FACILITATING POSITIVE COUNSELLING OUTCOMES FOR CLIENTS WITH AN INTELLECTUAL DISABILITY

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In loving memory of

my father, Mr. Quentin A. Kerns, 1924-2006

and my supervisor, Associate Professor Anne Bray, 1944-2008

Abstract

People with an intellectual disability experience the same range of emotional and mental needs as the general population. However, in comparison to the wealth of general counselling research, there is a relative lack of research involving clients with an intellectual disability. In particular, there is a scarcity of research exploring the clients' subjective experiences of counselling. This thesis therefore seeks to gain a better understanding of this under-explored area of counselling practice by inquiring of the two parties most intimately acquainted with the counselling process – clients and counsellors. Complementing the views of clients and counsellors, the views of support workers and key informants are also described.

Using a qualitative case study methodology, six clients with an intellectual disability were interviewed about their subjective experiences of counselling. Interviews were also conducted with their counsellors and with nominated support people. These interviews took place over a period of several months. In addition, single interviews were conducted with four key informants in order to gain an understanding of the local health and disability support services.

This thesis explores the participants' understandings of disability and counselling, discusses similarities and differences to general counselling and describes the outcomes of the six clients in this study. This thesis highlights four systemic problems that complicate the delivery of effective counselling services: (a) poverty, (b) health inequalities, (c) difficulties in the disability support workforce, and (d) social stigma. The thesis also draws attention to the need for specialised education for both counsellors and the disability support workforce. Researchers are invited to pursue further research. Practising counsellors are invited to engage in a rewarding, albeit complicated, area of professional practice.

Acknowledgements

I would like to begin by acknowledging and thanking the loving and merciful God whom I serve.

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Many thanks to the University of Canterbury and the Health Research Council for their academic and financial support.

The PhD journey is often described as a lonely venture. However, thanks to the communities surrounding me, I did not feel alone. I sincerely appreciated the personal and academic support provided to me by the staff at the Donald Beasley Institute and by the research community at the College of Education. I value the personal support provided by my local church community, Hornby Presbyterian Community Church, my whanau in the USA, and my friends here in Christchurch. Special thanks to my dear friends, Ruth Hanover and Vanessa Roberts.

A PhD journey begins and ends with questions. My parents, Quentin and Faye Kerns, were the first people to nurture and encourage my propensity to ask questions. The enduring quality of their love and support remained present even after my father passed away in 2006. I am grateful for my adult children, David, Peter and Rebecca. They, too, ask questions of the world and pondered with me many questions related to this thesis. Thanks for wondering with me.

Where one journey ends, another one begins. Special thanks to my beloved husband, John Raffensperger, for journeying with me on this PhD adventure and being ready to journey with me on the adventures that are yet to come. Thank you so much for all your support.

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Chapter One: Introduction

This purpose of this thesis is to explore counselling for clients with an intellectual disability in order to gain a broader understanding of the complexities involved in this specialised area of practice. Increasing our knowledge of this phenomenon serves to provide useful information for practitioners and to identify topics for further research.

This thesis is based on data gathered between February 2007 and January 2009 in the Canterbury Region of New Zealand, specifically in Christchurch City and the Waimakariri District. In 2006, Christchurch City[1] had a population of 348,435; it was home to two major tertiary institutions, nine major hospitals, and 164 schools (Christchurch City Council, 2007). The Waimakariri District is a rural area located north of Christchurch and in 2006 its population was 42,834 (Waimakariri District Council, 2007).

1.1. The starting point of this thesis

I had my first experience providing counselling[2] for a client with an intellectual disability[3] in 2003. Although I was keen to facilitate positive outcomes for this client, I was confronted by gaps in my own knowledge. I also became aware of many factors that seemed to interrupt the counselling process. I wanted to know what I could do to more effectively facilitate positive outcomes for clients with an intellectual disability. Therefore, I sought to increase both my "practical knowledge" as well as my "formal knowledge" (McLeod, 2003, p. 10). I sought to increase my practical knowledge by talking to colleagues who had experience working with people with an intellectual disability. I sought to increase my formal knowledge by reading the literature.

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[1] In 2006, the Banks Peninsula was amalgamated with Christchurch City.

[2] The term counselling will be discussed in Chapter 2, Section 2.3.

[3] The term intellectual disability will be discussed in Chapter 2, Section 2.2.

I approached the literature with the same mindset that I had when practising counselling, that is, the client was at the forefront of my thinking. Therefore, I was curious about the experiences of clients with an intellectual disability. What was counselling like for them? From their point of view, what kinds of things facilitated the counselling process and what kinds of things interrupted it? How did they perceive their outcomes? I quickly learned that compared to the wealth of general counselling research, there is a relative lack of research involving clients with an intellectual disability and research which explores counselling from the vantage point of clients with an intellectual disability is extremely rare.

The next hurdle I encountered was the gap between research and practice. I found articles about counselling interventions and outcomes for clients with an intellectual disability, but struggled to incorporate the findings into my practice. Many of the articles seemed to have the aim of validating interventions rather than offering suggestions for how to improve practice. According to McLeod (2003) this is common in general counselling literature as well:

> The aim of most outcome studies has been to establish the efficacy of a particular approach to therapy….In many other fields of human service work, evaluation research is carried out with the explicit aim of improving current service delivery…For the most part the relationship between therapy outcome studies and practice has been implied, indirect and diffuse. (pp. 136, 137)

I searched the literature hunting for articles with direct applications to my work with clients with an intellectual disability. The more literature I read, the more gaps I noticed. I also noticed that many assumptions were made about clients with an intellectual disability, even though their voices were noticeably absent in the counselling literature. This troubled me. I grew concerned about how these gaps and assumptions were impacting service provision. As suggested by Lofland, Snow, Anderson, and Lofland (2006) I used my current situation as a starting point for research. The basis of this thesis was my desire, as a practitioner, to learn how to more effectively facilitate positive outcomes for clients with an intellectual disability.

1.2. The research questions

The question of effectiveness is prominent in the small body of literature that explores counselling for people with an intellectual disability. Considerable discussion surrounds the question: "Is counselling effective for clients with an intellectual disability?" As a practitioner my interest in effectiveness is driven by my desire to facilitate positive outcomes for all my clients, including those with an intellectual disability. It is not sufficient for me to know that "Yes, counselling is effective for people with an intellectual disability." Or, "No, counselling is not effective." If counselling is effective, I want to know what factors contribute to the achievement of positive outcomes, so that I can incorporate more of those factors into my practice. If counselling is not effective, I want to know where the problems lie and what can be done differently to more effectively promote positive outcomes.

A number of assumptions undergird evaluations of effectiveness. Assumptions are made regarding the nature of counselling, how outcomes are measured and whose perspective is taken into account. When evaluating the effectiveness of counselling for clients with an intellectual disability assumptions are also made regarding the nature of an intellectual disability and its impact on the counselling process. It is assumed that counselling is different for people who have an intellectual disability. Given the numerous gaps in research, I found myself questioning the common assumptions embedded in the question, "Is counselling effective for clients with an intellectual disability?"

Like others before me, I have chosen to enter into the research debate that surrounds that question, but not by seeking an answer to a yes or no question. A simplistic binary approach does not do justice to the complexities of either the counselling process or the lives of those with an intellectual disability. Instead, I have chosen to interrogate the question and its underlying assumptions.

- What is an intellectual disability?

- What is counselling?

- What factors influence counselling outcomes?

- Is counselling different when a client has an intellectual disability? If so, what is different and what remains the same?

- Whose perspectives are taken into account when assessing outcomes?

By exploring those questions, I hoped to gather information which would help me to address the overarching question that inspired me to do research:

- How can counsellors more effectively facilitate positive outcomes for clients with an intellectual disability?

1.3. Exploring the questions

I was interested in learning what counselling was like in its natural setting. I had questions of meaning and perspective. Qualitative research is well suited to exploring phenomenon in their natural settings as well as exploring questions of meaning and perspective. "Qualitative approaches are able to delve into complex processes and illustrate the multifaceted nature of human phenomena" (Morrow, 2007, p. 211). According to Creswell (2003) questions of "what" and "how" are well suited to qualitative research (p. 106).

I was also interested in doing research which could inform counselling practice. Case studies often serve as exemplars for practice-based disciplines (Flyvberg, 2006), and are well suited to "making sense of processes of change" (McLeod, 2003, p. 99). Case study research tends to generate findings which are relevant to practice. Therefore this study was designed as a qualitative case study. I decided to conduct multiple interviews over a period of several months for three reasons: (a) Because we would be talking about sensitive information, I anticipated that it would take time to establish trust. (b) I was interested in gathering information about both the counselling process and counselling outcomes. (c) I was aware that there is often a time interval between a given intervention and the achievement of a positive outcome.

1.4. Position statement

Although this thesis is situated within the domain of qualitative research, I consider it to be, first and foremost, an extension of my counselling practice. The nature of this project is in keeping with the nature and values of counselling. As a researcher I built relationships with the research participants. These were "professional relationships based on ethical values and principles" (New Zealand Association of Counsellors, 2002, p. 26). By seeking to learn from a client group that is frequently ignored or marginalised, I was showing "respect for human dignity" (New Zealand Association of Counsellors, 2002, p. 26). By seeking to improve services for an underserved population, I was seeking "to increase the range of choices and opportunities for clients" (New Zealand Association of Counsellors, 2002, p. 26). Undergoing a detailed ethical approval process demonstrated my desire to act "with care and respect for individual and cultural differences and the diversity of human experience" (New Zealand Association of Counsellors, 2002, p. 26).

The skills used during the research interviews were similar to the skills used in more traditional counselling settings. The core conditions of empathy, genuineness and positive regard are a necessity when conducting research. Interviewing research participants requires a range of counselling skills such as keeping pace with the participant, listening, reflecting, paraphrasing, summarising, and questioning. In particular, interviewing clients with an intellectual disability required extra sensitivity and care not only because of their disability, but even more so because their lives were all too often littered with unpleasant experiences.

1.5. The organisation of this thesis

This thesis is composed of eight chapters, a reference list and appendices.

Chapter One provides an introduction to this thesis.

Chapter Two reviews existing research involving clients with an intellectual disability, highlighting numerous gaps in research. This chapter explores the concepts of disability

and counselling. It discusses how one's understanding of these terms can influence one's practice. The chapter also reviews research exploring the many factors that influence outcomes of clients with an intellectual disability and literature which explores their subjective experiences.

Chapter Three begins by describing my motivation for doing this project and its intended purpose. My motivation centred on counselling ideals, counselling knowledge practices and counselling ethics. The intention was to help "generate a more inclusive hermeneutical micro-climate" for listening to clients with an intellectual disability, people from the community and professionals (Fricker, 2007, p. 171). In order to create this micro-climate I chose to use a model of qualitative inquiry called "responsive interviewing" (Rubin & Rubin, 2005). This chapter discusses the nature of qualitative inquiry as well as the characteristics of responsive interviewing. It then discusses the ethical considerations for interviewing people with an intellectual disability. The chapter concludes with a brief description of the theoretical underpinnings.

Chapter Four details how the project was designed and carried out. At the local level, this project was developed in response to a previous New Zealand study which suggested that specialised training would enable counsellors to work more effectively with clients with an intellectual disability (Raffensperger & Miller, 2005). In addition to responding to the counsellors' perceived need, an extensive consultation process was carried out to ensure that this project was relevant to other local stakeholders. This project was designed as a multiple case study which followed six cases over a period of several months. This chapter details the ethical approval process, the recruitment process, the consent process, the data collection process, the data analysis process and the data presentation.

Chapter Five presents the participants' descriptions of the concepts of disability and counselling. The way that participants understand disability has the potential to influence how they engage with support services. The way that they understand counselling has the potential to influence how they engage with the counselling process.

This chapter highlights the themes important to each participant group and themes that are consistent across all four groups.

Chapter Six explores the question, "Is counselling different for clients with an intellectual disability?" It highlights findings which described the similarities and some key differences and difficulties. Similar to many New Zealanders the clients in this study were experiencing common presenting problems such as depression, anxiety, and loss. However, poverty, prejudice and inconsistent support created a number of difficulties for them. The chapter concludes by discussing the bridges that counsellors extended in response to those difficulties.

Chapter Seven uses two case studies to provide specific examples of the themes raised in Chapters Five and Six. This chapter also addresses the question, "Was counselling effective for the six clients who participated in this study?" Although all six clients experienced some positive counselling outcomes, in some cases, a lack of consistent, appropriate support appeared to inhibit the achievement of particular outcomes.

Chapter Eight discusses ways to incorporate these findings into counselling practice. The chapter begins by discussing the research questions and highlighting implications for counselling practice. Next the chapter discusses the strengths and limitations of the study. The chapter concludes with recommendations, invitations and ideas for future research.

The reference list points the reader to the works referred to in this thesis.

The appendices provide the reader with other information relevant to this thesis.

1.6. Presentation style

> We live in a conversational world. The relevance of conversations in social science goes beyond the use of conversations as an additional empirical method. It includes conversations between researchers and the public about the truth and value of the knowledge produced in interview conversations about a conversational world. (Kvale, 2007, p. 144)

Counselling involves conversations between counsellors and clients. Qualitative research involves conversations between researchers and the participants. So too, I view the presentation of research to be a conversation between the author and the reader. Therefore this thesis is presented in a more conversational style than the purely formal style typical of many doctoral theses.

Chapter Two: Literature Review

2.1. Introduction

People seek professional counselling for a variety of reasons. Common presenting problems are relationship or family problems, depression, personal growth, anxiety, and anger/abuse (e.g., Manthei & Duthie, 2003). People with an intellectual disability bring similar issues to counselling (Hodges, 2003; Larkin, 1992; Parkes, et al., 2007; Wittmann, Strohmer, & Prout, 1989) because they, too, experience the same range of emotional needs and mental health needs as the general population. Prevalence estimates of the emotional and mental health needs for this client group range from similar to that of the general population (e.g., Beail, 2003) to occurring more frequently than the general population (e.g., Harum, 2006).[4] Historically these needs have been addressed by pharmacological or behavioural interventions (Caine & Hatton, 1998; Hodges, 2003; Moss, 1998). However, increasingly over the past 20 years, counselling interventions have been explored as ways to address the emotional, behavioural and mental health needs of this client group (Lynch, 2004).

Counsellors aim to be effective in their practice (e.g., Wampold, 2001, p. 4). Thus researchers strive to understand what contributes to positive outcomes. And, indeed, there is a wealth of research pertaining to that question. However, there is relatively little research involving clients with an intellectual disability. "Research on cognitive-behavioral and psychodynamic psychotherapy with people who have mental retardation is negligible when compared to the volumes reported in *What Works for Whom?*''(Beail, 2003, p. 471). "The literature reporting outcomes of psychotherapeutic interventions in people with learning disabilities is extremely limited….Evaluations of psychotherapeutic approaches are conspicuous by their absence" (Willner, 2005, p. 74).

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[4] Kerker, Owens and Zigler (2004) reviewed 52 prevalence rate articles and discussed the numerous challenges associated with estimating prevalence. The initial difficulty arises in diagnosing mental health issues in people with intellectual disabilities. Taylor, Lindsay, and Willner (2008) considered that the prevalence rates vary according to the methodology used. They have gone on to state that "people with intellectual disabilities have mental health problems that are not detected and so remain untreated" (p. 724).

No doubt a number of reasons exist for this shortage of research. However, it is interesting to note that just as having an intellectual disability has been cause for exclusion from the community, so, too, this characteristic has been cause for exclusion from counselling outcome research. "For various reasons, learning disability has traditionally been an exclusion criterion for good-quality outcome research within the full range of psychological treatments" (Royal College of Psychiatrists, 2004, p. 6).

Since 2003, there have been several reviews of the effectiveness of counselling interventions for those with an intellectual disability (Beail, 2003; Benson, 2004; Prout & Nowak-Drabik, 2003; Sturmey, 2004; Willner, 2005). Though the reviewers' conclusions regarding effectiveness differed, similar themes were reported. The reviewers noted the relative lack of counselling effectiveness research for this client group, in contrast to the wealth of general counselling effectiveness research. They noted the pervasiveness of behavioural interventions used in such counselling. They also noted methodological problems in the research which included a lack of randomised controlled trials, and insufficient descriptions of the clients, the interventions used or the outcomes achieved. All the reviewers stressed the need for further well-conducted research involving this client group. This thesis was undertaken in response to this call for more research.

The aim of this chapter is to explore the research questions and to provide background information relevant to the findings. The first section of the chapter explores the nature of an intellectual disability. The section begins by clarifying the definition and terminology used in this thesis. Because an important theme in the findings was the provision of support, this section has also included background information regarding disability support services in New Zealand. The second section of this chapter explores the nature of counselling. This section begins by clarifying the definition and terminology used in this thesis. Next it explores ways of viewing counselling and how different ways of viewing counselling influence how outcomes are assessed. The remainder of the chapter explores in detail two themes which are relevant when assessing counselling outcomes, but which are rarely explored in relation to clients with

an intellectual disability: (a) the many factors that influence counselling outcomes and (b) the client's subjective experience.

2.2. What is an intellectual disability?

This thesis is focused on a particular client group, clients with an intellectual disability. For purposes of research and education, groups are often formed based on common client characteristics such as their presenting problems or age or ethnicity or, as in this case, their disability. When clients with common characteristics are grouped together it is essential to clarify that characteristic. It is also equally important to emphasise that any client group that is formed around a common characteristic is not homogenous. It is actually a heterogeneous group of individuals.

An emphasis on heterogeneity is of the utmost importance when discussing clients with an intellectual disability. Considerable stigma surrounds people with an intellectual disability. They are often viewed in light of their disability, rather than their personality, age, gender, ethnicity or some other characteristic. They are frequently referred to en masse with a certain amount of prejudice. Thus, it is with some reluctance that I have grouped together unique individuals in this thesis. I have chosen to do so because this particular characteristic often hinders their access to effective counselling services.

2.2.1. Definition

For the purposes of this thesis, the term intellectual disability will be used to refer to "a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; A reduced ability to cope independently (impaired social functioning); which started before adulthood with a lasting effect on development" (Department of Health (United Kingdom), 2001, p. 14).

2.2.2. Terminology

I wish to alert the reader that a multiplicity of terms have been used to refer to this disability.

As far back as one can remember, workers have searched for a correct nomenclature, an agreed division between normal and defect and an agreed series of divisions within defect itself. It is still not uncommon for a section of this nature within a monograph or report to draw attention to the existing terminological confusion …

Part of the difficulty arises from the deeply rooted attitude of many members of human society towards anyone who appears to deviate widely from the normal for that community. 'Of course we will help you build a hostel for the subnormal — provided it is not going to be next door.' There is the consequent natural wish of all involved to find a series of pleasant-sounding terms to describe those so afflicted. (Worters, 1968, pp. 27-28)

As was common in Worters' time, there still exists today a certain amount of "terminological confusion." As indicated by Worters, social stigma played a significant role in the array of terms used decades ago and, as noted by Bray (2003), social stigma has continued to play a role in recent times. "Many different names are still used for the same phenomenon [i.e., intellectual disability]. Names change over time, particularly when their connotations or stigma become so derogatory in common usage, that they are no longer acceptable" (Bray, 2003, p. 1). For example, in 2007 an association in the United States changed its 130 year old name from "American Association on Mental Retardation" to "American Association on Intellectual and Developmental Disabilities." For this association its name change was related to "establishing a new standard in disability terminology and making way for a more socially-acceptable way of addressing people with intellectual disabilities" (American Association on Intellectual and Developmental Disabilities, 2006).

In addition to varying over time, terms also vary from country to country. In addition in different countries the same term can be applied to significantly different disabilities. For example, in the United Kingdom the term "learning disability" refers to the same disability as the term "intellectual disability" as defined previously (Department of Health (United Kingdom), 2001, p. 14). However, in the United States of America the term "learning disability" refers to a significantly different group of disabilities (National Dissemination Center for Children with Disabilities, 2004). In spite of the multiplicity of terms that the reader will encounter in the referenced articles, I have chosen to write using a single term, "intellectual disability," throughout this thesis.

Just as specific terminology connotes meaning, so, too, does word order. Different schools of thought exist regarding how to modify words such as people or person with words referring a disability. At this point in time, across the world, some organisations prefer to use the term "disabled people." This serves to remind the listener that society plays a role in disabling people (e.g., Prime Minister's Strategy Unit, 2005). Others prefer the use of people first language and say "people with a disability," because "people first language puts the person before the disability" (Self Advocates Becoming Empowered, n.d., p. 2). While I recognise that society plays a role in creating disabling barriers for people with an intellectual disability, I wish to emphasise the humanness that all people share regardless of their ability. Therefore I have chosen to use people first language. This choice of word order is in keeping with the preferences of a number of organisations run by and for people with an intellectual disability (e.g., Self Advocates Becoming Empowered, n.d.).

Throughout this thesis, the reader will encounter a variety of terms used by authors from times past and from many countries. Some of the terms used may sound unpleasant to our ears, perhaps even unkind. Despite my effort in choosing respectful language, I acknowledge that the terms used in this thesis are likely to sound unkind in years to come and may, even today, sound unpleasant to someone from another location. The passage of time and one's current location pose unavoidable difficulties for authors. Therefore I am relying on the reader to impart respect to terms which have become outdated.

2.2.3. Ways of conceptualising disability

A number of disability scholars and activists have contrasted two ways of thinking about disability — the medical model and the social model (e.g., Oliver, 1990, 1993). The medical model locates the disability within the person and assumes that the disability can be objectively measured or diagnosed. This model generally offers a deficit-based diagnosis of the disability and offers interventions which focus on curing, alleviating and preventing the deficit. The social model, on the other hand, locates the disability within society. It recognises that differences in individuals do exist, but

asserts that the disability resides outside the individual and is a subjective, socially constructed phenomenon. This model offers interventions which focus on identifying and reducing barriers.

While the social model of disability has motivated positive changes in support services, some scholars consider that it does not pay sufficient attention to the nature of personal impairment and they consider that there is a "third movement" which emphasises "the importance of the lived experience of impairment" (Thomas, 2002, p. 52). It also calls for attention to be paid to the differences in the lived experience of different categories of disabilities and to the underlying assumptions present when categorising disabilities (p. 53). Hughes (2002) summarised this view as "impairment is social and disability is embodied" (p. 66).

2.2.4. From concept to practice: A brief history of disability support in New Zealand

The way in which disability is conceptualised has an impact on the ways in which support is provided. For example, current government policy in New Zealand is based on the social model of disability. As stated in the New Zealand Disability Strategy, "disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have" (Dalziel, 2001, p. 3). Two of the values stated in this strategy are inclusion in the community and person-centred support (p. 21). However, person-centred support and inclusion in the community have not always been the stated objectives of the New Zealand government.

Similar to many western countries, prior to the late 1960s, support services funded by the New Zealand government were based on the medical model (Office for Disability Issues, 2002). Support was "delivered to disabled people mostly in segregated settings such as large institutions, residential care units, special schools and clinics" (Sullivan & Munford, 2005, p. 20). People with a disability were seen as having deficits and the provision of support was expert driven. (It is important to note here that four of the six

client participants were born in the 1960s. Therefore it was this model of best practice that shaped their early childhood experiences of support provision.)

Across the world in the 1950s and 1960s there was considerable dissatisfaction with this method of service provision. This gave rise to disability activism in the 1960s and by the 1970s governments in several western countries began forming policies around disability rights and initiating changes to existing service provision (e.g., Scotch, 1989). In New Zealand, alternatives to government funded services first emerged through the volunteer sector. Harold and Margaret Anyon had a son with an intellectual disability. They were dissatisfied with existing support options. In 1949 they gathered together other parents and formed a parents' association which by 1953 had a membership of 1000 (NZ History, n.d.). This Association was originally called Intellectually Handicapped Children's Parents' Association. It is now known as the IHC. What began as a volunteer association eventually received government subsides following a 1959 report from the New Zealand Branch of the British Medical Association. According to Millen (1999) this report "criticised the mental deficiency institutions as too custodial, too large and too isolated, and for placing insufficient emphasis on education, training and rehabilitation" (p. 46). Government policies began changing in 1964 with regard to educational services (Education Act 1964) and in 1975 financial assistance was provided for people with disabilities to remain in the community (Disabled Persons Community Welfare Act 1975).

Although community support services were being delivered in the 1970s, many people with intellectual disabilities continued to receive government funded support in institutional settings. Some people lived in psychopaedic hospitals; these were designed specifically to provide care for children with intellectual disabilities. Others lived in psychiatric hospitals which also provided care for people with mental illness. According to census data, in 1971 there were 4,329 people with an intellectual disability living in psychiatric and psychopaedic hospitals. In 1976 there were 4010 people and in 1981 there were 3850 people (Department of Health, National Health Statistic Centre, 1983,

p. 13). Table 1 shows a breakdown of these numbers by age groups.[5] In 1981 nearly half the people living in psychiatric or psychopaedic hospitals were people with an intellectual disability.

Table 1: Breakdown of ages and number of people living in hospitals

(Adapted from: Department of Health, National Health Statistic Centre, 1983, p. 13)

Age group	1971 Number of people	1976 Number of people	1981 Number of people
0-9 years	405	288	190
10-19 years	1091	1055	902
20-29 years	893	934	973
30-39 years	594	578	667
40-49 years	528	438	417
50-59 years	439	359	359
60-69 years	271	230	205
70-79 years	90	114	110
80 years and older	18	14	27
Totals	**4329**	**4010**	**3850**

In 1981 more than half of the 3850 people had been living in hospital care for 10 or more years. Over 1000 had been living there 20 or more years (Jack, 1985). Jack expressed concern that "unlike most psychiatric patients, there is little turnover among

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[5] These numbers do not include children with an intellectual disability who were living in residential special schools.

the mentally retarded" (p. 49). Many of these people continued living in hospitals for the next 10 to 20 years. In the 1990s, as a result of health care reform and restructuring, New Zealand began a process of de-institutionalisation and resettling people into the community (Joseph & Kearns, 1996; Mirfin-Veitch, 2005). This process ended in 2006 when Kimberley Hospital, the last of New Zealand's large institutions, was closed. In 2002 when the plans for Kimberley's closure were being made 349 people with an intellectual disability were living there (Gates, 2006).

Not all people with an intellectual disability resided in institutions. According to Jack (1985) in 1973 approximately 500 people with an intellectual disability were accommodated in the community by the IHC. By 1983 the IHC was accommodating approximately 2,250 people in the community (p. 47). There were also people with an intellectual disability who did not receive services from either the IHC or from the large institutions. However because large numbers of adults with an intellectual disability have experienced institutional living, it is important to consider the emotional and psychological repercussions of institutional living.

In the first instance, living in an institution means that one is not living with family. Mirfin-Veitch (2005) explored 35 families' responses to the de-institutionalisation of a local psychopaedic hospital. Here is how she summarised the enduring feelings which institutionalisation engendered for many families:

> … the reverberations of removing a child from the family home sometimes had the effect of creating an enduring sadness in many families. The now adult siblings of men and women with intellectual disabilities appeared to continue to try and make sense of the dislocation that had occurred within their family. Many struggled with the sadness caused by their brother or sister going to live in an institution while at the same time recognizing that the stress and difficulty of caring for a child at home had caused real problems within their family. (p. 216)

Baker and Blacher (Baker & Blacher, 2002) surveyed 106 family members of people living in institutions in California. The family members reported both advantages and disadvantages to the out of home placements. Disadvantages included negative feelings on the part of the child living in the institution, including "losing contact and sharing

with the family" and "rejection, desertion, loneliness, and anger" (Baker & Blacher, 2002, p. 7).

In some cases residents of institutions were subjected to horrific conditions.[6] For example, in 1978 the Citizens for Human Rights responded to reports regarding poor conditions in Porirua Hospital, a New Zealand psychiatric hospital. "The first reports received seemed too abhorrent to be credible. However reports continued to be received from ex-patients and relatives. They told of similar incidents…and described the same conditions" (Citizens' Commission on Human Rights Research Department, 1978, p. 1). The report went on to detail numerous instances of abuse, misuse of electroconvulsive therapy, over-medication and gross neglect. They considered that "it has become abundantly clear that psychiatric patients are the most neglected group of individuals in New Zealand today" (p. 2). In recent years legal action has been taken against a number of different institutions due to allegations of sexual abuse, physical abuse, emotional abuse and neglect. Some cases have been settled in favour of the claimants. Other cases, including one against Porirua hospital, are still under negotiation.

The era of institutional support is coming to a close around the globe (e.g., Department of Health (United Kingdom), 2001; U.S. Department of Health and Human Services, 2000). In this decade New Zealand government policy clearly favours community inclusion and person-centred support. So what do the lives of adults with an intellectual disability look like now? Research by the National Health Committee (2003b) "found that adults with an intellectual disability have difficulty accessing rights of citizenship. Their lives are very different from other New Zealanders and not consistent with the NZDS [New Zealand Disability Strategy]" (p. 6). The National Health Committee went on to state, "The committee believes this is the first piece of work in its 10 years' existence that deals with a group of the population whose rights of citizenship are not being taken seriously (p. 6). The National Health Committee considered that there was "systemic neglect" of their health and developmental needs (p. 8, 26). According to Bonardi (2009) although efforts have been made since then to improve services, "poorly

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[6] Although this section is focused on the conditions in some New Zealand institutions, some institutions in other countries also had appalling conditions (e.g., Blatt & Kaplan, 1974).

integrated services, a lack of attention to …health issues… and inflexibility in the service system continue to figure prominently in the discourse regarding publicly funded services" (p. 1).

Although the National Health Committee (2003b, 2004) and Bonardi (2009) noted a number of problems, they also encountered situations that were going well and acknowledged movement towards community inclusion and person-centred support. Bonardi described three government-funded options which provide more flexibility than traditional settings — Individualised Funding, Supported Independent Living and Home and Community Support Services.

Individualised Funding provides funding to individuals to hire and manage their own workers. It began as a pilot programme in Christchurch in 1998 (Ministry of Health, 2003) and in 2009, it became available nationwide as a permanent option for people with a disability (S. Macaulay, personal communication, November 10, 2009). If an individual with a disability does not have the necessary skills to manage the funding on their own, a family member or friend can act as their agent and manage the funds on their behalf. In other countries similar funding schemes allow these agents to be paid; however in New Zealand, they act strictly on a volunteer basis. In January 2009, there were 238 people utilising Individualised Funding (Bonardi, 2009, p. 22).

Supported Independent Living provides funding to agencies that then provide support to individuals in their own homes. According to Bonardi (2009) "there are only a limited number of provider agencies in New Zealand who provide supports to people with intellectual disability through this model" (p. 23). Some providers have expressed interest in moving towards this model, but encountered difficulties in changing their existing government contracts.

Home and Community Support Services is new programme which funds a set number of hours for "core" personal support services and for "flexible" support services such as accessing community activities. These new specifications were introduced in 2007 (Marshall & Leighton, 2008). The programme was "rolled out in 2008" and because this

is a relatively new program, little information is available regarding the number of people receiving this service and their outcomes (Bonardi, 2009, p. 23). With the establishment of Individualised Funding as a permanent option, many people who currently receive Home and Community Support will now be eligible for Individualised Funding (S. Macaulay, personal communication, November 10, 2009).

