClain (2005), undergraduate training modules should continue to include the training of collaborative goal setting practice and the use of goal setting tools. This training needs to be supported in the field by clinical educators during student placements so that students can practice goal setting techniques and learn to translate their tacit knowledge into practice. Training and education should also be provided within the workplace for new graduates as well as experienced clinicians about the benefits and use of collaborative goals setting practices and use of tools.

In summary, the results of this inquiry have many implications for occupational therapy practice, policy development and management practices of child and family services and for clinical training in the area of collaborative goal setting.

6.4 Limitations of the Inquiry

This inquiry has explored the phenomenon of collaborative goal setting from the perspectives of parents of children with disabilities and occupational therapists using qualitative research methods. A number of limitations both within the inquiry design and sample of participants and in the data gathered need to be acknowledged.

6.4.1 Inquiry design

As with many qualitative inquiries, this research was small in scale and represented only a portion of the perspectives of occupational therapists and parents of children with disabilities accessing a therapy service in Canberra, Australia. One in-depth interview only was conducted with each participant and participants were sent a member-checking summary to ensure that their information was represented by the researcher correctly. Limiting data gathering to one interview and member check may have limited the depth of information gained. Participants were able to draw on as much of their goal setting experiences as they preferred thus they had the opportunity to represent their whole goal setting experiences. The purpose of this inquiry was to gain an insight into the collaborative goal setting experiences of parents of children with disabilities and occupational therapists. It was not to derive theory or make generalisations about these experiences.

6.4.2 Sample of participants

This inquiry is limited to the experiences of parents and occupational therapists in a defined child and family service in Canberra. Participants were not recruited on a national or international scale. The number of inquiry participants interviewed was limited by the time constraints associated with the researcher's candidature and unfortunately there was insufficient time to interview all volunteers.

Parents volunteered to participate in this inquiry and represented children of varying ages and disabilities receiving occupational therapy from Therapy ACT. At least four of the five parent

participants were tertiary educated. Three of the five parents were employed at least part-time. Not all mothers interviewed were from traditional two parent families. One mother was divorced and had shared custody of her daughter with her ex-husband. One mother was Japanese and her interview was conducted with the use of an interpreter. This sample of parents was informed about services for their children and families and was also actively engaged in collaborative goal setting with therapists to varying extents. It is unknown how accurately this sample of parents represents the wider breadth of parents who access therapy services at Therapy ACT.

The occupational therapists also volunteered to participate and only therapists that were delivering services to children and families were invited to participate. The sample of occupational therapists was an accurate representation of the therapists delivering services for children and families at this specific therapy service. This sample included both female and male therapists and therapists ranged in their length of experience from two years to twenty plus years. There were other occupational therapists within this therapy service, who currently provided services to adult clients and but had previous experience of service delivery to children and families. These therapists were excluded and may have been able to offer further insights.

This inquiry does not have information about the families or other occupational therapists that did not respond to invitations to participate in this study or those that could not be included due to time constraints. Therefore results from this inquiry cannot be generalised to all families and occupational therapists engaged in therapy services at Therapy ACT. The findings from this inquiry may not be generalised to the wider therapy community at a national or international level, however each reader of this inquiry may be able to infer some relevance to their own situation.

6.4.3 Data gathered

While every opportunity was taken to tap into the experiences of parents and therapists through interviewing, narrative and document review, collaborative goal setting remains a dialogue between parent and therapist that is generated by very private motivations and feelings. At best, research can only gather external data and make inferences about the nature

of the experience that accompanies collaborative goal setting for parents of children with disabilities.

6.5 Recommendations for Future Research and Intervention

This inquiry was an exploratory study into the collaborative goal setting experiences of parents who have children with disabilities and occupational therapists within an Australian context for children of all disabilities from birth to eighteen years of age. The findings of this inquiry have led to the identification of several avenues for further investigation.

This inquiry has demonstrated that the collaborative goal setting procedures used at Therapy ACT need to be clarified and established more systematically. Any implementation of changes to current collaborative goal setting procedures should be evaluated by inclusion of parent's and therapist's perspectives to ensure that the changes have been effective.

Research about best education practices for staff to develop competence to engage parents in collaborative goal setting should also be explored and implemented. Such training should also be evaluated by therapists and service users to determine its effect.

The impact of the routine use of goal setting tools by occupational therapists and other therapists in child and family practice is another avenue open for exploration. This would help determine to what extent the use of such tools ensure that goal setting practice is truly family-centered without being totally family or therapist driven. Also little is known as to whether the use of such tools increases client outcomes, and what those outcomes might be within the family and child practice arena.

The application and implementation of child-focused goal setting tools within an Australian context has yet to be explored. Despite the recent development of such tools in Canada and the USA (Mandich et al., 2004; Missiuna et al., 2006), there is no published Australian research that has used them. Also little is known about the impact of such tools from the perspectives of the children, parents and occupational therapists using them.

The utilisation of a trans-disciplinary service delivery model such as the Team Around the Child has received recent attention in the early childhood field as a more coordinated means to plan and deliver collaborative services to families and young children with complex disabilities (Luscombe, 2010). However it is unknown whether this model can be applied to school aged therapy services. Evidence around the utilisation of trans-disciplinary teams in providing services to school aged children has been scarce and also requires further investigation.

The results from this exploratory inquiry into the collaborative goal setting experiences of parents who have children with disabilities and occupational therapists have identified a platform on which to launch further research into the collaborative goal setting practices within the child and family field. Further research should focus on making changes to current practice and to what extent such changes have on client outcomes.

6.6 Conclusion

This inquiry has investigated, compared and contrasted the collaborative goal setting experiences of parents of children with disabilities and occupational therapists. Consistent with other literature, collaborative goal setting was viewed as a complex and dynamic process. Both parents and occupational therapists valued participation in collaborative goal setting however their experiences had different impacts on their lives and roles in the goal setting process. Its purposes were to establish a therapeutic relationship between parents and therapists, establish an action plan for therapy involvement and to facilitate parent's development of competence for managing and living with their child and learning to utilise therapy services as required. All participants agreed that current processes could be refined. This was the first inquiry within an Australian context to explore the collaborative goal setting experiences of parents of children with disabilities of all ages and types of disabilities and occupational therapists. This study makes a unique contribution to the body of literature in occupational therapy and child and family practice about participants' experiences of collaborative goal setting. It has identified the need to modify current practices to facilitate parent's improved understanding and participation in goal setting, as viewed as an essential element of family centered practice and required by occupational therapists' codes of ethics.

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Appendix 1

Participant Advertisements



Would you like to tell us about your experiences of goal setting with occupational therapists?

Collaborative goal setting between therapists and parents who have children with disabilities is considered best practice. However little is known about how parents experience goal setting with therapists. Here is your opportunity to tell us about your experiences and thoughts about how we may improve goal setting practices for parents who have children with disabilities and their families.

If you:

- ☒ And your child have accessed occupational therapy services at Therapy ACT within the past 12 months
- ☒ Are willing and able to participate in interviews

then you can have your say about what your goal setting experience was like for you and your family.

If you are interested in participating in this research project, or would like more information, please call

Cate Hilly on 6205 1242 or

Email: catehilly@act.gov.au



OCCUPATIONAL THERAPISTS

Would you like to tell us about your experiences of goal setting with parents?

Collaborative goal setting between occupational therapists and parents who have children with disabilities is considered best practice. However little is known about how parents and occupational therapists experience collaborative goal setting. Here is your opportunity to tell us about your experiences and thoughts about how we may improve goal setting practices for parents who have children with disabilities and their families.

If you:

- ☒ Are working at Therapy ACT and goal setting with parents who have children with disabilities
- ☒ Are willing and able to participate in interviews

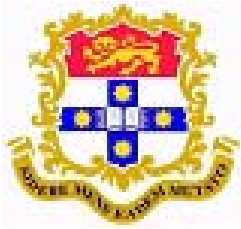
then you can have your say about what your goal setting experience was like for you and your clients.

If you are interested in participating in this research project, or would like more information, please call

Cate Hilly on 51270 or
Email: cate.hilly@act.gov.au

Appendix 2

Participant Information Sheets



Information Sheet for Participants

What are the collaborative goal setting experiences of parents and occupational therapists?

Purpose of research project:

You are invited to participate in a research project about parents' and occupational therapists' meanings of goal setting. This project is called "*What are the collaborative goal setting experiences of parents and occupational therapists?*" You have been selected to participate because you and your child are clients of Therapy ACT and have participated in collaborative goal setting with an occupational therapist.

Although there are many benefits reported about parent's participation in goal setting such as promoting family ownership of therapy needs and direction; joint-decision making between families and therapists; identifying the family's unique needs there has been little investigation about how parents actually experience participating in collaborative goal setting and what goal setting may mean to parents. It is suspected that parents and occupational therapists may have different meanings about collaborative goal setting.

This project is being conducted by Cate Hilly as part of a Masters of Applied Science (Occupational Therapy) by Research under the supervision of Dr Christine Chapparo from the Discipline of Occupation and Leisure Sciences, The University of Sydney and Nicole Ison from the University of Western Sydney.

What is collaborative goal setting?

As a client of Therapy ACT, you have participated goal-setting with your child's occupational therapist to discuss your therapy concerns and needs for your child and family. This is a part of standard practice at Therapy ACT used by therapists to develop a plan of action for therapy services. An Action Plan was written by your child's therapist/s in consultation with you that described the agreed therapy and family actions. Therapy ACT recognises that is best practice to use collaborative goal setting with families who have children with disabilities and their therapists using tools such as Action Plans. Your child's occupational therapist may select other goal setting tools such as The Canadian Occupational Performance Measure (COPM) or Goal Attainment Scale (GAS) to record your collaborative goal setting. The COPM was developed by occupational therapists to help therapists and clients identify and prioritise occupational therapy goals related to self-care, school/work, and leisure activities. The GAS is a generic goal setting tool that develops individual goals for children with the therapist and family. The GAS enables small increments of change to be recognised and measured. Both COPM and GAS goals identified are weighted by the family

to rate their relative importance out of a possible score of ten and are both used to measure the change in the therapy goals over a period of time and intervention.

What will you need to do?

You will be required to participate in 1-2 interviews with the interviewer face to face at a time and place that is convenient to you to discuss your recent occupational therapy goal setting experiences. The interview can be private or you can ask a friend to be there with you. Everything will be kept strictly confidential. The interview will take about 1 hour and may involve a follow up interview or telephone call. The interviewer will ask you for your permission to tape-record the interview conversation and to take notes during the interview so that it can be analysed later. Your participation is voluntary. If you decide to take part, you do not have to answer any questions that you do not want to answer. You can also stop being part of the interview at any time that you want to.

What other information will be collected?

Extra information about the purpose and history of your child's occupational therapy goal setting at Therapy ACT will be collected by researcher by reviewing your referral information, goal setting document and any other relevant report information in your child's therapy file.

Occupational therapists employed by Therapy ACT will also be interviewed about their experiences of goal setting. The information that you provide will not be discussed with the occupational therapists.

Benefits and risks

This project will lead to a better understanding about how parents and occupational therapists experience collaborative goal setting. It will lead to further knowledge about the experiences of goal setting and how goal setting practices may be improved. It is hoped that future goal setting practices may be more meaningful and useful for parents. There are no direct benefits to participating in this project. Your participation is voluntary. No payment or other remuneration will be provided.

It is highly unlikely that there will be any risks to you by participating in this project as interviewing parents about their goal setting needs is part of normal clinical practice. Should you however become upset or uncomfortable during the course of this project, Cate or her supervisors, who are all qualified occupational therapists, will be happy to discuss any concerns with you or help you find another person to talk to if you wish. You may access social workers at Therapy ACT for assistance if concerns arise after the interview. Please contact your child's therapy team or phone Intake on 6205 1246.

Confidentiality

Your privacy and personal details will remain confidential at all times. Only the researchers will have access to information about your child, you and the other participants. When the project is finished, a report about the study will be written. This report will be available for other people to read and hear at conferences. The report will only present research findings and examples of comments that participants make. It will not reveal identifying information about any individual and no one will be named. All study information that is collected about you and your child as a result of participating in this study will be stored in a locked brief

case, filing cabinet and electronic files will be password protected. All of the information you provide will be destroyed five years after publication of the research. Up until five years post-publication, this information will be stored at the University of Sydney's Archives Facility.

Your rights

Participation in this study is entirely voluntary. You will only be interviewed and your child's file reviewed if you sign a consent form. You will have the opportunity to check the information that the investigator collects and make any changes at anytime during or at the end of the interview. If in the future, you change your mind about being involved, you can withdraw your consent to participate. You do not need to provide any reason. This will not disadvantage you in any way or effect services you are currently or about to receive from Therapy ACT.

If English is not your first language and you would like to participate in this project, an interpreter can be arranged without cost to you. You may also like to access the by phoning. Cate can provide you with information about this service if you request this.