2.2.5. Implications: A need for counsellors to be informed about intellectual disabilities

The above three models of service provision demonstrate significant movement towards the Disability Strategy's aim of community inclusion and person-centred support. As community inclusion becomes more of a reality, people with an intellectual disability will have the opportunity to access a range of community activities and services which historically have been difficult for them to access. This includes increased opportunities to access mainstream counselling services. Unfortunately, as Hornby (1994) and Olkin (2002) have noted, the topic of disabilities is often not covered in generic counsellor education programmes. Razza (2008) and VanderSchie-Bezyak (2003) discussed this lack of professional training in the topic of intellectual disabilities and the difficulties this lack of knowledge can pose for clients. They highlighted the need for changes in curricula.[7] In addition to making changes in curricula, there is a need for practising counsellors to be better informed. Making changes to curricula and the provision of opportunities for up skilling would likely benefit counsellors who, like me, may find themselves working in a community counselling service and providing counselling for someone with an intellectual disability. Contemplating how to better inform counsellors gives rise to a number of basic questions. What is meant by the term counselling? What is already known about counselling for people with an intellectual disability? What information is lacking? Who can best provide that information?

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[7] Counsellors often work alongside other professionals such as clergy, psychiatrists and social workers. In these related fields, there is also a scarcity of research and specialised education about intellectual disability (e.g., Anderson, 2005; Bell & Williamson, 2003; Chaplin, 2003).

2.3. What is counselling?

Just as a client group is made up of unique individuals, so, too, the counselling profession is made up of a heterogeneous group of individual counsellors. These counsellors "maintain diverse approaches to their work, but also promote an image of being part of a unified occupational group" (J. Miller, 2001, p. 19). They are unified in this field of practice by their desire to facilitate positive outcomes for clients.

2.3.1. Definition

For the purposes of this thesis the term "counselling" will be used to refer to work which is:

> primarily an interpersonal treatment that is based on psychological principles and involves a trained therapist and a client who has a mental disorder, problem, or complaint; it is intended by the therapist to be remedial for the client's disorder, problem, or complaint; and it is adapted or individualized for the particular client and his or her disorder, problem or complaint. (Wampold, 2001, p. 3)

The word "interpersonal" implies that counselling involves a relationship between a counsellor and a client. The word "trained" indicates that counselling is a professional activity. The word "remedial" captures the notion that counselling involves a transformative process.

2.3.2. Terminology

This field of practice is referred to using a range of terms including counselling, counselling psychology, therapy, psychotherapy, psychological interventions, and psycho-social interventions. Authors choose to differentiate between these terms on the basis of the problems addressed (e.g., Manthei, Stanley, & Gibson, 2004) and on the approaches used to address the problems (e.g., Kazdin, 1986; Roth & Fonagy, 2005). While such differentiations are useful for practitioners, they are not central to the purposes of this thesis. For this reason I have chosen to use a single term and apply it to a range of approaches that seek to remediate a range of problems.

2.3.3. Ways of conceptualising counselling

As Wampold (2001) has so aptly stated, "understanding psychotherapy is a daunting task" (p. 1). In his book, *The great psychotherapy debate: Models, methods and findings,* Wampold (2001) has contrasted two "meta-theories" or lenses through which counselling is viewed — the medical model and the contextual model. As conceptualised by Wampold, the medical model includes the following five components: (a) the client problem, (b) a psychological explanation for the client's problem, (c) a mechanism of change, (d) specific therapeutic ingredients, and (e) specificity (pp. 13-14). Here, "the specific ingredients are assumed to be responsible for client change or progress to therapeutic goals" (p. 14). Striving to understand counselling by means of the medical model, one focuses on how the counsellor "cures" (p. ix) and offers practice implications which tend toward specific interventions or treatment manuals. The contextual model, on the other hand, examines components that are common to all therapies: "(a) an emotionally charged confiding relationship with a helping person; (b) a healing setting that involves the client's expectations that the professional helper will assist him or her; (c) a rationale, conceptual scheme or myth that provides a plausible… explanation of the…symptoms; and (d) a…procedure that requires the…participation of both client and therapist and is based on the rationale underlying the therapy" (p. 206). Striving to understand counselling using this model, one tends to focus on how the client "heals" (p. ix) and offers practice implications which can be generalised across approaches.

Additional insight on counselling practice can be gained by expanding the focus of the contextual lens to include not only the counsellor, the client and the counselling process, but also the environment in which the counselling takes place. Saltmarsh (2009) considered that professional practice "is never … separable from the … contexts within which it is conducted" (p. 157). By acknowledging the difficulty in separating professional practice from its context, one also acknowledges the "tensions, contradictions and possibilities" (p. 161) that exist in that field of practice.

2.3.4. From concept to practice: Assessing the outcomes of clients with an intellectual disability

According to Wampold, "the medical model holds the superordinate position in academia, particularly in the research environment" (p. 28). Indeed, much counselling research is based on the counsellor's viewpoint (Gordon, 2000) and, as seen in the extensive review by Roth and Fonagy (2005), tends toward specificity, that is, specific interventions for specific problems. Although often held as the standard, there is acknowledgement in general counselling literature that viewing counselling solely in light of the medical model, does not account for all that takes place in counselling (e.g., Hubble, Duncan, & Miller, 1999; Lambert & Ogles, 2004). General counselling research has a body of literature which has sought to understand counselling using the contextual model. Studies have explicitly explored the healing process of clients (e.g., Duncan, Miller, & Sparks, 2004; Hubble, et al., 1999) as well as the clients' subjective experiences (e.g., Rennie, 1994b; Ward, 2005). However, in the small body of literature[8] pertaining to clients with an intellectual disability, it is rare for counselling to be explored in this manner.

For example, when writing about the need for further research involving clients with an intellectual disability, Prout, Nowak-Drabik and Johnson (2000) recommended that future researchers strive to adhere to "contemporary standards" (para. 19). "Key points across these standards include: …thoroughly describing disorders…assessing for comorbid diagnoses…utilizing a structured treatment manual that can be easily followed…" (para. 10). This particular set of standards has the client's problem and what the counsellor does to address the problem as its focus, thus, it is indicative of viewing counselling through the medical model lens.

Willner (2005) in his review of the existing literature stated, "Sadly, in the field of learning disability, RCTs [Randomised Controlled Trials] of psychological treatments

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[8] In their review which covered literature from 1968-1998, Prout and Nowak-Drabik (2003) found an initial pool of 103 studies which were specifically about counselling for clients with an intellectual disability. This is, indeed, small when compared to the "thousands" of articles Wampold (2001) examined (p. xiii).

are extremely sparse. … Therefore, the present discussion must rely largely on inferior sources of evidence. However, even within the existing evidence base of suboptimal research designs, the literature is astonishingly small" (p. 74). Again the medical model is held as the standard.

A recurring theme in this body of literature seems to be a desire to either prove or disprove the effectiveness of counselling for this client group.

> Within the general psychotherapy literature, the process–outcome research agenda relates to the relative importance of different components of talking therapies. However, research in learning disabilities is still in the throes of emerging from a state of widespread scepticism about the feasibility of using talking therapies at all. (Willner, 2005, p. 81)

An example of this debate can be seen in the journal *Mental Retardation* in 2005 and 2006. Sturmey (2005) published an article entitled, "Against psychotherapy for people with mental retardation." This article generated several responses in favour of counselling (Beail, 2005; Hurley, 2005; King, 2005; Taylor, 2005). In 2006 Sturmey wrote his response to the responses. Although their discussion covered a number of different angles, "the evidence" desired by all parties was congruent with the medical model.

2.3.5. Implications: A need to consider contextual factors

Viewing counselling solely through the medical model lens is problematic. Not giving due consideration to contextual factors significantly restricts the profession's ability to assess the effectiveness of counselling for this client group. Some factors enhance the likelihood of positive outcomes and other factors interrupt the counselling process. Some factors, such as specific techniques, relate to "how the counsellor cures." Other factors, such as a client's personal assets, relate to "how the client heals" and still other factors, such as social stigma, relate to the practice environment. To accurately assess the effectiveness of counselling for clients with an intellectual disability, it is necessary to consider not only the wide range of factors that influence client outcomes, but also the complexities involved in assessing outcomes. Section 2.4 explores the many factors

that influence outcomes.[9] Section 2.5 discusses the complexities involved in assessing outcomes.

2.4. Factors that influence counselling outcomes

For organisational simplicity, these factors have been divided into three sections: client factors, counselling factors and environmental factors. However, as with many theoretical divisions, I acknowledge that the line of demarcation between these factors is at best blurry.

2.4.1. Client Factors

Although people with an intellectual disability are typically identified by shared common impairments, they also share common personal assets such as strengths in concrete thinking, including a "sophisticated manipulation of visible and tangible reality" (Levitas & Gilson, 2000, p. 49), and a tendency to follow an idea rigorously to its conclusion (Wolfensberger, 1988, p. 67). Recognition and utilisation of a client's personal resources is a key factor in promoting change. Tallman and Bohart (1999) have suggested "that it is the mobilization of client resources which is therapeutic and not the application of a technique to a problem" (p. 119).

Unfortunately, the recognition of a client's low cognitive ability often takes precedence over the recognition and utilisation of that same client's personal resources. Low cognitive ability has frequently been cited as a factor which reduces one's ability to benefit from counselling (Benson, 2004, p. 353) and such clients "are rarely offered the full range of psychotherapeutic options" (Mohr, 2007, p. 13). However, "over the past decade this assumption has been increasingly challenged" (Willner & Hatton, 2006, p. 1) both explicitly and implicitly. Literature specific to clients with an intellectual disability challenges this assumption explicitly by exploration of adaptations to specific techniques, by identifying the specific skills used in those techniques and by accurately assessing the necessary skill level needed to benefit from cognitive therapy (Joyce,

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[9] Portions of section 2.4 have been published in the *British Journal of Guidance and Counselling* (Raffensperger, 2009). The article can be found in Appendix I.

Globe, & Moody, 2006; Oathamshaw & Haddock, 2006; Willner, 2006). This notion is implicitly challenged in general counselling literature by the assertion that it is a focus on client's resources, not their deficits, which promotes positive change (Tallman & Bohart, 1999).

Although there are many client factors which are likely to influence the outcomes of this client group, low cognitive ability still remains a key focus in outcome research. Very few other factors have been explored. Rose, Loftus, Flint and Carey (2005) explored five variables and their influence on outcomes for clients with an intellectual disability. Three of the variables considered were client factors: (a) the participants' receptive vocabulary, (b) age and (c) gender. The study included 50 participants and 36 people from a waitlist control. After an initial assessment, the participants attended a 16-week group session focused on anger management, and were assessed three to six months later. The findings suggested that group interventions for anger management for people with intellectual disabilities are effective (pp. 313-315). The findings also suggested that a higher receptive vocabulary improved outcomes. These findings supported findings by Willner, J. Jones, Tams and Green (2002) who conducted a study on the efficacy of anger management for people with intellectual disabilities. This study did not have a special focus on variables that influenced client outcome; however, the researchers noted that improvement during treatment appeared to be strongly correlated to verbal IQ (p. 232).

The existing research on the influence of client factors is limited and narrow in focus. The narrow focus on low cognitive ability and the accompanying lack of exploration of other factors perpetuates, perhaps unintentionally, the notion that one's disabilities take precedence over one's abilities and resources. This narrow focus is an invitation to explore the broad range of client factors that have been well recognised in general counselling literature (e.g., Clarkin & Levy, 2004, pp. 194-226); client factors such as age, gender, ethnicity, socio-economic status, and personal assets affect counselling process and outcomes. In particular, this gap invites exploration of the personal assets and resources of a client group whose abilities and strengths often go unnoticed. For example, Paredes (2008) has invited further exploration on the sense of humour of

people with intellectual disabilities and the role that it can play in improving well-being and quality of life.

The need for a wider research focus is supported by Rose et al. (2005) who stated that "there is a considerable amount of variance unexplained." They suggested that "a larger number of variables need to be taken into account," i.e. "more comprehensive measures of individual characteristics," numerous "staff characteristics," and other environmental factors (p. 315).

2.4.2. Counselling factors

Common factors

Inside the counselling room, both the client and counsellor contribute to the quality of the working alliance. Client attributes, such as active participation and attachment style, influence the quality of the working alliance (Bachelor & Horvath, 1999). Counsellor attributes such as interpersonal skills, communication skills, experience, and attitudes influence the quality of the working alliance (Horvath & Bedi, 2002) and the quality of the alliance influences client outcomes (Bachelor & Horvath, 1999; Horvath & Bedi, 2002). Schoen (1995) has suggested that these factors are important to consider for clients with an intellectual disability.

When researching outcomes for clients with an intellectual disability, several therapist attributes could be examined, e.g., personal qualities, training, experience, and attitudes. Personal qualities such as warmth, empathy, genuineness and unconditional positive regard are considered essential when working with this client group (Schoen, 1995). Counsellors' training and experience have an influence on counsellors' perceptions of their ability to work effectively with this client group (Raffensperger & Miller, 2005). Counsellors' 'perceived competence' appears to influence the provision of services to clients with an intellectual disability (Mason, 2007, p. 246). Counsellors' perceptions of themselves as well as their attitudes toward their clients have an influence on potential outcomes, at times preventing engagement in the counselling process. Such attitudes include 'therapeutic disdain', the reluctance of therapists to engage with clients with an

intellectual disability, and 'diagnostic overshadowing,' the tendency to attribute negative symptomology to an intellectual disability (e.g., Kroese, 1998, pp. 315-316; Mason & Scior, 2004, pp. 85-90; Williams & Heslop, 2005, p. 237).

Although general counselling literature includes numerous studies which have explored the influence of these common factors on client outcome in the general population, only a few studies have explicitly explored the influence of common factors on the outcomes of clients with an intellectual disability (Rose, et al., 2005; Strauser, Lustig, & Donnell, 2004; Williams & Heslop, 2005). Interestingly the findings from these few studies have mirrored the findings from numerous studies involving the general population. That is, the quality of the working alliance and the presence of outside support impact counselling outcomes (Bachelor & Horvath, 1999, pp. 137-139; Beutler, et al., 2004, p. 292; Clarkin & Levy, 2004, p. 213).

Rose et al. (2005) explored two therapeutic variables, the experience of the therapist and the presence of a support person for the client during the group sessions. They found that the presence of a support person during the sessions contributed positively to the outcomes (p. 315). Similarly Willner et al. (2002) found that "the clients who did best overall were accompanied to the group by carers" (p. 234).

The working alliance

Strauser et al. (2004) confirmed the importance of the therapeutic relationship. When describing the background to their study, they stated that "no research has addressed the impact of the working alliance on the counselling relationship with individuals with mild mental retardation" (p. 217). In this study, former clients of a vocational rehabilitation service were invited to respond to a telephone questionnaire designed to explore the relationship between the working alliance and outcomes. Although this study had a low participation rate, the results supported the importance of the working alliance on client outcomes.

An example of how one might cultivate a strong working alliance can be found in an article by Brooks and Davies (2008). They are currently involved in a participatory

research project with people with an intellectual disability, which, among other goals, "is trying to see if counselling and therapy helps people with a learning disability feel better" (p. 128). They discussed some of the steps they took to establish a working alliance with their co-researchers. Building this alliance took time, patience, and an awareness of "roles, boundaries and power differentials" (p. 130). "Ownership grew with time" (p. 130) and as one of their co-researchers, a person with an intellectual disability, said, "You've got to be more patient with people with learning disabilities, it takes time to learn" (p. 131).

Specific techniques

In addition to providing ample time, patience, and relational sensitivity, counsellors can enhance the likelihood of positive outcomes by utilising techniques specific to their clients' needs.

As is typical in counselling, clients with an intellectual disability present with a variety of issues and counsellors work using a variety of theoretical models. There are examples in the literature of presenting problems such as couple counselling (Larkin, 1992), challenging behaviour (Berry, 2003; Bissell, Phillips, & Kroese, 2005), depression (Jahoda, Dagnan, Jarvie, & Kerr, 2006; Lunsky & Palucka, 2004), anxiety (Dagnan & Jahoda, 2006), anger/aggressive behaviour (Rose, Dodd, & Rose, 2008), self-harm (V. Jones, Davies, & Jenkins, 2004), grief (Stoddart, Burke, & Temple, 2002; Summers, 2003), psychosis (Haddock, Lobban, Hatton, & Carson, 2004), adjustment disorders (Levitas & Gilson, 2001; Levitas & Hurley, 2005), offending behaviour (Lindsay & Taylor, 2005), nightmares (Kroese & Thomas, 2006; Willner, 2004), and trauma/sexual abuse (Cederborg & Lamb, 2008; Hollins & Sinason, 2000; Mansell, 2002; Mansell & Sobsey, 2001). Practitioners may also be called upon to work with families whose children have intellectual disabilities (Hornby, 1994; Lindenbaum, 2000) and in some families both the children and the parents have disabilities (Taube-Schiff & Serbin, 2006).

Although counsellors use various theoretical models, the majority of published articles have described the use of behavioural interventions, cognitive-behaviour therapy or

psychodynamic psychotherapy. A few articles have described the use of other models, e.g., person-centred counselling with children (Flitton & Buckroyd, 2002), person-centred play therapy with adults (Demanchick, Cochran, & Cochran, 2003), narrative therapy (Foster & Banes, 2009; Matthews & Matthews, 2005), rational emotive therapy (Schneider, 2001), group therapy (Tomasulo, Keller, & Pfadt, 2004), family therapy (Haddock, et al., 2004), brief therapy (Anger & Hawkins, 2000), and solution focused therapy (Stoddart, McDonnell, Temple, & Mustata, 2001).

The focus of this section is the wide range of factors that influence client outcomes. Therefore, it is beyond the scope of this thesis to review the many articles which describe specific counselling approaches. However, this type of article represents an important segment of the small body of literature which explores counselling for clients with an intellectual disability. Therefore a brief review of four articles describing different counselling approaches can be found in Appendix A.

General adaptations

Practitioners using a variety of models may find it useful to adapt their current techniques when working with this client group. Whitehouse, Tudway, Look, and Kroese (2006), Mansell (2002), and Gallagher (2002) offer some useful general accommodations/adaptations that have been used by practitioners. "In working with those with learning difficulties we will *usually* need to slow down, both in our communication and in the speed with which therapy proceeds" (Gallagher, 2002, p. 207). It is helpful to use concrete, plain language and provide ample time for the client to respond in conversation. The counselling style may end up being more directive, i.e., structured, including more prompts, suggestions, and activities. Counsellors may need to allow more flexibility with session length and location. Involving the client's support network may also be helpful.

Interestingly these adaptations are remarkably similar to suggestions made by direct care staff in a 2004 New Zealand study.[10] The following quotes were provided by

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[10] For a description of this study and previously published data, see Raffensperger and Miller (2005).

support workers in response to the question, "What specific issues should a counsellor consider when working with an adult with an intellectual disability?"

> Have a good understanding of the persons support network. Being flexible in the meeting place to ensure person is relaxed.

> Councillors [sic] need to be familiar with the effects of institutional living on people.

> The level and kind of support available to that person for on-going progress.

> Gain some background information on the specific problem from families, caregivers, etc. Have an interest in intellectual disability.

> Supports client receives. Possible repercussions following session

> Using visual cues and physical way of representing situation

> Think in pictures rather than use words. Use more body language.

> Regular liason [sic] with clinical team. Being creative in developing practical strategies.[11]

Counsellors are encouraged to remember that "all people (especially children, the elderly, the less educated, non-English speakers, and those with mental illness or disabilities) understand more than they are able to communicate or demonstrate" (Gallagher, 2002, p. 209).

2.4.3. Environmental factors

Outside the counselling room there are many factors that can impact on a client's outcome. Issues of power and self-determination are likely to affect a client's ability to actively engage in the counselling process (Kroese, 1998, p. 316). Social support is often limited (National Health Committee, 2004, pp. 117-128), possibly because of the social stigma attached to having an intellectual disability (Jahoda & Markova, 2004). People with an intellectual disability are vulnerable to abuse and exploitation and are victimised at a higher rate than the general population (Morano, 2001). "Having a disability can pose as a major problem for achieving redress after abuse" (Lewin, 2007,

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[11] These previously unpublished quotes were taken from data gathered in the 2004 New Zealand study which is detailed in Raffensperger and Miller (2005).

p. 170). They often have physical or sensory impairments and often live with unaddressed health needs (National Health Committee, 2004, pp. 53-66). They often have limited income (Mirfin-Veitch, 2003) and difficulties with transportation. "Accessible and affordable transport has been highlighted as a key service gap for people with disabilities in New Zealand" (National Health Committee, 2003a, p. 7). Speaking of clients with an intellectual disability, the Royal College of Psychiatrists (2004) stated that "without support for travel, psychotherapy may be ruled out or fail, regardless of their ability to make use of it" (p. 40).

Cottis and O'Driscoll (2009) recognised that "the therapist works hard to provide a high quality therapy experience and the therapy service itself exists as part of a wider environment" (p. 177). They wrote up two case studies which explicitly explored the intersection of their work with the clients and the wider context in which the counselling took place. However, the focus of this article was not directed towards exploring how the wider environment impacted the clients' outcome. Its focus was on informing counsellors about how to work effectively with those who were providing support to the client.

Although researchers acknowledge the impacts of this social context on the well-being of this client group (e.g., Dagnan & Jahoda, 2006; Dagnan & Waring, 2004) and appear to be "moving beyond individualistic cognitive models of mental health problems to the development of integrative models of mental health problems incorporating issues such as stigma, self-determination and socio-economic status" (Willner & Hatton, 2006, p. 2), outcome research which considers the influences of environmental factors is extremely limited. Considering the numerous environmental factors which could influence counselling outcomes, I was disturbed at the difficulty of finding articles which explicitly explored the influences of environmental factors on counselling outcomes for clients with an intellectual disability.

Although such counselling articles were noticeably absent, numerous related studies have explored the influences of life events, living conditions and social support on the well-being of those with intellectual disabilities (Hastings, Hatton, Taylor, & Maddison,

2004; Heller, Miller, & Hsieh, 2002; Lunsky & Benson, 2001; Lunsky & Havercamp, 1999; Williams & Heslop, 2005).

Hastings et al. (2004) gathered information regarding recent life events and psychiatric symptoms from 1131 adults with intellectual disabilities. They found that "exposure to one or more [stressful] life event in the previous 12 months was associated with an increased risk for affective disorder" (p. 44).

Heller et al. (2002) examined the impact of various environmental factors on the well-being of adults with intellectual disabilities. Findings from this eight year study suggested that environmental factors such as opportunities to make choices, the physical attractiveness of the residence, and involvement with family "influenced the long-term well-being of adults with mental retardation" (p. 372). Williams and Heslop (2005) explored the mental health support needs of young people with intellectual disabilities. In this study, the young people considered friendship to be an important mediator of stress and a source of support. At the same time, they "expressed a degree of tension in the establishment of friendships: several people had been bullied…" (p. 239). Similar themes were discussed by Lunsky and Havercamp (1999) and Lunsky and Benson (2001). Findings from their studies suggested that the relationship between social support and well-being for those with intellectual disabilities is similar to the general population; that is, the quality of social support has significant influence on well-being.

The importance of attending to environmental factors was described by Kroese and Thomas (2006) and Willner (2004) in their case studies of clients who were having recurring nightmares. Kroese and Thomas (2006) pointed out that their intervention "stresses having control over one's safety, it is essential that the client's home life is stable and without danger" (p. 79). Similarly, Willner (2004) commented on the positive influences of caring staff in his client's living place. Willner also noted the influence of a good working alliance; the intervention "was built on a foundation of pre-existing good relationships with the therapist and supporting care staff" (p. 462). Given the high turnover of staff in the disability sector (e.g., Test, Flowers, Hewitt, & Solow, 2003), the frequency of relationship disruptions (e.g., Runnion & Wolfer, 2004) and the high

incidence of crime and abuse experienced by people with an intellectual disability (e.g., Horner-Johnson & Drum, 2006; Wisconsin Coalition Against Sexual Assault, 2003), it is imperative that more attention be given to the influences of a client's home life on counselling outcomes, particularly in regards to relationship stability and personal safety.

A heightened awareness of the environmental factors that can interfere with the counselling process and a willingness to creatively work around these barriers is a necessity for practitioners working with this client group. In the first instance, accessing counselling services is not easy for this client group (Raffensperger & Miller, 2005). Such barriers may be as simple as finding one's way to the counselling office. Remaining actively engaged in the counselling process is likely to be difficult if a client has limited social support, transportation difficulties, limited finances or unaddressed health needs. If a client is having difficulty making forward progress in counselling, it may be that factors outside the counselling room have interrupted the counselling process. A counsellor's awareness of relevant environmental factors and subsequent creative responses can enhance the forward progress of their clients.

Achieving positive outcomes is at the crux of the debate regarding the effectiveness of counselling for clients with an intellectual disability. To enhance the likelihood of achieving positive outcomes, it is necessary to consider the numerous factors that influence the outcomes of clients with an intellectual disability. Although there has been little research exploring these factors, their influence on client outcomes has long been recognised. The following quote from Ayers and Duguay (1969) succinctly wraps up this section:

> The emotional problems, the level of intellectual functioning, personality characteristics (motivation, self-concept and temperament), communication factors, learning ability, parental influences, and environmental factors are critical variables that necessitate consideration in counseling the mentally retarded. Regardless of the particular theoretical counseling technique or mode of therapy employed, all of these variables directly and indirectly influence the overall adjustment of the retarded. Hence, it is imperative that counsellors become aware of them. (p. 50)

2.5. The complexity of assessing counselling outcomes

Numerous methodological issues arise in the assessment of counselling outcomes. In general counselling literature there is debate concerning: (a) what to assess, (b) how to assess it and (c) from whose perspective it should be assessed. It is well recognised that assessing counselling outcomes is complex.

> It is unfortunate but true that no single measure of the outcome of therapeutic intervention is either reliable or comprehensive enough to serve as the sole indicator of clients' gains (or setbacks). Rather, a variety of methods, measures, data sources, and sampling domains (e.g., symptomatic distress, functional impairment, quality of life) is necessary to fully assess therapy outcomes. (Kendall, Holmbeck, & Verduin, 2004, p. 27)

As the previous quote indicates to gain a comprehensive understanding of counselling outcomes, it is necessary to utilise a variety of measures across a variety of domains. Wampold, Lichtenberg and Weahler (2002) have suggested that "multiple perspectives should be employed including clients, program provider (e.g., therapist, program instructor) and third-party payers or MCOs [Managed Care Organizations]" (p. 209). The matter of perspective has an impact on what one chooses to measure and how it is measured. In the body of literature which explores outcomes for clients with an intellectual disability a range of domains have been measured, a range of measures have been used, and a range of perspectives have been sought. However, the feedback from clients has only been sought in a limited way.

Studies which assess the outcomes for clients with an intellectual disability often seek feedback from multiple perspectives. For example, the majority of the studies in the review done by Prout and Nowak-Drabik (2003) relied on "observable behavior" as an outcome measure (p. 84). Observable behaviour continues to be used as an outcome measure, as in the study by Parkes et al. (2007). They used anonymised case notes from a "multidisciplinary team of healthcare professionals" (p. 374) and assessed outcomes based on "increased daily living skills, improved confidence, self-esteem and behaviour, and finding employment" (p. 373). This study, like many which rely on observable behaviour, used multiple perspectives, but the clients' perspective was noticeably absent.

In general counselling research, the client's perspective is recognised as important; however research exploring the client's perspective is comparatively sparse in comparison to research from the counsellor's viewpoint (Gordon, 2000; Manthei, 2005). McLeod (2001a) drew a distinction between two types of studies which explore the client's perspective. One way of exploring the client's perspective is to use self report measures which allow "clients only to respond in accordance with sets of researcher-defined categories, typically incorporated into a rating scale or questionnaire" (p. 201). Another means of exploration is to allow the clients to talk about their understandings of counselling in their own words, that is, by exploring the client's subjective experiences.

With regard to outcome assessments which have sought the perspectives of clients with an intellectual disability, this has been done primarily by using questionnaires and scales. Sometimes the questionnaires are developed by the investigator (e.g., Strauser, et al., 2004). Other times researchers rely on standardised outcome measures (e.g., Foster & Banes, 2009). Some researchers are careful to state whether or not these standardised measures have "good reliability" with people with an intellectual disability (e.g., Beail, Warden, Morsley, & Newman, 2005). It is important to note, however, that clients' feedback was limited to aspects which the designer of the measure had deemed to be important. People with an intellectual disability had no opportunity to contribute to the development of those measures. Therefore, it is possible that important aspects of their outcomes were not inquired about.

Brookes and Davies (2008) have identified that gap and are currently working with people with an intellectual disability to create an outcome measure that takes their perspective into account. In this participatory research project counsellors and researchers are working together to adapt an existing outcome measure called Clinical Outcomes in Routine Evaluation– Outcome Measure [CORE OM] which measures four domains: well-being, problems/symptoms, functioning and risk (p. 128). They have identified "a missing domain… the heart of which is living with a learning disability and how this impacts on feelings" (p. 131).

In addition to using and improving the existing methods of outcome assessment, the profession's assessment of outcomes could be enhanced by considering the client's subjective experience. Research on the client's subjective experiences reminds practitioners "of what it is like to be in the other seat" and exploration of what clients think is helpful and not helpful provides "a reasonable starting point for a model of what is involved in effective therapy" (McLeod, 2001a, p. 201). McLeod (2001b) and Manthei (2005) have highlighted the need for qualitative research which explores the subjective experiences of clients; such research has the potential to yield "extremely valuable insights" for counsellors (Manthei, 2005, p. 551).

Counsellors, such as myself, who work with clients with an intellectual disability would likely benefit from such "valuable insights" gleaned from clients' experiences. However, there is very little research exploring the subjective experiences of clients with an intellectual disability. With the exception of this thesis, to my knowledge, no such studies have been done in New Zealand and very few have been done worldwide. The lack of the client's perspective in an already small body of literature serves to emphasise the pressing need for more research.

2.6. The perspectives of clients with an intellectual disability

I began my search for first hand client accounts when I was seeking to up-skill as a practitioner. As I was reading about different counselling approaches, I happened up the following quote. Here is what Michael, a 32 year old with an intellectual disability, said about his counselling experience.

> It helps you find better ways to act…helps you to know about other people and why they act funny…Someone you can tell things to and they won't always be on judging you - and they won't blab it around. (Prout & Strohmer, 1994, pp. 16-17)

Finding that quote embedded in a book suggested to me that other firsthand accounts were likely to exist, but were not readily accessible to busy practitioners. As my subsequent hunt demonstrated, published accounts that detail the client's subjective experiences of counselling are rare. For this reason, this section makes reference to both research based and non-research based publications.

Madeline Hombert (2006) edited a book which describes 15 stories of people who "have both ID [intellectual disability] and a serious mental illness" (p. 11). Each person is introduced briefly by the psychiatrist and then their story is told by themselves and/or a family member. These stories are not focused on counselling per se, but rather on their experiences of having an intellectual disability and a mental illness. I have chosen to share excerpts from two of these stories. The first story makes specific references to counselling and the other story provides an example of creative self expression.

Robbie wrote a long candid story about his life. In his story he made some specific references to counselling. He first mentioned counselling in relation to feeling "an experience of craving in [his] throat and chest" (p. 149) that occurred some years after having given up crack and LSD. He also talked about having counselling twice in relation to his sexual identity. "A huge part of my deteriorating health was due to being lonely for a sweetheart. … I was struggling with my sexual identity. Counselling didn't really answer it for me, but it gave me the chance to explore my thoughts and talk openly" (pp. 152, 153).