You may access the information collected about you or your child at any stage by contacting Therapy ACT 6205 1242. You will be given a copy of the study results at the end of the study.

We appreciate your participation in this research project. This information sheet is for you to keep. If you have any questions regard to your participation in this project, please do not hesitate to contact any of us (details below):

Cate Hilly	Dr Chris Chapparo	Nicole Ison
BAppScOT	PhD, MA. OTR	BAppSc(Hons)OT, PhD
MAppSc candidate	Principal Supervisor	candidate
Therapy ACT	The University of Sydney	Associate Supervisor
Ph: 6205 1242	Ph: (02) 9351 9206	University of Western Sydney
Email:	Email:	Ph: 0438 819 846
cate.hilly@act.gov.au	c.chapparo@fhs.usyd.edu.au	Email: n.ison@uws.edu.au

NOTE: This study has been approved by The University of Sydney's Human Research Ethics Committee. If you have any complaints or reservations you may contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 or gbriody@usyd.edu.au.



Information Sheet for Participants

What are the collaborative goal setting experiences of parents and occupational therapists?

Background to project:

As an occupational therapist of Therapy ACT working with children and families you engage in collaborative goal setting with parents of children with disabilities as part of service policy. This includes development of an Action Plan for all clients in consultation with the children/parents/caregivers and other team members. In your regular clinical practice, you may also use other goal setting tools such as The Canadian Occupational Performance Measure or Goal Attainment Scale with clients to develop and record collaborative goal setting.

Purpose of research project:

You are invited to participate in a research project about parents' and occupational therapists' meanings of goal setting. This project is called "*What are the collaborative goal setting experiences of parents and occupational therapists?*" You have been selected to participate because you are an occupational therapist employed at Therapy ACT and have participated in collaborative goal setting with parents.

Although there are many benefits reported about parent's participation in goal setting such as promoting family ownership of therapy needs and direction; joint-decision making between families and therapists; identifying the family's unique needs there has been little investigation about how parents actually experience participating in collaborative goal setting and what goal setting may mean to parents. This study aims to address these issues.

This project is being conducted by Cate Hilly as part of a Masters of Applied Science (Occupational Therapy) by Research under the supervision of Dr Christine Chapparo from the Discipline of Occupation and Leisure Sciences, The University of Sydney and Nicole Ison from the University of Western Sydney.

What will you need to do?

You will be required to participate in 1-2 interviews with the interviewer face to face at a time and place that is convenient to you to discuss your recent occupational therapy goal setting experiences. The interview can be private or you can ask someone else to be there with you. Everything will be kept strictly confidential. The interview will take about one hour and may involve a follow up interview or telephone call. The interviewer will ask you for your permission to tape-record the interview conversation and to take notes during the interview so that it can be analysed later. Your participation is voluntary. If you decide to take part, you do not have to answer any questions that you do not want to answer. You can also stop being part of the interview at any time that you want to. Your participation in this study is entirely voluntary and will not affect your treatment as an employee at Therapy ACT in any way.

What other information will be collected?

Parents who have accessed occupational therapy services at Therapy ACT will also be interviewed about their experiences of goal setting. The information that you provide will not be discussed with parents or other therapists. Parents participating in this project may also consent to their child's file being reviewed by the researchers to gain relevant information about the goal setting context and history.

Benefits and risks

This project will lead to a better understanding about how parents and occupational therapists experience collaborative goal setting. It will lead to further knowledge about the experiences of goal setting and how goal setting practices may be improved. It is hoped that future goal setting practices may be more meaningful and useful for parents. There are no direct benefits to participating in this project. Your participation is voluntary. No payment or other remuneration will be provided.

It is highly unlikely that there will be any risks to you participating in this project as discussing goal setting practices with occupational therapists is a typical part of clinical supervision and mentoring practices. Should you however become upset or uncomfortable during the course of this project, Cate or her supervisors will be happy to discuss any concerns with you or help you find another person to talk to if you wish.

Confidentiality

Your privacy and personal details will remain confidential at all times. Only the researchers will have access to any information that you or other participants provide. When the project is finished, a report about the study will be written. This report will be available for other people to read and hear at conferences. The report will only present research findings and examples of comments that participants make. It will not reveal identifying information about any individual and no one will be named. All study information that is collected about you as a result of participating in this study will be stored in a locked brief case, filing cabinet and electronic files will be password protected. All of the information you provide will be destroyed five years after publication of the research. Up until five years post-publication, this information will be stored at the University of Sydney's Archives Facility.

Your rights

Participation in this study is entirely voluntary. You will only be interviewed if you sign a consent form. You will have the opportunity to check the information that the investigator collects and make any changes at anytime during or at the end of the interview. If in the future, you change your mind about being involved, you can withdraw your consent to participate. You do not need to provide any reason. This will not disadvantage you in any way or effect your treatment as an employee at Therapy ACT.

You may access the information collected about you at any stage by contacting Cate Hilly on 51270 or email. You will be given a copy of the study results at the end of the study.

We appreciate your participation in this research project. This information sheet is for you to keep. If you have any questions regard to your participation in this project, please do not hesitate to contact any of us (details below):

Cate Hilly	Dr Chris Chapparo	Nicole Ison
BAppScOT	PhD, MA. OTR	BAppSc(Hons)OT, PhD
MAppSc candidate	Principal Supervisor	candidate
Therapy ACT	The University of Sydney	Associate Supervisor
Ph: (02) 6205 1242	Ph: (02) 9351 9206	University of Western Sydney
Email:	Email:	Ph: 0438 819 846
cate.hilly@act.gov.au	c.chapparo@fhs.usyd.edu.au	Email: n.ison@uws.edu.au

NOTE: This study has been approved by The University of Sydney's Human Research Ethics Committee. If you have any complaints or reservations you may contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 or gbriody@usyd.edu.au.

Appendix 3

Interview Guides

Parent Interview Guide

Purpose of interviews:

1. To elicit in-depth subjective accounts of parents' experiences of collaborative goal setting with occupational therapists
2. To explore parents' meanings of collaborative goal setting
3. To compare parents' experiences to those elicited from occupational therapists
4. To ask parents about how they think goal setting should look like, exploring their roles in the process, what they would like their roles to be, frequency of evaluation of goals, ownership of goals

Interview process:

1. Introduce self to participant and prompt rapport building discussion
2. Remind participant of the purpose of the research project and the interviews
3. Review written information sheets
4. Complete written consent form
5. Explain the use of the tape recorder/note taking and remind participant that the tape recorder may be turned off at any time at their request
6. Complete the interview
7. Ask participant if they have any further comments to make or information that they would like to discuss
8. Thank participant for their time, remind them of the confidentiality of their responses, and arrange time for a follow up interview

Anticipated interview questions/focus areas:

The interviews will commence with broad opening questions about how/why the family accessed occupational therapy and their understanding of goals and goal setting. Example questions include:

“Can you tell me about your child and family and why you access occupational therapy at Therapy ACT?”

“Can you tell me about goals – what do you think a goal is?”

“Can you give me an example of one of your goals?”

“Tell me about your experience of a goal setting appointment with your child’s occupational therapist?”

Responses to these opening questions will be explored in depth with subsequent questions. Based on gaps within the literature, it is possible to identify focus areas, or issues, which are likely to be identified as relevant and explored in-depth during the interviews. These focus areas include:

- What goal setting means to parents
- Expectations of goal setting
- Impact of goal setting on parents/family/child with a disability
- Advantages/disadvantages of goal setting
- Factors that influence goal setting
- Roles of parents and perceived roles of occupational therapists in collaborative goal setting and what they would like their roles to be
- Frequency of evaluating goals to review progress
- Ownership of goals – Who decides on the goals and directs the course of intervention? Who should own the goals?
- How goal setting could be improved

Not all focus areas will necessarily be discussed with every participant. The depth of discussion about each issue will vary depending on the relevance of the issue to the individual participant. The issues will not necessarily be discussed in the above order as the ordering of issues and specific questions to be asked will emerge in response to progression of each interview. Due to the emerging nature of qualitative research, focus areas and questions will also be adapted as the interviews and concurrent analysis progress.

Therapist Interview Guide

Purpose of interviews:

5. To elicit in-depth subjective accounts of occupational therapists' experiences of collaborative goal setting with parents
6. To explore occupational therapists' meanings of collaborative goal setting
7. To compare occupational therapists' experiences to those elicited from parents
8. To ask occupational therapists about how they think goal setting should look like, exploring their roles in the process, what they would like their roles to be, frequency of evaluation of goals, ownership of goals

Interview process:

9. Introduce self to participant and prompt rapport building discussion
10. Remind participant of the purpose of the research project and the interviews
11. Review written information sheets
12. Complete written consent form
13. Explain the use of the tape recorder/note taking and remind participant that the tape recorder may be turned off at any time at their request
14. Complete the interview
15. Ask participant if they have any further comments to make or information that they would like to discuss
16. Thank participant for their time, remind them of the confidentiality of their responses, and arrange time for a follow up interview

Anticipated interview questions/focus areas:

The interviews will commence with broad opening questions about the occupational therapists' work history and experiences of goal setting with families and their understanding of goals and goal setting.

Work history questions

- “When did you graduate?”
- “How long have you worked as an occupational therapist?”
- “How long have you worked in family and child services?”
- “How long have you worked at Therapy ACT?”
- “Have you worked in family and child services outside of Therapy ACT?”

Broad goal setting question?

“Can you tell me about your experiences of collaborative goal setting with parents?”

Responses to these opening questions will be explored in depth with subsequent questions. Based on gaps within the literature, it is possible to identify focus areas, or issues, which are likely to be identified as relevant and explored in-depth during the interviews. These focus areas include:

- What goal setting means to occupational therapists
- Why and how do occupational therapists set goals with parents
- Expectations of goal setting
- Impact of goal setting on therapy service
- Advantages/disadvantages of goal setting
- Factors that influence goal setting
- Roles of occupational therapists and perceived roles of parents in collaborative goal setting and what they would like their roles to be
- Frequency of evaluating goals to review progress
- Ownership of goals – Who decides on the goals and directs the course of intervention? Who should own the goals?
- How goal setting could be improved

Not all focus areas will necessarily be discussed with every participant. The depth of discussion about each issue will vary depending on the relevance of the issue to the individual participant. The issues will not necessarily be discussed in the above order as the ordering of issues and specific questions to be asked will emerge in response to progression of each interview. Due to the emerging nature of qualitative research, focus areas and questions will also be adapted as the interviews and concurrent analysis progress.

Appendix 4

University of Sydney Human Research Ethics

Approval Letters



The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee

www.usyd.edu.au/ethics/human

Senior Ethics Officer:

Gail Briody

Telephone: (02) 9351 4811

Facsimile: (02) 9351 6706

Email: gbriody@usyd.edu.au

Room 313, Level 3, Old Teachers College –A22

Human Secretariat

Telephone: (02) 9036 9309

(02) 9036 9308

Facsimile: (02) 9036 9310

7 July 2008

Dr Chris Chapparo
Discipline of Occupational Therapy
Cumberland Campus – C42
The University of Sydney

Dear Dr Chapparo

Title: *What are the collaborative goal setting experiences of parents and occupational therapists? (Ref. No. 11166)*

Masters Student: *Ms Catherine Hilly*

Your application was reviewed by the Executive Committee of the Human Research Ethics Committee (HREC), and in doing so has ratified your study to include the Masters student – Ms Catherine Hilly.

The Executive Committee acknowledges your right to proceed under the authority of *The Spastic Centre Human Research Ethics Committee (HREC)*.

Please note, this ratification has been given only in respect of the ethical content of the study.

Any modifications to the study must be approved by *The Spastic Centre Human Research Ethics Committee (HREC)* before submission to the University of Sydney Human Research Ethics Committee.

Yours sincerely

Gail Briody
Senior Ethics Officer
Ethics Administration

cc Ms Catherine Hilly, The Spastic Centre of NSW, Southern Tablelands Rural Therapy Team, PO Box 233, Kippax ACT 2615



The University of Sydney

Human Research Ethics Committee

Web: <http://www.usyd.edu.au/ethics/human>

ABN 15 211 513 464

Gail Briody
Manager
Office of Ethics Administration

Marietta Coutinho
Deputy Manager
Human Research Ethics Administration

Telephone: +61 2 8627 8175
Facsimile: +61 2 8627 8180
Email: gbriody@usyd.edu.au

Telephone: +61 2 8627 8176
Facsimile: +61 2 8627 8177
Email: mcoutinho@usyd.edu.au

Mailing Address:

Level 6
Jane Foss Russell Building – G02
The University of Sydney
NSW 2006 AUSTRALIA

Ref: MC/KR

24 June 2009

Dr Chris Chapparo
Discipline of Occupational Therapy
Cumberland Campus – C42
The University of Sydney
Email: C.Chapparo@usyd.edu.au

Dear Dr Chapparo

Title: What are the collaborative goal setting experiences of parents and occupational therapists? (Ref. No.11166)

PhD Student: Ms Catherine Hilly

Your application was reviewed by the Executive Committee of the Human Research Ethics Committee (HREC), and in doing so has ratified your study to include the Masters student – Ms Catherine Hilly.