Another person in the book named Riia described her OCD both in words and in paintings. Riia described herself as follows:

> I am twenty years old and I have Obsessive Compulsive Disorder. Looking back I realize this problem has been with me all my life, although it was not diagnosed until I was fifteen years old. At that point I began to realise that the time consuming routines I did, the lists I made and the repetitious thoughts I had were largely a result of this disorder. … There are good days and bad days, but I find that as I learn to gain control of my situation, the good days are starting to win out. (p. 79)

Figure 1 shows one of her eight paintings.
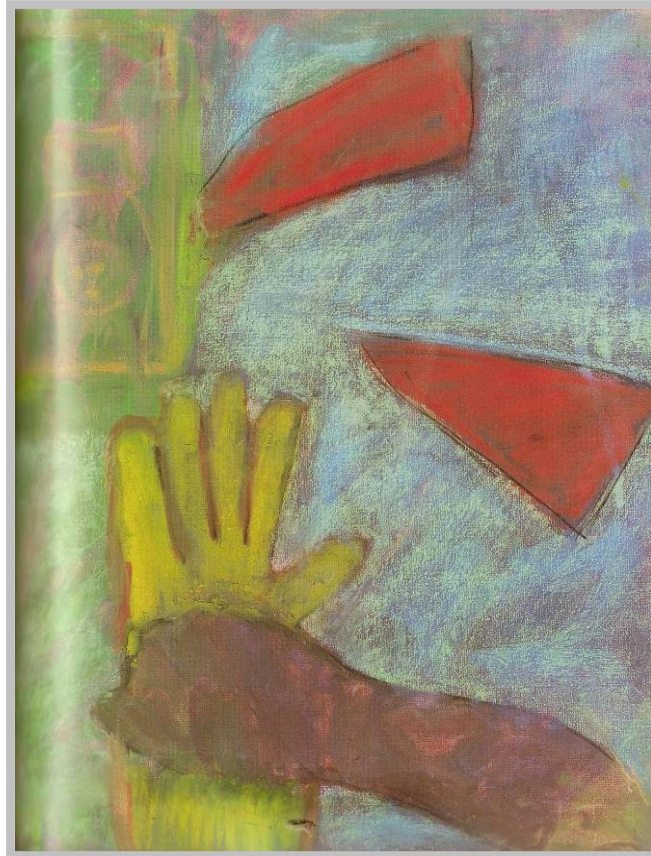
Figure 1: "Stopping the lime coloured hand"[12]

"The lime coloured hand represents … reaching up to turn off the light switch. The purple represents the need to keep it on" (p. 90).

Self reflection and personal insight are often considered to be an integral part of the counselling process. And people with an intellectual disability are often assumed to lack the necessary personal insight to benefit from talking therapies. Robbie's and Riia's vivid self reflections challenge this belief as do the remainder of the firsthand accounts in this section.

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[12] From *Success stories from the frontline: Intellectual disabilities and mental health (*p. 91) edited by Madeline Hombert, Port Coquilam, British Columbia, Canada. Friedlander/Donnelly. Copyright 2006 by Robin Friedlander, Tina Donnelly, Madeline Hombert. Reprinted with permission. For letter of permission see Appendix 2.

June Patterson described herself as an outgoing person with a learning disability. She has been abused twice and had received counselling. She told her story to Gill Levy and her story was published in magazine called Community Living (Patterson & Levy, 2007). June said, "If I hadn't had counselling, I'd be a different person now. I'd probably be sitting in my little corner, bored, isolated and chain smoking. I'd feel suicidal" (p. 24). June talked about the process she went through in reporting her abuse. June talked about her need for support during that process "The police were really terrible when I reported the abuse" (p. 24). She was upset when the police refused to allow her support person to be present during her interviews. Neither of her abuse cases ended up being taken to court.

During this process she also became upset because "the social worker and the district nurse had a big meeting without [her]" (p. 25). She got angry when she learned that the social worker had talked to her psychiatrist about what she had thought was confidential information. Once they explained the limits of their confidentiality, she felt better about that, but she wished they had explained that to her in the first place. June spoke positively about the way her counsellor handled issues of confidentiality

> I just couldn't believe how great therapy was when I finally got it. I trusted this therapist because it's my session but she has to write reports for social services. She shows me her reports. … The therapist and I have an agreement about what can be shared with the social workers. (p. 25)

June considered counselling to be very helpful. Through counselling she learned "to be stronger, to challenge people and to say no" (p. 24).

Karen McGuirl, another woman with an intellectual disability shared publicly about her experiences of counselling. In 2000, Karen McGuirl and her counsellor, Aine O'Reilly, gave a joint presentation at a conference for counsellors (McGuirl & O'Reilly, 2000). The project was described as an exploratory case study and was situated in a constructivist framework. The first portion of this paper dealt with the ethical issues raised by involving people with an intellectual disability in research and by involving a client in research in a public setting. A number of ethical dilemmas arose and were discussed over a one year period between Aine, Karen and Karen's support network. For example, one issue was confidentiality and anonymity. If Karen was identified as an

author, the data would no longer be confidential. However, if she were not identified, she would lose the opportunity to speak out for herself. For Karen, it was important to be able to speak up, to be listened to and to know that what she has to say can make a difference.

> **Aine:** Why are you doing this paper?

> **Karen:** I feel it needs to be talked about – out there. Because people might think that it did not matter because we were disabled – and there are thousands of us.

Karen described a wall that exists between those with an intellectual disability and those without. For example, when Karen was a young adult her support service took her to sewing classes. She did not like sewing and wanted to attend a different class, "like machine knitting." She was told she had to stay in sewing "for the rest of my life." This wall that separated her from the rest of the world did not exist solely at that particular day service.

> **Karen**: It was like a wall, like bars being put between you and me. … It was from the outside. … It was everywhere, all around us. … You never saw us – we were hidden away – it was like once they got you in they kept you in. Now we sit beside you in the buses. We have bus passes. … I was going mad. It was like they put you in a place for mentally handicapped, and that was where they kept you, forever. It felt bad. … I could not even think because I was in such a bad humour. (p. 14)

From Karen's point of view this wall posed communication limits both for her and for those on the other side of the wall. Karen "tried to talk but nothing happened."

> **Aine:** What did it feel like, not to be heard, not to be listened to?
> **Karen:** Horrible. I felt like I was going around the bend. I felt I was killing myself. (p. 15)

As time passed Karen began hitting against that wall by physically hitting other people with an intellectual disability.

> **Karen:** I knew it was wrong, it was not them I wanted to get at, but what could I do? (p. 15)

In their paper it was not clear how much time had passed from her first physically aggressive action to when Karen began counselling. She received counselling from Aine for 2 ½ years. Karen valued having Aine listen to her and it helped her to find

alternatives to violence. Aine worked with Karen and, when necessary involved Karen's support network.

> **Aine:** In therapy, anytime you threatened violence, or I thought it was possible…others had to be involved… How did you feel about that?
>
> **Karen:** Because I trusted you … Sitting and listening – it's very important. You need someone from the outside…
>
> **Aine:** How do you see that violence now?
>
> **Karen:** It's gone now. … The listening part was the key.… The [support service] had changed from not listening to listening, not shoving us in the corner. (p. 15)

Aine went on to discuss this case in detail in relation to ethical principles and constructivist concepts. She closed the paper by expressing concern about the absence of the voice of people with intellectual disability in discussion of counselling.

> **Aine:** The strangeness of the absence of people with learning disabilities themselves (rather than their carers, professionals[sic]) from public, professional and in particular therapeutic discourses reflects Karen's discription [sic] of their 'absence' from the world. This absence appears to me to allow much of our thinking about people with learning difficulties to go unexamined (p. 24).

Macdonald, Sinason, and Hollins (2003) also noted the absence of clients' subjective experiences in research. "To date, however, there appear to be no studies exploring the subjective impact of psychodynamic therapy on people with LD [learning disabilities]. This is regrettable, given the sensitivity and unique value attached to the client's subjective experiences in this treatment approach" (p. 434). They explored the subjective experiences of nine clients with an intellectual disability. Their study had two aims, to "elicit clients' views on their experience of group analytic therapy" and "to identify both positive and negative aspects of clients' experience of group analytic therapy" (p. 435). Single semi-structured interviews were conducted with nine clients "drawn from two psychodynamic groups for people with learning disabilities in an inner-city learning disabilities service" (p. 435). Four were men and were part of a group of five clients who were receiving counselling for sexual offending and had been meeting together for 5 years. Five were women drawn from a group of six women who had been meeting together for less than 2 year. It was not stated why they were

receiving group counselling (p. 436). This project was situated in a transcendental realist framework and the data were analysed using Interpretive Phenomenological Analysis (p. 437).

Several key themes were identified. The authors considered that the overall tone of the comments seemed positive (p. 443). "A major theme was that psychotherapy created an opportunity for participants to express themselves in a supportive environment" (p. 439). Given the lingering belief that people with an intellectual disability are not likely to gain benefit from a "talking therapy" it is interesting to note that all 9 participants considered that "talking characterizes therapy" (p. 439) and were able to reflect on both the positive and negative aspects of talking about problems. Being able to talk about one's own problems was helpful.

> I find it helpful that you can go somewhere and talk about problems. (p. 440)

However, talking about problems was sometimes considered distressing.

> …it's a bit scary.

> …a bit anxious sometimes. … I like to have a fag before I go in there. … It gives me … inspiration. (p. 443)

Listening to others talking about their problems was sometimes difficult.

> I don't like him just upset. … Every time he gets upset that make me, me wind up. (p. 444)

The authors considered that "the largest conglomeration of negative themes seems to relate to the participants' desire to avoid emotional pain, which is increased in various ways by participation in the group" (p. 443).

The authors acknowledged that this study had several limitations. It was a subjective study situated in a particular context and therefore lacked generalisability. Differences between the men and women's group were not addressed. The authors expressed concern that they may have had a biased sample; the two group members who did not participate may have had more negative experiences. The authors acknowledged that they themselves were "enthusiastic" about the group counselling and this may have affected the participant's responses (p. 447). Another limitation was that the participants

sometimes had difficulty understanding some of the questions. The final limitation mentioned was "the lack of credibility checks" (p. 448). Due to time constraints they were not able to formally check the findings with the participants. Also, they were not able to triangulate the data with other sources.

In spite of the limitations detailed by the authors, this study was of immense interest to me. It was one of very few published accounts of the subjective experiences of clients with an intellectual disability. And it was one of only two published in peer reviewed research journals. Although the authors chose to conclude the article by highlighting its limitations, it seems more fitting to end discussion of this pioneering study by highlighting its strengths.

Rigorous qualitative research exhibits characteristics such as goodness, trustworthiness and coherence (e.g., Arminio & Hultgren, 2002; Kline, 2008). Goodness involves doing projects which are of value. This study by Macdonald, Sinason, and Hollins (2003) details the experiences of an under-represented client group and is therefore of value to the profession. In particular, they sought to understand what the clients considered to be helpful and unhelpful in counselling. The authors demonstrated trustworthiness by providing explicit detail of how the project was carried out. Sufficient detail was provided in the article and in the appendices to carry out a similar project should one wish to do so. The authors were careful to detail not only what they did, but also their professional and philosophical viewpoints, thus demonstrating coherence to the reader.

Merriman and Beail (2009) again highlighted the absence of studies exploring the subjective experiences of clients with an intellectual disability. They referred to the study of group therapy by Macdonald, Sinason and Hollins (2003) and pointed out that "there is no such study on individual therapy" (p. 43). In the study reported by Merriman and Beail (2009) semi-structured interviews were conducted with six men with an intellectual disability who had been receiving counselling for two years or more. Each participant was interviewed one time and the interviews lasted between 15 and 35 minutes "depending on the verbal abilities of the client" (p. 43). The interviews covered the following topics: "the referral process, the client's experience of therapy,

the client's relationship with the therapist, their views and others' view of therapy, changes that may have been prompted by therapy, [and] positive and negative aspects of therapy" (p. 43). The interviews were transcribed and then analysed using interpersonal phenomenological analysis. The aim of this study was "to better understand the nature and essence of the client's experience" (p. 43).

The six participants had been referred to counselling for "problems associated with 'inappropriate behaviour', which fell into three broad categories: forensic or offending behaviour, behaviour that was socially inappropriate or dangerous, or difficulty dealing with emotions" (p. 43). Most of the men were aware of why they had been referred.

> I was hitting people. I think that's the reason (Interview 5). (p. 43)

> I worry about things (Interview 1). (p. 43)

The authors considered that some of the participants had "a general understanding that therapy was a place where problems and difficulties could be talked about" (p. 44) but were uncertain "what therapy would involve" (p. 44), and described feeling nervous or uncertain when they began counselling.

> I was a bit nervous. I didn't know what to say. I got a bit tight, scared of what he might do to me. (p. 44)

The participants considered counselling to be private and expressed that it was helpful to talk to someone about their problems.

> I felt great when I started talking to him and getting things off my chest which I'd done in the past to stop me doing it again. I was a great relief. (p. 44)

The participants described their counsellors in positive terms and seemed reluctant to speak negatively about them. One of the themes the researchers noticed was that the participants seemed to be "dependent in their relationship with the therapist" (p. 44).

> X sorts my problems out. I've had problems the last three weeks and he wrote them down and sorted it out. I leave it to him to sort things out. (p. 44)

Because these participants were in long term therapy at the same organisation, they experienced a change of counsellors. Sometimes a change would be short term because the counsellor was away temporarily. According to the researchers, those absences

"seemed to be dealt with quite pragmatically….However, longer term changes appeared to have more impact" (p. 44).

> I came to see Y before X…Yes, we got on nicely right up to the end—pity he had to leave…bit like pass the parcel. (p. 44)

The participants spoke of having made changes in their behaviour and also in how they felt.

> I was really down at the beginning. I was bottling everything up and couldn't cope with it. It's different now…Everything was going wrong. That's all changed now. (p. 45)

The authors considered that exploration of the clients' subjective experiences was important because "at last, professionals and governments are taking the views of service users seriously" (p. 45).

2.7. The key aims of this thesis

This review has drawn attention to a need for counsellors to be informed about the topic of intellectual disabilities and a pressing need for more research involving clients with an intellectual disability. In particular there is a need for research which views counselling through the contextual model and explores "how the clients heals" (Wampold, 2001, p. ix) and the environment in which counselling takes place (Saltmarsh, 2009). As highlighted in this chapter, the social experiences of people with an intellectual disability have historically been fraught with complexities and these complexities enter into the counselling room along with the client and have the potential to interrupt the counselling process. The purpose of this thesis is to gain a better understanding of how clients and counsellors work together in spite of these complexities in an effort to achieve positive outcomes. In keeping with the work of McGuirl and O'Reilly (2000), Brooks and Davies (2008), Macdonald et al. (2003) and Merriman and Beail (Merriman & Beail, 2009), this thesis aims to bring the experiences of clients with an intellectual disability into the realm of professional knowledge. Adding their "valuable insights" (Manthei, 2005, p. 551) to professional discourse has the potential to challenge our thinking and make us better practitioners.

Chapter Three: Methodology

3.1. Introduction

The aim of this chapter is to acquaint the reader with the beliefs, values and practices which influenced this inquiry. Within the domain of qualitative research, this is typically accomplished by using a paradigmatic approach to methodology. A paradigm is a set of beliefs that strives to answer questions of ontology (What is the nature of reality?), epistemology (What is knowledge?) and methodology (How do I seek knowledge?). Using this approach to methodology, authors provide descriptions of common research paradigms and then situate their inquiry within a particular philosophical belief system. The rationale for situating one's inquiry within a particular philosophical paradigm is that one's worldview has a profound influence on how one approaches research.

> All research is interpretive; it is guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied. Some beliefs may be taken for granted, invisible, only assumed, whereas others are highly problematic and controversial. Each interpretive paradigm makes particular demands on the researcher, including the questions the researchers asks and the interpretations he or she brings to them. (Denzin & Lincoln, 2005, p. 22)

As Denzin and Lincoln (2005) so aptly stated, one's worldview not only shapes how one approaches research but it also "makes particular demands on the researcher" (p. 22). However, it is not only one's worldview that has the potential to influence one's approach to research; the ethos and values of one's profession also have that capacity. Counselling practice is governed and shaped by ethical codes and shared understandings. And these in turn, have the potential to influence one's approach to research as well as to make demands on researchers. For example, a "particular demand" placed on researchers by the New Zealand Association of Counsellors is beneficence. "Counsellors should limit the demands of any research exercise to what can be justified in terms of benefit to individuals or the community" (New Zealand Association of Counsellors, 2002, p. 35).

The research questions arose from my counselling practice and I viewed this inquiry as an extension of my professional practice. Thus, it was specifically my interpretation of counselling principles which shaped this research rather than a particular research paradigm. Furthermore, this thesis is concerned, not with broad philosophical questions, but rather with how questions of ontology, epistemology and methodology relate specifically to counselling practice. What is the nature of counselling? What is the knowledge base of counsellors? How can researchers seek knowledge in keeping with counselling ethics and practices? For these reasons, I have chosen not to situate this inquiry within a particular research paradigm, but rather within the domain of counselling practice. This chapter describes how counselling principles, values and ethics influenced the design and implementation of this inquiry.

3.2. How counselling practice shaped this research

> The driving force of research is the area between knowing and not knowing. Something is known but it is not enough. Research that has meaning takes off from that point, which ultimately comprises a personal felt sense of a need to know. (McLeod, 2003, pp. 8-9)

I began my inquiry into this topic when I working as a counsellor with a client with an intellectual disability. Over time I became acutely aware of the many gaps in my counselling education. I felt like I didn't "know" enough about counselling people with an intellectual disability. If I were "better informed" then I could provide more effective counselling services. I then discovered that many other counsellors also felt like they didn't "know" as much as they wanted to "know" about working with this client group (Raffensperger & Miller, 2005). My desire to inform my own practice expanded to include a desire to inform other counsellors, too. I needed to think through what it means for counsellors to "know" something so that their practice can be "better informed." If I wished to design a project to inform myself and other counsellors then I needed to explore the epistemic practices of counsellors, that is, what counselling knowledge is, what counsellors want to know about intellectual disabilities, and how counsellors prefer to learn.

Of course it is only possible to explore "the epistemic practices of counsellors" in a general theoretical way. Each individual counsellor holds a unique set of beliefs about counselling. For example, I practice counselling primarily using a strengths-based model. Clients come with problems on their mind, and I hunt for exceptions to those problems. I work with clients to recognise these exceptions and utilise their strengths to find solutions. However, other counsellors practice using a deficit-based model and thus work with clients to understand the problem and to reduce its occurrence. I tend to think systemically about the clients, their relationships with others and their environment outside of counselling whereas other counsellors work solely with what is going on inside of the individual client. In spite of our individual differences together we form an inquiring community that provides therapeutic services to clients.

I was curious about this large, diverse inquiring community to which I belong. How is counselling knowledge acquired? Who is "allowed" to contribute to the knowledge base of counselling? Who are the people that know about counselling for people with an intellectual disability? My exploration of these questions began by considering professional values, and then contemplating the profession's common epistemic practices, examining testimonial and hermeneutical injustice, and in the end, striving to be a "responsible hearer" (Fricker, 2007).

3.2.1. Counselling principles

Aspects that unify the diverse community of counsellors are common values and principles. These are expressed in professional Codes of Ethics. These codes, which vary across counselling associations, provide a set of principles for the profession and are assumed to guide practice. Although one can find controversies in the ethical base of counselling (e.g., Cornforth, 2006), the following principles are often cited as "fundamental" (Heppner, Kivlighan, & Wampold, 1992, p. 79) or "basic" (McLeod, 2003, p. 167): (a) nonmaleficence, (b) beneficence, (c) autonomy, (d) justice, and (e) fidelity. The specific code that guides my practice is the Code of Ethics of the New Zealand Association of Counsellors. "This Code applies to all NZAC Members and Applicants in the full range of their professional practices. Professional practice may

include work in the roles of: counsellor, supervisor, therapist, trainer, educator, **researcher**, advocate, mediator, consultant, manager, coach, community worker, group facilitator, mentor, psychotherapist and spiritual advisor [my emphasis]. The generic terms "counsellor" and "counselling" apply to all professional roles undertaken by Members. (New Zealand Association of Counsellors, 2002, p. 25). Because research is considered "professional counselling practice," I wanted these ideals to guide how I gathered knowledge and, subsequently, used that knowledge.

3.2.2. Counselling knowledge practices

How is counselling knowledge acquired?

"Counselling is a practical field…like all practical domains, it presupposes a body of knowledge" (Willard, n.d., p. 1). McLeod (2003) suggested that this body of knowledge is composed of two distinct parts — "formal knowledge" and "tacit, experiential or practical knowledge" (p. 10).

Counsellor education programmes typically require that students demonstrate proficiency in acquiring both formal knowledge, e.g., critiquing counselling literature, and in practical knowledge, e.g., evaluation of their practical work. Once a counsellor is in professional practice, it is typically expected that the counsellor's knowledge of counselling will increase through professional development, the supervision process and by his or her work with clients. One possible means of professional development is reading research literature. Unfortunately, many practitioners do not read research articles and thus, research often has a limited impact on counselling practice (Lambert, Bergin, & Garfield, 2004; Manthei, 2004; McLeod, 2000). There is frequent reference in the literature to this gap between research and practice, not only in counselling but also in related fields such as social work (e.g., Lampropoulos & Spengler, 2002; McLeod, 2001b; Padgett, 2004; Sprenkle, 2003).

Another means of acquiring knowledge comes through the practical knowledge domain via the supervision process. Clinical supervision has long been recognised as a valued source of learning for counsellors (e.g., Granello, 2000). Beginning with their formal

education and following on through their professional career, counsellors seem to value the 'lived experience' of fellow practitioners. This way of learning and sharing information, also called an epistemic practice, implies that counsellors are comfortable learning from the testimony of credible witnesses.

Who is allowed to contribute to the knowledge base of counselling?

So, whom do counsellors consider to be credible witnesses? Although counsellors do not frequently read research, the extensive use of clinical supervision indicates that they value the input of professional colleagues. Additionally, counsellors often talk about learning from their clients (e.g., Kemp, 1984). While there seems to be a wide range of contributors to the practical knowledge domain, the formal knowledge domain limits its contributors to those who managed to find their way through the publishing process. The research portion of published literature even further limits its contributors to those who have adhered to rigours of research protocols. On the one hand counsellors readily learn practical knowledge from other professionals, from clients and perhaps even from the wider community. On the other hand there are very few avenues for clients and the wider community to contribute to the formal knowledge base. This epistemic practice of holding two distinct knowledge bases seems to disadvantage both counsellors and their clients.

Could a research project bridge this gap between practical learning and formal learning? Was it possible to design a project that adhered to established research conventions as well as allowed counsellors to learn in familiar ways, that is, by learning from the lived experience of colleagues and clients? Kazdin (2008), Padgett (2004) and Rennie (1994a) have suggested that qualitative research could be a way to lessen the gap between research and practice. However, as McLeod (2001b) has stated, "The much noted 'gap' between research and practice in counselling and psychotherapy will not be closed by replacing quantitative studies with qualitative ones, but by producing qualitative studies that practitioners *want to read"* (p. 204).

Who knows about counselling for people with an intellectual disability?

So what would a counsellor *want to read* about counselling for people with an intellectual disability? Presumably a counsellor would prefer to read something written by, that is, learn from, someone knowledgeable about the topic. Underneath the content question rests the epistemic question, "Who knows about counselling for people with an intellectual disability?"

The two parties most intimately acquainted with the counselling process are the client and the counsellor. In case studies I was able read about counsellors' experiences and counsellors' renditions of clients' experiences. However, I was disappointed at how difficult it was to find firsthand accounts of what clients with an intellectual disability had to say about their experiences of counselling. As the literature review demonstrated, the pathway from this client group's subjective experiences to the formal knowledge domain is rarely travelled.

In spite of the increased interest in exploring the client's perspective in counselling, the perspectives of clients with an intellectual disability are seldom sought in formalised studies. Because only a small percentage of people have an intellectual disability[13], one would expect to see a smaller percentage of studies. However, the obvious dearth of research begs me to question the status quo. Is this simply an oversight or have some unjust prevailing attitudes silently slipped into counselling practices?

Difficulties in having one's knowledge deemed credible

In many areas of their lives, people with an intellectual disability face difficulties in having their knowledge deemed worthwhile and/or credible. Miranda Fricker (2007) has described two forms of epistemic injustice — testimonial injustice and hermeneutical injustice.

> Testimonial injustice occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word; hermeneutical injustice occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their

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[13] According to Bonardi (2009) the prevalence rates for adults are estimated to be 7-13 per 1000.

social experiences. An example of the first might be that the police don't believe you because you are black; an example of the second might be that you suffer sexual harassment in a society that lacks that critical concept. (p. 1)

In testimonial injustice a speaker is "wronged in their capacity as a giver of knowledge" (p. 7). In hermeneutical injustice "someone is wronged in their capacity as a subject of social understanding" (p. 7).

Being overlooked or having one's experiences trivialised or ignored are expressions of testimonial and hermeneutical injustice. People with intellectual disabilities experience disadvantages both systemically and interpersonally. In the legal system, people with an intellectual disability face numerous difficulties when they have been victims of crimes. Studies reviewed by Petersilia (2001) have suggested that less than half, sometimes as few as 3%, of these crimes are reported to authorities. "Police believe that victims with disabilities lack credibility" (p. 683). People with an intellectual disability are also at a disadvantage in the medical system where there is "systemic neglect of the health of adults with intellectual disabilities" (National Health Committee, 2003b, p. 26). Interpersonally, people with an intellectual disability experience high levels of social stigma which has wide ranging negative impacts (e.g., Gallagher, 2002; Jahoda & Markova, 2004). Unfortunately, counsellors are not immune from trivialising the experiences of people with an intellectual disability. Attitudes such as "therapeutic disdain," the reluctance of therapists to engage with clients with an intellectual disability (Kroese, 1998), and "diagnostic overshadowing," the tendency to attribute negative symptomology to an intellectual disability (Mason & Scior, 2004; Reiss, 2000; Williams & Heslop, 2005) end up trivialising the client's experiences. Such attitudes fall short of counselling ideals.

3.2.3. Counselling ethics: Knowledge, power and justice

> …my interest is in epistemic practices as they are, of necessity played out by subjects that are socially situated. This socially situated conception puts questions of social identity and power centre stage, and it is the prerequisite for the revelation of a certain ethical dimension to epistemic life — the dimension of justice and injustice. …Philosophers are very keen to understand what it is to get things right. That's fine, but we should not stop there if we want to understand human practices that only very patchily approximate the rational ideal. The focus on justice creates an impression that it is the norm and injustice the unfortunate aberration. (Fricker, 2007, p. vii)

As I thought through each of those epistemic questions I found myself returning to counselling ethics, in particular to justice. Like philosophers, counsellors are keen to aim towards justice and thus it stings to learn that one's profession runs the risk of perpetrating injustice towards the very people we intend to serve, our clients. Where I had hoped to find knowledge, I found silence. The numerous gaps in our collective understanding not only disadvantage our clients, they disadvantage counsellors, too. These gaps leave us open to the prevailing attitudes and practices of those around us. And if these prevailing attitudes and practices are unjust, then we, too, may end up practising unjustly.

Silence is an invitation to listen and listening is what counsellors do best. The presence of widespread testimonial and hermeneutical injustice moves me to ponder the question posed by Fricker (2007): "What sort of hearers should we be in a society in which there are likely to be speakers whose attempts to make communicative sense of their experiences are unjustly hindered" (p. 168)?

3.3. The intention of this project

> In practical contexts where there is enough time and the matter is sufficiently important, the virtuous hearer may effectively be able to help generate a more inclusive hermeneutical micro-climate through the appropriate kind of dialogue with the speaker…. Alternatively (again, practical context permitting), the virtuous hearer may seek out extra corroborating evidence; for instance by consulting other relevantly placed people — people with a similar social identity and experience to the speaker. (Fricker, 2007, pp. 171-172)

My intention with this project was to begin by helping "to generate a more inclusive hermeneutical micro-climate" for listening to professionals, clients with an intellectual disability and people from the community. I envisaged that creating such a micro-climate would require skills similar to those which counsellors use on a daily basis as they create therapeutic spaces for their clients. I anticipated that this would be a time consuming process, but that generating such a space was "sufficiently important" that it deserved ample time.

In addition to creating a listening space, I needed to decide on "the appropriate dialogue with the speaker" (Fricker, 2007, p. 171). Frequently counselling researchers frame up research dialogue using quantitative measures, preferably using measures which have been standardised and normed for specific participants. In such a dialogue, the researcher asks set questions, and the participant answers those questions. I was hesitant to frame this dialogue using quantitative measures for three reasons. First of all, starting in a silent space, it seemed premature to be selecting measuring tools, when I was not even sure what I would find in that space. Secondly, my intended audience, that is, practising counsellors, has expressed difficulty in using research to inform their practice; numerous authors have suggested that qualitative research might be more accessible for practitioners (e.g., Berrios & Lucca, 2006; McLeod, 2001b). Finally, because some of my participants would be "speakers whose attempts to make communicative sense of their experiences are [frequently] unjustly hindered" (Fricker, 2007, p. 168), I did not want to use research methods which would narrowly limit the ways in which they could express themselves. Limiting my participants' means of expression to quantitative measures which I had chosen would also limit my ability to listen. In this silent space, adjacent to systems whose attitudes and practices, at times, fall short of counselling ideals, it behoves me not to limit my ability to listen.

3.4. Qualitative inquiry

> Qualitative interviews are conversations in which a researcher gently guides a conversational partner in an extended discussion.… Unlike survey research in which exactly the same questions are asked to each individual, in qualitative interviews each conversation is unique, as researchers match their questions to what each interviewee knows and is willing to share. (Rubin & Rubin, 2005, p. 4)

Qualitative inquiry is often used to explore understudied, complex social phenomena (e.g., Miles & Huberman, 1994, p. 17). However, numerous schools of thought exist regarding how to approach the exploration of such phenomena. As Dey (1993) has stated "qualitative research is noted for its lack of established procedures and agreed canons governing the conduct of enquiry" (p. 221). Because my goal was to establish conversational partnerships with research participants, I chose to use a model of qualitative inquiry called "responsive interviewing" (Rubin & Rubin, 2005).

The purpose of responsive interviewing is to "obtain the interviewees' interpretations of their experiences and their understanding of the world in which they live and work" (Rubin & Rubin, 2005, p. 36). This purpose coincided with my aim of exploring the subjective experiences of clients with an intellectual disability, their counsellors and their support people. Because this exploration was happening in an arena that is understudied, the method of inquiry needed to be "flexible and adaptive" (p. 36); responsive interviewing relies on the interviewer's ability to listen carefully and to change direction when necessary.

Another important characteristic of this type of interviewing is the understanding that a relationship is being formed between the interviewer and the participants and that "the personality, style and beliefs of the interviewer matter" (p. 36). This statement acknowledges the fact that the manner in which I approached research participants would be different than another person's manner. The relationships formed would be different. Therefore the information which was divulged to me by participants would likely be different to that which would be disclosed to another researcher.

3.4.1. Communication theory

> It is obvious that communication is a conditio sine qua non of human life and social order. It is equally obvious that from the very beginning of his existence a human being is involved in the complex process of acquiring the rules of communication, with only minimal awareness of what this body of rules, this calculus of human communication consists of. (Watzlawick, Beavin, & Jackson, 1967, p. 13)

Communication is the basis for establishing counsellor/client relationships and researcher/participant relationships. Various frameworks have been proposed for examining theories of communication. I have chosen to discuss my views in relation to those of Watzlawick et al. (1967). Paul Watzlawick was a theoretician, teacher and counsellor and was influential in the development of brief therapy (Ray, 2007).

An important premise in this theory is that communication has a context or frame of reference. From the very beginning of this project I made the assumption that each participant would be communicating with me from a unique frame of reference. I assumed that these different vantage points could result in different renditions of the same event. I further assumed that each individual would be situated within a wider context and that my awareness of participants' environments would enhance my ability to make sense of their communications.

> Failure to realize the intricacies of the relationships between an event and the matrix in which it takes place, between an organism and its environment, either confronts the observer with something "mysterious" or induces him to attribute to his object of study certain properties that object may not possess. (Watzlawick, et al., 1967, p. 21)

Another axiom postulated by Watzlawick et al. is that communication involves both relational and content aspects (p. 54). I believe that the relational aspects of communication often colour the content that is presented to researchers. Rubin and Rubin (2005) have suggested the following common reasons that people choose to participate in qualitative studies: (a) "they want to be helpful in solving a problem" (p. 90); (b) "they often need to talk about terrible experiences they have had" (p. 91); (c) they participate "to gain favorable publicity for their social or politic concerns" or "to get out their side of story" (p. 91). By acknowledging the complex interplay between the relational and content aspects of communication, I also recognised that the content

presented to me at a given time would likely be different to that which would be presented to another researcher, or even presented to me at a different time.

I also agree with another supposition proposed by Watzlawick et al. (1967); "human beings communicate both digitally [verbally] and analogically [non-verbally]" (p. 66). They expounded on the breadth of analogic communication as follows:

> We hold that the term must comprise posture, gesture, facial expression, voice inflection, the sequence, rhythm, and cadence of the words themselves, and any other non-verbal manifestation of which the organism is capable, as well as the communicational clues unfailingly present in any context in which an interaction takes place. (p. 62)

As mentioned previously, "from the very beginning of his existence a human being is involved in the complex process of acquiring the rules of communication" (p. 13). This process includes the acquisition of both verbal and non-verbal communication skills. Many people with an intellectual disability have difficulty acquiring the same set of communication skills as those around them. This puts them at a disadvantage when communicating their views to others. Because this thesis is in written form, I have necessarily reduced the breadth and richness of the participants' analogic communication into verbal form.

3.4.2. Rigour in qualitative research

Given the complexities and nuances of human communication and the difficulties inherent in translating its richness into a written medium, it becomes necessary to discuss the concept of rigour in qualitative research. "Rigor is the means by which we show integrity and competence: it is about ethics and politics, regardless of the paradigm" (Tobin & Begley, 2004, p. 390). As discussed by Guba and Lincoln (2005), controversies regarding rigour exist not only between quantitative and qualitative researchers but also within the domain of qualitative research. Because I am interested in achieving rigour in the specific domain of the counselling profession, I have chosen to discuss my work according to three themes outlined by Kline (2008).[14] Rigorous qualitative research exhibits the characteristics of trustworthiness, demonstrates

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[14] "The goal of this editorial is to help qualitative researchers in counselor education submit manuscripts that report findings of rigorously conducted qualitative research" (Kline, 2008, p. 210).

methodological rigour; and is coherent; that is, "the entire project…utilizes a consistent epistemological perspective" (p. 212).

The starting point for establishing rigour is the provision of explicit detail about what the researcher actually did; the details of this project are described in Chapter Four. Such candour enables the reader to determine the validity or trustworthiness of the information presented (e.g., Lofland, et al., 2006; Richards, 2005). Trustworthiness in qualitative research refers to a number of qualities including authenticity and credibility (Denzin & Lincoln, 2005; Guba & Lincoln, 2005).

According to Sears (1992, p. 149) and Mirfin-Veitch (2005, pp. 67-68) authenticity can be demonstrated by the researcher's capacity to be empathetic, to immerse himself or herself in the participant's world with all its richness and complexities, and to treat participants with respect and understanding. Similarly, practising counsellors strive to listen empathetically to clients, to view the world from the client's perspective and to treat clients with respect and understanding. Genuineness, empathy, and unconditional positive regard are considered core conditions for counselling practice (Rogers, 1992). I conducted the research interviews with the same core conditions in mind as when I conduct counselling interviews. I leave it to the reader to judge whether the written portion of this thesis also demonstrates these hallmarks of both qualitative research and counselling practice.

The notion of credibility is discussed in relation to both research participants and readers of written manuscripts (e.g., Charmaz, 2005; McLeod, 2001b, 2003). "The facticity of the research data can only be established by checking it against other sources of information" (McLeod, 2003, p. 95). I strove to achieve credibility with research participants by monitoring our mutual understanding during the interviews and by offering participants the opportunity to read the transcripts, making any necessary corrections or additions. Although some participants were interested in reading through the transcripts, several others declined. Because six of the participants had difficulty reading I wrote out summaries of the interviews and read the summaries to them, making changes at their request. (See Appendix F for a sample interview summary.) I

have endeavoured to achieve credibility with readers of this manuscript by providing "enough evidence…to allow the reader to form an independent assessment" (Charmaz, 2005, p. 528). Charmaz (2005) has suggested that researchers demonstrate "intimate familiarity with the setting or topic," provide data that are "sufficient to merit the researcher's claims," and that "there are strong links between the gathered data and the researcher's argument and analysis" (p. 528). In this study data about each case were gathered from multiple sources, thus allowing for triangulation of the data.

In addition to demonstrating qualities of trustworthiness, Kline (2008) has suggested that research be methodologically rigorous and coherent. He referred to one aspect of methodological rigour as "goodness"; this establishes "the value of a qualitative study" (p. 211). Arminio and Hultgren (2002) elaborate on this concept by posing six "dimensions in which to situate research goodness": (a) "the philosophical stance," (b) "the methodological approach," (c) "the method," (d) "the representation of voice," (e) "interpretation and presentation," and (f) "implications for professional practice" (p. 450).

First of all, the philosophical stance of the researcher "must be made clear to the reader" (p. 450). For this reason, earlier in this chapter I detailed my ethical, epistemological and theoretical assumptions. Second, the methodological approach that one chooses must be supported by those assumptions. "It is methodology that adds clarity to how the data are collected and the means for its interpretation" (p. 452). The phenomenon under exploration in this thesis was counselling for clients with an intellectual disability. "Counselling is both a process and a relationship" (Department of Education, 1971, p. 5) and is reliant on communication between clients and counsellors. The data were gathered in semi-structured and unstructured interviews in the context of a relationship that developed over time. It is fitting that the assumptions which were discussed centred on relationships and communication.

Third, the method used must be congruent with the first two dimensions and must be made transparent to the reader. Fossey, Harvey, McDermott and Davidson (2002) have suggested three questions to consider when evaluating transparency. "To what extent

have the processes of data gathering and analysis been rendered transparent? How were rival/competing accounts dealt with in the analysis? To what extent do the processes of data gathering and analysis give privilege to participants' knowledge?" (p. 724). I invite the reader to bear in mind those questions when reading the remainder of this thesis.

The remaining dimensions that Arminio and Hultgren (2002) discussed were "the representation of voice" (p. 452, 454-455), the art of "interpretation and presentation" (p. 455-457), and "implications for professional practice" (p. 457-458). The role of qualitative researchers is to listen to participants and then present what the participants have said to other people in a new way. This role has been likened to that of a bricoleur (e.g., McLeod, 2001b, pp. 119-129) or a curator in a museum or art gallery (Cole & Knowles, 2001, p. 115). For my work in this thesis, I prefer the image of a curator. As Andrew Smith (2006) has stated, "The curator of a gallery is responsible for taking a collection of works and presenting it in a way that makes an impact on viewers. … A researcher has a parallel challenge when confronted with the representation of data" (p. 28). I viewed the participants' words as valuable pieces. My role has been to frame and present their words in a context that was difficult for them to access on their own, with the hope of impacting professional practice. This thesis serves as an academic frame for the participants' voices. Chapters Three and Four have described the process that was used to interpret and present their voices. Chapter Eight provides recommendations for practice.

The art of framing participants' words relies on a researcher's ability to distinguish between the participants' voices and the researcher's own emotional responses and previously held biases. Similarly, counselling practice relies on practitioners being able to maintain a reflective stance which differentiates the clients' narration from the counsellors' responses to that narration. Both counselling and qualitative research involve the formation of interpersonal relationships. And when dealing with "emotionally laden subjects" both counsellors and qualitative researchers are faced with a similar need to effectively manage their own emotional responses (Rager, 2005, p. 23).

In order to maintain a reflective stance, practising counsellors typically engage in self-care activities, peer supervision, and personal development. During this research project I implemented similar strategies. Throughout this project I regularly engaged in self-care activities such as enjoying my garden, baking, and spending time with family and friends. I met regularly with my academic supervisors as well as with a mentor in the community who was familiar with disability related issues. In these conversations I was able to unpack my own responses to issues which arose during this project. As a person of faith, my personal development included regular involvement in a church community and taking a distance learning paper entitled, "Theological Reflection." In addition to honing my skills as a researcher and counsellor, I wished to improve my ability to reflect on my actions in light of my faith. Consistent use of these strategies, particularly during the data analysis process, assisted me to separate the participants' words from own responses to their words

In this section a number of qualities have been put forward as criteria for evaluating the rigour and value of this thesis. Anne Bray (2000) has succinctly stated what I consider to be the most important measures for disability research.

> We must ensure that research is undertaken for a clear purpose - to directly or indirectly improve the lives of people with disabilities… We must also take responsibility to ensure our research does influence change in a positive and timely manner.

3.5. Conclusion

Inquiry into this topic was begun because of my curiosity as a practitioner. Rather than viewing curiosity as "a vice" or "as futility," Foucault perceived curiosity as "care." Curiosity "evokes the care one takes of what exists and what might exist" (Foucault, 1994, p. 325). This inquiry was driven not only by concern about the current state of counselling for this client group but also by hope for what might exist. Thus, the topics explored cover not only the participants' current experiences of counselling, but also their hopes for what could exist. The status quo bids practitioners to stay with the familiar, but curiosity invited me to be ready "to find what surrounds us as strange and odd" and "to throw off familiar ways of thought and to look at the same things in a different way" (Foucault, 1994, p. 325).

Chapter Four: Method

The aim of this chapter is to describe how this project was designed and carried out.

4.1. Consultation process

This project was developed in response to a previous study which suggested that specialised training would enable counsellors to work more effectively with clients with an intellectual disability (Raffensperger & Miller, 2005). In addition to responding to counsellors' perceived needs for further information, I wanted this project to be relevant to the perceived needs of other interested parties, such as people with intellectual disabilities, family members, disability support services, mental health professionals and the local community. This led to an extensive consultation process which began in February 2005, prior to my July 2005 enrolment as a PhD student, and carried on until July 2006. These conversations with counsellors, psychologists, disability support providers, people with an intellectual disability, researchers, and other members of the community helped to shape the design of this project.

Some of these conversations occurred prior to my enrolment as a doctoral student; others occurred prior to the formal acceptance of my proposal and all of these conversations took place prior to obtaining ethical approval for this project. Because these conversations took place at different stages of the research process, consultants were informed about the current stage of the project. For example, "I am considering doing a research project." "I have just enrolled as a PhD student." "I will be submitting an ethics application soon." I thanked the consultants for their time, but I did not make any future commitments to them, that is, I did not promise to give them reports on the study. However, I left open the possibility of future discussion of this topic. I viewed the initial consultation process as laying a foundation for future dissemination.

The aims of these initial conversations were to let the consultants know of my interest in this topic, to listen to issues and concerns relevant to them and determine if there was, indeed, a perceived need for such a project. My early conversations indicated a high level of interest in this topic. I was encouraged to proceed with designing a project. I

continued to use these consultative conversations to obtain specific feedback on details of the project such as the wording in drafts of information sheets and consent forms. Particular attention was paid to the design of the information sheets and consent forms for people with intellectual disabilities. For example, one conversation prompted the use of pictures on these forms; other conversations prompted re-wording of the text. The reader can view the information sheets and consent forms in Appendix D.

While I retained the electronic copies of the email correspondence, due to the timing and aims of these face-to-face consultations, those conversations were not recorded. On occasion, with verbal permission from the consultant, notes were taken during the conversations. These notes contributed to the development of the project design.

4.2. Project design

Because I was investigating "a contemporary phenomenon within its real-life context" (Yin, 2003, p. 13), this project was designed as a case study exploring counselling for clients with an intellectual disability. The aim was to follow each case for one year. One case was followed for 11 months, one for 12 months, two for 14 months, one for 18 months and the final case for 21 months. In addition to being bounded by time, each case was bounded by activity (counselling), geography (located within the province of Canterbury), and client group (clients with an intellectual disability). Each case was viewed from more than one perspective. Four cases were viewed from the perspectives of the client, the counsellor and a support person. Two cases were viewed from the perspectives of the client and the counsellor, because these two client participants chose not to include a support person in this study. To obtain a perspective of the local context of these cases, single interviews were held with four key informants.

4.3. Ethical Approval Process

After settling on a design I sought ethical approval from two ethics committees. As a student at the University of Canterbury, I was required to seek approval for my project from the University of Canterbury Human Ethics Committee (UCHEC). Because my research included participants with a disability and because my potential participants

might be either employees or patients in the health system, my project was considered 'health' research. Although some universities are accredited to review 'health' research, the University of Canterbury does not have this status. (A. Loveridge, personal communication, November 25, 2005). Projects such as mine are referred to the Health and Disability Ethics Committee (HDEC). "A copy of the HDEC application form sent to that Committee must be sent to the Chair of the University Human Ethics Committee for approval" (University of Canterbury, 2007).

On 31 July 2006 I submitted ethical approval forms to the HDEC. The committee reviewed the forms on 21 August and recommended a few minor changes and written evidence of Maori consultation. I submitted those changes and written evidence on 15 September and 20 September, respectively. I received approval from the HDEC on 5 October 2006 committee and subsequently submitted the relevant ethical approval forms the UCHEC and received approval from that committee on 20 October 2006. I then began recruiting and interviewing participants. Letters of ethical approval can be found in Appendix C.

4.4. Inclusion criteria

4.4.1. Clients

The inclusion criteria for the clients were that:

- They were over the age of 18.

- They were recognised as having an intellectual disability.

- They were receiving counselling when the recruitment began.

- They had completed verbal and written consent procedures.

Identifying clients as having an intellectual disability has relied on four subjective measures: (a) the clients' self-identification, (b) the clients' childhood school experiences, (c) the provision of services by an intellectual disability support service, and (d) the current perceptions of the clients, counsellors and support people. Given that

this study is about participants' subjective experiences and given the influence that social perceptions play in the provision of counselling services, relying on these measures is sufficient for the purposes of this study.

4.4.2. Counsellors

The inclusion criteria for counsellors were that:

- They were over the age of 18

- They provided counselling for a client in this study.

- They had successfully completed a tertiary counsellor education programme.

- They held membership in a professional association.

- They had completed verbal and written consent procedures.

4.4.3. Support people

The inclusion criteria for support people were that:

- They were over the age of 18.

- They had been nominated by the client.

- They had completed verbal and written consent procedures.

4.4.4. Key informants

The inclusion criteria for key informants were that:

- They were over the age of 18.

- They were involved in providing support services or mental health services for people with intellectual disabilities.

These services often are in a position to refer clients to counselling and/or fund counselling. In order to better understand the local context in which this counselling

took place, it was necessary to be aware of how disability services, mental health services and other service agencies operated.

4.5. Participant descriptions

4.5.1. Introduction

Providing sufficient detail about the participants enables the reader to position this thesis within its local context. Because the data analysis process tends to break apart individual stories in order to organise the data into themes, some researchers strive to preserve a sense of wholeness by writing participant vignettes (e.g., Southern, 2010, p. 24). These vignettes give the reader an opportunity to become more intimately acquainted with each individual participant. Because I particularly wished to emphasise the heterogeneity of counsellors (refer to page 21) and people with an intellectual disability (refer to page 11), writing vignettes of each the 19 participants appealed to me.

However, acquainting the reader intimately with the participants is at odds with maintaining their privacy. Confidentiality can be breached by writing in such a way that participants can be recognised. Tolich (2004) identified two types of confidentiality — external and internal. Maintaining external confidentiality can be achieved by writing in such a way as to avoid recognition by parties outside of the research project. Internal confidentiality, on the other hand, has to do with being recognised by others who are involved in the research project.

Because the local disability community is small, people working in this area can have relatively high profiles. Therefore descriptions of the key informants, counsellors and support people have been kept brief and general. The clients are less likely to be recognised by outsiders and since they are central to this project, I have written vignettes describing them in more detail. This is in keeping with the recommendation that researchers provide more detailed descriptions of clients with an intellectual disability (e.g., Benson, 2004; Prout, et al., 2000). In order to describe the uniqueness of

each client, they have each been given a pseudonym: Tom, Kaye, Margaret, James, Ian and Roger.

Although they may not be recognised by outsiders, there is a very real possibility that a client could be recognised by their counsellor or their support person. In order to maintain internal confidentiality, some of the clients' comments have been anonymised. This protects their privacy, but risks losing the uniqueness of each individual as well as making it very difficult to talk about outcomes without confusing the reader. In this thesis I am walking a fine line between clarity and confidentiality. Sometimes I have chosen to link clients' comments with their pseudonyms in order to paint a clear picture of the clients. In these instances I have balanced the possibility of divulging identifying information, with the likelihood that other participants may already some of the information and that they are unlikely to be reading this thesis.

There were 19 participants in this study. Six were counselling clients, five were counsellors, four were support people, and four were key informants. Twelve of the participants were women; seven were men. One participant identified as Irish, one participant identified as Dutch and the remaining 17 participants identified themselves as New Zealand European. In conversations about their ethnicity, I learned that of those 17, four had immigrated to New Zealand. Two were permanent residents and two had become citizens.

4.5.2. Clients

Of the six counselling clients, five spent portions of their childhood living separate to their families. Two clients spent significant portions of their childhood in what they each referred to as "boarding school." I perceived that sort of living situation as "an institution." One client lived at home until teenage years and then spent time in foster care, and then moved into a residential care facility. The other two lived primarily with their families but spent time in health camps and/or foster care. For one, simply discussing his childhood caused visible anxiety and interestingly, the health camp was spoken of as a positive experience. The other recalled health camp as a traumatic experience with a long lasting impact.

One of the six clients grew up with family, transitioned as an adult from the family home to supported living in the community, and continues to be an integral part of the family.

During this study, two clients were living in their own rented places; one rented a house and the other in a Housing New Zealand flat. One participant lived in a flat owned by a disability service. One participant was living at home with her parents at the beginning of the study and is now living on her own in a government-subsidised flat. Two were living in group homes run by intellectual disability support services. One home was located in the community and the other home was part of a gated set of residential homes. One client was involved in a programme which offered both individual and group counselling. The other clients were receiving solely individual counselling.

Tom

Tom is a 26 year old New Zealand European. He enjoys basketball, drama, computers and horses. He is energetic, outgoing and has a wide range of interests. As his support worker said, "He's enthusiastic about many things. …He's got … that kind of personality, you know, jovial, loud – quite loud. … He's a typical Kiwi bloke — rugby, beer and cricket and chat the girls up …"

Tom has received support from intellectual disability residential services as both a teenager and as an adult. Tom considered that he had a disability:

> **Tom:** I've, um, - trouble with, um, reading and writing at times.

Here is how his support person described his disability:

> **Support person:** [Tom] has a, um, moderate to mild intellectual disability but social skills and consideration of others is a big one with [Tom].

At our first interview the counsellor readily identified Tom has having an intellectual disability.

> **Counsellor:** [Tom]… certainly does have an intellectual disability. …He functions, you know, quite well.

However after working with the client for several months, there was occasion to reassess Tom's abilities. This what his counsellor said at the final interview:

> **Counsellor:** He functions really well sort of socially … but some of the staff … sort of felt that sometimes … people overestimated his abilities. And I thought, well that's important and I wanted to make sure that, you know, we weren't doing that in treatment, sort of expecting too much from him. … So I'm about halfway through the WAIS-3 at the moment.… It actually seems like, um, maybe the other way. Maybe he's sort of actually brighter, um, than we anticipated. … He might be an IQ of 70-something rather than, you know, below 70.

Kaye

Kaye is a 32 year old New Zealand European. She is creative and enjoys poetry, crocheting and drawing. She loves her dog. She takes pleasure in giving gifts to her nieces and nephews. I was a recipient of her warm-heartedness the first time I met her. When Kaye, her counsellor and I met together to talk about the information sheet, Kaye presented me with a picture that she had drawn for me. When the study began she was living at home with her parents; she has since moved into a flat of her own. When she was living with her parents she helped them out with housework, gardening and looking after their animals.

Kaye did not attend special classes as a child, but is recognised by a disability service as having a disability. Both Kaye and her counsellor identified that she has an intellectual disability.[15]

> **Kaye:** I was very slow at learning, writing and reading and everything. … I have to learn things at my own pace. I can't um do it too fast otherwise I'll make a mess and I don't want to make a mess. I take my time.

> **Counsellor:** I'd say the disabilities that she struggles with are, um, her intellectual disability and her depression.

Formal assessments, such as the WAIS-3, and social perceptions both play a role in identifying who does and who does not have an intellectual disability. Sometimes formal assessments are used to identify people and to determine eligibility for services.

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[15] Kaye opted not to include a support person in this study.

Other times social perceptions are the factor which determines who provides services. The following quote illustrates how Kaye was initially denied access to activities for people with an intellectual disability because of a lack of "formal diagnosis."

> **Counsellor:** We tried to put some in place some community activities for [Client]. … We found that she couldn't access any of them because she had never had a formal diagnosis. … The doctor's always said that she has an intellectual disability.

On the other hand, one counsellor "didn't feel comfortable" working with her because she was informally perceived as having an intellectual disability, and referred her on to the counsellor in this study.

> **Counsellor:** She was referred to me by my supervisor because my supervisor didn't feel comfortable counselling intellectually disabled people. …I suppose … the reason why my supervisor felt she had an intellectual disability was how she presented. It's quite obvious when you talk to [Client] that she's got a disability but it's never been formalised.

Fortunately for Kaye, she was referred on to a counsellor who was comfortable working with her and a formal diagnosis was eventually located.

> **Counsellor**: … the doctor wrote away for it. … She qualified [for the activities] once she got the piece of paper that stated the diagnosis.

Margaret

Margaret is a 46 year old New Zealand European. She is quick to smile, knows lots of people and loves to sing. ABBA used to be one of her favourite groups. She is actively involved in community groups for people with disabilities. As her support person [a sibling] said, "[Margaret] has had the ability to develop strong friendships with normal people around her. She's by far remembered the most on her birthday out of all us kids. People from way back always remember her, because she does have a bubbly personality in there."

Margaret attended special schools as a child and is currently living in supported accommodation through an intellectual disability provider. Margaret did not recognise

the word "disability." but she was familiar with the terms "special needs" and "IHC"[16] Those words meant:

> **Client:** It means there's a workshop… It's like people with wheelchairs and stuff. …Like crippled people.

Margaret did not self-identify as having "special needs." However, both her counsellor and her support person considered that she had an intellectual disability.

> **Counsellor:** [Margaret] has an intellectual disability and Down syndrome with a distorted view of her abilities and denial of disability.

> **Marilyn:** Does [Margaret] have a disability?
> **Support person:** Most definitely. [Laugh]
> **Marilyn:** And how would you describe her disability?
> **Support person:** She is, I would suggest, medium range of Down syndrome, if you understand where I'm trying to classify that.

James

James is a 45 year old New Zealand European. He has a fun sense of humour and enjoys pottering around in his garden. He is actively involved in disability-focused organisations and thinks carefully through disability related issues. He has a particular sensitivity to issues of privacy and confidentiality. When we were going through questionnaire he asked me, "You have passed this with your ethical committee, have you?" When asked what prompted that question James replied, "Because you started asking some personal type questions. And normally people got to be really careful when they answer the person-like questions." His counsellor also spoke of this quality, "He's extremely aware of boundaries and confidentiality."

James attended a special school as a child and is currently receiving support from an intellectual disability service provider. Both James and his counsellor considered that James had a disability.[17]

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[16] IHC is the name of an organisation in New Zealand that has supported people with an intellectual since 1949. Over the years the term "IHC" has come to be used in colloquial speech to refer to people with an intellectual disability even if they are not a part of this organisation.

James: I'm mildly intellectually. … I'm … a pretty nearly a borderline case.

Counsellor: [James] has borderline intellect. … [James] is below average intellectually — very aware of the difficulties and frustrations involved in being of neither average ability nor mentally retarded but in between. … I think [James'] anxiety is probably, in many ways, more disabling than his intellectual ability.

Ian

Ian is a 40 year old New Zealand European. When the study began he was in fulltime employment, as he had been for the past 22 years. He got up five days a week at 3:10am to go to work. He said, "Once the alarm goes on, I'm out of bed." He and his wife have been married 12 years and they have a child who is in primary school. He, his wife and their child have intellectual disabilities. During the course of this study, due to difficult circumstances, he left his job to stay home and look after his family. Although leaving his job was in response to a difficult situation, it resulted in some new opportunities for him. He became involved in a training course and has increased his involvement in a disability-focused community organisation.

Ian is not receiving support from a disability service. He did not attend special classes as a child, but was frequently teased in school for being slow and was put at the back of the class. Here is how Ian, his counsellor and his support person described his disability:

Ian: I'm a bit, um, [pause] slow…I can't read and, um, [st] spell. And I [st] stutter. … When I was … [a] child …I had … trouble with learning.

Counsellor: Learning disability–difficulty retaining complex information, reading, speech impediment.

Support person: I see [Ian] is quite borderline… if you talked about IQ tests and all that, but I don't always agree with all that stuff. … He amazes me in his drive to be a good parent…But he does have, he does have [sic] a disability.

Roger

Roger is a 47 year old New Zealand European. During the week he goes to reading classes and volunteers at a video shop and at a disability service. On the weekends he

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[17] James opted not to include a support person in this project

likes to relax and do nothing. He has an avid interest in trains and planes. He enjoys office work and travelling. He has been to Europe and the United States. Someday he would like to go back to the United States and see the Statue of Liberty and go to the Emmy Awards. If only space travel were possible, he would "like to go in outer space and, ah, land on the moon and see what the moon is like." His counsellor said, "He probably would enjoy life in a big city."

Roger attended a special school as a child and is currently living in supported accommodation through an intellectual disability provider. Roger was uncertain about the meaning of the word "disability."

> **Roger:** I keep hearing that. I think it has something to do with your life or something like that…Disability might mean handicapped or something wrong with your brain. Not sure.

When asked if he had a disability, he replied, "I don't think so. I don't know." Both his counsellor and his support person considered that he had an intellectual disability.

> **Support person:** He's got numerous ones [disabilities] now. His intellect. His hearing. His ability to, um, function without help. He doesn't have that; he needs help… He had meningitis when he was six months old and that did damage the hearing and the brain.

> **Counsellor:** [written response] Intellectual disability, displays symptoms/behaviours of Autism

4.5.3. Counsellors

The five counsellors, four women and one man, ranged in age from 32 years to 58 years. One worked in a counselling agency with a focus on a specific target group. The other four worked in private practice; two of these four also worked for a social service agency which provided counselling as part of its services. The counsellors were experienced in working with people with an intellectual disability. One had 30 years experience working with people with an intellectual disability doing therapy and counselling. Another counsellor had 25 years working with people with an intellectual disability in another human service occupation and 3 years of counselling. Another counsellor had worked off and on for 38 years in other human service occupations and for 6 years in counselling. One counsellor had seven years of counselling clients with an

intellectual disability. One counsellor had four years experience working with people with an intellectual disability both in counselling and in another human service occupation.

4.5.4. Support people

The four support people, one man and three women, ranged in age from 44 to 69. Two were family members who had known the clients since their birth. One was a friend who had known the client for seven years and considered the client to be like "an extension of my family." One was a paid support person who had worked with the client for nine years.

The support people were keenly interested in the well-being of the clients. They invested themselves in the clients' lives, juggling their own limitations and the clients' needs. These two support people describe this juggling as follows:

> **Support person:** I try to keep in touch just whenever I can. And stay reasonably close to where she's at and what she does in the house, without getting too involved or interfering… I'm forever feeling guilty that I don't offer sufficient time to her. I don't have her over at my place often enough. Whenever I'm having a, a family gathering I will always include [Client], …even though it's a bit of a hassle sometimes [laughs]….she just loves family, so.

> **Support person:** I love [client and family]…but sometimes I need a break from them… because I contact them every day.… Sometimes I do find it quite draining.… We'd never want them to know how draining they are.

4.5.5. Key informants

The four key informants, three women and one man, ranged in age from 44 years to 55 years. Two worked for residential and advocacy services and two worked for mental health/behavioural services. All held tertiary degrees and had considerable experience working with people with an intellectual disability. One had worked with people with an intellectual disability for seven years, the second for 15 years, the third for 20 years and the fourth for 36 years. One key informant worked for an organisation that provided services for 60+ people and the others worked for organisations that provided services for 200+ people.

The key informants demonstrated a high level of commitment to the people who used their services. They expressed satisfaction in their work.

> **Key informant:** It is really satisfying work. They're so, um, interesting to work for, with [sic]. And you learn so much about yourself and so much about human beings and ethics.

As the following conversation illustrates, they devoted personal time to improving the outcomes of people with an intellectual disability.

> **Marilyn:** So your job includes training or educating as well?
> **Key informant:** No. No. This is just a sideline. …
> **Marilyn:** Can I ask, how much time outside of your paid hours do you spend in this work?
> **Key informant:** Oh, it also varies…Oh, I guess most days I'd be here until about 6 or 7 and a bit of weekend time. Half a day maybe.

They also demonstrated this commitment as they struggled to meet the wide range of needs despite having limited resources.

> **Key informant:** For example, if I want to do it [respond to a particular need]. I would have to take time out of here. We're already so thin on the ground here. I would struggle.

4.6. Recruitment process: Inviting participants into conversation

The project began with three distinct groups of participants — counsellors, counselling clients, and support people. Each group received their invitation to participate from a different source. I contacted counsellors directly, explained the project to them using the information sheets and answered any questions that arose. Counselling clients were then invited to participate by their counsellors. Support people were invited to participate by the counselling clients. There was one exception to this format; through an organisation called "People First" I made the acquaintance of one counselling client who was interested in participating in the project. In this case, I contacted the client directly and then also spoke with the client's counsellor.

4.6.1. Finding and inviting counsellors

At the time this project received ethical approval I was acquainted with only three counsellors who were currently working with clients with an intellectual disability. In

November 2006 I began networking with other professionals to see if they knew of any other counsellors who might be interested in this project. Networking included phone calls, face to face conversations, as well as a presentation at a local counselling centre. Through these contacts I discovered two other interested counsellors, making a total of five counsellor participants.

Although some counsellors were previously known colleagues and others were first time acquaintances, the initial conversations about the research project were handled similarly. After introductions and initial pleasantries, I showed the counsellors the information sheet and we discussed any issues or questions that arose. The counsellors agreed to consider their existing clients and discuss the project with clients whom they thought might be interested in helping with the project. The client was then given time to consider whether or not they wished to know more about the project. After obtaining consent from the clients, I then met again with the counsellors and obtained their written consent.