The Executive Committee acknowledges your right to proceed under the authority of *DHCS Research and Data Sharing Committee*.

Please note, this ratification has been given only in respect of the ethical content of the study.

Any modifications to the study must be approved by *DHCS Research and Data Sharing Committee* before submission to the University of Sydney Human Research Ethics Committee.

Yours sincerely

Marietta Coutinho
Deputy Manager
Human Research Ethics Administration

cc **Ms Catherine Hilly**, 11/60 Copland Drive, EVATT ACT 2617
Email: chil6737@mail.usyd.edu.au

Appendix 5

ACT Government Human Research Ethics Approval

Letter

Ms Catherine Hilly
11/60 Copland Drive
EVATT ACT 2617

department
of disability,
housing &
community
services.

Dear Ms Hilly,

Thank you for your application to conduct the research project: *What are the collaborative goal setting experiences of parents and occupational therapists?*

The Department of Disability, Housing and Community Services Research and Data Sharing Committee considered this application on 17 December 2008. After consideration of the merits of the project in relation to its methods, requirements and potential risks, the Committee has made a recommendation to me that it be approved for conduct.

In giving my approval for the conduct of this research, I impose a condition that you comply with any specific directions of the DHCS Research and Data Sharing Committee and your nominated project sponsor.

Further I must advise you of your responsibilities to inform the Research and Data Sharing Committee and your nominated sponsor of:

- any proposed changes to the research protocol, research personnel, information statement or consent form;
- any serious adverse events occurring during the course of the research; and
- the achievement of key milestones relating to the research project including the commencement and cessation of data collection and the completion of the research report.

Should you have any queries, please contact Dr Anne Jenkins, secretariat of the DHCS Research and Data Sharing Committee on 6205 0082.

I wish you well in this valuable research.

Yours sincerely



Sandra Lambert
Chief Executive

19 January 2009

Appendix 6

Consent Forms



Informed Consent

What are the collaborative goal setting experiences of parents and occupational therapists?

Researcher's Names: Cate Hilly, Chris Chapparo, Nicole Ison

Participant's Name: _____

Having read the information on the information sheet, and having asked any questions about the project, please read the following statements and tick the appropriate boxes.

I have had the purpose of the project explained to me. ☐

I have had the potential benefits and risks of the project explained to me. ☐

I have read and understand the information sheet. ☐

I understand what I will be required to do during the project. ☐

I understand that my participation in this project is entirely voluntary and that I can withdraw at any stage or not answer any questions that I do not want to answer, and that if I do, it will not affect my future treatment at Therapy ACT in any way. ☐

I understand that when I am interviewed the interview will be audio-taped ☐

and written notes will be taken and I consent to this.

I understand why my child's file will be reviewed and consent to this file review. ☐

I also understand that the information relating to my participation in this project is confidential. I agree that research data gathered from the results of the study may be published, reported at conferences and shared amongst staff at Therapy ACT, provided that I cannot be identified. ☐

I know who the researchers are and I know how to contact them. ☐

I have been given a copy of the information sheet to keep. ☐

I have had the opportunity to ask questions about the project and have had my questions answered appropriately. ☐

If you agree with the above, please sign below

Signed (Participant): _____ Date: _____

Signed (Researcher): _____ Date: _____

Signed (Witness): _____ Date: _____

Relationship: _____

NOTE: This study has been approved by The University of Sydney's Human Research Ethics Committee. If you have any complaints you may contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 or gbriody@usyd.edu.au.



Informed Consent

What are the collaborative goal setting experiences of parents and occupational therapists?

Researcher's Names: Cate Hilly, Chris Chapparo, Nicole Ison

Participant's Name: _____

Having read the information on the information sheet, and having asked any questions about the project, please read the following statements and tick the appropriate boxes.

I have had the purpose of the project explained to me. ☐

I have had the potential benefits and risks of the project explained to me. ☐

I have read and understand the information sheet. ☐

I understand what I will be required to do during the project. ☐

I understand that my participation in this project is entirely voluntary and that I can withdraw at any stage or not answer any questions that I do not want to answer, and that if I do, it will not affect my future treatment at Therapy ACT in any way. ☐

I understand that when I am interviewed the interview will be audio-taped and written notes will be taken and I consent to this. ☐

I also understand that the information relating to my participation in this project is confidential. I agree that research data gathered from the results of the study may be published, reported at conferences and shared amongst staff at Therapy ACT, provided that I cannot be identified. ☐

I know who the researchers are and I know how to contact them. ☐

I have been given a copy of the information sheet to keep. ☐

I have had the opportunity to ask questions about the project and have had my questions answered appropriately. ☐

If you agree with the above, please sign below

Signed (Participant): _____ Date: _____

Signed (Researcher): _____ Date: _____

Signed (Witness): _____ Date: _____

Relationship: _____

NOTE: This study has been approved by The University of Sydney's Human Research Ethics Committee. If you have any complaints you may contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 or gbriody@usyd.edu.au.

Appendix 7a

Examples of Transcripts with Inquirer's Coding

Parent Interview

Parent Interview Transcript 5/11/09

C: Well thank you again for agreeing to participate in this interview. The first question is just wanting you to tell me about your child and your family and why you have accessed Therapy ACT.

P: My eldest son Cameron has dyspraxia; verbal, oral and maybe the motor coordination dyspraxia, um. Cameron is 4 and Dominic is 2. Dominic has poor muscle tone so far

C: Ok

P: But that's it

C: Ok so Cameron is the 4 year old and Dominic is the 2 year old

P: Yeah. Dominic hasn't seen any occupational therapist but Cameron has.

C: Ok. So who has Cameron seen? He has seen OT...

P: Yeah we um saw Jemima twice

C: Yeah

P: And now we're seeing Annalise but he has also seen, we accessed the speech therapy a lot

C: Ok

P: It was Catherine but now we see Marg Blakey a lot. It was group sessions but now we do one on one

C: Ok, has he accessed physio as well?

P: Drop in physio

C: Oh, that's right

P: And Dominic's now having speech therapy but that is it

C: Ok,

P: So he's just having speech, Dominic.

C: Ok. So can you just broadly tell me about goals and what you think a goal, what a goal means to you, or what a goal is?

P: A goal would be something that you're not able to perform at the moment but hopefully with some guidance you can do a few different steps and train yourself to actually achieve a task that you couldn't previously achieve

C: Ok

P: That's what I reckon (laughs)

C: Yep that's fine. Yep, yep. So you mentioned steps to achieve

P: Yeah, sort of like break it down into smaller components and practice it until you can achieve the larger goal

C: Yep, ok. And what does goal setting or the process of goal setting what would it mean to you?

P: Um, I guess to first identify where deficiencies are and where and where like my child falls behind his age group

C: Ok

P: Um and then working out what needs to be done and how where going to be doing it

C: Yeah, yeah sure. And have you set, do you think you have set goals with an occupational therapist?

P: Um, well after I spoke to you I've been looking through the paperwork

Impact / outcome
of goal setting

getting
knowledge
learning

C: Yeah, that's ok

P: And, and um although, I realise now by looking back that there have been goals that have been set

goals are not explicit

C: Yeah

P: And definitely exercises and activities which we should be focusing on

C: Yep

P: But um I guess some of the goals aren't, like I'm a very black and white person because I have a scientific background

C: Yep

P: And some of the goals don't seem to be black and white do you know what I mean?

Experiences

C: Ok

P: Like to improve um his ability to use scissors and things like that

C: Ok

P: It is very hard to judge when he has achieved the goal

C: Yeah, sure

P: So all they do is just make you go through these um activities and try and find something that is interesting for him, because he goes off the track all the time

C: Ok

P: And I just try and practice them and hope that long term it will be beneficial but ah

p's role

C: Yeah

A: I can't say that it is something that I have actually sat down and thought that this is the goal that I have to achieve

C: Ok, so how um, so who set the goals then? Was it you that set in collaboration or was it the therapist or what happened?

P: In some instances I would say that I am a bit worried about this and I think he has fallen behind and that might have been from advice that I had been given through childcare or playschool.

C: Yeah, ok

P: So I had raised my concerns and then the occupational therapist has that data that tested him to see how he is doing in that area

C: Yeah

P: And then from there it seems to me that they have set the goals of what needs to be achieved

C: Ok, the OT has set the goals and how to achieve

P: Yeah, but though, always through discussion with me

C: Yeah, sure

P: And I give sort of feedback as to whether that would work with him or not

C: Yeah, ok, that's through discussion. So what do you feel the purpose of goal setting has been?

P: Um, personally I think to feel that you are achieving something really. I mean there is a case where a particular goal is a necessity you really need to get it done but um, when you've got a child with special needs and you're trying to deal with a lot of different areas, I think it is very comforting for the parent at least to know that you are getting somewhere.

issue around goal setting

C: Yeah, I think that is important too for that.
P: It is probably the main thing that personally I get out of it
C: Yeah, no, that's what I want to hear.
P: I should probably be thinking more about my child and what he needs to achieve (laughs)
C: No, no. That's exactly, that leads beautifully into the next question which is what impact that goal setting has on you, or your family or your child? So for you it helps you feel like you're getting somewhere.
P: Yeah, because I feel that my son's not interested in doing a lot of stuff so I really have to be extra motivated to get him to do it
C: Yeah
P: So I feel that it is more important for me to feel like I am getting somewhere then for him
C: Yeah, sure
P: Because he doesn't actually see it as being, if I can make it fun he just thinks we're playing a game and doesn't even realise that he is trying to, you know improve his skills
C: Oh, ok, yeah
P: Probably because of his age as well (laughs)
C: Oh yeah, probably
Pause
C: Does it have any impact on anyone else in the family or?
P: Um, yeah most of them get all of these sort of um weird looking art work (laughs)
C: Ah ok
P: Every day we try and make things so yeah my sister has a big pile of stuff that my 4 year old has made her
C: Yeah
P: I don't know, my husband's a bit um, he's interested, and like I give him, at the end of the day you know, Cameron usually has something to show his Dad
C: Yeah
P: Or tell him about what he has done. So I guess that provides an avenue of communication between the two of them
C: Ok
P: And he sort of takes an interest but leaves me to do most of the stuff. He doesn't really have the patience. So um it, it doesn't really impact on my other son because um I do most of my work with Cameron when he is asleep.
C: Ok, sure
P: But I am finding um when you've got two kids and now that I have to do therapy with Dominic that's a lot harder because I can never sort of get time one on one with him
C: Yep, ok, so how are you juggling that?
P: Um, not very well (laughs), but I'm thinking of probably asking my husband to take one, ah Cameron away so that I can do therapy with um Dominic
C: Dominic yeah

← p's role & expectation of self

"doing the therapy"

life is busy

p's role & expectation of self
"therapy parent"

P: Yeah, it's not too, I haven't really found a way around it other than to take Cameron away so that I can spend time with Dominic

C: Does he go to preschool?

P: Cameron is at, they are both in child care for one day a week

C: Oh, ok

P: Um, the same day. Cameron also does half a day in playschool so that morning I do try to do stuff with him but that is once a week that I have that time.

C: Yeah

P: And I usually come in here for speech therapy at that time

C: Oh, ok

P: So um, next year I will try to have some time with Dominic because he has sort of missed out a bit

C: Ah ha, oh dear. So what factors do you think have influenced the goal setting that you have done?

P: Um, can you expand on that a bit?

C: Yeah, so I guess when I was thinking about this, I was thinking of whether it was the model of our service or the personalities between the parent and the therapist or the time it took or, I mean because you were saying that really the OT sort of set the goals and and discussed with you and how to do it. I guess obviously um Cameron's developmental level must have influenced some of that goal setting

P: Yeah I'd say it's mainly the disability he has the dyspraxia and my um fear or obsession with him having problems with literacy

C: Oh

P: And writing and trying to do all of that sort of stuff. Like I've taken him. I was told to take him to a behavioural optometrist to try to get his eyes working properly

C: Ok

P: So I've done that he said he was fine

C: Ok

P: I think he basically said that there is nothing he can do until he goes to school anyway because he is too little

C: Yeah, probably mmm

P: So a lot of it has come from that I guess. His gross motor skills are very good

C: Yep

P: I guess gross motor skills are, I'm still trying to work this all out, but the physio side isn't it?