4.6.2. Inviting counselling clients

When a counselling client expressed interest in knowing more about the project, I was then introduced to the client. In three cases I was introduced by the counsellor. In two cases I arranged initial contact with the client through a support person at the client's residence. In the case mentioned in the previous paragraph, I was already acquainted with the client.

The initial meetings with all six counselling clients were handled similarly. After introducing ourselves and exchanging a bit of small talk, I asked the clients what they knew about the project. Then I read the information sheet to them and discussed any issues or questions that arose. Each potential participant was informed that it was their right to decide if they wanted to help with the project. They could say yes or no. I met six counselling clients and all six were interested in participating in this study.

It is my view this high level of interest at this point occurred because of the slow and careful recruitment process. One concern of the HDEC ethics committee was that the

participants had enough time to think about their involvement in the project. Each of the participants considered that they had had ample time. For example, in one case I emailed an interested counsellor at the end of October 2006. We met in November 2006 to discuss the project in detail. However, it was not until 13th April 2007 that I was introduced to her client. In another case, I met with a counsellor in January 2007 and met that counsellor's client in May 2007. Some delays occurred because of the counsellors' desire to avoid interrupting the counselling process. They chose to introduce the research project at a time that was suitable for their client. Some delays occurred because of the clients' need for ample time to come to a decision about participation. While this lengthy recruitment process may be perceived as inefficient or time consuming, it worked to create a relationship of trust between the counsellors, the clients and me.

4.6.3. Inviting support people

Recruiting support people was a straightforward process that did not involve networking or long waits. The support person was chosen by the client and was initially approached by either the client or the counsellor. For five of the six clients, after the client had completed the consent process, I simply asked if he or she could suggest a support person who might be interested in helping with the project. Two clients opted not to have a support person. Two clients spoke to the support person and then we arranged meeting so that the client could introduce me to their support person. The fifth client told me the name of the support person and I made contact on my own with that support person. For the sixth client, I was introduced to the client and support person at the same time by the counsellor.

Prior to our initial meeting the four support people received information regarding the project. In three cases, the support person had discussed this project with the counsellor. In the fourth case, I emailed information sheets to the support person prior to our initial meeting.

Though the introduction processes varied, the initial meetings were handled in a similar manner. After introductions and pleasantries, we discussed the project and then

completed the consent forms. All four support people were keen to participate in the research, readily gave their written consent, and the rest of the conversation was then recorded as the first interview.

4.6.4. A new participant group: Key informants

The initial project design called for five to six counsellor/client/support person trios. On 17th December 2007, this particular recruitment journey ended. I had now recruited four counsellor/client/support person trios and two counsellor/client duos. Almost 14 months had passed from the time of the initial submission to the ethics committees until the completion of this recruitment phase. There were many times during those 14 long months when I wondered if I would be able to find the number of participants that I desired. Fortunately, time did not run out; instead, time gifted me. This slow pace of recruiting gave me ample time to ponder the overall direction of the project.

4.6.5. Inviting key informants

During this time, in communication with both ethics committees, I decided to invite 'key informants' into the conversation. Because this project already included a large number of interviews, it was not feasible to interview more than four or five key informants. Because I had a number of contacts in both the mental health sector and in the disability sector, the difficulty was not finding suitable people to interview, but rather making choices about which people to interview.

I began by inviting two key informants from two government-funded agencies which provide mental health and behavioural support to people with an intellectual disability. I next contacted three key informants from disability support organisations. These contacts were made by phone and by email. Four key informants agreed to participate.

4.7. Consent process

Obtaining informed consent relies on the researcher's ability to communicate with participants. "Informed implies understanding and free consent implies a lack of

pressure" (New Zealand Association of Counsellors, 2002, p. 28). These underlying principles of informed consent remained the same for participants with an intellectual disability and for those without an intellectual disability. However, the methods used to monitor the effectiveness of communication differed as well as the time needed to convey new information.

4.7.1. Clients

Establishing ethical researcher-participant relationships

Counselling research upholds the same ethical principles as the counselling process. The welfare of the client, the quality of the collaborative alliance and the importance of informed consent and confidentiality are central to the counselling process as well as counselling research (New Zealand Association of Counsellors, 2002). Traditionally counselling has been considered "a collaborative process" or "working alliance" that is established between a client and a counsellor (Manthei, et al., 2004). Counselling research is also a collaborative process and "the quality of the researcher-informant relationship is of critical importance" (McLeod, 2003, p. 72).

Although people with an intellectual disability have been research participants for many decades, researchers have held differing views concerning the nature of the researcher-informant relationship. People with an intellectual disability have frequently been viewed as participants to be researched about (e.g., Clarke, 1991) and occasionally even researched upon (e.g., DuBois, n.d.). Increasingly they are being viewed as collaborators in the research process (e.g., Knox, Mok, & Parmenter, 2000). In order to work respectfully with people with an intellectual disability, I paid special attention to issues of informed consent, confidentiality and communication.

Obtaining voluntary, informed consent from people with intellectual disabilities involves important ethical considerations because of their vulnerabilities. People with intellectual disabilities often have fewer opportunities to acquire ordinary knowledge (Bray, 1998; Finlay & Lyons, 2001). Because they often have a reduced vocabulary and difficulty with abstract concepts, I took care to check their understanding of words such

as confidentiality and anonymity. Because they may not know what research is and how it might affect their lives, I took time to explain the nature of research in general, as well as the details of the specific research at hand. Because I was doing research that involved more than one interaction with the participants, I viewed informed consent as a process, rather than a one-time initial event. This strategy of "on-going consent" offered opportunities for making better-informed choices regarding participation (Knox, et al., 2000).

Because people with an intellectual disability often acquiesce to the requests of those perceived to be in authority (Bray, 1998), I chose an informal conversational style during the interviews. I endeavoured to establish relationships that were reciprocal rather than hierarchical. Reciprocity involves "the give and take of social interactions" (Harrison, MacGibbon, & Morton, 2001, p. 323). During the interviews I followed the social conventions present in other walks of life. For example, when the interviews took place in their home, I considered myself a guest and often brought flowers or baking as guests do in other contexts. When the interviews took place at other locations, such as cafés, then I was in the role of a host and the participant was the invited guest. As host, I paid for the cuppa. Another aspect of this informal, conversational style was that the interviews included discussion about non-research related topics such as, the weather, television shows, and so forth. The quantity of this rapport building conversation differed according to participant's conversational style.

In addition to bearing in mind professional counselling ethics, I also took into account the Code of Health and Disability Services Consumers' Rights. Here in New Zealand disability research falls under this code of conduct. In addition to the rights of informed consent, confidentiality and effective communication, research participants have a number of rights including the right to dignity and independence and the right to support (Health and Disability Commissioner, n.d.).

The on-going consent process

After having met once with the client to discuss the project, I then met with them to go over the consent forms. I began the consent interview by obtaining permission to record

this particular conversation. (The consent form can be found in Appendix D.) After obtaining consent, the remainder of our conversation was recorded. I then read the consent form to them. In order to check the effectiveness of our communication, from time to time I asked them to tell me in their own words what I had read to them.

Illustrative examples from two clients

Example 1:

> **Marilyn:** [Reading consent form to participant] "Information about my counselling is private." Do you know what the word private means?
>
> **Client:** Yeah. Private means uh. You got things to yourself and no one else is to know.

Example 2:

> **Marilyn:** So can you tell me in your own words what this study is about.
>
> **Client:** It's about, um, counselling
>
> **Marilyn**: Umhm. And what sorts of things do you think I want to find out about counselling?
>
> **Client:** Um. How it helped me.

However, even after being told about the study by their counsellor and then again in the information meeting with me, there were still gaps in the participants' understanding about the project. When the gaps were uncovered, I attempted to fill them in.

> **Marilyn:** Okay. The next bit is [reading the consent form] I understand the information I have been given.
>
> Client: Yep.
>
> **Marilyn:** Yep, can you tell me what the study is about?
>
> **Client:** Um. [Pause] oh [Pause]
>
> **Marilyn:** Do you remember?
>
> **Client:** No, not really.
>
> **Marilyn:** What would be your guess?
>
> **Client:** My guess would be um [pause]. Oh. [Pause] No. It's gone.
>
> **Marilyn:** It's gone. But it's about counselling, it's about what you're doing with [name], right is that how you say his name?
>
> **Client:** [repeats name].
>
> **Marilyn:** [name]. So this study is about counselling and it's so that people who are in counselling can tell us what it's like. So when, in the end, hopefully, we can know how to help counsellors do a good job.

In this example, although I had re-explained what this study was about, at this stage it was not clear how much this participant understood regarding the overall nature of this project. What was clear was that this participant was willing to talk to me and was willing for me to talk to his counsellor and his support person.

During this interview participants were also told about their rights to complain and were given information about the Health and Disability Advocates. This initial process of reading through the consent forms took about half an hour for each client and was the main focus of the first recorded interview. At the end of this interview, I asked each participant if they were still happy to have this conversation recorded; all six said yes. If they had said no, I would have erased the recording right then.

Because I consider informed consent to be an on-going process rather than an initial one-off event, I used strategies throughout the project to confirm their continuing consent. For example, we worked together to determine which parts of the conversation were recorded and which parts were not recorded. Many participants preferred not to record the conversation while we were sharing a cuppa. To give more control to participants, I showed them how to turn on and off the digital recorder and then I offered that they could be the ones to turn on and off the recorder.

Additionally on occasions when participants looked worried or concerned, I checked back with them to see if they wanted to carry on and tried to learn what sorts of things elicited the worry.

> **Marilyn:** Yeah? You don't look as comfortable as you did when we were having the cup of coffee.
>
> **Client:** Yeah, that's alright.
>
> **Marilyn:** Is it this tape recorder or this one? [Pointing to the questionnaire.]
>
> **Client:** Oh it's okay.
>
> **Marilyn:** Okay, okay, alright, we'll carry on. Um, what schools did you attend as a child?

Later on in this same conversation, we had the following exchange:

> **Marilyn:** … I'm just curious, because you do look a lot more relaxed now, was it that I was writing down that you didn't like?
>
> **Client:** [pause] Um…yeah because I just, um, talking about my life.

> **Marilyn:** Oh talking about your life is what made you – okay. Okay, cos – well thank you for doing that even though it was a bit hard, that just helps to understand a bit about what people's life's are like.

And a few minutes later,

> **Marilyn:** Was it was it okay that I was writing things down?
> **Client:** Yeah.
> **Marilyn:** Ah, so it was mostly thinking through all the stuff that was hard. Okay.
> **Client:** Sometimes I try and block it out.

Another strategy for confirming on-going consent was the provision of research updates. During the course of the project some additions and changes were made. The research updates informed participants of these changes, and when appropriate, requested their permission to implement changes. For example, I had a change of supervisors and wished to update the participants about that. At the same time I asked their permission to have someone other than me transcribe the interviews. A sample research update can be found in Appendix G.

The notion of on-going consent also meant that I did not take for granted their continued participation. After each interview I thanked participants for sharing their time and asked if they were happy to meet again. Then we scheduled the next meeting or organised to be in touch later by telephone. Five of the six participants carried on until the study ended. One participant chose to end his participation after three recorded interviews.

4.7.2. Counsellors, support people, key informants

Because these participants could read and write easily, filling out the consent forms took place quickly and was not the focus of the first interview, as it had been with the clients. Nevertheless, I still attended to the importance of clear communication and the on-going consent process. I fostered an atmosphere that allowed both the participants and me to ask for clarification when needed.

As with the clients, I did not take for granted the continued involvement of counsellors or support people. After each interview I thanked them for sharing their time and asked if they were happy to meet again. Then we scheduled the next meeting or organised to be in touch later by telephone. During the course of the study, one support person's health declined and she was relocated to a nursing care facility. This support person was keen to participate in the study, but was only able to be interviewed over a four month period due to health problems. All the counsellors and the other three support people remained involved through the course of the project.

4.8. Data collection strategies

4.8.1. Which words are research data?

Qualitative data are "usually in the form of words" (Miles & Huberman, 1994, p. 1). The participants and I shared many words with each other. Some words were saved in writing, some saved in audio recordings, some written as field notes, and others saved only in our memories. Like many researchers, I had the experience of participants saying fascinating things either just before or just after the recorded portion of an interview. Are all the words we shared considered research data?

Early on in this project I decided that research data would only consist of information that I had been given explicit permission to use. In the initial consent process, participants gave me permission to collect information by recording our conversations and transcribing those conversations. They also gave me permission to use information that they gave me in writing. Thus information gathered outside of those contexts was considered "off the record" and was not considered to be research data. In cases where participants disclosed interesting information off the record, I explicitly asked them if they were willing to have those words in the project; then they were asked to repeat what they had said with the recorder turned on.

4.8.2. Questionnaires

After obtaining initial consent from participants, the next step for them was filling out a questionnaire. The questionnaires can be found in Appendix E. The purpose of the questionnaires was to gather demographic data and to open discussion about counselling and disabilities. Some participants answered the questions orally; others wrote down their answers. Once again, there was a noticeable pacing difference between participants with and without an intellectual disability. For the participants with an intellectual disability, the questionnaire was the main focus of our second recorded interview. For the other participants, the first interview included the consent process, the questionnaire as well as discussion on other topics.

With one exception, the questionnaires were completed during a recorded interview. One participant filled out most of the questionnaire during the interview but wanted more time to think about some of the answers. The completed questionnaire was then posted to me. As they were filling out the questionnaires, participants typically made spontaneous comments and/or asked questions. Therefore, I was able to gather richer data than had I only received written responses to written questions. For example, spontaneous remarks from counsellors highlighted the complexities surrounding the term "counselling."

> **Counsellor:** [reading questionnaire] years of counselling experience [pause]. What do I put there? Because, um, this is my first year, if you like, of actually uh practising as a counsellor. I've done, of course, two years of practical work during my training and I did pastoral counselling. I've done that forever probably [laughs].

4.8.3. Interviews

The primary means for collecting data was through recorded interviews. A few pieces of publicly available written information were included as data, with the permission of the participants. I conducted 72 recorded interviews with 19 participants (totalling 54 hours 53 minutes).[18] Interview schedules can be found in Appendix E. Just as my counselling

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[18] One client was known to have "sexual problems" In order to reduce the risk of inappropriate situations arising, a co-investigator was present with me during all but one of the interviews with that client. On one occasion the co-investigator was unable to attend the interview. The addition of the co-investigator was done with the approval of the two ethics committees.

practice tends to be strengths-based and systems focussed, so, too, the interview topics included questions about what is working well in the counselling sessions as well as questions about factors outside of the counselling process.

Prior to conducting the recorded interviews, I met with participants to talk about the research project. These unrecorded conversations were not used to collect research data; however the conversations helped to shape the researcher-participant relationship. They also served to highlight, once again, that it takes time to supportively include participants with an intellectual disability. I am grateful for the counsellors and support people who spent hours of their time supporting participants so they could comfortably participate. For example, at the request of the client, one counsellor attended the first two research interviews. At the close of the second interview the client was then comfortable to have a meeting with just me. In another example, a counsellor had arranged to introduce a client to me. The counsellor and I arrived on time at the café and awaited the arrival of the client. While we were waiting, the counsellor seemed confident that the participant would arrive. And indeed, after waiting 45 minutes the client, who had gotten lost, arrived.

4.8.4. Interview summaries

The participants were offered an opportunity to read the transcripts and make any necessary corrections or additions. Because the clients had difficulty with reading, I prepared written summaries of the transcripts. I read the summaries to the clients and they were given an opportunity to make corrections or additions to these summaries. A sample interview summary can be found in Appendix F.

Reading the interview summaries to the clients proved to be a time-consuming but valuable process in the data collection. They seemed to enjoy hearing their words read back to them and at times would elaborate on the information originally provided.

> **Marilyn**: [Reading summary] …and you told me about your family. You have a big extended family [written summary sentence ends here] with cousins and stuff?

Client: Um. Um. Yes. I have. Um. My mum's got nine on her side and my dad's got uh five original no four original…on his side and then my nana married… and she had nine kids all up. Altogether.

Marilyn: Wow.

Client: …I've got a lot of family.

Marilyn: You got a lot of family

Client: A lot of relatives but we have nothing to do with our relatives at all.

This particular client had told me previously about the large extended family. By discussing it again in response to the summary, the client responded by elaborating on the previous description. This iterative process of conversing, then later hearing a summary of that conversation, and then conversing again enabled clients to be more articulate than had they been given only one opportunity to speak about a given topic.

4.9. Data analysis

The data were gathered and analysed in keeping with the overall intention of this project — to inform counsellors and other mental health professionals about how they might work more effectively with this client group. Qualitative data analysis "involves a kind of transformative process in which raw data are turned into "findings" or "results" (Lofland, et al., 2006, p. 195). Numerous schools of thought exist regarding the procedures for turning raw data into findings. As demonstrated by Slaughter et al. (2007), not only do different methods of analysis produce different findings, but even researchers using the same method of analysis view the data differently. Had this data been analysed by a different researcher or by using a different method of analysis, the subsequent findings chapters may well have looked different. In fact, I, myself, could have organised the data differently using the same method if I had chosen a different research focus.

The first step in the data analysis process was to transform face to face conversations into digital audio recordings. The audio recordings were then transformed into written transcripts.[19] Although a given interview progressed through the analysis process in a

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[19] I transcribed 28 interviews and portions of 3 interviews. A professional transcriber completed the 3 partial interviews and transcribed the remaining 41 interviews. After receiving those transcripts, I listened to the interviews to ensure accuracy. I made occasional corrections to the transcripts when necessary.

relatively linear fashion; my own experience was far from linear. There was a period of time when the processes of gathering data, transcribing interviews, and analysing data were happening concurrently. Thus each process served to inform the other. For example, when transcribing interviews, I noticed ways to improve my interviewing skills. For example, I learned to leave longer time intervals after asking questions. Also, the process of analysing data highlighted areas to be explored during subsequent interviews.

The data were organised and managed both manually and by electronic means using a software programme called NVivo 8. Similar to numerous other software programmes,[20] NVivo 8 functioned as a time-saving tool; it enabled me to sort and code data electronically.

The analysis of the written transcripts incorporated the general principles of generic qualitative analysis (McLeod, 2001b, pp. 130-160) and the processes of qualitative content analysis (Graneheim & Lundman, 2004), thematic analysis (Braun & Clarke, 2006; Gibson & Brown, 2009) and case descriptions (Yin, 2003). As with many methods of qualitative data analysis (e.g., McLeod, 2003, pp. 84-85), the first step was to immerse myself in the data. In so doing, I noticed the nuances of the researcher-participant relationship. For example, we mutually encouraged one another. I found many instances where I encouraged participants.

> **Marilyn:** So you can give me any ideas you have on doing it better, okay?
> **Client:** Well I'm not an expert in counselling, you know.
> **Marilyn:** Oh no, no. But you are an expert on being a research participant.
> **Client:** Yeah. I could do that.

I also found many instances where participants encouraged me.

> **Marilyn:** Yeah. So do you have anything else that you think would be good
> for me to know today about? About how things are for you guys or about
> counselling, or anything you wish you could tell counsellors?

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[20] NVivo 8 was one of many software programmes that I used during this project The following software programmes were also invaluable during the course of this project: Microsoft Word 2003, Excel 2003, Endnote X2, DragonNaturally Speaking 9.5, Olympus Digital Wave Player, Olympus DSS Player, Internet Explorer 7, and Safari 4. I would be remiss if I failed to mention Windows XP, the software which operates the computer.

Client: [Pause] Just you need to keep up the good work.

As practitioners we are frequently told that counselling clients do what they can to help out their counsellors. Perhaps research participants behave similarly.

After immersing myself in the data, the next step was to identify content areas and organise the data accordingly. My interpretation of counselling values and principles provided the framework that shaped the design of this study. Similarly, my interpretation of the counselling process framed how I organised the data. Figure 2 illustrates how I viewed the counselling process.

```
┌─────────────┐   ┌─────────────┐   ┌─────────────┐   ┌─────────────┐   ┌─────────────┐
│ Presenting  │ ▶ │ The referral│ ▶ │ Engagement  │ ▶ │ Termination │ ▶ │  Outcomes   │
│  problem    │   │  process    │   │     in      │   │             │   │             │
│             │   │             │   │ counselling │   │             │   │             │
└─────────────┘   └─────────────┘   └─────────────┘   └─────────────┘   └─────────────┘
```
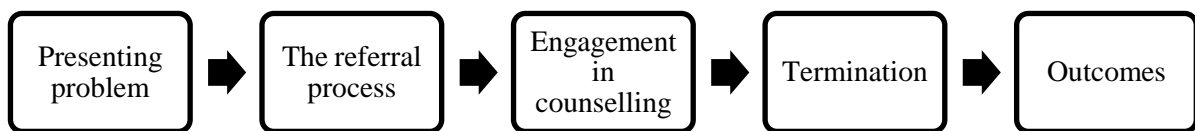
Figure 2: The counselling process

I view counselling as beginning with a reason for seeking counselling. This is frequently referred to as "the presenting problem" (Gladding, 2001, p. 94). Next comes the process of choosing to pursue counselling and then looking for a counsellor. Sometimes this process is initiated by the client (self-referral) and other times the referral process is initiated by a professional involved with the client, or by a family member or friend of the client. Once a counsellor has been found, a client and counsellor engage in the counselling process. At some stage, the work of counselling comes to an end and the counsellor and the client disengage from the counselling relationship. This process is referred to as "termination" (Gladding, 2001, pp. 120-121). Throughout counselling and most notably at the end, there is hope for positive outcomes. Using the principles of content analysis and thematic analysis I organised the data from all 19 participants into these five content areas. I then coded or, as described by Graneheim and Lundman (2004), I looked for "meaning units" (p. 106). I then condensed these meaning units and generated themes in each content area.

According to Braun and Clarke (2006), "a theme captures something important about the data in relation to the research question, and represents some level of patterned response or meaning within the data set" (p. 82). I analysed the themes by: (a) examining commonality, (b) examining difference, and (c) examining relationships (Gibson & Brown, 2009 p. 128-129). For example, one theme that was common throughout my data was financial concerns. Within the one theme, commonalities and differences were examined as well as how financial concerns were related to other themes.

In addition to organising the data into the five content areas related to the counselling process, I also went through all the interviews and organised the data according to the two research questions: (a) "What is a disability?" and (b) "What is counselling?" Once again, the data were coded and themes were generated.

Because I was interested in learning about factors outside of the counselling process, I also organised the data according to the four participant groups and looked for content areas within each group. The content areas were then analysed following the processes described in the previous paragraphs. During this organisational process, there was some repetition of what had been explored using the counselling process framework. However, rather than focussing solely on the counselling process, I concentrated on the environment surrounding the counselling. I wanted to understand the commonalities and differences in the environments of each of the participant groups.

Appendix H includes a coding example and several diagrams which illustrate the various ways the data were organised and the themes which were derived from each content area.

4.10. Data presentation

The final phase of thematic analysis is producing the written report in which the researcher "tell[s] the complicated story of …[the] data (Braun & Clarke, 2006, p. 93). During this phase I pulled the content areas together to address the research questions

and chose extracts from the data which illustrated the themes drawn from those content areas. Appendix H includes diagrams which illustrate how content areas were pulled together to write the participant descriptions (Section 4.5, pp. 67-76) and the three findings chapters (Chapters Five, Six and Seven).

Chapter Five presents findings related to two research questions that were asked on the questionnaires: (a) "What is a disability?" and (b) "What is counselling?" The questionnaires can be found in Appendix E. In addition to providing direct answers to those questions, the participants also volunteered comments related to those topics throughout the interviews. In this chapter the findings are presented using the collective voice of each participant group, thus obscuring individual voices.

Chapter Six presents findings related to the question, "Is counselling different for clients with an intellectual disability?" In this chapter, the findings are presented thematically, focussing on the similarities and differences in providing counselling to clients with and without intellectual disabilities. In order to highlight these themes, individual stories have been broken apart, thus losing the uniqueness of each case.

Chapter Seven presents findings related to the question, "Was counselling effective for these six clients?" The chapter begins by re-assembling the six cases and giving the reader a glimpse once again into the individual lives of Tom, Margaret, James, Ian, Kaye, and Roger. Just as the initial participant descriptions needed to balance descriptive detail and participant privacy, so, too do these final participant descriptions. After briefly describing the outcomes of Tom, Margaret, James and Ian, this chapter presents two cases studies, Kaye and Roger. These case studies illustrate the themes presented in Chapters Five and Six.

These two case studies were written using a strategy that Yin (2003) called "developing a case description" (p. 115) with the intention of highlighting features of interest to counsellors. Professional counselling practice has the tradition of presenting case studies in order to inform other counsellors. A book written to teach trainee counsellors about writing case studies has stated: "Case studies should highlight learning on behalf

of the therapist…The main utilisation of a case study will be to enable other professionals to monitor and comprehend the process" (Papadopoulus, Cross, & Bor, 2009, p. 4). Counselling case studies are traditionally presented from a single perspective, that of the counsellor. However, in case study research, the consideration of different perspectives is a characteristic of an exemplary case study (Yin, 2003, p. 163). Merging these two traditions, these two cases are presented from multiple perspectives with the aim of informing other professionals.

Because the aim of this thesis is to explore an understudied phenomenon from multiple perspectives, it is necessary to differentiate these vantage points. Such differentiation allows for exploration of similarities and differences. However, differentiating the views of four participant groups introduces the possibility of repetition or confusion. At this point I must ask for the reader's indulgence. At times, the reader will encounter similar material four times and I invite the reader to attend to the nuances in each description. Other times the reader will encounter one theme presented from multiple perspectives. To minimise potential confusion quotes from the research interviews begin by identifying the speaker.

Chapter Five: Participants' understandings of disability and counselling

5.1. Introduction

The aim of this chapter is to introduce the reader to the participants and to explore their understandings of the nature of disability and counselling. I consider familiarity with participants and their understandings to be foundational for exploring the remainder of the findings.

5.2. What is a disability?

5.2.1. The clients' perspective

While two of the clients were hesitant about this concept, (One thought maybe it had to do with "something wrong with your brain." The other client talked about this notion in regards to physical differences, "people with wheelchairs and stuff.") The other four clients recognised the word disability and talked about it both conceptually and in relation to themselves.

The clients' understanding of disability relied on an elusive benchmark known as "normal." When one's performance did not measure up to that standard, one was viewed as having a disability.

> **Client:** Disability is someone that have problems in actually performing something they cannot perform properly…They just do things more slower than the normal person does…They do not understand too well, so you got to explain to them in plain language.

This elusive benchmark of "normal" was not just a concept for them; it featured in their lived experience.

> **Client:** I just couldn't learn fast enough…I just couldn't keep up.

When one cannot "keep up" with the norm, one's social experiences are subject to the views and practices of the wider community. Teasing and bullying during both

childhood and adulthood was a recurring theme and had emotional repercussions, as comments from these two clients illustrate.

> **Client:** I was very slow at school and got really teased…So that's why I went into my own little world, because of the teasing.

> **Client:** I had, you know, trouble with learning…and they just put me at the back of the class…I used to get a lot of cheek. Yeah, cos I had a disability… They were making fun at me… I felt awful.

Because this thesis focuses on professional practice, it is of particular importance to note that the views of the professional community have the potential to profoundly affect the lives of those with disabilities, as was the case for these two clients:

> **Client:** Well, when I was born…they sent me to a normal kindergarten. And a specialist there said to my father, [Client's name] is not right. He cannot go to a normal school.… Then the specialist said… You've got two choices…for me to go to a private or a state. … They decided to go private. Going private, of course, cost my father lots and lots of money when I was a child, till I was about 30 years of age.

> **Support person:** He'd had an intelligence test, and he would get no further than 16, they said. And then they said a hearing aid wouldn't help him. Of course it would have helped him…In those days, 20 odd years ago, you believed the doctors were god. And priests were even godder… And I think that [Client's name] has lost a lot through his deafness and he's just sort of sat back and hasn't taken much notice.

Aspects of these interview excerpts encapsulate this participant group's understanding of disability. In plain and simple language their view can be summarised as follows: A disability is when you are "not right." You can't measure up to everybody else and so you need help. The people around you might help you, they might ignore you or they might tease you. Help can be costly. Sometimes you will like the help and sometimes you won't.

5.2.2. The counsellors' perspective

The counsellors viewed disability in contrast to "average" or "able" or "functioning." People with a disability were seen to have difficulty keeping up with their peers.

> **Counsellor:** Either a person has to work harder to do something that the average person wouldn't have to or is unable to do that. … Presumably a condition that makes the person less able or unable to keep up with…most of his peers in whatever areas are affected by the disability which can be global or specific.

Disability was subject to a particular point of view.

> **Counsellor:** Sometimes the disability is perceived differently by different people. It might be perceived differently by me, the doctor, the family member, the person who's got the disability. So I wouldn't like to think that it was set in stone.

One counsellor considered that a disability was permanent rather than temporary.

> **Counsellor:** My own definition of a disability is some aspect of a person's life that they struggle with all the time. It's not like it's a temporary thing. It's a permanent thing.

Another aspect of disability, in particular an intellectual disability, was the need for on-going support. The counsellors expressed concern when this need for on-going support did not appear to be understood by key organisations involved with the clients.

> **Counsellor:** With on-going support, the progress that they've made can be sustained…They[social welfare] need to understand that someone with an intellectual disability is going to need some kind of on-going support for the rest of their lives to avert crises…I think someone like her [the Client] would need on-going support for a long time.

Disability was recognised as having a social component. "Society" was seen to play a role in determining one's acceptance and expectations of one's performance.

> **Counsellor:** A physical or neurological condition that affects effective mobility or social "functioning" and acceptance in society

Because people with a disability have difficulty meeting those expectations, they were seen to be disadvantaged.

> **Counsellor:** I think it is when people are disadvantaged in their society, the sort of society in which they reside. … one of things I think about sometimes is if you have an intellectual disability then you have to work harder and it's probably harder if you're mild or borderline um it's not apparent to other

people that you are having to work a lot harder to solve a particular problem or to carry out a task. And that disadvantages you and you get more frustrated and more tired. You make more mistakes.

Counsellors spoke of the "teasing and vulnerability and exploitation" experienced by people with an intellectual disability.

> **Counsellor:** …you know, you always get teasing and vulnerability and exploitation. But then that's only a percentage of the population that will do that.

As the following quote illustrates, some groups are accepting of people with an intellectual disability while other groups exclude them solely on the basis of their disability.

> **Counsellor:** [Client] does go to a woman's group at the [Church name] … which is accepting of her even though she has a disability. When I asked [another church] if they had anything on offer, I was appalled with their response, Marilyn. They told me that no, she wouldn't be welcome because, um, people in the parish would view her as a danger to their family. And that they didn't encourage people to come along with disabilities for that reason. It would frighten the children.

The counsellors' viewpoint can be summarised as follows: Disability was viewed in contrast to average and was subject to a particular point of view. Inherent in having an intellectual disability was a need for on-going support. Counsellors expressed concern when this need for on-going support was not understood by support services. The counsellors considered that society's acceptance or lack thereof, plays a key role in the social experiences of people with an intellectual disability.

5.2.3. The support people's perspective

The support people also spoke of disability in relation to the elusive benchmark of "normal."

> **Support person:** A disability is someone who can't perform the normal functions socially, mentally, of life as we see it.

The phrase "as we see it" added the nuance that disability is something that is perceived from a particular viewpoint. What is considered "normal functions" for one group of people may be different for another group. Another support person stated this idea more bluntly:

> **Support person:** What is a disability? It's only what other people perceive a disability…People aren't perceived to be the same as what the majority are. Maybe it's a minority thing.