C: Yeah, yeah

P: And fine motor skills are the OT. So um that's why we try to focus more on that. But I guess I just, I don't know, in talking to the occupational therapist I am sort of thinking about all the skills he needs for sitting down at school

C: Oh ok

P: Because we are getting to that age

C: Yeah

P: Um

C: So that's really influencing what goals the goals are

factor's
influencing
goal setting

stage of life
prep. for school

P: Yeah
 C: Because of those skills for school
 P: I think that probably a year ago I was more concerned about him crossing the midline
 C: Ok
 P: And that sort of stuff but I think he has overcome that now so I want him to sort of use scissors more and do more writing. His writing is very um behind, I think we're still trying to, the other day we were trying to get him to hold the pencil the right way
 C: Oh yeah
 P: He does really well for a day and then forgets it completely
 C: Oh, ok, yeah
 P: But I sort of think that until he sort can hold a pencil or a pen it's going to be hard work
 C: Yeah, ok. So what role do you think that you took on with that goal setting process?
 P: Um, I see my role was just, rather than necessarily sitting there
 C: Yes
 P: And thinking have I achieved this goal or not? Just to do as much, as many of the exercises as I can fit in
 C: Yeah
 P: That's always been my goal
 C: Ok
 P: This process of if I can do that and focus um his, focus the exercises you know on the guidance that I've been given then everything else will fall into place
 C: Sure. And role did the OT take in that process do you think? So obviously a bit of a guiding role?
 P: Yeah, yeah definitely guidance yeah. Um, reassurance. Some things I thought were quite bad they said no, no he is not doing to badly in that area.
 C: Ok
 P: So that was good. I guess a supportive role, um
 C: Mmm
 Pause
 C: So I guess you mentioned before I guess coming back to how those goals were set, you mentioned um that the OT sort of set those goals. How did the OT do you think? Was it the knowledge that she had on development and sort of knowing what to work on? Or how do you think it happened?
 P: Um, I don't know. I sort of saw the goals as being um quite um, um how would you put it, not very black and white
 C: Yeah
 P: Very general
 C: Yep
 P: Like to improve this area, to improve that area. So it was more like a topic.
 C: A topic yeah
 P: A topic or an area or a field that this is, that we're going to concentrate on. Not specifically we will get Cameron to do this.

view of OT
role

C: Ok
P: Yeah, so it was more like a general heading (laughs)
C: Yeah sure. More of an aim or an objective.
P: Yeah
C: Yeah, ok, ok and what role did you think Cameron took, takes on in the process?
P: Um, can I just say um in the last bit. I don't want to be ah, maybe I'm being if I was to sit on, maybe because I'm focussing on the activities that I look at
C: Yes, yes
P: Even though the occupational therapist has written just the goals, I can't say that I have focussed on them
C: No, that's fine
P: So I might be giving them a bit of a hard
C: No, no, I just want to, like I said to you before what I we're wanting to get is a bit of a picture of what, what, what is happening in practice at the moment
P: Yeah
C: So I get a sense that goals are almost a starting point, ah certainly from talking to the therapists they're saying that they're not set in concrete they change a lot as we go through
P: Yes
C: But it's sort of a starting point to guide
P: Yes
C: Almost the course of therapy or the direction of where to head, so
P: Because I can't say that, I mean
C: Yeah
P: It might be my problem that I haven't read it properly
C: That's ok
P: But even when we have had the meetings it hasn't been, it hasn't sort been a big thing
C: Focus
P: Like this is the goal, it is more just talking about where he fits
C: Yep
P: And what I can do to help rather than setting the goals
C: That's fine
P: It was more of just a discussion
C: That is useful to know about that it wasn't made prominent because I mean, I think that some people will communicate more clearly than others and that's just different therapy styles, different ways of doing it
P: Yeah, yeah. I guess because I am interested because I have had two different therapists really rather than some people who have just the one
C: Yeah
P: But I mean yep, having said that, I feel that I'm being really negative but I feel
C: I don't think you are
P: Still that the contact has been very, very positive and very helpful
C: Mmm

focus for P.

P: And maybe just not in this area
 C: In this area yeah. That's ok
 P: Because I don't think that that's detracted from what I have got from them
 C: No, no, I'll actually go this way, would setting specific goals help you to understand occupational therapy and where therapy is going? Like if we were to sit down and do more specific goals?
 P: Yes I think it would because I'm thinking again of the scissors guide
 C: Yep
 P: I got one of the handouts, where I don't know, there was about 15 steps of how to progress through
 C: Yes
 P: And that's great because I remember getting Cameron and some you know quite flimsy paper
 C: Mmm
 P: And getting him to cut out circles and then I went maybe that's a bit hard. And I went through it and yeah they said straight lines first and use thicker card. And so, yeah, if you haven't got the background I think you can definitely gain from someone giving you more descriptions on how to achieve a goal.
 C: Ok, so that is how you would see it as more descriptions on how to or the steps
 P: Yeah the steps, the steps to achieve the particular goal
 Pause
 C: And that would be useful because you could see what to do next?
 P: Yeah, in particular because I take Cameron to Gymparoo as well
 C: Yep
 P: Um, and he does an integrated learning system
 C: Ah ha
 P: Programme too and all that sort of involves is, like one particular thing is throwing
 C: Yep
 P: And I just struggle to get Cameron to throw anything
 C: Try
 P: Try or compete at all, which may be more, I think that's maybe more physio or OT
 C: That's half and half
 P: Yeah, but um you know some people say to use the bean bags that there easier to catch but I haven't had success with that sometimes its bigger balls
 C: Mmm
 P: Or sometimes its balloons and you know I would really benefit from someone saying if your child isn't good at catching this is how we break it down
 C: Break it down, oh ok
 P: Because each, the integrated learning programme isn't linked I think necessarily to neurological development
 C: Oh ok

*How to improve
goal setting
steps & more
descriptions*

P: And so that's very difficulty and I don't give a lot of trust in that
 C: Yes
 P: Um, but gymberoo is quite good. But, but even so, I just keep getting different opinions on how to get him to, and I think it is just quite important concept to get him to do the hand eye coordination
 C: Ok, yeah
 P: But I'm just struggling in that area so if I had a step by step guide on
 C: How to do it
 P: Yeah once your child can do this, then you can try them on this
 C: Yeah
 P: And then progress them in that area
 C: Ok, ok, so what would the advantages be, so what would be the advantages be of goal setting if you did more specific goal setting?
 P: Um, I just think it would be more motivational
 C: Yep
 P: And um more encouraging and particularly if you have sort of large goals and smaller goals you would just always feel like, both me and Cameron would feel like we're progressing
 C: Ok, yeah. And do you think there would be a way that we could almost communicate goals to Cameron in a way that he understood?
 P: I guess using the reward charts and things (laughs) when he can do this. I mean I do that now like, um, try to play soccer out in the backyard with him
 C: Mmm
 P: And then most of the time it is trying to get him to run up and kick the ball. And I try not to use it
 C: Yeah
 P: Because I don't want him to always think that he needs to have a reward to do anything
 C: Yeah
 P: But if he's really having a bad day I'll use it. Um, and there is I sort of said that even if you can kick the ball across this line 10 times
 C: Yep
 P: You know we might go and have a chocolate milkshake
 C: Yeah
 P: And that definitely works with him. He definitely understands that at his age, yeah
 C: Ok
 Pause
 C: And what about, are there any disadvantages of goal setting do you think? Would there be, could there be any disadvantages?
 P: Um, I don't know if it's linked to goals, but sometimes if I want him to achieve something and he just can't because of the dyspraxia he can't do it, I know I get very frustrated. So but I mean that would only be if you took the goals to the extreme
 C: Yeah
 P: If you pushed him too quickly and you wanted to achieve it too early. Those sorts of things could sort of be detrimental but I guess

large & small goals

learn as a parent

it comes down to cranky, cranky parents (laughs) so, but, yeah I don't know. Maybe having time frames um or maybe when you set a goal

C: Yeah

P: Maybe you set a difficulty level or something so that, you know if it is five stars it is really hard, then you wouldn't be so inclined to push them

C: Yeah

P: If it's an easier goal then you know it would be more easily achievable but then I guess that might be impossible with all the kids being different. Some kids pick up things quickly and others take longer

C: Yeah

P: I don't know whether that would be feasible.

C: Well I think it is, I think it takes a very clever therapist to tailor it right down

P: Yeah

C: I guess this leads right down into the next question that I have is if you were to engage in say a more collaborative goal setting process how would you like it to look? So you're saying possibly time frames, looking at a difficulty level and obviously you mentioned breaking it down into step by steps.

P: Yeah, um, I don't know. I suppose the only thing would be to make it um having a chart or those pictures, just those visual cues so that Cameron could understand as well

C: Ok, yeah, for Cameron to understand. So if you did, if we could change the process, who would direct the goal setting part of it do you think?

P: Um, I think, I think because it is more specific it would be more child dependent so I think the parent would have to provide more guidance.

C: Ok

P: As to what their child could achieve

C: Yep

P: Whereas the therapist would I guess give more direction as to what needs to be achieved

C: Yeah

P: Um, where their lacking. Yeah the parent would have to say I think he can do this

C: And who would own the goals?

P: Mmm, um, I don't know. I don't think Cameron would be into it (laughs). So I guess it would probably be the parent providing most of the guidance, like, actually getting the child to achieve it. I don't know yeah I would probably say the parent

C: And if it was a based goal have you got any time frame for reviewing those goals or any idea about when you would like to have goals reviewed?

P: No, no actually and that's probably something that I would really like to see because of

C: Yes

help child
participate/
understand

potential
parent & OT
roles

P: With Jemima I think he saw her once here and then she came to our house

C: Yep

P: Um but that wasn't really the follow up. It was a follow up in that she wanted to know where Cameron was now at

C: Yes

P: And how we progressed further from there but not necessarily looking back retrospectively at saying that this is what we've achieved

C: Yep

P: And I think that would really help

C: Ok

P: Um, and with the new therapist we're seeing now we have only seen her twice so we did have a review

C: Yep

P: But likewise, um I sort of said where should I go from now, and I think it was advised to just stick with the same exercises

C: Oh, ok

P: So

C: Sure, so when, how, if you were to have regular reviews what, what would that depend on? Would that depend on Cameron's progress or would you like them within a set timeframe or what would you think?

P: Um, I would definitely like to have set timeframes. At the moment it's like probably every few months or once a term

C: Ok, yeah

P: I think I am one of these parents who is always keen to have more (laughs), more reviews

C: So what would work for you?

P: Um, I 'spose that once a term isn't too bad but I guess now that I have been doing the same exercises for nearly two terms

C: Yeah

P: It's starting I feel that I need a bit more guidance maybe and a little bit more direction. Um, when I had my second review just recently

C: Mmm

P: There were definitely areas that I worried about that I got reassured about but still yeah, I don't know, I probably definitely want um a bit more direction.

C: That's alright, more direction. So I guess if you are working on the same thing for two terms you want to know what's the end point of that?

P: Yeah

C: Or when do we change

P: Yeah

C: Yeah

P: Well some of it is quite specific like she sat down and looked at Cameron while I filled in the card about whether he was right hand or left hand dominant

C: Mmm

P: It still seemed 50 50 but she could see that he was you know, definitely seeing a preference for his right hand. Which was good because then I could stop doing all of that

C: Yes, yep

P: And now I make him use the right. Yeah so it is easier now when I get him to write his name, I know that I can put it in his right hand. So that was helpful. I progressed in that area.

C: Yeah

P: But yeah I would like us to sort of more closely look at goals

C: Yep

P: And see where he has achieved them and which are the main focus areas

C: Yep

Pause

C: So I guess by doing that you need to look at more closely look at the goals to see what has been achieved and what, what part of the goal you may be working on

P: Mmm, 'cause when I had the review it was more like just a few more ideas like you can try this, you can try that. But still just generally doing most of the same thing. I probably wanted it to be a bit more tailored, a bit more focussed

C: Ok, yep

Pause

C: Ok, have you got any other comments about goal setting?

P: Um, I don't think so, no.

C: Are goals set, for Cameron, are they set with just each physio, speech, OT or do they do them together as a multidisciplinary?

P: No, I would say that um, out of all the therapies that we're having, occupational therapy would be the most goal specific one.

C: Yep

P: Speech seems to be far more, just practice it

C: Yep

P: I know that they focus on particular areas

C: Yeah

P: But I never sort of, of any handouts that I have had from speech therapists, even the private ones that I see, or the ones at Therapy ACT

C: Yeah

P: Been an goals at all.

C: Ok

P: And physio, we've only been to the drop in so

C: Ok, yeah

P: We just got exercise sheets there because he's flat footed and a few other things

C: Oh, ok, yeah

P: Um. Yeah I guess maybe for dyspraxia it is difficult as a disability to work out when they have achieved goals because they can do it one day but the next day they won't

C: Mmm

P: It's very much that with speech. Like it is hit and miss, its 50/50 he can say it and other times he won't and you think you've got it and you go back and he hasn't got it so I don't know whether that is an impact

C: It will impact on it won't it?

P: Yeah, maybe for other people that have kids without dyspraxia with other disabilities it is more clear cut when they achieved the goal

C: Yeah. OT explains COPM, SMART and GAS goals (not transcribed) (goal setting tools).

Tape turned off.

Appendix 7b

Examples of Transcripts with Inquirer's Coding

Occupational Therapy Interview

Occupational Therapy Interview Transcript 7/10/09

C: Thank you Tracy for agreeing to do this I just want to get some demographic stuff first

C: "Ah When did you graduate?"

OT: 2006

C: OK How long have you worked as an occupational therapist?

OT: 2 ½ years

C: Yes, and how long have you worked in family and child services?

OT: 2.5 years

C: And have you worked for Therapy ACT the whole time?

OT: Yes I have

C: So, in general terms can you tell me about your experiences of collaborative goal setting with parents?

OT: Ok, um this, this year has been my probably my most experienced year with actually of doing a collaborative approach

C: Yes, yep

OT: With families which has been working really well and we've also included multi-disciplinary in parts which works even better

C: Yeah, yep. Sure, ok can you tell me what the purpose of goal setting is?

OT: Ah so that we understand and we're are on the same path for achieving the outcome that the family are trying to achieve

C: Yeah

OT: So that everybody is aware of who needs to do what to achieve that outcome

C: Yep

Pause

C: And how are you setting goals with parents?

OT: Um with some families I have been using the Canadian Occupational Performance Measure

C: Yep

OT: Um to find out the full gamete of all their concerns a really holistic approach

C: Yeah

OT: And with other families they, the referral is quite clear about a really specific issue that they have so we discuss that issue and work out a goal linked to that

C: Sure and so you said before that sometimes your doing things, are you doing all your goal setting as a multi-disciplinary approach?

OT: No, if it comes through with a referral where we can do it as a multi-disciplinary approach we use it

C: Yeah

OT: But where we can't when then it is just the OT involved, then I don't

C: Sure, yeah

OT: So the main multi-disc that I have been using here is because the client has been on a waiting list and has been um with speech

C: Ok, are they most of those transitioning kids do you find?

OT: Ah, I think because we've got a new speechie involved

*Experience of
goal setting*

*Impact / outcome
of goal setting*

*Factor influencing
goal setting
experience*

C: Ok, yeah
 OT: We've kind of reviewed the clients together
 C: Ok
 OT: And set up the regular reviews together which has worked quite nicely
 C: Yep
 OT: Particularly for the new speechie
 C: Yeah, sure. So what, what are you thinking? Are you going to keep doing it that way do you think?
 OT: We would like to if we can and try to get physio as well
 C: Ok
 OT: Which is a bit harder
 C: Yeah
 OT: Given the workload
 C: Mmm
 OT: But it would be really good and I started doing it with the other speechie there are two speechies that I work with
 C: Ok
 OT: I'm hoping to continue. It's been really good for families, I think, to have that
 C: Yeah
 OT: Approach where they can decide which goals that they want to work on
 C: Yep
 OT: In terms of everybody, so it's not just OT
 C: Yeah, sure
 OT: So they consider all the factors at once
 C: Yeah. So when you're setting them as a team are you using an Action Plan?
 OT: Yep
 C: For all of the
 OT: Yep, so we use an Action Plan. I haven't done a COPM, no I haven't done a COPM with families yet because, families I used it for were families that were transitioned
 C: Ok
 OT: So families that were completely new to me
 C: Ok
 OT: Where as all the families that I have dealt with speech have been families that I've already been involved with in general
 C: Ok
 OT: And tacking on the speechie into it
 C: Yeah
 OT: And changing our approach a bit
 C: Sure
 OT: It's worked really well for both Speech and um OT in that we can discharge a bit easier. Being able to say we are working on this, this and this in speech and it OT, Oh I don't really have any issues for OT
 C: Sure

OT: And we say we will discharge for now and they can come back in

C: Ok

OT: And that's a lot easier than doing it single discipline

C: Yeah

OT: They don't feel that they're getting kicked out of the service because someone is working with them

C: Ok

OT: That's worked really well (laughs)

C: Good, so why do you think that is?

OT: I think the families just, they're feeling like their getting, they still have contact with us

C: Yep

OT: Whereas if it was just us as a single discipline

C: Mmm

OT: Working away oh well we don't have any issues anymore, ok we're going to discharge you it's almost like they're completely out of the system

C: Mmm

OT: But when you do it joint, someone stays involved they just seem to cope with that a lot better

C: Ok

OT: They still have a connection and a contact

C: Yeah

OT: And I think when you run along, parallel to each other doing your own thing, the families don't see that connection

C: Ok

Pause

OT: I don't know

C: Yeah sure

OT: That's kind of what I

C: Yeah, yes

OT: Interpreted from it but it worked both ways so speechies are able to discharge sometimes and we're able to discharge sometimes

C: So how have you found using the COPM with, so you said that some of the clients are new to you?

OT: Yep

C: And how have you found using that tool?

OT: Um, its been good I think the biggest problem is that it opens a gamete

C: Yeah

OT: Of responses

C: Yeah, yep

OT: Um so I was using quite frequently with the, the new clients to me

C: Yep

OT: And I did use it with some of my ongoing clients but in a more brief way in that I got the measurement done

C: Yeah

OT: But not the whole interview which is a bit naughty I know
 C: Yeah sure, that's ok
 OT: Um and that worked really well. So we pretty much did the measurement for each of our goals on our Action Plan
 C: Ok
 OT: And that was a nice way to be able to put a measurement beside whatever our goal was.
 C: Yes
 OT: Um and the families, I think, coped with that a lot better because we already gone through the process of working out what our goals were. I don't think doing the COPM again
 C: Yes
 OT: It just would have confused them
 C: Of course, it would have been a bit much if you had discussed the goals already then why
 OT: Why are we going through them again? Yes
 C: So what do you see are the advantages of collaborative goal setting?
 OT: Collaborative with families?
 C: Yes or with the other therapists as well
 OT: Um it's been really good in finding out what the family really want to work on and not on what the OT thinks that they should work on
 C: Sure
 OT: Um, and I think that the age group that I'm working being adolescents and going into adult, um that parents have quite a clear idea of what they can and can't achieve by then
 C: Yep
 OT: Um so knowing what they would like to work on is much easier because they know what they're ready to almost give up on so toileting and stuff is kind of goes out the window a bit more
 C: Sure
 OT: They've been there done that and tried it
 C: Mmm
 OT: They've accepted that its not going to work
 C: Yes
 OT: Or they've come to their solution
 C: Yes
 OT: They don't need help with it any more so I think the collaborative approach has really helped with refining what they would like to achieve
 C: Yes
 OT: And being able to prioritise it according to what they think as well as give them our opinion um and discuss maybe we should work on the wheelchair before we work on something else
 C: Yes
 OT: And explain to them why
 C: Yep
 OT: And then go with obviously whatever they choose but hopefully they will be more informed about (pause)

parents learning

C: Ok so we talked about, I guess you probably talked to me already about the advantages of multi-disciplinary collaboration

OT: Yep

C: Um with, yes certainly helping to discharge everyone's goals so its easier to um. Are there any other advantages to the MD?

OT: I think also to be able to let the family concentrate on a few things at once

C: Yeah

OT: When we work in parallel and not collaboratively I find that sometimes we set too many goals for each discipline and the family has so much going on and you don't know that the speechie is doing or what, or what um effort that family have having to put in to speech therapy as well as us or as well as physio

C: Yeah

OT: Sometimes they probably just can't cope or they don't want to tell us that they can't cope with what were asking them to do sometimes families feel a bit

C: Mmm

OT: Pressured I think

C: Yeah sometimes from us

OT: Yeah they feel like they should be giving their child the best they can but they can't do that at home because they don't have enough time to do all that.

C: Yep

OT: And I think doing the multi-disc you can really tell with them what, what time factors they have at home to be able to do it

C: Yeah, sure. Do you see any disadvantages with collaborative goal setting?

OT: Sometimes the families have unrealistic goals

C: Yep, yep

OT: Um, and it can be harder to try and work out a process through that

C: Yeah

OT: Um, that's probably the main thing

C: So how are you working through, what strategies are you using to work through that?

OT: Um, with one case we've done a bit of trial and error so that the family can actually see that it doesn't work

C: Yeah

OT: And explain to themselves that something might not work um so for other families it's just been discussions that we've been able to work out a good Action Plan is shared

Pause

OT: So I suppose another factor to my, working in school as well is that the teachers have their collaborative input at, at times as well which can be good or bad

C: Yeah, sure

OT: For similar reasons

C: Yeah

OT view of parents' experiences

other agencies eg school

OT: And letting the family and the teachers work out what they want separate to what we're thinking as well

C: Ok, sure. What does goal setting mean to you?

OT: In terms of?

C: Yeah like the concept we hear at Uni a lot

OT: Yep

C: And like we learn about a gold standard or something of what we have to do as part of our studies as occupational therapists but each of us have a different

OT: Different view of it

C: Yeah

OT: Um for me goal setting would be really working out and setting over arching goals so that we know where we're headed and what we're planning and then working out the actions so that we can achieve that goal. I think it's helpful for me, um as a therapist, so that I know where I'm going and what I need to do next

C: Yes

OT: Um, I'm kind of organised, strategic type personality anyway so it works for me

C: Ok, yep

OT: Um and I think some families find it really good so that they can, they do know where we're going

C: Yes

OT: It's not something unexpected that's going to happen

C: Yeah. And what about families, what do you think goal setting might mean to them?

OT: Um that's a tricky question (laughs) pause um, I think some families that I'm working with, find the big picture stuff a bit hard so the long-term goals a quite hard for them to comprehend so we do quite a lot of smaller

C: Yeah

OT: I think it can be overwhelming, I think for them

C: Yes

OT: The whole goal setting process. Um and other families I think, just take it on and they love it

C: Yeah

OT: It depends on where the family is and

C: All that kind of stuff

OT: I think the families that I have done it with have found it good because they have got something concrete

C: Yeah

OT: Prescriptive almost, they know what's coming and what they have to do, what the therapist will do

C: Yeah

OT: Um, but I don't know if that's what they think (laughs). But I think that's what they think

C: Ok, yep

OT: But I think it can be quite overwhelming in the beginning for them to go ok what are the major goals here

C: Mmm

view of parents' perspectives

factor: "type" of family

views of parent's perspective

OT: Especially if its goals that um I suppose the age group again comes in to factor

C: Mmm

OT: When they realise that their kid will never walk

C: Yeah

OT: They're going to need a wheelchair; they're going to need a power chair. They're big things

C: Yes, so do you find that your families are, are they still finding it really hard, they are still finding it really hard to predict where things are going to head or do they have a bit more

OT: Some families yes and some families no

C: Ok so there's still a variation

OT: I couldn't even say it's the more complex clients

C: No

OT: The one or the other, it is a mixture across I think of some families really understand the disability and understand where they are going and understand what will pop up in the future

C: Yep

OT: And other families just have no idea

C: Isn't that interesting

OT: I've got a few families that um have some mental health issues I suppose

C: Mmm

OT: Almost depressive kinds of parents and I think they find it hard

C: Yeah

OT: They like it once we've made the plan because they know what is coming but I think they find it really hard to plan ahead

C: Yeah

OT: And make task lists and things like that

C: Sure

OT: So working collaboratively obviously helps those families a lot

C: Yeah

OT: Um but it is quite confronting for them

C: Mmm so how do you deal, how do you deal with it?

OT: Um

C: When they're confronted by oh my god they're wanting me to think about how I can move forward with my child

OT: I suppose to just talk them through it to give them ideas and to scale it down if I can see that they're confronted by a big goal obviously scale it back to something smaller

C: Yep

OT: That would appear less confronting to them

C: Sure

OT: Basically

C: Yeah, yeah, so do you find that you get a more positive response when you do that?