They further implied that inherent in notion of disability was a need for support.

> **Marilyn:** What is a disability?
>
> **Support person:** Something that you can't do to the, um, the full amount. What would you say? You can't, you know, fulfil the things you want to do without help in some way.

Prejudice, discrimination and teasing were associated with having a disability, as these two support people indicated.

> **Support person:** Disability is, [sic] it's like discrimination…Well, we've gone to a picnic somewhere and cleared the area literally…As far as I can see, the majority of people don't want them in the community…I think people are frightened…We're all a bit scared of the unknown.
>
> **Support person:** He was made fun of.

The impact of professional practices can be seen in the following quote:

> **Support person:** Another woman I know, that [Client] know[s] well…She is 20. …She had a baby. … The partner has a disability. She has a disability… While she was in labour, Child Youth and Family went to court and got a custody order of that baby… In the letter that they sent her, while she's in labour, it said that she may appear at the court. But that would have been a bit difficult… I think she had the baby for a day and then they came and took it. …It makes me realise that, you know, we talk about, you know, having equal rights for people but then they're not. … It's so sad. … So [Client], you know, he was terribly upset for [this woman].

The support people's view can be summarised as follows: Disability is viewed in relation to normal, but not everyone perceives disability in the same way. Having a disability means that one has trouble doing what others can do and thus is in need of support. People with disabilities are sometimes subjected to prejudice, discrimination and teasing. Professionals can have a huge impact in the lives of people with disabilities.

5.2.4. The key informants' perspective

> **Key informant:** And what is a disability? Well, that's a big question, isn't it? … You've got the three words, haven't you, disability, impairment and handicap…

This quote highlights the breadth and complexity of this concept and the numerous synonyms used to describe disability. For the key informants, disability existed in relation to a concept that was referred to as "normal" or "mainstream." Disability was seen as a difference that "inhibits" or "restricts" one's life.

> **Key informant:** An impairment that inhibits a person's life in some way

Disability was recognised as having a social component. A person with a disability was subject to the views of "society."

> **Key informant:** Critically, disability is also socially constructed in that society may impose a sense of acceptance or non acceptance, and value/non-value on a person.

Included in their concept of disability was a need for support. Not only did society have a role in determining one's "acceptance or non-acceptance," it also had a role in providing support. "Good support and resources" were viewed as empowering. Key informants described the difference that positive support can make.

> **Key informant:** And whether you are handicapped by something is more to do with society's response to you, isn't it? … How much extra help and resources you get … Blind people aren't necessarily handicapped by their condition if they have lots of good support and resources to do what they want to do.

At times, however, the provision of beneficial support was "just not possible."

Key informant: But that's the lot of being disabled. You live in that world where you are completely dependent on other people making decisions that are going to benefit you. Sometimes in reality it's just not possible. Or sometimes in people's realities, it's just not possible.

The key informants' view can be summarised as follows: Disability was acknowledged to be a complex concept. They, too, viewed disability in relation to normal. Disability was seen as a difference that restricts one's life. Inherent in their concept of disability was a need for support. Society was seen as playing a role both in attitudes toward people with disabilities and in the provision of support. Positive support has the potential to empower people with disabilities; however the provision of positive support is not always possible.

5.2.5. Summary

There was considerable agreement across all four participant groups regarding the nature of disability. That is, disability was perceived and experienced in contrast to "normal." People with a disability are often in need of support. Society plays a key role in their social acceptance and in the provision of support.

Although the four groups expressed these similar themes, their differing perspectives had different nuances. Many of the clients' comments seemed congruent with the medical model, that is, disability was seen to be located within the individual. For example, "I was slow." "Something is wrong with your brain." The clients talked about the wider community's response to them, and they experienced situations where support enabled them to reach their goals as well as situations when lack of support meant they couldn't achieve their goals. However, they did not seem to locate disability within society. Given the prevailing attitudes during their childhood years, this frame of reference is not surprising. Professionals, family members and the wider community repeatedly located disability within the individual. "A specialist there said to my father, "[Client's name] is not right." "Mum put me on a disability allowance … when I was 15 or 16."

On the other hand, the key informants, counsellors and support people, perceived disability as located both within the individual and within society. Some talked specifically of clear diagnostic criteria, thus locating disability within the individual, but also expressed concern about the socially-constructed barriers that were faced by people with an intellectual disability. Others expressed discomfort with formal diagnoses, but acknowledged that individuals had disabilities and differences. They, too, talked about the barriers that existed within society. The perceptions of these three groups seems to be most congruent with the "third movement" (e.g., Thomas, 2002), that is, that disability is a lived experience that involves both personal impairment and barriers created by society.

5.3. What is counselling?

5.3.1. Introduction

There is significant debate in the literature regarding the effectiveness of counselling for clients with an intellectual disability. Underlying this debate is the question of whether these clients have the ability to understand and derive benefit from primarily talking-based therapies in contrast to therapies which are primarily behavioural. Engagement in counselling relies, to some degree, on one's understanding of its nature and purpose. Therefore, it is important to explore what these six clients understood counselling to be.

5.3.2. The clients' perspective

All the clients considered that counselling was talking to someone about problems or issues with the expectation of receiving help. Here is what four different clients had to say about counselling and problem solving:

> **Client:** Counselling is…to help you deal with a problem… It's someone to listen to you.

> **Client:** It's a person that you go to get help and sort out stuff in your life.

> **Client:** [Counsellors] Listen to what you've got to tell them and then…try and give you a hand, sort out what your problem is out.

> **Client:** It's about solving problems, your own problems.

Although they expected to receive help from their counsellors, the clients did not expect the counsellors to solve the problem for them. The clients viewed themselves as having an active role in the counselling process. Counselling was viewed as a working alliance. And, according to these three clients, counselling is not easy; it "takes a lot of work."

> **Client:** When you go to counselling your [counsellor] is helping you but you are also helping yourself as well. As I was saying, get all these advice and you got it all, you've got to work on it.

> **Client:** Because it takes a lot of work …to get over things…It took a lot of work to talk about all the problems.

> **Client:** We get given homework at the end of each group. … It's usually…either draw some pictures or write something… I got a few wee challenges out of that one…Sometimes it can be difficult to… start putting things in place.

Although a few clients mentioned that their counsellors sometimes used diagrams or drawings, the clients considered counselling to be primarily a talking therapy. The following six quotes, one from each client, describe counselling as talking with the counsellor.

> **Client:** I just tell her what's been going on and tell her what I'm doing and ah um if I have any problems or anything you know.

> **Client:** We talk about how things have been going the past month … is there any problems. Talk about my anxiety.

> **Client:** I just talked to [Counsellor] … and then [Counsellor] talked to me.

> **Client:** That's more like just talking and usually I'll explain you know how things, try and catch up and stuff about how things have been going at the house here and - and all that so yeah.

> **Client:** We talk about our … life history, and get them all sorted out.

> **Client:** If I have any trouble with my family or if I'm under a lot of stress and strain I can talk through it.

Counselling is not only about solving problems; it is also about hopes and dreams. For example, two clients hoped to move into their own flats. Another client hoped "to be more happy." This process of sorting out problems and talking about hopes and dreams was viewed as private and confidential. The counselling relationship was viewed as "separate" or different to other relationships.

> **Client:** I keep it separate from my family because I don't want my family to know that I'm stressing out too much…If I got anything worrying me, I can tell my counsellor and she doesn't tell no one else. None of my extended family or nothing like that. She keeps it confidential.

In summary, the clients viewed counselling as talking confidentially to someone about problems with the expectation of receiving help. They understood that counselling involved work on their part. They were working together with the counsellor to solve their problems. Counselling was also a venue for exploring hopes and dreams.

5.3.3. The counsellors' perspective

The counsellors viewed counselling as having a variety of approaches which shared a common purpose and values. The purpose was to help clients with their problems.

> **Counsellor:** There is a wide range of therapeutic approaches all aimed at helping the client cope better with whatever their problems or issues.

Shared values included empathy, respect and safety.

> **Counsellor:** Providing an empathic, respectful and safe environment to explore self, "issues," and hopes

They viewed counselling as a professional practice which incorporated a body of knowledge.

> **Counsellor:** The provision of a service based upon best practice guidelines which aims to reduce problematic or distressing behaviours, thoughts or emotions for the client.

However, some of the counsellors also felt that they had provided counselling in other professional roles prior to receiving formal counselling training.

Counselling was seen as a working alliance. The clients were viewed as active participants in the change process:

> **Counsellor:** It's more really to work together; I can't help her to change unless she helps herself.

> **Counsellor:** Counselling [is]…listening to what they say, noticing their body language and walking with them, once they've evaluated where they're at, and how they got there and how they would like to have things differently…and then walking with them as they explore the things they can do to address those issues.

Personal growth and increased self-awareness were considered integral parts of counselling.

> **Counsellor:** It's always been to get them to know themselves…to look within and expose themselves to themselves…to allow them to see their core and how beautiful it is.

In summary, counsellors viewed counselling as a professional practice with many different approaches but shared purpose and values. The purpose was to establish a working alliance with clients in order to help clients "cope better" with their problems or issues and to increase their self awareness.

5.3.4. The support people's perspective

These four support people viewed the counselling as an avenue for obtaining help to manage difficult circumstances, as illustrated in the following two examples.

> **Support person:** We discussed that all at the time, when we thought, how are we going to handle [pause] the situation? So it was decided first up that the counsellor could take her, then maybe too, as a side issue, that she, um, [pause] she was shown, or made aware of the seriousness of it.

> **Support person:** And I needed help quickly…And I wanted the counselling, you know, to provide, to stop him doing it and why and you know.

Having a counsellor's assistance in difficult circumstances was much welcomed.

> **Support person:** Well, there's always issues…It was… a relief to me…I've always been an ear for [Client] anyway, but I didn't want to be the counsellor. I didn't want to know everything.

They considered that counselling was intended to help people with their problems; it was considered to be professional and confidential.

> **Support person:** I think it helps people with their problems. If they've got problems they don't want to discuss with other people, other than, you know, one private person.

> **Support person:** I see counselling as, um, [pause] a discussion with a, ah, a professional person [pause] who has the ability to read the situation and offer [pause] appropriate guidance.

Counselling was also viewed as an avenue for increasing personal insight.

> **Support person:** What is counselling? … well for [Client] to improving…quality of life…a better understanding of himself

Counselling was viewed as confidential between the client and the counsellor, but roles of the support people as well as their experiences of the lines of confidentiality were varied. Two of the support people were involved in the referral process and seldom engaged with the counsellor regarding the process.

> **Support person:** And, of course, I was never privy to any of the counselling with [Counsellor's name].

Another support person was involved in the referral process and maintained regular contact with the counsellor regarding the well-being of the client. This support person was not privy to the content of the counselling sessions, but maintained communication with the counsellor. The fourth support person participated in review meetings with the client and counsellor and provided on-going support as the client attempted to integrate new skills.

> **Support person:** Our job is to, well to listen and talk, you know. I'm, I always, you know, I say "good side, bad side?"… Or he'll come to me and

he'll say – like he came home from [counselling] yesterday and he'd said,
"Oh I'll need to talk to ya," you know, and he told me what had happened.

In summary, the support people viewed counselling as helpful support during difficult circumstances. Counselling was viewed as a professional practice that was intended to help people with their problems.

5.3.5. The key informants' perspective

Counselling was viewed as a helping profession. Their understanding was that counsellors possessed a knowledge base and skills which were used to help people with problems or issues.

> **Key informant:** Application of psychological knowledge to help people

In particular, providing counselling for people with an intellectual disability was considered to be "a pretty specialised field."

Counselling was viewed as a process that happens within the context of a "therapeutic relationship."

> **Key informant:** Broadly it encompasses a process of empowering, guiding and framing life experiences and beliefs of individuals, within the context of a therapeutic relationship based on warmth, congruence and empathy.

> **Key informant:** It's a process where people can talk and be heard; be guided towards choices, decisions, clarity, problem solving; be referred on to other therapies.

It was considered to be confidential.

> **Key informant:** It's confidential and not everyone in the organisation has to know my business.

Counselling was also seen to include an aspect of personal growth or insight.

> **Key informant:** The value of counselling is in fostering and nurturing, helping an individual to grow and develop and attain who they are.

In summary, the key informants viewed counselling as a process intended to help people with their problems, choices and personal growth in the context of a professional, confidential relationship.

5.3.6. Summary

Two key themes were present in all four participant groups: (a) The purpose of counselling was to assist clients to work through problems or issues and (b) counselling consisted primarily of confidential conversations between the client and the counsellor.

The counsellors and the clients also noted that counselling was a working alliance. The key informants, counsellors and support people mentioned that in addition to helping with problems, counselling could also assist with personal growth and increased self awareness. The key informants, counsellors and support people considered counselling to be a professional activity. The clients did not mention that aspect. However, four of the six clients were involved in paying their counsellors and so were aware of counselling being different to another type of conversation.

These themes are consistent with the definition posed by Wampold (2001) which considered that counselling involves a relationship between a "trained therapist" and "a client who has a …problem" and that the counselling is intended to "be remedial" for those problems (p. 3). It is of particular importance to note that the clients in this study demonstrated a similar understanding of counselling to the other participant groups and that the clients' understanding of counselling was consistent with a professionally recognised definition. The themes also confirm that the participants were discussing the same field of practice under exploration in this thesis.

5.4. Conclusion

This chapter has focused on the participants' descriptions of the nature of disability and counselling. Their descriptions bear remarkable similarity to professional understandings of these concepts. However, a client's intellectual disability and subsequent reliance on others for support introduces difference into the practice of counselling, thus creating a unique area of practice.

Chapter Six: Bridging differences

6.1. Introduction

The aim of this chapter is to explore the question, "Is counselling different when a client has an intellectual disability?" Perceptions of difference have often been used to separate people with an intellectual disability from people without an intellectual disability. Karen McGuirl described this separation as a painful wall that excluded her from the rest of the world. (See page 41.) And indeed, even in counselling research, people with an intellectual disability have been excluded (e.g., Royal College of Psychiatrists, 2004, p. 6). Although this chapter highlights key differences, I do not mean to imply that the differences are greater than the similarities. I do not view these differences as a dividing wall; a wall assumes that everything is different. I view the counselling process of people with an intellectual disability to be similar in nature to that of other client groups. However, there are some key differences in how the counselling process is implemented. By acknowledging both similarities and key differences, one is less likely to use difference as a separation, and it becomes easier to recognise our commonalities. Additionally, when disability-related differences are combined with limited resources and prejudice, difficulties arise which can hinder the achievement of positive outcomes.

This chapter has five sections: (a) background information, (b) participants' perceptions of the referral process, (c) ways that participants bridged the differences and difficulties that occurred during the referral process, (d) client characteristics, and (d) ways that participants bridged the differences and difficulties that occurred during the counselling process.

This chapter begins by presenting background information about government funding schemes which pay for counselling. This has been written because financial concerns were a central theme in the data. Next the chapter describes the participants' perceptions of the referral process, noting the similarities and differences to that of clients without an intellectual disability and highlighting difficulties experienced by the participants.

Then the chapter describes the ways in which these differences and difficulties were addressed. Next the chapter explores client characteristics, noting the similarities and differences to clients without an intellectual disability and highlighting difficulties experienced by the participants. Then the chapter describes the ways in which these differences and difficulties were addressed. The chapter concludes with a discussion summarising the key findings.

6.2. Background information: Government funding for counselling

In New Zealand, the government assists with counselling costs via three different funding schemes — Work and Income New Zealand (WINZ), the Accident Compensation Corporation (ACC) and Family Court counselling.

WINZ "provides financial assistance and employment services throughout New Zealand" (Work and Income New Zealand, 2009a). Among the many benefits offered by WINZ is the Disability Allowance. This means tested benefit "is a weekly payment for people who have regular, ongoing costs because of a disability, such as visits to the doctor or hospital, medicines, extra clothing or travel" (Work and Income New Zealand, 2009b). The term "disability" can be applied to common presenting problems provided that the problem "is likely to last six months or more" and causes "a reduction in independent functioning to the extent that they need… ongoing supervision or treatment from a registered health professional" (Work and Income New Zealand, 2008, p. 31). The counselling must be provided by a counsellor who is a member, either full or provisional, of a professional association approved by WINZ. The Disability Allowance can be used to funding counselling "where the need for counselling is directly related to the person's disability and the cost of counselling is not met by another agency. There are restrictions on the number of counselling sessions that can be included in a Disability Allowance" (Work and Income New Zealand, 2008, p. 32).

ACC "provides comprehensive, no-fault personal injury cover for all New Zealand residents and visitors to New Zealand" (Accident Compensation Corporation, 2009a). ACC funding is not means-tested. A specific cover that is offered is funding for

counselling when someone has "suffered a mental injury as the direct result of a personal injury… [The personal injury] may relate to either a physical injury…or sexual abuse or assault… Mental injury means a mental health condition that results in your [sic] having significant difficulty functioning as you normally would, including the way you behave, think and act" (Accident Compensation Corporation, 2009c).

In June 2009 ACC proposed changes in the funding process related to sexual abuse. The new process was called the Clinical Pathway. In order to qualify for ACC funding clients now need to be assessed by a practitioner "trained to carry out a DSM-IV diagnosis. …In addition ACC will consider diagnoses using other relevant clinical tools where that is appropriate to the client's needs" (Accident Compensation Corporation, 2009b, p. 1). These changes were implemented in October 2009.

Counsellors in New Zealand expressed considerable concern regarding these changes. They felt that there was insufficient consultation between ACC and the professional associations and that this new pathway would make it too difficult for clients to access counselling. This concern was expressed through organised protest marches held in Auckland, Wellington, Christchurch and Dunedin on 19 October 2009.

"The Family Court is a division of the District Court. It was established under the Family Courts Act 1980 as a place where New Zealanders could get help with family problems" (New Zealand Ministry of Justice, n.d. -a). Family court can arrange for free counselling for couples who are having relationship problems. Couples can be "married, in a civil union, or in a de facto relationship, whether heterosexual or same-sex" (New Zealand Ministry of Justice, n.d. -b). Referrals are made to counsellors who have been approved by the Family Court. As of 1 February 2010, there are 62 Family Court approved counsellors Christchurch (G. Crossen, personal communication February 1, 2010). The Family Court also refers couples to Relationships Services and Presbyterian Support.

All three funding schemes can be accessed by people with an intellectual disability. However each poses certain limits. ACC funding is limited to presenting problems

which have their basis in either a physical injury or a sexual assault. Although WINZ funding can cover a wide range of presenting problems, a limitation arises for people who have counselling needs as well as other on-going disability related expenses. From 1 April 2009 through 31 March 2010, the maximum Disability Allowance is $55.88 per week (Work and Income New Zealand, 2009b). For someone who is already using some of this allowance for on-going disability related expenses such as medical costs, consumables such as hearing aid batteries, and transportation, the amount left to pay for counselling would be minimal. Family court counselling is for couples only and is limited to six hours of counselling (New Zealand Ministry of Justice, n.d. -b). Interestingly, family court counselling was not mentioned by any of the 19 participants.

6.3. Participants' descriptions of the referral process

6.3.1. Introduction

As Wampold's definition implies, the pursuit of counselling begins by indentifying a "disorder, problem or complaint" (2001, p. 3) and then choosing counselling as a means of addressing the problem. With the exception of mandated referrals, adult clients typically identify their own problems and self-initiate engagement in counselling.

6.3.2. Similarity: Common presenting problems

The six clients in this study readily identified their presenting problems. One client began counselling after a job loss, allegedly for "pinching stuff." One began counselling after a relationship break up. One was getting help for depression and other problems.

> **Client:** With depression and the things of… my life. … I nearly went off the rails a bit…Nearly committed suicide… We had a lot of problems…People tried to take [child's name] off us and before then it was my family. Mum and dad split up…and then my brother died.

Three clients mentioned having anxiety. For one client anxiety was the primary issue for receiving help.

> **Client:** I really need a lot of counselling at the moment. … I've got a lot of…anxiety…She [the counsellor] helps me with anxiety and with other problems in my life…

Another client talked mostly about receiving help for obsessive-compulsive disorder [OCD], but also mentioned having anxiety. Another client was getting help specifically for "some sexual problems," but also mentioned having anxiety.

Job loss, relationship issues, depression, grief, suicidal thoughts, OCD, anxiety and sexual problems are common presenting problems.

6.3.3. Difference: Referral initiated by others

A key difference was that for five of the six clients, their engagement in counselling was initiated by other people. This is similar to the findings of the Royal College of Psychiatrists (2004). "Self-referral for treatment is very unusual. In a previous database of 160 adults [with an intellectual disability] referred to a therapist at the Tavistock Clinic, none was a self-referral" (p. 39).

Two of the clients in this study began counselling as a result of the initiative of carers at their group homes. Two clients described receiving assistance from their mothers.

> **Client:** My mother told me, "You should come and meet, speak to someone." I don't know how that happened. Ah, I don't know. I don't know whose idea that was.

> **Client:** Mum was worried …She went to the community centre up here and got [Counsellor]'s number and she rang [Counsellor] and that's how I met her.

One client experienced a referral process with several layers. This client had never heard of counselling. The client had a problem and talked about it with a friend. Upon hearing about the problem, the friend suggested counselling and sought a referral from the disability support service.

> **Client:** We talked to um [Friend] and [Friend] got a hold of [Disability Support Co-ordinator]… He's the boss for the night services and he got a hold of [Counsellor's name]. He knew [Counsellor's name] was a counsellor for disability people.

One client in this study did not identify that others had initiated counselling on his behalf. He had had counselling a number of times previous to engagement with the counsellor in this study.

Relying on others to initiate becomes a barrier when, for a variety of reasons, others fail to establish a successful engagement in counselling. Support workers, friends, family and people working in disability services are in a position to facilitate counselling referrals. However, according to key informants and support people, a number of barriers make the referral process difficult.

6.3.4. Difficulty: Others may not recognise the problem

In the first instance a client's problem may not be recognised by others. Disability support agencies experience staff shortages and high staff turnover. Staff shortages can create situations where meeting everyday needs becomes a challenge.

> **Key informant:** [Referring to staff shortages in a residential service] It's just crisis mode all the time. People just grabbing whoever comes because you've got to fill the positions. Because you are dealing with people. If you've got empty, you know, someone's got to be there.

With frequent staff changes it is difficult for support workers to know what a given person's usual behaviour is, thus making it difficult to recognise when a problem has surfaced.

> **Key informant:** People come; people go so that creates issues in itself around people knowing what's the norm for a person. If they're behaving, is this their normal behaviour? But they could have had, you know, three different staff people who see the people and think that's their normal behaviour. But if they knew them longer, they would realise it wasn't.

6.3.5. Difficulty: Lack of appropriately trained counsellors

Although some problems slip under the radar, the key informants readily acknowledged that when considering the people who used their services, they noticed many problems which could be addressed by counselling. However the referral process was considered

very difficult. The key informants expressed a desire to refer clients to counsellors who were appropriately trained. Finding such counsellors was difficult.

> **Key informant:** We do identify where we believe people need psychotherapy. But finding and identifying who might provide that is kind of like searching in the dark for a needle in the haystack. It's just there are very, very few people out there who are appropriately in a position to offer it.

When searching for a counsellor, one support person approached a disability support service, described the presenting problem and asked for a counselling referral. The service suggested one counsellor who worked with the particular presenting problem. That counsellor was based in Auckland (762 kilometres away) and would come to Christchurch when there was a group of clients with the same presenting problem. The support person did not want to wait and continued searching for a local counsellor.

When I was recruiting counsellors for this study, I, too, experienced difficulty in finding counsellors whose practice incorporated clients with an intellectual disability. As I was writing up this thesis, I explored the availability of ACC and Family Court counsellors. According to the ACC website dated October 2009, there were 120 ACC registered counsellors in the Canterbury region (Accident Compensation Corporation, n.d.). Of those 120 counsellors only 4 mentioned having a special interest in intellectual disability. According to G. Crossen, a Family Court Coordinator, not many referrals come through for people with an intellectual disability. If such a referral were to come through, she would need to make some phone calls, but she thought she probably could find a suitable counsellor (G. Crossen, personal communication February 1, 2010).

6.3.6. Difficulty: Prejudice

Another stumbling block in the referral process is the belief that clients with an intellectual disability cannot derive benefit from counselling. Key informants, counsellors and support people noticed this prejudicial attitude amongst people who were in a position to refer people to counselling. Sadly, this attitude was also present in counsellors, making this hurdle even more difficult to navigate.

> **Key informant:** I recently had a psychotherapist from another mental health service say categorically to me over the phone that you can't do cognitive therapy with intellectually disabled people.

Counsellor: Some of the people [at the counselling agency] just do not like working with intellectually disabled clients… My colleagues… say, "Well, why did you do that?" You know, or "Why? Because they're not really going to change." Or, "They're not really actually going to get anywhere." And you get that from some of the staff in the houses sometimes.

Support person: I know quite a lot of Down Syndrome people with terrible eating problems, and I feel like maybe if there was counselling, around eating… it might help. But … when I've suggested it to families, I've just been poo-hooed. At work there's a lot of people that [pause] wouldn't see it as even an option… [because they think] it wouldn't work.

6.3.7. Barrier: Financial constraints

Because counselling is a professional activity, it incurs a financial cost. In Christchurch counselling fees typically range from $50 to over $100 per session; sessions generally last 50 minutes to an hour. Sometimes fees are advertised as "negotiable" and some agencies offer low cost or free counselling.

"Adults with an intellectual disability typically experience low levels of income. In fact, many men or [sic] women with an intellectual disability live on or below the poverty line" (Mirfin-Veitch, 2003, p. 1). Financial constraints can stall engagement in counselling.

> **Support person:** Because that was a concern for us, how were they going to pay for it [counselling]?

When combined with the perceived need for counsellor expertise, sometimes the referral process was drawn to a halt.

> **Key informant:** She is very confused about it and worried and it would have been fantastic for her to have had someone to talk to.
> **Marilyn:** But what stopped the process?
> **Key informant:** Money…
> **Marilyn:** What about pursuing avenues of, you know, like low cost counselling in the community?
> **Key informant:** They aren't the people who understand intellectual disabilities. … That's the big thing. Funding and those with experience and training.

Sometimes the needs of people with an intellectual disability go unnoticed due to high staff turnover. Other times their needs are noticed and a difficult referral process is traversed successfully. Other times the referral process is deemed "too difficult" and their needs are noticed, but ignored.

> **Key informant:** A lot of people with disabilities, their issues have been brushed aside because it's been too difficult maybe or they haven't had the right people who can help them through those sorts of issues… I don't think we've been that proactive in seeking out counselling generally. I mean there's the odd person, yes, but generally speaking, no. There wasn't an easy avenue, didn't quite know where to go and also the cost.

6.4. Bridging differences during the referral process

According to the key informants, many people with an intellectual disability present with counselling needs, but a difficult referral process frequently impedes engagement in counselling. Financial constraints, a lack of specially trained counsellors, high staff turnover and prejudicial attitudes create barriers in the referral process. The clients in this study were able to successfully engage in counselling because of the support they received from family members, support workers, friends and other professionals. They received personal support in locating counsellors and received financial assistance to pay for counselling. Of the six clients, only one client paid for counselling out of pocket. Three received the WINZ Disability Allowance to fund their counselling. One client was receiving counselling from a charitable trust which provided counselling free of charge to clients. One client's counselling was being paid for by a third party which, according to the support person, "did the damage."

6.5. Participants' descriptions of client characteristics

Like all counselling clients, these six clients came to counselling with a combination of resources and problems. Mobilising client resources is a key component in counselling (e.g., Bond, et al., 2001; Tallman & Bohart, 1999). Therefore it is important not to ignore existing client resources and it is equally important not to assume the presence of resources which are actually problematic.

6.5.1. Similarity: Commonality of human experience

During our interviews considerable time was spent talking about family life. I interpreted this to mean that family was important to these clients.

> **Client:** My mother wants some help with some furniture, so I'll be going. I'll be getting up early and go to her house.

> **Client:** This year I got a present for my sister, a present for my mum, a present for myself and a present for my dad. And I got a present for the kids, but I got…to split that up into four or five kids.

And, as is typical in family life, some events were enjoyable and others were worrisome.

> **Client:** I went to [family member's house]. See our… family. It was good.

> **Client:** I'm worried about sissy. She could be expecting again. We nearly lost her when she was having [baby's name]. She lost blood and…we nearly lost her… I'm very afraid.

Having a disability does add a measure of complexity to family life, but it does not diminish the commonality of human experience. For example, reaching adulthood is commonly linked with desire for more independence. Kaye and Tom, the youngest two participants, hoped to live in their own place some day. Parenting is another common human experience. All parents acknowledge that parenting is a lot of work, and as Ian noted:

> It's quite hard bringing up a family when you got a disability because you've gotta work …that much harder.

People in their forties and fifties share the common experience of parents ageing. During the course of this study, the parent of one client passed away and the parent of another client became unwell and moved into a nursing home.

While these clients shared much in common with other New Zealanders, their engagement in counselling was affected by three significant differences. They had limited financial resources, a range of health needs and/or sensory impairments as well as a need for consistent, on-going support.

6.5.2. Difference: Limited financial resources

When the study began, five of the clients were full-time beneficiaries and one participant was in fulltime employment. In addition to his employment income, he and his family received financial assistance from the government, that is, disability allowance and child disability allowance. During the course of the study this client left his job and became a beneficiary.

Though the clients relied on government assistance for their daily needs, some of the participants earned supplemental income. One client had regular access to opportunities for supplemental income, i.e., gardening, collecting pinecones to sell, and helping with activities in the residential setting. Another client had occasional opportunities to earn money, i.e., earning $35 for helping students with a project. Two clients were involved regularly in volunteer work.

Although the financial situations of these clients are similar to many adults with an intellectual disability, the high percentage of beneficiaries is in sharp contrast to the majority of counselling clients. This is a qualitative study which used purposive sampling, a non-probabilistic sampling technique. Therefore it is not appropriate to draw conclusions from statistical information. However, for illustrative purposes only I have chosen to use percentages to emphasise this glaring contrast. This study began with 83% of the clients being beneficiaries and ended with 100% being beneficiaries. This stands in contrast to demographic data gathered from a low cost counselling agency in Christchurch between 1999 and 2001. Manthei and Duthie (2003) reported that during those five years only 22-38% of the clients who sought counselling were beneficiaries (p. 89).

6.5.3. Difference: Multiple health needs and/or sensory impairments

Like many others with an intellectual disability, these six clients have a range of health needs and/or sensory impairments. Kaye has asthma, allergies, eczema, headaches, migraines, back pain, and she wears glasses. I noticed that during many of our interviews she was coughing and she frequently mentioned having fallen. She was on

the waiting list to see a specialist because of "a shadow behind my heart." Her counsellor mentioned that "something's wrong with her lung." James has high blood pressure, and diabetes. He also told me that he has been to see a heart specialist who told him that his heart was "beating a little bit too fast." Roger wears a hearing aid. Margaret wears glasses. During the course of this project she had a fall in which she broke her arm and her glasses. Ian has asthma and wears glasses. During the course of the study he acquired a hearing aid. Tom has allergies and hay fever.

As the following quote illustrates, physical health impacts emotional well-being and visa versa.

> **Client**: I can't shake this damn cold. [Cough, cough]. [Sniff]... My breath starts to tighten, really hurts underneath my breast. That's the only pain I get. So I got up and tried to help [family]. But I haven't been feeling too good lately. All the stress and worry.

In the following example, the sudden appearance of a physical health problem exacerbated the client's anxiety.