OT: Um I haven't had too many incidents

C: Yeah

OT: Where I've felt

C: Sure

OT: Concerned about it. But yeah brining it back and I think that with the families that are more anxious, more um concerned parents we do a lot more small goals

C: Ok

OT: Quicker goals

C: Yep

OT: So they can see the outcomes quicker as well. So we meet more often to review those clients

C: Sure

OT: I think. Ah and they tend to be families who have lots of things going on

C: Yeah. Like as in general life

OT: Yeah, yep and I've got one particular interesting family that um the disability has been acquired more recently

C: Ok

OT: So it hasn't been ongoing. And they find it really good to sit down and plan. Feedback that they've given me like, doing that goal setting has been really good for them to know what to expect, they don't know what to expect because they haven't lived with it, they're in their first wheelchair, they don't know what to expect next

C: Ok

OT: So I think that sitting down and having regular reviews and goal setting discussions has been beneficial for them

← can improve goal setting

C: Yep. So do you find that the goal setting has really helped them, I guess understand the disability and

OT: And what's coming, yeah. It gives them some idea as they don't have any idea about processes so what, how do I get my wheelchair because the first one just came while she was still in hospital

C: Ok, yeah

OT: It was all done kind of, not so in, not that they didn't do it properly the first time

C: Yes

OT: But it wasn't obviously in-depth to the family because it was all, while there was all medical stuff going on

C: Sure

OT: So they found it really helpful to actually know what's coming next and know what to expect next

or education role

C: Yeah

OT: I use that time when I do my reviews and goal planning

C: Mmm

OT: To talk to some of these families that don't know some of the major milestones coming up like in the ACT it's 16 you've got to apply for your pension and at 18 apply for guardianship

OT: So

C: Yeah

OT: There the kind of things I talk about to families

C: Ok

OT: So just so that in their heads with the whole future planning thing it makes sense for them

C: Yep
 OT: Um, and like we don't set any goals for any of those things but I think the family appreciate that understanding of what else is happening
 C: Yeah
 OT: Of what we're considering in the future instead of it just popping up and all of a sudden oh we need to do this
 C: Yeah
 Pause
 C: What are your expectations from goal setting with the parents?
 OT: Of the parents?
 C: No what do you expect from it?
 OT: From it
 C: Yeah
 OT: Um that we can develop a realistic Action Plan really. With goals and actions to achieve in whatever timeframe we set
 C: Yeah, ok
 OT: I'm trying to do reviews six monthly or some families I end up doing termly
 C: Yes
 OT: Um yes so I think the expectation at the end of the session would be that we have a plan to work on for the next amount of time
 C: Yes, ok
 OT: And that the family would know what we're working on
 C: Yeah
 OT: And that the family would know also that we can change at any time. So if they find something else, or something changes then it can be changed. It's not set at all (laughs)
 C: Yes.
 Pause
 C: And do you think your experiences are actually matching those expectations?
 OT: Experiences?
 C: Your experiences of goal setting?
 OT: Yeah, yes I think part of it, most of my experiences so far have all been quite positive
 C: Yes
 OT: I haven't had any too bad occasions, in terms of, I tend not to be too prescriptive in those reviews
 C: Ok, yeah
 OT: And just kind of go with the family more than anything and so we come to the outcome that we wanted
 C: Sure
 OT: They normally work out. Pause. Some families want to get straight to the point
 C: Yeah
 OT: And tell you their story
 Unintelligible C & OT
 C: So how does the goal setting actually impact on the therapy services that you provide?

*shared
ownership*

OT: With where therapy is going in terms of? Um?

C: Yeah what you're doing or what you're doing what's there

OT: I do, it makes it easier for me to follow

C: Yeah

OT: You've got it all written there

C: Yeah

OT: What you do so it's quite, it's certainly easy for me to follow or somebody else to pick up if needed

C: Yep, that's right

OT: That's what I think

C: Yeah

Pause

OT: People can work out where you are on your process and what to follow up on

C: Mmm

Pause

OT: Ok, does that answer your question?

C: Yeah. I've been writing down some of the things we've been talking about um looking I guess at factors that are influencing your experiences of collaborative goal setting with parents and you certainly mentioned teachers input into the goal setting

OT: Mmm

C: Um you talked about the anxiety/depression say the mental health

OT: Yes

C: Status of the family and their ability to plan ahead

OT: Yep

C: And also I like that idea, that concept of the size of the goal so that

OT: Yep

C: Smaller goals expect to be more achievable, easier to write down and obviously the frequency of reviewing is helping

OT: Yep

C: With that

OT: I think that the other factors that are influencing

C: I guess the other is the need of the speech pathology

OT: Yeah I think that's going to be a big factor um

C: Yeah

OT: Moving towards families only having or the client only having three goals at once, *service model requirements*

C: Yeah

OT: I think that will have a big factor on whether we, what we put we have or what times

C: Sure

OT: So I suppose that will balance it out doing a bit of Speech here, and having a consolidation, doing OT while consolidation of Speech. Or doing it together and then having a break those kind of things

C: Mmm

OT: It's very individual I suppose, *individual needs*

C: Yeah, yeah. And are there any other factors influencing?

OT: Um, I wouldn't say so other than if other services are involved I suppose

C: Yeah

OT: That (unintelligible)

C: I guess family's understanding of the disability I guess is another one too, isn't it?

OT: Yeah

C: When families kind of know what works best, what they want

OT: That's right. So with the families that really know what they want I haven't tended to use the COPM so much

C: Yeah

OT: But I do with families that come in with not so much of an idea

C: Yeah

OT: About what the actual problems are that they're having and we can talk through using the COPM for that and it normally comes to a really good outcome

C: Ok

OT: They understand what the problems are where, where they need some help

Pause

OT: But the other services I think is a big factor in terms of waiting on

C: Yeah

OT: Equipment waiting lists

C: Yeah

OT: For other services,

C: Services

OT: Starting with a service which then pulls through

Laughs

OT: That happens regularly, yeah

C: So when setting goals with families, what role do you take on and what role do you think the parents take on?

OT: Um, from my so far, it has been very not therapist driven but I suppose I take more of a leadership role,

C: Ok

OT: In that um but the discussions I think are completely open

C: Sure

OT: For the families to give me information so I don't know

C: Yeah that's fine

OT: The way that you describe that is up to you

C: Yeah so the discussions are open

OT: Yeah o for some families I need to um, prompt them, using the COPM to do that to work out the different areas of their life and things like that

C: Mmm

OT: And of the families whatever they bring up

C: Sure

OT: But I think some families need prompts but most of the time it's driven by them

C: Ok, so that's mostly driven by the parents?

OT role

parent's role

parent's drive
goal setting

OT: The actual setting of the goals

C: Ok

OT: I suppose is driven by me

C: Yes

OT: So families don't know what to do, what goals are, first off

C: Yes

OT: And they just want to get on with it. Do you know what I mean?

C: Yeah, sure

OT: Um so that's why I think I 'spose I take the leadership role because we have to set these goals and work out an Action Plan about this is where we go but the families are the ones that drive what the goals are, pause, with prompting where necessary to stay on track

C: And um is this the roles that you would like, that ideally you would like to have for yourself and the parents? Where you take the leadership role and drive?

OT: I think it works ok in that I suppose as a government service we need to get specific things on paper

C: Yeah

OT: Um so by having that more leadershipy type, not really leadership, but me driving

C: Yeah

OT: What information I need, um, and letting the families choose the goals

C: Yes

OT: About their lives.

C: Ok

OT: So they really bring up what, then again with prompting if needed, but bring up what their concerns are so I think that works well and how they want to achieve that, I suppose as well

C: Ok

OT: Part of the discussion would be how do you think you can fix that

C: Yeah

OT: And what do you think can we do to help you fix that so I try and let it be family or client driven

C: Yeah

OT: But take on that over arching leadership role

C: Yeah, yeah because it is your understanding it is your expertise isn't it?

OT: Yeah

C: So you're evaluating goals depending on every term or every six months, depending on the clients

OT: Yep its more reviewing an Action Plan type of thing

C: Yeah

OT: So sometimes the goals haven't been achieved and they continue

C: Yeah

OT: Or some goals go away because the issue does, isn't current anymore

goals change

C: Yeah, sure. And what factors are impacting on the frequency of the evaluation do you think?

OT: Um again probably the family, whether the family find it ok to have short goals or long goals

C: Ok

OT: And I think also what we're working on so prescribing a wheelchair takes a long time

C: Yeah

OT: Compared to finding spoon to eat with or something

C: Ok, sure

OT: Which are short term. So I think that the timeframe of the goal tends to be a factor

C: Ok, yeah

Pause

C: Ok, when setting goals with the family, who decides on the goal and directs the course of intervention? You said it is usually families who are making that choice.

OT: Yeah, so some need prompting to work out what their concerns are but I try to prompt them or they come up with their goals.

C: Yeah, sure

OT: What are the things you would like to work on, what are the problems that you have been having?

C: Yeah

OT: So I try to push it to be, otherwise the family don't really own it

C: Yeah, yep

OT: Um and that works quite well

C: Good

OT: I suppose that I drive it, but the family come up with the idea

C: Yeah

OT: And make the goals

C: Sure

Pause

C: So who do you think should own the goals? Should the family own the goals?

OT: Yep, the client

C: Yep, family, client, yep. And why?

OT: Because its them its not me

C: Yes, yep

OT: It's their, they're the ones that have referred for a particular problem so I think it's their goal to own, theirs to achieve even if most of the actions are done by us

C: Yes

OT: Um, I still think the client is the one who owns it

C: I guess it's a bit like health isn't it, when you take charge of your health

OT: I don't know if clients see it that way but I think they do

C: Yeah

OT: I've got a few families who definitely see it that way

C: Yeah

Pause

ownership

OT: Um I think it depends what time as a therapist you have that's all. And government service provision as well

C: Yeah

OT: Um, whether the families feel like they own it or not sometimes its more put upon them this is your goal this is your, pause, yeah, pause

C: So how do you think goal setting could be improved?

OT: Um, I think basic, having that structure to it, so making sure you put your review dates and

C: Yes

OT: Those types of things. I think I've done it to remind myself over the last year of working

C: Yeah, ok

OT: I have my diary and that makes sure that I put a review date in, um making sure that I go to see the family and do the whole discussion instead of just getting the referral, seeing them for the wheelchair and going ok well this is your goal

C: Ok

OT: Um, using that collaboration has been really good

C: What about that multi-disciplinary process?

OT: The multi-disciplinary has worked really well as well. In these cases I suppose.

C: Has it been redundant in other cases do you think?

OT: Um, well we haven't really approached it too much with joint physio well that's because of the locality and

C: Yeah

OT: Problems with that

C: Yep

OT: Um, so I think it becomes redundant in some cases where we haven't used it

C: Yeah, its worked well

OT: Even if we have completely separate goals it has worked well

C: Ok

OT: Which has been interesting

C: Yeah.

Pause

C: And are you thinking you will continue?

OT: It will depend on service provision

C: Yeah

OT: But, um, yep it has worked well for us

Pause

C: Ok, is there anything more you would like to say about goal setting?

OT: I don't think so, it was quite timely as I had my Action Plan training this morning

C: Oh....

Tape switched off

Appendix 8

Example of a Quotation Bank

Theme 1: "An obscure concept": Learning to goal set

Sub-theme i) "You learn as a parent": Parents learning how to engage with and use therapists

i a) "First identify where deficiencies are": Gaining knowledge re: child's disability, difficulties, diagnosis

"For quite a while it was unclear how disabled she was. She didn't have any specific syndrome... it wasn't clear whether she would be...intellectually disabled even sort of to a moderate level" (Mary pg 1)

"She can't keep up the pace of other kids. And learning wise numeracy and spatial things are harder but she's learning to read and she's learning to write. And she's also learning to write with a laptop" (Mary pg 2)

"But all that's not knowing with [Josie]" (Mary pg 2)

"The long, long-term goal might be... for Jessie to talk in sentences, when she was 2 or 3 and we were doing Makaton but at that point we don't know if it's that's going to happen" (Mary pg 12)

"It's a bit overwhelming you've got to improve a whole lot of skills to get a certain outcome" (Mary pg 12)

"First identify where deficiencies are ...and where my child falls behind his age group" (Lyn pg 1)

"It's mainly the disability he has the dyspraxia and my um fear or obsession with him having problems with literacy" (Lyn pg 4)

"How old will she be [Tommiko] able to do that...because she can't do it now" (Keiko pg 1)

"At the beginning she was a bit tense because she felt under pressure ...she was expecting her a bit better and she was comparing her to other children" (Keiko pg 4)

"If she has epilepsy we really want to talk to the doctor about that." (Tommiko pg 5)

"I know that my children's development is spiky and uneven and I know what that means in terms of autism" (Marie pg 4)

"I went to a workshop this year... I learnt more in a day than I learnt from any therapist goal setting with me about anything... it helped me realise that there was stuff that I was doing without actually realising it that was working really well" (Marie pg 8-9)

"In the area of her of not knowing how to help her development in those areas has been, that's been I 'spose the biggest kind of area that I felt supported in" (Margaret pg 11)

i b) "I have to do the therapy": Learn what is therapy

"In the early days, the early days I found it difficult, the way, I don't think we were really setting goals. It was more like we had meetings and it was the concept of do this and it will help your child develop. And so that's a kind a global emorphis goal almost" (Mary pg 4)

"The parent is, you know, following the instructions of the therapist for the general good of the child" (Mary pg 4)

"The connection between those activities and an outcome isn't clear and linear" (Mary pg 4)

"The daily experience of being a therapy parent is and goal setting is around ... jobs/tasks, but that's not really the goal. The goal is something beyond that but... that's what you end up focusing on" (Mary pg 5)

"When I look at it now, I think...that programme, is quite intensive in a way... what I think now is that I don't mind the way it has worked out because we learned to integrate therapy into life" (Mary pg 6)

"Back then I had a higher level of desperation and urgency about fixing things ...and there were a couple of things that I got very enthusiastic about and pursued that turned out to be total dead ends" (Mary pg 6)

"How much do parents have to learn it themselves or learn it from other parents. That's part of how I learnt it was other parents telling me." (Mary pg 7)

"All they do is just make you go through these activities and try and find something that is interesting for him" (Lyn pg 2)

"I just try and practice them and hope that long term it will be beneficial" (Lyn pg 2)

"I have to do the therapy" (Lyn pg 3)

"She needs a lot of stimulation" (Keiko pg 1)

"She has a weak spine and neck so we have exercises" (Keiko pg 2)

"I have no idea of what we are doing and why" (Marie pg 6)

"Where are we going? Why are we going?...If I don't have direction....I am disinclined" (Marie pg 6-7)

"So for the first four months his OT kind of watched him watch the Wiggles... So how do you goal set things like that?"(experience of OT not goal setting) (Marie pg 23)

"I see when we don't practice it's easy for her to slip back" (Margaret's understanding of the impact of practice/therapy) (Margaret pg 3)

"We always came away with our page of suggestions...I could stick them up and be reminded of what to do...I've still got one stuck on my kitchen wall" (Margaret pg 10-11)

i c) *Learn what are goals and learn to goal set*

ici) "Making decisions about what and where": Parent's perceptions

"A goal is something that you want to achieve that is concrete. And you know when you've got there. It is measurable and specific." (Mary pg 3)

"You see many words around it and I think everything gets lost in that ...but I find goal the most concrete... the most common usage term, that, that doesn't get too complicated" (Mary pg 3)

"Well having a think about what would be achievable both what you would want but also what's doable." (Mary pg 3)

“Making decisions about what is happening and where you want to go.” (Mary pg 3)

“Early development is ... you’re working on ...sensory processing, you’re not working on specific skills but as they get older you can work on specific skills that adults recognise more and can see more as a goal” (Mary pg 4)

“The goal would be conducting the therapy with the child. I will be giving the child these experiences.” (Mary pg 4)

“I was trying to get the therapy embedded in life and use that model....and it kind of felt like I was dragging everyone else a long a bit” (Mary pg 5)

“I mean goals with starting school...[they] started to focus on formal learning writing and then as she is getting older they focus on life skills.” (Mary pg 9-10)

“So goals are all implicit not explicit” (Mary pg11)

“And when you’re not a therapist seeing them [the goals] as important is kind of difficult at times” (Mary pg 12-13)

“A goal would be something that you’re not able to perform at the moment but hopefully with some guidance you can do a few different steps and train yourself to actually achieve a task that you couldn’t previously achieve” (Lyn pg 1)

“I realise now by looking back that there have been goals that have been set” (goals are not explicit) (Lyn pg 1)

“Some of the goals don’t seem to be black and white” (Lyn pg 2)

“It is very hard to judge when he had achieved the goal” (Lyn pg 2)

“I can’t say that it is something that I have actually sat down and thought that this the goal that I have to achieve” (Lyn pg 2)

“I want him to sort of use scissors more and do more writing” (Lyn pg 4)

"I sort of saw the goals as being ...not very black and white...very general. Like to improve this area, to improve that area. So it was more like a topic.

...Not specifically we will get [child] to do this...it was more like a general heading (laughs)" (Lyn 5)

"I'm focussing on the activities that I look at even though the occupational therapist has written just the goals. I can't say that I have focussed on them" (Lyn pg 5)

"Sometimes if I want him to achieve something and he just can't because of the dyspraxia he can't do it, I know I get very frustrated. So but I mean that would only be if you took the goals to the extreme if you pushed him too quickly and you wanted to achieve it too early. Those sorts of things could sort of be detrimental" (learning how far to push and what goals to set) (Lyn pg 8)

"It is sort of like an aim" (Keiko Pg 2)

"She hasn't really set the goals yet but she said that if she did...she realises that it is important to set goals like this" (Keiko pg 3)

"We haven't done much goal setting" (Keiko pg 3)

"It takes ...a while ... to understand that those small... goals are actually worthwhile for a start...and it is worthwhile pursuing them" (Marie pg 3)

"Is for my child to be independent and to function and to hopefully in some way shape or form spend time with and um, keep up in some way their peers" (Marie pg 5)

"At the beginning ... It's too overwhelming" (Marie pg 5)

"I've learned...to bring someone with me [to the goal setting appointments]" (Marie pg 5-6)

"I don't know why we're doing it [related to goal setting] if I don't understand why I am doing something...I won't do it" (Marie pg 20)

"Goal setting is looking where a kid is and looking where you want them to be which is as close to their aged peers" (Marie pg 20)

"You want them to be independent" (Marie pg 21)

"It would be nice to see her more involved...If someone could teach me I'd be happy to learn" (Margaret pg 6)

i c ii) "They don't know what goals they want": Occupational therapist's perceptions of parents learning to set goals

"I find that you often will ask them you know what are your goals ...and they don't have a good understanding of what OT is" (Peter pg 1)

"They don't know what goals they want to do often a number of their comments are about ... they don't know what normal is" (Peter pg 1)

"I think some parents come in and its usually a new parent, that goes I don't know why I'm here or I've been told by the school that I need to come but I don't know why, and yeah and I think that that's sometimes can be a little bit of another role for the therapist to actually say well look I'm actually sorry but your child is delayed" (Peter pg 8)

"I've got a couple of parents that have a developmental delay of their own and they don't know that the kids should be more advancing and have the capacity to advance but their environment's not supporting that" (Peter pg 9)

"A lot of the parents feel that they don't have those skills to set the goals" (Peter pg 11)

"Parents often come in and look for answers, they're looking for answers or input even sometimes when they don't know what they're looking for they just want assistance" (Peter pg 14)

"Often parents with babies like with the MDs or particularly with the younger aged children don't have any specific areas of concerns, such as a client of three months with cerebral palsy, but she just wants to know about general development" (Carol pg 3)

"So in many cases they are guided by us as to what see are the important issues" (Carol pg 3)

"Sometimes some things we find are going to be a priority before other things to be addressed like positioning or seating or sensory issues that really affects what the goal is going to be the priority" (Carol pg 3)

“So some parents when we ask them what the individual priorities are and will say no we’ve come to find out from you because you’re the experts” (Carol pg 3)

“But then as the families are in the system for a bit longer then they are able to identify and I suppose they have had experience” (Carol pg 3)

“Often the younger children they are more reliant on us to set the goals and for direction” (Carol pg 4)

“And then sometimes you find that as children get older that parents are using that same terminology that you use, that you’ve introduced for them from the beginning” (Carol pg 7)

“Often it’s an ongoing process... we might set all these goals in an MD but then when parents actually get the report and have a think about it but they find that oh no actually I want them to learn to eat too ... So sometimes you can do all of these nice documents but it changes or the child, especially the children with autism, have different issues that come up or they shift...so in those cases I don’t write a new Action Plan. I’m flexible with the parents and this is what is important for now” (Carol pg 8)

“Sometimes the families have unrealistic goals...and it can be harder to try and work out a process through that... we’ve done a bit of trial and error so that the family can actually see that it doesn’t work” (Jane pg 5)

“I think some families that I’m working with, find the big picture stuff a bit hard so the long-term goals a quite hard for them to comprehend so we do quite a lot of smaller [goals]” (Jane pg 6)

“I ... just talk them through it to give them ideas and to scale it down if I can see that they’re confronted by a big goal obviously scale it back to something smaller that would appear less confronting to them” (Jane pg 7)

“I think that with the families that are more anxious, more concerned parents we do a lot more small goals. Quicker goals so they can see the outcomes quicker as well. So we meet more often to review those clients” (Jane pg 7)

“I’ve got one particular interesting family that the disability has been acquired more recently so it hasn’t been ongoing. And they find it really good to sit down and plan. Feedback that they’ve given me like, doing that goal setting, has been really good for them to know what to expect. They don’t know what to expect because they haven’t

lived with it. They're in their first wheelchair, they don't know what to expect next so I think that sitting down and having regular reviews and goal setting discussions has been beneficial for them" (Jane pg 7)

"The actual setting of the goals I suppose is driven by me. So families don't know what to do, what goals are, first off and they just want to get on with it" (Jane pg 11)

"Sometimes clients don't know what their goals are... I tend to ...bring it back to what did they come in for? Like what they see as their main concerns... And so you come from that, and usually you end up coming from some goal setting. Probably in those cases it might be slightly less collaborative though. In that they might be...my goals that they are just going along with. It might be hard to judge" (Ann pg 5)

i d) Learn how to live with your child

"I think we pretty well understand her now and after 5, 5 and ½ years of being therapy parents and working through all this we're feeling pretty comfortable" (Mary pg 2)

"It really has gotten easier, and easier" (Mary pg 2)

"Everything in [Josie's] life has settled now. We have a really good partnership with the school... I am sure there will be future phases of it... you know that sort of fighting phase...where you have to kind of agitate and push for what you think your child needs" (Mary pg 5)

"Sometimes if I want him to achieve something and he just can't because of the dyspraxia he can't do it, I know I get very frustrated. So but I mean that would only be if you took the goals to the extreme if you pushed him too quickly and you wanted to achieve it too early. Those sorts of things could sort of be detrimental" (learning how far to push and what goals to set) (Lyn pg 8)

"She is eating very well, she is sleeping very well and she doesn't really cry...she is quite easy. She is always quite quiet...So I'm also quite calm" (Keiko pg 4)

"I'm pretty good at ... getting support and resources" (Marie pg 14)

"I have to let her grow up...and me grow up by letting go so letting her be more independent" (Margaret pg 7)

i e) Learn how to use therapy as required

“At the end of the day you just want to be a parent anyway and not be the therapist”
(Mary pg 8)

“So there’s a rhythm to energy and attention to therapy...To make appointments, to ... really pay attention to it and then a break. And then just kind of let it ride and so whatever we do we do. And those cycles at different points in the cycle the goals are different (laughs). At one point it is sort of resting the system and having fun and enjoying each other and at other point it is....doing the therapy and pushing through difficulties.” (Mary pg 10)

Sub-theme ii) “They just want action”: Occupational therapists thoughts about parent’s perceptions

“I really think that parents really want a physical thing that they can see like a physical attribute that improves...they want a functional change” (Peter pg 5)

“I think that sometimes parents find the concept of goal-setting a bit obscure they... don’t quite grasp a measurable goal or they have unrealistic goals” (Peter pg 11)

“They just want action” (Carol pg 3)

“Some parents... just don’t feel comfortable writing or aren’t able to articulate as clearly what they want” (Carol pg 7)

“Sometimes families feel a bit pressured I think... they feel like they should be giving their child the best they can but they can’t do that at home because they don’t have enough time to do all that” (Jane pg 4-5)

“I think some families that I’m working with, find the big picture stuff a bit hard so the long-term goals a quite hard for them to comprehend” (Jane pg 6)

“I think it can be overwhelming, I think for them the whole goal setting process... other families I think, just take it on and they love it” (Jane pg 6)

“I think it can be quite overwhelming in the beginning for them to go ok what are the major goals here” (Jane pg 6)

"I think some families really understand the disability and understand where they are going and understand what will pop up in the future and other families just have no idea" (Jane pg 6)

"I think the family appreciates that understanding of what else is happening of what we're considering in the future instead of it just popping up and all of a sudden oh we need to do this" (Jane pg 8)

"So families don't know what to do, what goals are, first off and they just want to get on with it" (Jane pg 11)

"I think it probably, at most, would be a target or a direction of where they're going. Like an aim, or purpose that something's happening. I would say is what they would probably more see it as so much vaguer or general" (Ann pg 6)

"I think some parents have found it quite a strange thing to go through initially but have ... have found it quite beneficial because they can see what exactly were their children's goals...and what areas of life it was affecting... their lives and what they needed to improve upon" (Michael pg 1)

"Probably it's a way for them to get their story out and validate their concerns and...their hopes and dreams for their kid and what they want to achieve exactly" (Michael pg 4)

"I still get the feeling that ...most clients that I deal with and families and parents still have that very old medical [model] in mind, and they kind of see the therapist as someone who sets the goals or drives intervention" (Michael pg 5)

Sub-theme iii) "Developing my own technique": Occupational therapist's learning

"I think my biggest challenge with the goal setting has been is developing my own technique and trying to extract the goals from parents" (Peter pg 1)

"I'm still developing ...I'm still finding comfort zones in my goal setting" (Peter pg 5)

"I'm still finding my own way of setting goals and my own way of empowering a goal setting discussion... I get in there and I am very solution focussed that person will present a problem and I will present a solution" (Peter pg 5)

"I still find it hard that when the parents are completely fixated on an unrealistic goal that's unachievable how you actually break that down with empowering the parent so that parents... are making it realistic" (Peter pg 14)

"I'm actually taking more time now than in my initial assessment I do take time out to actually talk with the parent and the child, if they're able to, to actually identify those goals and areas. And then take time at the end to re-hash over" (Peter pg 6)