> **Client:** I was not feeling too good on Christmas Day. I was sweating away and everything and then ...my heart began to play up. My heart started to go a bit funny. ... When I see that happening, I think, "Oh shit what is going on?" And then started to get anxiety over it. ... I wanted to see [Counsellor]. Course she couldn't see me until February. Everything closed bloody down. I couldn't see my normal doctor... It was really, you know, then seeing other doctors that don't actually know you.

6.5.4. Difference: A need for plain language and more time

The clients' intellectual disability was clearly a point of difference. Due to the nature of their disabilities, the clients experienced communication difficulties. Plain language was seen as a way of promoting clearer communication.

> **Client:** They [people with a disability] do not understand too well, so you got to explain to them in plain language.

> **Counsellor:** A big difference in checking out understanding and using the plain understandable language. ... The flow of communication is slower, but actually ... in the healing and the processing it's very much the same. I mean everybody is individual and everybody works differently in that sense.

More time was needed to take on board new information.

> **Client:** I have to learn things at my own pace. I can't um do it too fast otherwise I'll make a mess and I don't want to make a mess. I take my time.

> **Key informant:** You know, if the same case came up to mainstream and you could deal with it an X number of sessions, with our clients, as you well know, you might as well triple that. You might quadruple the length of time because of language problems because of memory problems.

6.5.5. Difficulty: Time constraints

Health and disability support services readily identify a range of needs, but face a number of resourcing issues, including a lack of time.

> **Key informants:** Perhaps to answer your question … what sort of resources would I need? Perhaps it's about the one resource, and I don't know how we can buy this, is **time**. The one thing that I don't have is time. And you think, well, if I had more clinicians who were better trained etc. because the current clinicians do their best, they are a great bunch. You think more clinicians? More training? But actually, what we also need is more time. We need more time to do intensive work with people and to do it on an individual level.

Counsellors and support people also referred shortages of time in contrast to the many needs they observed. Many people working in the disability field work diligently in a particular sphere of practice and observe needs outside that particular sphere which they do not have time to address.

> **Counsellor:** Probably like me, they haven't got time to address it [a particular need outside of counselling], and often the cry is — and it's a genuine cry, "It's not my responsibility." … In putting things right in a lot of situations would be — "Oh well my job description is daaaa. It's not my responsibility to daaaa." … I think we all end up in our boxes, "can't do that, it's not my job."

The participants in this study were keen to promote positive outcomes for people with an intellectual disability. However, balancing their available time and energy with perceived needs was a juggle that at times caused them to "struggle" or feel drained or "guilty." Refer back to pages 75-76.

6.5.6. Difference: Reliance on others for support

Another disability related difference was a need for on-going appropriate support. During the research interviews each of the six clients were aware of their need for literacy support and relied on my help with reading the forms. This awareness of their need for support and their reliance on other people was evident in our conversations. They spoke of receiving practical help such as transportation, cooking, and literacy support as well as social support.

> **Client:** I also go out with my caregiver. We do shopping on a Friday…. This afternoon I have to go … to the video shop. My mother is going to drop me off there anyway.

> **Client:** She [a friend] supports us with lots of things. I mean to say if we want to talk to her about things, we can ring her up and talk to her… Say if we get letters from um WINZ and stuff like that, then she'll help, help to read them out to us.

> **Client:** Somebody helping me… [Name], care person. She's helping me get jobs.

6.5.7. Difficulty: Inconsistent or inappropriate support

As the following quote illustrates, inconsistent support can jeopardise the accomplishment of personal goals.

> **Client:** The person I used to get a ride with, um, she left People First and then she finished working here as well. So there was no way of us guys getting there.

In this case, a lack support with transportation resulted in a loss of social support.

Inappropriate support can have a negative impact on general well-being. For example, one client expressed frustration regarding some long standing difficulties with a particular support worker.

> **Client:** [The support worker] just…sits there and does nothing and gets paid for it… better than sitting there and giving us orders.

As the following example suggests, staff turnover impacts emotional well-being. [21]

> **Support person:** [Support worker] who was [Client's] friend in this house when she was care giving here.
>
> **Client:** Yeah she was.
>
> **Support person:** But I don't know what happened when [Support worker] left. It was a bit of a cloudy issue, the whole thing…It was a bit of a loss, losing [Support worker].
>
> Client: Yes.
>
> **Support person:** Because you'd formed a good relationship, you two, hadn't you?
>
> **Client:** Yes, yes.

Counsellors and support people expressed concern regarding the quality of support provided to people with an intellectual disability. Sometimes the quality of support was seen to be good, but high staff turnover was seen as a problem.

> **Support person:** It's a wonderful place, it really is. It's a shame that they have difficulty getting a stable staff. A lot of sort of part-timers … They move on. Someone else comes. They last a short time. They move on.… It's a bit unsettling.

Other times concern was expressed regarding the quality of the support provided.

> **Counsellor:** They have staff members working with them who … vary wildly in their level of skill, um, vary significantly in terms of … their motivation to be doing that job.… For a lot of people it's a job that they do because they can't gain other employment, perhaps more so than, you know, genuine interest in that work.

This counsellor highlighted the difficulties this posed for clients.

> **Counsellor:** I think they [the clients] often live [pause] under very trying circumstances.

Although the overall state of the disability workforce was of concern to the participants, it is important to note that they also mentioned instances when they were pleased with the support provided. At times support workers went the extra mile to provide support.

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[21] This client chose to have a support person present during our interviews.

> **Support person:** [Client's] trousers needed taking up for the ball and [a support worker] took them home and sewed them up and … [referring to the support worker] she's great.

6.5.8. Difficulty: Social stigma

Social stigma played a significant role in the experiences of these clients. Teasing and bullying were a part of their childhood and being included as valued members of society continues to be difficult to achieve in adulthood.

> **Client:** I live independently in the community…The reality is that it is hard…It is frustrating as the community is not always a warm and supportive place.

It is well recognised that social stigma has a negative impact on well-being. Living with social stigma is linked to lower self-esteem, chronic stress, difficulty accessing appropriate health care, and poorer health outcomes (e.g., Link & Phelan, 2006; Ouellette-Kuntz, et al., 2005). People with mental health problems are stigmatised and people with an intellectual disability are stigmatised, thus resulting in "double stigma" for people with both mental health problems and an intellectual disability (Ouellette-Kuntz, et al., 2005, p. S11).

6.6. Bridging differences during the counselling process

These six clients presented to counselling with common presenting problems. However they also presented with communication and learning needs as well as a range of health needs, numerous experiences of teasing, bullying and social exclusion, and numerous experiences of both appropriate and inappropriate support. They had limited financial resources and variable levels of social support.

6.6.1. Taking time to establish a working alliance and to achieve outcomes

A counsellor's initial focus is on building rapport with the client and establishing a working alliance. These six clients spoke positively about their counsellors. I was impressed by their willingness to allow me to talk to their counsellors "about them and their counselling." The way they spoke about their counsellors further indicated that

they felt warmly towards the counsellors and considered them to be caring, responsive and supportive.

> **Client:** The counsellors are quite supportive of people that have bad way thoughts… [They] listen to what you've gotta tell them and then sorta um try and give you a hand, sort what your problem is out [sic]

> **Client:** She's nice to talk to and she listens. … She definitely listens to my problems when I have them…She's a nice lady.

> **Client:** [Counsellor]'s been a lot of help… I talked to a few people but… they didn't really understanding and care [sic].

I noticed that the counsellors' practices included extra measures of kindness such as providing cups of tea or walking clients to the bus stop.

> **Counsellor:** I provide a cup of tea for most people…It's a reinforcer. It's a nurturing that doesn't always happen in their lives.[22] It's part of my style.

As the following quote from a different counsellor illustrates, "simple little things," such as having a hot drink, helped to build rapport.

> **Counsellor:** The very first reason … she agreed to see me was because she'd never had a real cup of coffee in her life. And she'd gone past that café many times and it smelt so nice and could part of the counselling be a nice cup of coffee? Because if it is, I might come and talk to you. (Laughter). So the first few sessions were just enjoying the social experience of going and buying a cup of coffee and drinking it at a café. It all started from that really… and the thing that has benefited her the most is just being treated like an ordinary person. Because she was used to everybody sort of treating her differently because of the disability. So those are simple little things again.

Taking a few sessions to enjoy "the social experience of going and buying a cup of coffee illustrates the counsellors' willingness to spend more time than is typical establishing a working alliance. The counsellors were also aware that it could take "a long time" for clients to implement change.

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[22] One support worker considered that "people with an ID…they need probably more nurturing than what we do in some ways."

> **Counsellor:** Probably it's taken a long time with the trust over the years developing confidence. … [Client] is more receptive now. … I don't think the rapport was difficult…but I think he remained wary. I think his acceptance of me is much greater now. …
>
> **Marilyn:** How long did you sort of offer the suggestion of asking that guy about the movie before he [Client] actually did it?
>
> **Counsellor:** It could have been six months. It's a long time. And then to be turned down… we had to celebrate the fact that he asked. That was okay. That was good. And yes, you do get turned down.

This slow pace was needed for the clients and it provided more time for counsellors to learn about their clients.

> **Counsellor:** Progress is very slow with intellectually disabled people. … I think some people view that slowness and so on as very frustrating … Whereas I … look at it… a different way. … The slowness…doesn't really worry me because I think you're always gathering information. … If you're doing this sort of work, you need that longer period of time. … Something that obviously we can explain in a few minutes, but it's probably taken [Client] about two months to get.

The counsellors recognised that progress was likely to be slow, and worked in a patient, flexible manner.

6.6.2. Responding to the clients' communication and learning needs

Although counselling was described primarily as talking therapy, the counsellors used other forms of communication in addition to talking.

> **Client:** Sometimes she draws diagrams on the board to show me sometimes.

Another client described some learning that had taken place and how the counsellor provided cards with that information. The cards were helpful in recognising ways of thinking.

> **Client:** Well, at the moment we're working on Stinky Thinking[23], which is basically um like, at the moment we've got seven or so many cards and that help us realise the way we think.

A third client mentioned a chart that the counsellor had made. This chart was helpful in implementing new strategies.

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[23] The counsellor told me that "Stinky Thinking" referred to "cognitive distortions."

> **Client:** [Counsellor], um, made a wee chart for us, for, um, good things…
> and not so good things….When you're…, down and you can then go to the
> good things… like…have a bubble bath and stuff like that, yes, that make
> you feel good and when you're down…And… plus…talking…, to
> someone… Things like that… and my best one is the thing about the
> beach… When you're down… you think about the beach and the sea.

The counsellors also talked about using different communication styles to enhance
learning and communication.

> **Counsellor:** Different mediums [sic] I suppose because … just sort of
> talking and … writing stuff… I think has had limited impact for the guys
> with intellectual disabilities. So we try and use … lots of sort of pictures and
> graphical stuff… We do … role plays and acting … even songs …The
> reality is that … for all of us different forms of learning are more effective.
> We don't try and make it too sort of 'sit down and talk' sort of stuff because
> … for most of them, that's not an effective way of learning for them.

Their use of different communication styles also gave clients more opportunities for
self-expression.

> **Counsellor:** [Client] can be quite creative when we work.… We're doing a
> lot of empty chair work and drama.… I find that he works very well with
> that and he's like a different person.

In spite of using plain language, a variety of communications styles, and trying to gauge
client understanding, communication mistakes still happened, as these two counsellors
pointed out:

> **Counsellor:** It's always really easy … when you're working with people
> with intellectual disabilities, isn't it, to start at the wrong level. Like you
> assume that their level of understanding is there. … Often you can be wrong.
> It might be much better than you [laughs] assume, or … it's not as
> developed.

> **Counsellor:** I realised… we're slightly misunderstanding each other.

It is inevitable that counsellors make mistakes in counselling of one sort or another. One
counsellor spoke of the forgiving nature of clients with an intellectual disability and the
strength of the rapport which can be established.

> **Counsellor:** One of the real most enjoyable things about working with
> intellectually disabled clients, is that they're quite forgiving sometimes in
> terms of your own mistakes, you know. …Once you do develop a rapport,
> they're very very open generally — and I'm talking vast generalisations

obviously. Whereas often with mainstream clients I can never have that feeling about how well your rapport is developed, particularly with …clients referred to this service.

Taking time to establish a strong working alliance seemed to mitigate the impact of mistakes and miscommunications.

6.6.3. Responding to the complexities in clients' support network

The counsellors were acutely aware of the complexities in the clients' support network. The nature of a client's support network had a direct impact on how the counsellors chose to intervene.

> **Counsellor:** And it's not good, me setting a client up to fail. I have to… adapt what I'm thinking, what I'm saying. It's no good me advocating or encouraging a person to be assertive and independent if that has negative consequences. So it's trying to maintain some realism. I guess that's the difference working within this area than when you are working with someone who's of average whatever ability and they are independent.

Counsellors took on a supportive role when the client's existing support networks were not providing the necessary support.

> **Counsellor:** And sometimes it's support work that's needed. Purely support work. Dealing with day to day issues as they arise. That I see is not being done by the supporting agency. And really needs to be.

Often the first practical support provided was supporting the client to obtain access WINZ funding for counselling. As the following quote illustrates, the WINZ system can be complicated to navigate.

> **Counsellor:** It's quite involved trying to get the counselling funded through disability allowance. Getting anything funded through disability allowance is complicated. They do everything in triplicate. So I'm still working though that with [Client in study]. … But I've been trying for three months to get the forms completed and as quick as we send them in, they want some more.

Without appropriate support the clients' had difficulty in accomplishing certain tasks on their own and the counsellors stepped in with support in ways that they usually did not do for other clients.

Counsellor: Normally I wouldn't get involved with social welfare for counselling clients but if [Client]'s been having difficulty understanding what social welfare wants…about the only way to solve that is to get involved. …It needs to be sorted out so she can carry on with her plan.

Marilyn: You mentioned in the past that you were helping [Client] with his CV [curriculum vitae]. Do you do that sort of thing with the general population?

Counsellor: No.

(Laughter)

Counsellor: … But I see that outside of the counselling role.

The counsellors viewed this extra support as necessary. Some saw it as outside the counselling role, but one considered it to be part of a "holistic" counselling approach.

Counsellor: It's a holistic, sort of holistic approach really… I've been aware of the overlap in role between nurse, counsellor and support person in my role …And I don't think it's a bad thing, it's just a different model of counselling…The support side of it I think is really important.

Counsellors considered the intention of counselling to be promoting change. However, counselling was seen as only part of the change process.

Counsellor: I see counselling as just a part of the process of people making changes and yes, you help people focus and set goals and motivate, but it's got to be translated out in a practical basis. … [The client] has a lot of ideas, a lot of motivation, but I guess he doesn't always have the skills or the money which is a big one, to um, put some of those ideas into practice. So it's having someone [a support worker] who's receptive.

The counsellor described how this client now had a support worker who was assisting him to achieve some of his ideas. This practical support made a noticeable, positive difference in the counselling process.

In another case a client spoke of how receiving support from support workers helped to assist with engagement in counselling.

Marilyn: So what kinds of things help you to put those new things in place?

Client: … probably staff… like [name] always, she'll ask me, How things are going and that and ask me … How group's been and that?

In addition to being aware of the complexities in the clients' support networks, when appropriate, the counsellors worked collaboratively with their support networks in order to enhance the likelihood of positive outcomes.

> **Counsellor:** For us to have our most impact … we really try and work as collaboratively with the systems … and with other professionals. … Working with those clients we have as open as a relationship as is appropriate.

Having an involvement with other people in a client's life allowed issues to be addressed in a timely manner.

> **Counsellor:** Some carers like the reassurance really of having a therapist in the background. … They like the reassurance that things that may not come out, for example in the home, might not be addressed by the client with the carer, that it will be done here. If necessary, I can bring in the carer into the session and address the issues. … So in effect, I'm used as a communicator.

Having "a therapist in the background" also provided clients with a way of maintaining their progress. For example, one counsellor began working with a client in response to a particular situation. After the situation was resolved and some time had passed, the counsellor viewed the counselling as maintenance.

> **Counsellor:** It's maintenance. … I think it's probably for his mum's peace of mind. She just wants to know that once a month he can talk about anything that might be bugging him, that might be upsetting him.

6.6.4. Responding to the clients' health needs

In response to a client's health needs, one counsellor initiated collaboration with doctors.

> **Counsellor:** I got the GP involved and a neurologist…because of some problems he was having…There's nobody else in his life noticing these things. …I guess I never would have interfered in that sense with another client…because they could do that for themselves.

Another counsellor also spoke of working collaboratively with doctors and providing health education as part of counselling.

> **Counsellor:** Quite a lot of what I've done with [Client] has been health education as well.

The counsellors' responsiveness to clients' health needs was in keeping with the following recommendation made by a key informant:

> **Key informant:** It would be lovely if people [counsellors] could just be a little bit more aware of what they might be looking for in terms of vulnerabilities and co-morbidities. Be more watchful about general health issues. A lot more watchful about abuse issues. Um, cause there is every kind of abuse and exploitation in this group.

6.6.5. Remaining attentive to the clients' negative social experiences

These counsellors were aware that many people with an intellectual disability experience abuse, ridicule, teasing and bullying. They were aware of the long term impact of childhood experiences and remained attentive to the impact of current experiences.

> **Counsellor:** [Client]'s very conscious of his intellectual disability and being teased and being different and standing out and wanting a normal life, wanting to be able to interact normally, go to the pub and go anywhere really um and mix with another bunch of people and have a pint and a chat down the pub without being ridiculed, which often happens.

6.6.6. Spending time when money was not forthcoming

Four of the counsellors in this study were in private practice. Therefore their income was directly related to payments from clients and third party funders. One counsellor worked for an agency which provided free services to clients, thus the clients' limited financial resources did not impact this counsellor's income. The remainder of this section describes the experiences of the four counsellors who were in private practice. These counsellors typically spent time outside of the counselling session working on behalf of their clients. The counsellors were aware that working with clients with an intellectual disability meant that more time was spent outside of counselling session. Being fully aware of this fact, in some cases, counsellors made deliberate choices to work for little or no pay.

> **Counsellor:** One client, at the moment, pays me $5 [per session].
>
> **Marilyn:** Ah, did you get any other subsidies for seeing that client?
>
> **Counsellor:** No. And I drive to his place, so it's an hour and a half really [laughs]… but he is an abuser and he needs help and he's not going to get – and all the agencies are not picking him up so. … I just see the desperate need and they weren't going to get him to counselling or anything like that so.

In other situations, the counsellors worked with clients with the understanding that they would receive payment, but they did not receive payment. This occurred even when clients were eligible to receive funding for counselling. The typical arrangement for the WINZ disability allowance is that the money is deposited directly into the client's bank account and the client is responsible for paying the counsellor. In some cases the counsellors did not receive payment because of the clients' difficulties in managing their money.

> **Counsellor:** I hardly ever get paid [referring to payment from the client in this study]. … They do have to remember to go and get the cash out at the Cashpoint and sometimes they won't have it and then, of course, they forget that they didn't pay me that time and I'm not assertive if that's the word, to demand, you know, "oh well remember you owe me three sessions of money because…" and it gets very confusing…

In other cases, another party was intending to help sort out the payments, but the arrangement fell through.

> **Counsellor:** I'm thinking of someone right now that I've seen for seven or eight times, we just go on and I haven't been paid and that was… the difficulties of organising through other people. … [It] was supposed to be set up by the social worker and it didn't happen.

When payments were not forthcoming, counsellors expressed a range of feelings including resignation, frustration and ambivalence.

> **Counsellor:** Sometimes I shrug my shoulders. [Laughter] Sometimes it's just frustrating.

> **Counsellor:** And I just haven't got the heart to say, "Remember you only paid me $20 last time."…I guess I shouldn't bend the rules. It's maybe not good for the next counsellor that comes along or, you know, just because I'm not desperate for that extra $25 or whatever others are, others could be and it's, yeah. It's undervaluing counselling.

Furthermore,

> **Counsellor:** That takes time and effort to chase up WINZ and maybe the social worker to track some money down…. But then you ring the WINZ person who's not there. And they don't even return calls and it's just time consuming.

As one counsellor succinctly stated, "Working in this area is less well paid."

6.7. Discussion

The presence of an intellectual disability creates differences in counselling because of its associated communication and learning needs. The counsellors in this study responded to those needs by adapting their communication styles and by allowing for more time for clients to take on board new learning. If this were the only difference, the perceived shortage of counsellors could be remedied by educating existing counsellors about appropriate communication and teaching styles. Unfortunately, as this chapter has highlighted, many other difficulties commonly beset people with an intellectual disability. Poverty, health inequalities, difficulties in the disability support workforce and social stigma are well recognised as significant problems with wide ranging impacts. Because professional practice "is never … separable from the … contexts within which it is conducted" (Saltmarsh, 2009, p. 157), these systemic problems also impinged on counselling practice causing it to be different.

6.7.1. Limited financial resources

Adults with an intellectual disability often have limited income (Mirfin-Veitch, 2003). Limited financial resources were seen to inhibit initial engagement in counselling and also posed difficulties for private practice counsellors who relied on income from clients and third party funders. Accessing WINZ funding was considered to be complicated and time consuming. Additionally, clients with a disability often had to split that benefit between counselling and other disability-related expenses, leaving little for weekly counselling sessions. Counsellors responded by seeing clients monthly rather than weekly or by providing counselling for far less than the going rate. Limited financial

resources resulted in private counsellors stretching their practice to include some voluntary professional service.

6.7.2. Health inequalities

Having both a disability and a low income gives rise to a complicate range of issues, many of which are beyond the scope of this thesis. I refer the reader to *Income for adults with an intellectual disability* by Mirfin-Veitch (2003). Among other things, poverty is associated with difficulty in accessing healthcare and poorer health outcomes. Graham (2005) considered that "socioeconomic position is the fundamental determinant of health" (p. 101). According to Krahn, Hammond, and Turner (2006) a "cascade of disparities" exist "in health and health care access" between the people with an intellectual disability and people without an intellectual disability (p. 70).

> It is now generally recognized that persons with ID [intellectual disability] experience poorer health than the general population in many countries. Until recently, however, poor health was implicitly accepted as being an inevitable consequence of having a disability. With changing conceptualizations of health and of disability, this poorer health status is now recognized as a health disparity experienced by people with disabilities. (p. 79)

This difference has been of grave concern both nationally and internationally. For example, in New Zealand the National Health Committee (2003b) noted that "many adults with an intellectual disability endure prolonged suffering from health conditions that are treatable, relievable and curable, yet receive inadequate medical management" (p. 9.). In the United Kingdom, the Department of Health considered that:

> The health needs of people with learning disabilities may not be recognised by doctors and care staff who have no experience of working with people who have difficulties in communication. Health outcomes for people with learning disabilities fall short when compared with outcomes for the non-disabled population. (pp. 59-60)

Similarly, in the foreword of a 2002 United States government report Dr. Satcher wrote, "As Surgeon General I have focused on identifying and addressing some of our Nation's pressing unmet health needs and disparities in health and health care….Even a quick glimpse at the health status of persons with mental retardation, both children and adults,

reveals glaring deficiencies that must be addressed" (U.S. Public Health Service, 2002, foreword).

Attempts have been made to address this disparity in healthcare. For example, the United Kingdom has developed teams of professionals to "advise, assist and support" people with an intellectual disability and their carers with regards to health related issues. These teams "consist of Nurses, Care Managers, Physiotherapists, Occupational Therapists, Speech and Language Therapists and Psychologists" (Community team for people with learning disabilities, 2009). In New Zealand publications have been developed to inform health professionals about intellectual disabilities (e.g., Ministry of Health, 2001). However, according the IHC health disparities were still evident in September 2009.

> IHC is still waiting on the Ministry of Health to progress work on the health needs of people with intellectual disabilities. We are encouraged by the good hearing we received from Disability Issues and Associate Health Minister Tariana Turia when we met with her in September on these issues. Despite the known problems with access to and quality of health care for disabled people, there is no mention of health in New Zealand's submission on the UN Disability Rights Convention. (IHC, 2009)

Similar to many people with an intellectual disability, the clients in this study had a range of health needs and other sensory impairments. Given the high turnover and variable quality of the disability support workforce, these physical health issues were sometimes overlooked by the client's support network. Physical health and emotional health are intertwined. Thus, counsellors found themselves in the position of interacting with the client's support network to foster better physical health outcomes for their clients. While this is outside the bounds of traditional counselling practice, these counsellors were responding to an urgent need that has been clearly identified in the literature, that is the "systemic neglect of the health of adults with intellectual disabilities" (National Health Committee, 2003b, p. 26).

The presence of unaddressed health needs resulted in counsellors enlarging their practice to include a greater degree of attentiveness to clients' physical health.

6.7.3. Difficulties in the disability support workforce

Similar to other New Zealanders, the participants in this study expressed concerns about the disability workforce. New Zealand's Ministry of Health (2008) summarized the difficulties in the disability workforce as follows:

> Concerns were raised over the availability and quality of the disability workforce. It was recognised the disability sector has difficulty keeping staff. A lack of training and qualifications for workers and low pay rates were seen to contribute to this problem. Consumers felt there was at times a lack of acknowledgement of the value of support workers and no clear career pathway. Consumers also raised that although they might have assigned hours for support there was, at times, no-one available to provide that support. (p. 8)

Difficulties in the disability support workforce are neither new nor unique to New Zealand. Problems with "the performance and stability of direct support professionals" have been written about for over a century (Larson, Lakin, & Hewitt, 2002, p. 203). High rates of turnover and position vacancies are well recognised as causing problems for people with an intellectual disability (e.g., Test, et al., 2003). Beaty and Perry (1998), two people with an intellectual disability who rely on support services described it this way: "To us it is really simple – if agencies have good staff, we have good lives. If agencies have bad staff who aren't trained, don't understand our disabilities or have attitude problems, we suffer the effects" (p. 1).

In response to gaps in clients' support networks, the counsellors in this study assisted clients in practical ways such as filling out WINZ forms, writing CVs, and placing telephone calls. Such activities are not part of traditional counselling practice. However, the presence of unaddressed support needs resulted in counsellors extending their practice to include the provision of practical support.

6.7.4. Social stigma

Teasing, bullying and exclusion feature heavily in the lives of people with an intellectual disability. Social stigma permeates terminology choices (e.g., Bray, 2003; Worters, 1968) and interpersonal relationships (e.g., McVilly, Stancliffe, Parmenter, &

Burton-Smith, 2006; E. Miller, Chen, Glover-Graf, & Kranz, 2009). Professionals, including counsellors, are sometimes reluctant to engage with people with an intellectual disability (e.g., O'Driscoll, 2009; Ouellette-Kuntz, 2005). The counsellors in this study were aware of the negative impacts of teasing, bullying and social exclusion and spent time sharing social moments with their clients over a cuppa or during a walk to the bus stop. This flexible, friendly approach is in keeping with suggestions by R. A. Jones and Donati (2009) and the Royal College of Psychiatrists (2004). In light of the pervasiveness of social stigma, it seems fitting when working with people with an intellectual disability that counselling practice be characterised by kindness, warmth and friendliness.

6.8. Conclusion

These findings suggest that bridging differences in the midst of systemic problems takes the collaborative effort of clients, counsellors and the clients' support network. Receiving support during the referral process enabled the clients in this study to access counselling. During the counselling process consistent support seemed to enhance forward progress, whereas difficulties with support seemed to have a negative impact on well-being. The counsellors and clients spent time establishing a working alliance. The clients appreciated the caring and responsive support provided by the counsellors and the counsellors demonstrated sensitivity to the complexities of the clients' environment. The clients and counsellors worked together on counselling issues and sometimes on practical matters as well. Counselling progressed at the clients' pace. The counsellors modified their communication style. Many times, counsellors shared their expertise for less money than could be gained in other areas of counselling practice. As the following chapter illustrates, this collaborative effort resulted in each of the six clients achieving some positive outcomes.

Chapter Seven: Was counselling effective for these clients?

This chapter addresses the question, "Is counselling effective for clients with an intellectual disability?" The aim of this chapter is to explore the outcomes of the six clients who participated in this study and to provide two case study examples of counselling practice.

7.1. Introduction

When exploring counselling outcomes decisions need to be made regarding: (a) what to assess, (b) how to assess it, and (c) from whose perspective it should be assessed. Regarding what to assess and how to assess it, I chose to compare the participants' reports of the presenting problems and their hopes for counselling with the participants' reports of changes that they observed. Each case includes assessments from multiple perspectives.

Detailed case studies provide practitioners with useful examples of counselling practice. While detailed case studies are of interest and benefit to practitioners, certain ethical issues arise in the write-up of case studies. This chapter begins by discussing ethical considerations. It then briefly presents the outcomes of four clients and then presents two case studies. Most counselling case studies are written from the counsellor's perspective. Aside from the case study done by Karen McGuirl and Aine O'Reilly, I am not aware of counselling case studies which have attempted to present the viewpoint of clients with an intellectual disability. For this reason, in the two case studies I have separated the viewpoints, giving the reader a view of the same case from more than one perspective. The chapter concludes with a discussion of three themes relevant to these cases.

7.2. Ethical considerations

Earlier in this thesis, Tom, Kaye, Margaret, James, Ian, and Roger were individually introduced to the reader. I chose this style of introduction in order to highlight the heterogeneity of people with an intellectual disability. At this point in the thesis I would

like to preserve their individual stories, but, at the same time, must be careful to maintain their confidentiality. As McLeod (2003) has said:

> It is important to be aware that there are significant problems and challenges inherent in the use of narrative [qualitative] case studies….Sometimes the information can be too sensitive to disclose in a research report, or the research subject may be too readily identifiable. (p. 102)

In a small community, such as the disability community in Christchurch, the risk of participants being indentified is greater than in a larger community. As illustrated by the following quote, sometimes the issues that people with an intellectual disability are managing are well known to those working in the support services.

> **Counsellor:** for [Client] you know, he's known around [the residential service] as "the [his presenting problem]"… that's his identity… that's how a lot of people know of him.

While many clients in Christchurch have similar presenting problems, a detailed case study could provide enough information to identify individual participants.

Middleton (1993) considered that the small size of New Zealand posed particular difficulties with confidentiality. When writing up her case studies, Middleton prioritised the participants' confidentiality. She considered that in doing so, "some of the study's theoretical strength was lost" (p. 79). Like Middleton, I have chosen to prioritise confidentiality. Therefore I am presenting four cases briefly and two cases in detail. By presenting only two cases in detail, the study risks losing exemplars for practising counsellors. I have attempted to mitigate that loss by choosing two cases which exemplified common themes across the cases and, at the same time, were least likely to breach confidentiality.

In addition to protecting the confidentiality of research participants, there is a need to protect the privacy of "third parties who are mentioned in the narratives" (Haverkamp, 2005, p. 154). While the participants have given permission to use their information in the reports, third parties have not. Another reason for presenting only two cases in detail is to protect the privacy of third parties.

7.3. Tom

Information was gathered from interviews with Tom, his counsellor, and his support person. The interviews took place over an 11 month period. At the time the interviews began, the counsellor reported that Tom had been receiving counselling for three months. Prior to working with this counsellor Tom had worked with other counsellors.

According to Tom, his counsellor, and his support person, Tom began counselling because of sexually inappropriate behaviour. Tom's hope for counselling was "to stop the urges of the problem…and move into the community." To him moving into the community meant more "freedom."

> **Tom:** …having a girlfriend to live with me. …being allowed to go out and do things on me own, without staff. So like, at the moment, when I go out, um, shopping I have to have staff with me.