"I really would evaluate.... if it's a straight forward sort of client each session which would be six monthly to maybe eight monthly. If it's a complex child ... then would be probably about 12 monthly when we do a full MD review and that's where we review our previous Action Plan and then re-set the next one" (Peter pg 9)

"I've found that having [a] system I have been able to review goals and review Action Plans more efficiently" (Peter pg 10)

"We tend to use it more of a guiding document because ... we see the kids quite regularly we might review it say at 6 months or 12 months, so this is just a starting point. So if we put too specific the goals down then you need to review them so quickly. It's a lot of paperwork to go through"

(Carol doesn't place too much emphasis on goal setting) (Carol pg 6) (Carol's technique/emphasis)

"I use that time when I do my reviews and goal planning to talk to some of these families that don't know some of the major milestones coming up like in the ACT it's 16 you've got to apply for your pension and at 18 apply for guardianship...the whole future planning" (Jane pg 8)

"I tend not to be too prescriptive in those reviews and just kind of go with the family more than anything and so we come to the outcome that we wanted" (Jane pg 9)

"I probably started doing that (collaborative goal setting) more when I moved down here" (Ann pg 1)

"In School Age North, I used to keep a folder with all my Action Plans so I just checked them regularly to see where everyone was up to and that was a more efficient way of keeping track of everyone when you're trying to read their files." (Ann pg 7)

"If there hasn't been any sort of formal goal setting or collaborative goal setting with the family even in my progress notes, I always write a little plan of action which are a few goals and what I need to do" (Michael pg 3)

Appendix 9

Member Checking Summary



5th July, 2010

Dear Participant,

Thank you for participating in my research project "What are the collaborative goal setting experiences of parents and occupational therapists?" As discussed with you during your interview, I would like to get feedback from you about the information that I have collected. Rather than having another interview with you, I am writing to you to request written feedback about the themes that I have collected from the data. Attached is a member checking summary of my initial data analysis from both parent and occupational therapist participants.

Could you please have a read through and send back to me any comments or feedback that you may have about it? I am particularly interested to know whether I have interpreted your ideas correctly.

I have provided a pre-paid envelop for you to return any feedback. Alternatively you can email me at catehilly@yahoo.com.au. ***I would like to receive feedback by 14th July 2010. Please do not email feedback to my work email address (cate.hilly@act.gov.au) as I will be taking leave and will not receive it in time.***

Thank you again for your participation. I hope you enjoy reading this summary and I look forward to hearing from you.

Regards

Cate Hilly
BAppScOT
MAppSc candidate
Therapy ACT

*Hi Cate,
I have scribbled some
notes on this copy.
Good luck with it all.
I hope it helps OTs do
an even better job.*

The collaborative goal setting experiences of parents with children with disabilities and occupational therapists

The following is a summary of five major themes that have arisen from the interview data. This includes data from five mothers of children accessing occupational therapy services at Therapy ACT and five occupational therapists delivering services to children and families at Therapy ACT.

Theme One: "An obscure concept": Learning to goal set

This first theme described the importance of learning how to set goals before they could engage in collaborative goal setting. There were three view points discussed by participants: parents learning how to engage with and use therapists; occupational therapists' thoughts about parents' perspectives; and occupational therapists learning to develop their own goal setting techniques.

i) "You learn as a parent": Parents learning how to engage with and use therapists

Parents described many things that they needed to learn about before they could engage with therapists in collaborative goal setting and ultimately utilise occupational therapy services when required. This learning process included:

a) "First identify where deficiencies are": Gaining knowledge about their child's disability, difficulties, diagnosis and prognosis

Parents described the process that they went through and were going through in learning to understand about their child's disability. They identified initially feeling "overwhelmed" at "not knowing" how to help or where their child was at developmentally.

b) "I have to do the therapy": Learn what is therapy

Several parents referred to the concept of "doing the therapy" for their child without really understanding why they were doing what they were doing. They did not differentiate between occupational therapy and other therapies such as physiotherapy or speech pathology. They hoped that what they were doing would "be beneficial" and identified that their child needed "a lot of stimulation". However one mother identified that if she didn't know where she was going and why then she was disinclined to do any therapy. Parents required an understanding of what therapy and why it would help their child before they could actively participate in goal setting.

c) Learn what goals are and learn to goal set

Both parents and occupational therapists identified that parents went through a process of learning how to set goals. Often parents initially presented to occupational therapists without knowing how occupational therapists could help and how to set goals with occupational therapists. Parents struggled with goals being "implicit not explicit" and "not very black and white" which hindered their ability to learn to goal set. They found it "difficult to judge" when their child had achieved the goal. Some reported that they hadn't "done a lot of goal setting". Occupational therapists felt that parents didn't always have "those skills to set goals" and were in many cases "guided" by them to "identify the important issue" for goal setting. Occupational therapists described having a driving role in the goal-setting process to help families learn how to set goals.

d) Learn how to live with your child

Parents identified that over time they learned how to live with their child with a disability and that everything had "gotten easier". They learned how far to push their child's development and also how to get support and resources. One mother reported feeling "quite calm" because her child slept well, didn't really cry and was quite easy. This process was not necessarily a direct result of parent's engagement in therapy but was a crucial aspect of learning to be a parent of a child with a disability identified by parents.

Why is this here?
But for specific maybe.

e) Learn how to use therapy as required

Only one of the five mothers interviewed had reached this stage. She identified that at the end of the day she just wanted to be a parent and not the therapist. She described a cycle of her engagement in therapy and gave herself and her child permission to have breaks from therapy to experience just being a family.

ii) "They just want action": Occupational therapists' thoughts about parents' perspectives

Occupational therapists reported that when parents come to therapy often they "just want action" and don't expect to set goals. They were aware of the many emotional aspects of being a parent who brought their child to therapy such as feeling "pressured" and "overwhelmed".

iii) "Developing my own technique": Occupational therapists learning to develop their own goal setting techniques

The occupational therapists discussed developing their own goal setting techniques and systems. One therapist identified that he was still developing and finding a "comfort zone" in his goal setting. A more experienced therapist did not put too much emphasis on goal setting and viewed it only as "a starting point" to therapy and reported feeling comfortable with how she was goal setting with families.

Theme Two: "The things we would discuss became the goals": Goal setting experiences of parents and occupational therapists

Parents and occupational therapists experiences of collaborative goal setting were similar. There were six components to participants' experiences of goal setting: parents' experiences; the actual goal setting process; roles and ownership; goals change; and use of goal setting tools.

i) "Goals are often really open ended": Parent's experiences

Parents identified that goal setting had been mixed in with everything else and was not a clearly defined event. They identified having their page of activity suggestions but didn't always recognise specific goals.

ii) "We kind of melded those ideas together": The goal setting process

Both parents and occupational therapists described the goal setting process as just a discussion where they shared ideas and developed an Action Plan rather than a formal goal setting event. Goals were reviewed during therapy sessions rather than a specific review meeting. Goals were set by multi-disciplinary teams as well as between a

parents and an occupational therapist. Some therapists described a process of asking families about their main concerns, assessing the child and then more formal goal setting using the Canadian Occupational Performance Measure and/or Action Plan, whereas others did it more informally.

iii) "Both own the goals": Roles and ownership

Most parents viewed that they took an active, driving role in the goal setting process. Occupational therapists saw their roles as providing information to families about what they could offer and actually writing down the goals. Occupational therapists valued parents providing information about their child and communicating their needs and stories. Parents tended to view that they owned the goals yet occupational therapists viewed that both parties owned them.

iv) "The issues that were there are different now": Goals change

Both parents and occupational therapists reported that the goals set changed before they were reviewed. Occupational therapists accepted this as part of the process and tended to adjust their intervention plans accordingly. However one therapist did identify that sometimes she had to set limits around the goals so they could do "one thing at a time rather than trying to do everything".

v) "COPM, GAS and Action Plans": Use of goal setting tools

Only occupational therapists discussed using goal setting tools. Therapists valued the use of tools to structure their goal setting process; introduce their role to new families and facilitate reviews of goals. One of the five therapists reported that she didn't tend to use goal setting tools as she felt it put families through more hoops and detracted from action.

Theme Three: "It's just the beginning": The impact of goal setting on families' everyday lives and the occupational therapy process

Both parents and occupational therapists valued participating in collaborative goal-setting, however for each group it had a different impact. Parents' and occupational therapists' perspectives are presented.

i) "Life is busy": Impact of goal setting on parents' everyday lives.

Parents described "busy lives" and goal setting helped remind them what they needed to focus on and motivated them. Sometimes it added to their workload, was "guilt inducing" and put them "under pressure". However it did facilitate the development of their relationship with therapists and they felt like that they were heard by the therapists.

ii) "Beginning of the client's therapy life": Impact on the occupational therapy process

For occupational therapists goal setting was viewed as the beginning of the therapy process and a way to develop a therapeutic relationship with families. It was a communication tool to ensure families and therapists had a common direction and purpose. It helped to prioritise the family's concerns and provided something concrete to families about what everyone was doing. They also found it useful as a case management tool to keep track of their workload.

I would like them to be
used + have had
to get them used
to it. w. H.
program about
"Using the Copm"
I asked for a book
w. H.

Theme Four: “People vary in their life experiences”: Factors influencing goal setting experiences

Parents and occupational therapists discussed a range of factors that influenced their goal setting experiences. Viewpoints from parents and occupational therapists are presented along with another sub-theme of participants’ expectations of therapists, child and parents.

i) “The emotional aspect”: Parent’s perspective of factors influencing their goal setting experiences

Parents talked about internal factors including their own personality traits such as being “assertive”, being “practical” and “not too shy”; worrying about their child’s future and “living with an emotional burden”. They also raised external factors such as having a “shit night’s sleep”, support around them and many changes in therapists.

ii) “Depends on setting, the client and also time”: Factors identified by occupational therapists’ goal setting experiences

Therapists identified many more factors than parents influencing their goal setting experiences including

- Family factors - parents understanding of child; clarity of goals; parents experiences of other children; how families respond to goal setting; mental health issues and ability of parents to plan ahead and make task lists; how much goal setting they do generally; stage of grief and loss; whether they re-engage again after an intervention; family readiness
- Child factors – age group of child; stage of life the child is at; Duty of Care for the child vs family priorities
- Therapist factors – preparing for goal setting; having their own way of setting goals and empowering a goal setting discussion; going to professional development; personality of therapist
- External factors – school requirements; time to goal set and develop a relationship with the family; Therapy ACT service models; other disciplines; having an appropriate goal setting tool; staffing; waiting lists; other services; environment

iii) “She’s not the expert”: Expectations of therapists, child and parents

Both parents and occupational therapists discussed their expectations of themselves, parents, therapists and their child.

- Expectation of parent - Therapists felt that parents shouldn’t have to be therapists however they expected to have input from parents about the goals set. Parents saw that they had to do the therapy and remember to take time to do it
- Expectation of child – Parents all had their own unique expectations of their child. One parent was surprised by what her child could do; another didn’t expect much from her child; and another did not want her twelve year old to do baby things.
- Expectation of occupational therapist – Therapists hoped to inform parents and provide parents with a clear idea of what they could offer. Parents wanted help from therapists to provide therapy for their children and predict whether their child would reach the goals set

- Expectation of others – One mother described her expectation of her husband to take an interest but not really be involved in the therapy.

Theme Five: "More guidance, more direction": How goal setting could be improved

Parents and occupational therapists provided ideas about how to improve collaborative goal setting. Both viewpoints are discussed.

i) "Reinforce with the parents": Parents' ideas for improving goal setting

Parents wanted goals to be made more explicit with steps for achieving the goals time frames and difficulty levels. They wanted therapists to reinforce that what they were doing with their children was useful and to explain how and why. They valued having input from the therapist rather than just coming up with the goals independently. They wanted their child to be included in the goal setting process or make goals more child-focused based on what they child wants to do. They wanted practical information and resources to help to implement the goals.

ii) "Take the time to goal set": Occupational therapists' ideas for improving goal setting

One therapist was happy with how she was goal setting, however the other four therapists identified strategies to improve goal setting process. Therapists felt that setting goals within a multi-disciplinary team rather than as a single discipline was most useful. Some therapists felt that using a goal setting tool such as the GAS and or COPM would help structure the process. Limiting caseload numbers and allowing time for goal setting was viewed as a common theme by therapists.

Goal should not be set in stone as they become burdens.

*This is most important info in it all I feel.
I think the goal setting has to be guided by
reflection + review - i.e. it has to be evolving (co-evolved
by parents + therapists) because the factors affecting
outcome of input (therapy) are so changeable.*

Input Therapy
time available
parents understanding
skill →
child willingness
openness/receptiveness
suitability of therapy
practical for that point

outcome → *goal reached*

so outcome will vary

Have to continuously adjust in a feedback cycle.