Tom's counsellor and his support person spoke of having similar hopes for Tom.

A number of positive outcomes were noticed by Tom, his counsellor, and his support person. According to Tom and his counsellor, the specific behaviour which prompted the referral was no longer a problem. His support person reported that Tom had learned new skills and had increased in maturity and confidence. Tom acknowledged that some new skills have been easier to take on board than others.

> **Tom:** [I'm] getting some stuff, some useful things out of it, and some so not useful…Well, there's things I find easier to put in place for meself than some other things… around keeping myself safe and other people safe.

Tom's counselling was still in progress when the study finished. He was aware that achieving his goal of living in the community was subject to a "risk assessment" once the three year counselling programme was over. The support person felt that this counselling programme was the only available source of help for Tom and wondered what to do "if he doesn't get through it." The counsellor considered that Tom's goals for himself were "achievable and they're part of having a good life." However, the

counsellor expressed concern that Tom may not get the opportunity to achieve his goals because of the lack of follow-up support once the counselling programme has finished.

> **Counsellor:** Sometimes you feel quite sorry for that client group. And it certainly doesn't ever excuse um their offending, um but I think it is very important to take that broader contextual view and think, you know, what is life like actually for a lot of our guys on a day-to-day level, which actually means that it turns into year after year of, decade after decade of not much for them really … I sort of worry for him sometimes that the goals that he could make, he won't get a chance to make because there's not really the systems there or the support there um to give him a chance at doing it.

7.4. Margaret

Information was gathered from interviews with Margaret, her counsellor, and her support person. The interviews took place over a 14 month period. Margaret was invited to participate in the project while she was receiving counselling. However by the time the recruitment process had been completed, her counselling had finished. At the time the interviews began, the counsellor reported that Margaret had received counselling for 3 months; the final counselling session occurred one month prior to the first recorded interview. This was Margaret's first experience with counselling.

Margaret began counselling because of issues related to a job loss. According to the counsellor Margaret was referred "because of issues of stealing and anger." Margaret had been working at a nursing home. Some of the residents' personal items had gone missing. There was some suspicion that Margaret had taken the items, therefore she lost the job. Margaret acknowledged having taken biscuits and lollies, but not personal items. According to both Margaret and her support person, she was "like a little mouse" and had a history of "sneaking biscuits." Historically Margaret "did not do a good job in covering things up." From the perspective of Margaret and her support person, the job loss seemed to be predicated on breakdowns in communication and lack of support. If the problem at the job place had been handled differently, it is possible that Margaret may not have lost her job and thus, counselling may not have sought.

Counselling was initiated by others with the hope that Margaret would learn that what she had been doing was "not right" and was "a very serious matter." From the support person's point of view, that outcome did not eventuate. However, from the counsellor's

point of view, Margaret gained personal insight and continued to do so even after counselling finished.[24] Margaret knew the reason for the counselling referral and indicated a desire to stop "pinching biscuits." According to her support person, Margaret construed another meaning for counselling: Receiving counselling was a way to learn how to counsel others.

7.5. James

Information was gathered from interviews with James and his counsellor; James chose not to include a support person in this study. The interviews took place over an 18 month period. At the time the interviews began, the counsellor reported that James had been receiving counselling for five years. Prior to working with this counsellor James had worked with other counsellors.

According to both James and his counsellor he was receiving counselling because of anxiety. During the course of this study, his father died and this then became a subject for discussion in the counselling sessions.

In response to a question regarding his hopes for counselling James replied:

> **James:** Hoping to get through the problems I have. … Help me to deal with things.

James reported having a lot of anxiety a few months prior to our first interview. Five months later he reported that he was feeling somewhat better.

> **James**: I think it be not too bad at the moment…. A lot better since the beginning of the year. …

James credited both medication and counselling techniques with improvement in his well-being. Thirteen months later, the counsellor reported that "everything seems to be going okay." The presence of "a very, very good support worker" had enabled James to achieve some personal goals. The counsellor noticed an increase in confidence now

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[24] Because Margaret's counsellor had another role in the community, the counsellor continued to see Margaret from time to time after counselling had finished.

"that things at home that he's talked about say for a year, two years maybe, are happening."

James' counselling was still in progress when the study finished.

7.6. Ian

Information was gathered from interviews with Ian, his counsellor, and his support person. The interviews took place over a 21 month period. At the time the interviews began, the counsellor reported that Ian had been receiving counselling for 18 months. This was Ian's first experience of counselling.

A range of difficult life events occurred during Ian's childhood including parental divorce, death of a sibling, neglect, abuse, and violence. Difficult life events continued on into his adulthood where he experienced the loss of a parent continues to experience prejudice, bullying, and the constant threat of losing custody of his child. He presented to counselling feeling depressed and had had suicidal thoughts. According to his counsellor, the counselling referral made mention of "depression" and ""behaviours that weren't right."

Ian's hope for counselling was "to be more happy." In addition to receiving counselling, Ian also took medication for his depression. He credited both counselling and medication with helping him to feel better.

> **Ian:** I've been getting on quite well with counselling now. Yeah. I'm learning new ways of…trying to cope… with the depression… I think I'm getting a lot better.

Regarding his medication he said, "It just makes the life…much easier, when I take them."

His counsellor and his support person also reported positive outcomes. The counsellor considered that the client has gained personal insight and more confidence. In our final interview Ian's support person spoke repeatedly about how well he was doing.

> **Support person:** I can't believe how well [Ian's] going at the moment…
> [Ian's] mood seems a lot better… maybe [Ian] feels a bit more empowered…
> quite happy…things to look forward to.

Ian's counselling was still in progress when the study finished.

7.7. Kaye

Information for this case study was gathered from interviews with Kaye and her counsellor; Kaye chose not to include a support person in this study. I was first introduced to Kaye by her counsellor. In our initial meeting which was not recorded, we talked about the research project. At Kaye's request, her counsellor was also present during the subsequent two recorded interviews. At that point, Kaye was then comfortable to talk to me on her own.

> **Marilyn:** Do you want [Counsellor] to be there or is it okay if it is just you and me? Which way would you like?
>
> **Kaye:** Ah, just you and me.

Kaye and I met for an additional five interviews and I met three times with her counsellor. The recorded interviews occurred over a 12 month period. Prior to working with this counsellor Kaye had met one time with a counsellor some years previously.

7.7.1. From Kaye's perspective

Background

Kaye was the third of four children. She nearly died when she was "not even five months old." She started turning "blue, purple, all these colours" and she was rushed to the hospital. She nearly died. She spent some time in an incubator.

> Mum doesn't want to lose me at all because I was a special baby.

She got glasses as child because she was having trouble seeing the board at school. She attended the local schools where she experienced significant amounts of teasing. She also attended a Christian school which she liked because they taught her one-on-one and teasing was not a problem.

> I had really trouble at those other schools and, uh, all the kids teased me about all my, what I was wearing and even teased me about my glasses when I got them and I got rather down.

While she was at school she received some certificates for special subjects and she still has those certificates.

Her family had some trouble while she was growing up. People threw stones at their house and burned up the garage and the sleep-out.

> Me and [sister] a built a hut at the back, a sleep-out and we were going to sleep in it and someone lit that on fire, too! Lucky that we weren't in it.

Her dad was in and out of prison two times. When he was in prison, Kaye's mum found it difficult to cope and sent the children to health camp. During that time, the children were "taken off her."

> We went into welfare because of it. We were taken off her and then mum fight so hard to get us back, us kids. …Mum couldn't cope and she just sent us kids to a health camp to give her a break away from us, but mum fight so damn hard to get us back because of welfare. … She sent us there but later on social welfare…split us up again.

Her mother first got the boys back and then got the girls back. When Kaye returned home, she wouldn't go near her brothers.

> Me, my sister went to health camp and when I came back from that I was still in my I was 13 or 14 and I wouldn't even let my brothers near me because of something that I think happened in health camp and I cannot remember what happened.

Kaye's reaction to her brothers concerned Kaye's mother who sought counselling. A woman came to the home and met one time with Kaye. I asked Kaye if the counselling was helpful at that time. She replied:

> Oh kind of but I still … closed off. Go into my own little world. But it did help a little bit, but not much.

It took a few years before Kaye was comfortable to be around her brothers. She remained uncomfortable around men for some time after that. Eventually she was comfortable enough to begin a relationship with a man. They moved in together.

> It took me…29 years just to find someone because I was just that scared of men.

There were plans for a wedding, but then "everything fell to pieces."

> My ex really hurt me when he left.

The relationship break up was distressing for Kaye and her mother sought counselling for Kaye, who was at this time 30 years old.

Current context

During our interviews Kaye spent a significant amount of time talking about her family. She was living with her mother and father and spent time with her siblings and her nieces and nephews. She frequently mentioned spending time with family and organising gifts for them. She described her family as both a source of support and a source of stress.

During our interviews Kaye frequently mentioned a range of health related issues.

> I burned myself….I usually have accidents like that. And I drop things.

> My asthma keeps playing me hell.

> I just can't get rid of this damn cold and I had diarrhoea as well last…one or two days.

Kaye also mentioned feeling ostracised by her neighbours because of a situation related to her father.

Counselling process

Kaye began counselling because of her relationship break-up. As counselling progressed she also talked to her counsellor about other troubles as well.

> If I have any trouble with my family or if I'm under a lot of stress and strain I can talk through it. But I say good things about my family and sometimes I don't. … At the beginning I was down because of the breakup of my ex and what [he] done to my family and me.

I asked Kaye, "What do you hope for when you go to counselling?" She replied:

> I need to… just…get things out of my system, what's bothering me. What things are going wrong and which things are going right and stuff like that.

Midway through our interviews, I asked Kaye if she would like to draw a picture about counselling. She drew the picture of her dream house shown in Figure 3.

Figure 3: My dream house

Here is what she told me about this picture:

> It's my dream house… Maybe one day I'll get what I want, want but at the moment with my finances going completely kaput, ah, um, my ah, my hands up. And counselling still helps anyway.

Kaye began taking medication for depression while she was in counselling. She talked to her counsellor about the medication. "[Her counsellor] said it was a good idea." In addition to crediting counselling with helping her feel better, she also credited her medication.

> Mum was worried. So we went to doctor and doctor prescribed me some depression tablets because I was so damn low … I've been sleeping a lot and lacking in energy and oh he gave me these depression tablets and they've been helping.

Outcomes

In our final interview which occurred four months after she gave me the picture of her dream house, she gave me the picture which is shown in Figure 4. She told me that "things are starting to happen."

> I got work experience. … I'm going to meet people of my own age. Um, and do cooking classes. … They've got coffee groups, and I can do things. … I'm on the top of the waiting list for housing New Zealand.

Figure 4: Trying to swim on my own

Here is how she described this picture:

> It's me trying to swim on my own. Trying to stand on my own without mum being there or anyone, um, to interfere into my own life. And I got things to do. And stuff like that I've got the sun, the moon … Just trying to stand on my own 2 feet… My mum and dad are still there, but if I do want to go and

> see them I can… It's like I'm trying to stand on my own without me
> depending on my mum and dad all the time and trying to keep myself
> balanced and not getting hurt again. And I've got plenty of people around
> me. That's what the sea is. People who surrounding me, like parents, people
> that I need, I can depend on. That's what the sea is.

Later in that conversation I asked her how she might like to introduce herself in my thesis. She looked toward her hopes for the future and said,

> I'll just say that my name [is Kaye.] … I used to live with my parents … and
> I'm trying to stand on my own two feet. And I got my dog, and I've got my
> family, and I've got support, and I will slowly get my confidence back.

Some months after completing the recorded interviews I met up with Kaye's counsellor in another context. She told me that Kaye has moved into her own flat and has finished up counselling. After completing counselling, her counsellor continued to have a supportive a role in her life until Kaye was well settled in her new flat.

Kaye dreamed of a place of her own and is now realising her dream. Embodied in her concrete triumph are the intangible measures that are typically sought when evaluating counselling outcomes. She was conscious of "trying to keep balanced" in order to avoid getting hurt again. Her self confidence has been built up. In our final interview she told me, "I'm rather happy" and then again a few minutes later, "I'm pretty happy."

7.7.2. From her counsellor's perspective

Background

Although Kaye's counsellor did not discuss much about Kaye's background, the few comments she did make, shed additional light on Kaye's description. The counsellor considered that Kaye's mother and sister also have an intellectual disability. Although the counsellor had not met her father, she had the impression that he does not have an intellectual disability. He does, however, have "other issues." The counsellor's impression from talking to Kaye and her mother was that Kaye's attendance at school was not consistent. She attended mainstream schools, without the assistance of a teacher

aide. The counsellor considered that Kaye's family was "very dysfunctional" and that Kaye had had limited opportunities while growing up.

> And just little things that we take for granted … she'd never experienced.

Kaye initially presented to counselling with "depression and difficulty coping with the failed relationship."

During the course of counselling "lots of other issues" surfaced.

> Low self esteem … her lifestyle, how she looked, whether she was independent, how she coped with her family. …. And issues too, as far as her physical health how she could utilise her life in a different way, what goals she would like for the future and how she saw herself and how other people saw her.

Counselling process

At the time the interviews began Kaye and her counsellor had been meeting together for two years. Initially they met fortnightly. During the course of the study they met every three or four weeks depending on Kaye's needs.

The counsellor described her approach as "person-centred." In her work with Kaye she used "a holistic approach" which combined counselling and support.

> Counselling is specifically listening, reflecting … counselling is mostly working on what's going on inside the person, but support involves what's going on outside the person as well.

Her work with Kaye included:

- Traditional counselling skills such as listening, observing, reflecting and problem solving

  > She didn't like going into the butcher's shop. It was full of nice young men and they all had her on a wee bit and … she felt embarrassed but she practised some things to say back to them.

- Collaborative work with other professionals

  > I've had quite a lot of dialogue with the doctor.

- Practical support

  > We've gone and done an application for a council flat.

- Education

  > Quite a lot of what I've done with [Kaye] has been health education as well, to address things like depression, asthma, skin allergies… how she copes with life and how she feels.

This counsellor's work came under the scrutiny of others. This counsellor took the time to explain to colleagues the reasons for her "unconventional" practice.

> I had a meeting with the social workers…because they didn't quite understand what helped [Kaye] and what didn't help [Kaye]. And they thought it was quite unconventional that I would take her on appointments and we'd meet at a coffee shop and things like that. And I explained to them that this is a girl from a very dysfunctional family who's never had any contact with anybody that had a relatively normal lifestyle. And just little things that we take for granted that she'd never experienced …How can you say to somebody "make a choice" about something when they've had no experience of what that means? So she needed to have experience of lots of little things… Until she's had an experience of these things, she can't choose whether that's something she wants to do or not.

The counsellor was aware that Kaye needed time to take on board new information.

> [Kaye] took probably about six months to realise that there would be a relationship between how she's feeling physically and how she was feeling mentally… Even stress — … she hadn't realised the effect that stress can have on you.

Outcomes

Kaye's counsellor noticed several changes in Kaye since they first met. Kaye has grown in confidence.

> She presents much better. When I saw her first saw her …she'd come in [to the coffee shop] and she'd be all bowed down like this and her head would be like this and she'd shuffle to the table and she'd have a cup of coffee and she'd sit down like this. When you see how she is now. She bowls in there and she greets people… she chooses her own drink. She's changed so much. … prepared to make new friends. …much more assertive.

The counsellor felt that now Kaye sees herself differently. According to the counsellor Kaye's mother used to say that "she was an adult trapped in a nine year old girl's body." At the beginning of counselling the counsellor noticed that Kaye "was very aware that she had a disability and that she looked and behaved differently to other people" and now Kaye sees herself as a woman.

> Since she's been going into the café and everybody greets her, is just nice to her. She said, "I feel like a woman now." And then one day she said, "I feel like a pretty woman today." She had a new jersey on.

The counsellor also noticed that Kaye is now able to plan for her future.

> She's actually planning her life now and you've got quite a clear idea of where she wants to be and how she's going to get there. Whereas at the beginning, she had no idea of what life could be like if it wasn't how it was now. So she didn't have a perception of what was in the future, let alone how to get there.

In our final recorded interview Kaye's counsellor talked about the collaborative effort involved in supporting Kaye to apply for a government-subsidised flat.

> And her case manager was very good too, her WINZ case manager. Because when they asked him for his input, he said he really didn't want her living at home. He felt that it was detrimental to her well-being and her health. So he was very much an advocate of her being independent.

7.7.3. Summary

This case illustrates how a holistic approach to counselling assisted Kaye to achieve a number of positive outcomes. Kaye began counselling as a result of a relationship break-up. She was depressed and hurt. When the study ended she described herself as happy and her counsellor noted that she was more confident and assertive. Kaye dreamed of having her own flat and with her counsellor's assistance, she now has realised that dream.

Like many people with an intellectual disability, Kaye experienced teasing, bullying, and trauma in her childhood and social exclusion continues to play a role in her adult

life. Kaye described how those experiences caused her to withdraw and "go into [her] own little world." Kaye has numerous health issues which impact on her well-being. As a beneficiary, Kaye has a limited income. Working with Kaye in a holistic way, these issues were addressed alongside her depression and hurt. Table 2 summarises the counsellor's approach to these issues.

Table 2: Holistic counselling interventions

Problem	Interventions
Teasing	Practiced possible retorts to teasing
Social exclusion	Provided positive social experiences, e.g., going together into the café and ordering drinks Supported Kaye in finding another living situation and in making new social connections
Health issues	Worked collaboratively with her doctor Provided health education for Kaye
Limited income	Helped Kaye with her WINZ forms and met with Kaye and her case manager Assisted Kaye with her application for government funding housing options

This case also illustrates how counsellors working in this manner are scrutinised by their colleagues. This counsellor responded by meeting with those colleagues and explaining the reasons for her "unconventional" practice.

7.8. Roger

Information for this case study was gathered from interviews with Roger, his counsellor, and his mother who was his support person in this study. I conducted six recorded interviews with Roger, three interviews with his mother and eight interviews with his counsellor. There were a larger than usual number of interviews with his counsellor because his counsellor also had another client who was participating in this study. Generally our interview discussions alternated clients. These interviews occurred over a 14 month period.

7.8.1. From Roger's perspective

Background

Roger was born overseas and came to New Zealand when he was 2 ½ years old. He and his mother went to "some sort of a place" and "had to say some words" and then they became New Zealand citizens.

When he was a little boy, he remembers going on an airplane with his father and looking out the window at another airplane in flight. When he was small he lived with his family and went to the local kindergarten.

> I went to that kindergarten… and I stayed there until it was time for me to go the … boarding school. I went to a boys' boarding school run by the brothers and I stayed there until it was time for me to leave.

While he was at the boarding school in the South Island, his family moved to the North Island. On school holidays he flew by airplane from the boarding school to home and back again. While at boarding school he got "some sort of trophy for being well dressed and that."

His father died when he was 14 years old. When he left boarding school he lived with his mother until he got his own flat. After living in his own flat for a while, he moved to flat in an old people's complex.

> I stayed there [the old people's complex] until it was time for me to come here.

He currently lives in a flat located in a cluster of flats operated by a disability support service.

> [The flat] really belongs to the [disability support service] but … it's my flat now. … They do run it. But I live in it. It is my flat. I also share with a caregiver, actually.

Caregivers are on site from 4pm until 11 am. During morning and afternoon hours, they rotate among the flats. At night one caregiver is on duty for all the flats. This caregiver sleeps over in the second bedroom in Roger's flat.

> I don't know how many caregivers there are. But they all have turns you know. Looking after us and that. We got relievers as well. Saturday I had a reliever… I had never seen her before. … [A staff person] told me that she was 21 but she didn't look it. …She looked more like a teenager.

Roger mentioned to me that some day he would like to live more independently.

Throughout his adult life, he has taken several classes at the polytechnic. At the time of the study he was taking reading classes. During the week he volunteers at a disability support service and at a video shop.

Roger told me that he has OCD and anxiety.

> It's about cleaning … You can't touch something dirty or whatever … you can only touch something that is clean. … I got all this dirtiness on my mind.

When he first heard people using the words OCD and anxiety, he did not recognise those words. When they explained what the words meant, he recognised the symptoms.

> I never heard of anxiety before … but when she mentioned the word, I knew what she meant anyway.

Roger thinks that his OCD started when he was about 17 years old and was attending a religious camp.

> I think it might have started off when I went to some sort of… religious camp …I didn't seem to be very happy there … well it was the first time I'd

ever been to a religious camp, and I thought to myself, I don't think I'll go
to… any more religious camps, since I wasn't happy there.

Prior to seeing his current counsellor, he was receiving help for his OCD from a
psychiatric nurse. He started seeing the counsellor in this study at his mother's
recommendation. According to Roger, his counsellor is helping him with his OCD and
"anything else that is on [his] mind."

> **Marilyn:** What do you hope to get from talking to [counsellor]?
> **Roger:** Keep talking to her and hope that somewhere along the way it would
> probably go away.

Counselling process

Roger described counselling as sitting down and talking.

> We sit down and talk. … I just tell her what's been going on and tell her
> what I'm doing and … if I have any problems or anything.

From time to time his counsellor gives him ideas of what he "should try to do."

> …she has told me that I have to try and you know touch things even if it's
> dirty or it doesn't look dirty … I've tried, but it's not really that easy. But
> sometimes I kind of reckon if the door handles are dirty …I give them a
> wipe.

Outcomes

Roger said that talking to his counsellor helped. Throughout our interviews on occasion
he said his OCD and anxiety were better, but most of the time he said that they were
about the same. His OCD has been with him a long time, and it has not changed much
for him.

7.8.2. From his mother's perspective

Background

Roger was the second of three children and was developing normally until he was six
months old.

> He had an illness when he was six months… that did damage the hearing
> and the brain. … The damage done to his ear was affecting the balance and
> he didn't walk until he was a year and 10 months old.

When he was 4 ½ he had an adenoid operation and lost hearing in his left ear. At that time the doctors did not recommend a hearing aid.

> He'd had an intelligence test, and he would get no further than 16, they said.
> And then um, they [the doctors] said a hearing aid wouldn't help him.

He attended the local kindergarten. He was tested before going to school and the kindergarten said that he could spend an extra year there. However, Roger's mother described that when Roger turned five, he insisted on leaving kindergarten and going to school. His mother said:

> I was pregnant with a baby with the youngest girl and he decided, "I'm five. Now I will go to school." He decided he would go. A bit of disruption, but he went, but it wasn't quite like kindergarten. [Laughter.] When he was about eight his father went to Vietnam for a year. So I took him home for a year or 10 months. And when he came back he wasn't settling in at the school and he wasn't going forward. So, someone told us about the … boarding school.

Roger was nine years old when he went to boarding school. In recent years, it has come out that staff at this school had been sexually abusing students. Legal action was taken and Roger was one of many who received financial compensation. When Roger was a child, his mother had thought that he was doing okay at school. However, during the investigation process her son disclosed that he had been beaten up.

> I can't understand why he didn't tell me he'd been beaten up by one of them. He told his story to this Father [Name]. And a lot of it was …the big boys were bullies.

In light of the fact that many boys had been sexually abused while at the boarding school, Roger's mother also felt concern that he, too, may have been sexually abused. Roger's memories of school bullies were long lasting. Roger's mother recounted to me a story from when Roger first began taking adult classes at polytechnic.

> We'd gone for an interview. …She [a woman from polytechnic] rung up and said, "Yes, you can go." … [Roger] said, "Will there be bullies?"

After Roger left boarding school he lived with his mother for a while. Then he moved into a little flatlet that was connected to a larger house. The house and flatlet were run by a disability support service. Caregivers looked after the residents living in the house. Roger lived by himself and went to the "big house" for his meals. The arrangement worked well for quite some time, until two situations caused concern around Roger's safety.

> That lasted quite a while until…. They had five boys there, I think, one was rather large. He'd been in trouble with another Trust Home. … [One day] he presented … with a pen knife. Fight. So the [caregiver] got the boys and put them all in the van and … took off. Left [Roger] in his little flatlet next to the garage with this guy wandering around with his knife. So I was a bit disgusted with that.

> Another time … one Saturday night … [Roger] was feeling sick and he came out of his flatlet and walked across in a … winter's night, to the caregiver's window and knocked on the window and said can you get me to the hospital or doctor's or something because I'm sick. And he was vomiting all over. And [the caregiver] put him back to bed. … [Roger] was in great pain and I was in Australia and this was a Saturday night. Sunday he stayed in bed. Monday he didn't go to work; he was sick. So they left him at 9 o'clock with a jug of orange juice and the main house open, "Go and get yourself something for lunch." And the telephone. Nobody rang him to see how he was. Nobody got him a doctor or anything. So um, this Wednesday, a caregiver came on and he looked at [Roger] and rang [Roger's] sister and his sister had pneumonia and was seven month pregnant and said, "Get him a doctor!" So they got him a doctor and the doctor said…he had pneumonia.

Roger lived in a few different types of arrangements after living in that flatlet. Roger wanted to live on his own, in a flat. His mother considered various options. She chose his current living arrangement because she considered that it provided some amount of independence and privacy but in a "a safer environment than being in his flat and have people come in, you know, three times a week."

At the start of this study Roger had been receiving counselling on and off for about 15 years; his mother initially sought counselling for him because of his OCD. She sought counselling from the counsellor in this study for a different reason. A situation arose that caused her a great deal of concern. When she went to pick Roger up from a community class she discovered that he had been brushing up against some of the

female staff. She made inquiries and learned that he had been "pushing into ladies" in other settings as well and no one had mentioned it to her. At this time, Roger was working with a psychiatric nurse regarding his OCD, but Roger's mother felt the service the nurse worked for was "inundated" and she wanted help "quickly." She began searching for a counsellor.

> He was pushing into ladies and it's the thing that the [staff at the boarding school] did to them….And I needed help quickly. I wanted the counselling, you know, to provide, to stop him doing it and why and you know. He knew it was wrong. And I was told by the [disability support service] that they had one woman and she was based in Auckland and she would come down when there would be a group with the same problem.

She did not want to wait for such a group and continued to ask around for referrals. Someone at a community agency referred her to the counsellor in this study. She sought counselling for Roger because of his "inappropriate touching and behaviour" which she considered to be sexual in nature and related to possible historic sexual abuse. She considered his OCD to be separate to this behaviour. At some point after he began receiving counselling from this counsellor, Roger was discharged from the service that was providing help for his OCD.

> …others at [government funded health service] decided that, well, if he is getting private counselling he doesn't need us. And they've got a long waiting list.…They think that, you know, but it's not fair because, if they have different approaches. He went to counselling … not for his OCD, but for something else.…They [the government funded health service] discharged him. They've got that many on the books.

Although she considered his discharge "unfair," she was aware that the health service had a large client load and limited capacity. Since Roger was no longer receiving help for his OCD, his counsellor "had to take over the OCD as well. … It's all mixed in now."

Roger's mother initially paid for this counselling herself. At some stage she decided to ask the boarding school to pay for it.

> I approached them and they said they would pay for about 10 sessions. But they have continued to pay.

Counselling process

Roger's mother considered that the impact of Roger's mistreatment will be with him for the rest of his life. So she asked the school if they would fund counselling long term.

> I didn't get an answer, but I asked, "Would they be willing to do it for the rest of his life type of thing, you know." To keep his counselling. Because I think they need it. I'm mean they've had something like that in their lives and I think they need to be sure that they can talk to somebody or you know, help them through.

Roger's mother sought counselling for a specific issue, but sees counselling as long term support need for Roger. She frequently commented about how well Roger got along with his counsellor.

Outcomes

Roger's mother was keen to participate in the study; however, her deteriorating health cut short her involvement. She was involved for only three months. In those early interviews, no data were gathered about Roger's outcomes.

7.8.3. His counsellor's perspective

Background

The counsellor first had contact through Roger's mother who both telephoned and wrote a letter. Roger and his mother came together for the first counselling session. Roger's mother provided the counsellor with "a potted history of his life" detailing "how he born, what went wrong … all the trials and tribulations." The counsellor considered that it was "maybe it was therapeutic for her to be pouring out all." The counsellor felt that it was "interesting" but that "a lot of it wasn't particularly relevant to the relationship between [Roger and her]." In that first session they "talked about how it might, you know, be nice to just talk with [Roger] and, of course, she [Roger's mother] was quite happy with that."

Roger's mother's remained in contact with the counsellor. From time to time she would call the counsellor with concerns. At Roger's next session, the counsellor would wait to see if Roger brought it up. If he did not mention it, she would say, "Your mum told me,

this happened, you know, is that bothering you?" If it was bothering Roger, they would talk about it.

> And sometimes mum's concerns are not [Roger's] concerns at all, so we don't pursue it.

The counsellor also heard about Roger's life from Roger. She heard about the bullies and other unpleasant experiences at boarding school. Based on what Roger told her, she did not think that he had been sexually abused.

> There were some…experiences which are relevant and have affected him but they weren't the forms of abuse that his mother suspected. I suppose normal school stuff, being in trouble for things he didn't realise why he was in trouble and you know being quite afraid of the wrath of the headmaster or the teachers or you know, some teachers he didn't get on with and didn't like — those sorts of things.

Roger was aware the other boys had been sexually abused, and the counsellor gathered that "he had been approached… but no was taken as an answer." However, Roger has maintained that he himself had not been sexually abused.

> There certainly were some um behaviours at [boarding school] that disturbed [Roger] but sexual abuse is not one of them. Repeatedly you know over two years he'd occasionally come back to it and I'll query it and it's always been the same story — quite adamant that that didn't happen.

Unlike Roger's mother, his counsellor did not think that Roger was brushing up against women for sexual reasons. She thought that his behaviour was related to his OCD.

> [Roger's mother] thought [Roger] was hiding something, um; an experience she suspected may be some sexual abuse while he was at a school when he was younger. … [Roger]…has maintained it didn't happen to him. … I'm absolutely convinced … he was being genuine … in his mind … he may have touched something or someone that he felt was dirty. Now … he needed to wipe off that contamination. And so he would just brush up against somebody and most of the staff happened to be female. …And his fear was, also somewhere … in his understanding was, if you touch men, they'll think you're homosexual.

Counselling process

When counselling first began, she and Roger sometimes met weekly and sometimes fortnightly. This study commenced when they had been meeting together for 18 months. At this time, "things [were] much better" and the counselling sessions were held once a month.

> Every month which is really just catching up, and going over any hiccups and anything that's upset him along in that month.

This counsellor described her way of working as "person-centred, integrative, humanist and self-explorative." Counselling sessions involved talking, personal exploration, empty chair work and psychodrama. The counsellor described Roger as "quite creative."

Interventions and outcomes

One specific positive outcome was that Roger stopped brushing up against staff. In the course of her work with Roger, the counsellor provided Roger with information regarding personal boundaries.

> We also explained why um to [Roger] …that's what people think if you brush against them or you come too close … we talked about personal space and you know worked together, saying that this is a safe space — this is threatening to people, if you come too close.

She worked with Roger to find an alternative behaviour to "brushing up against the ladies."

> Now he'll use a tissue to wipe off the germs and then he can throw the tissue away. So he doesn't need to wipe it on anybody else.

Although the features of the OCD are still present for Roger, his behaviour is now more socially acceptable for those around him.

The counsellor recognised that many people with an intellectual disability had difficulty understanding the social norms around boundaries and touching.

> Normal understanding of boundaries and touching … and sticking to the rules are quite complex for them.

She felt that many of the staff misunderstood Roger's attempts at social interactions. She considered that misunderstandings between staff and people with an intellectual disability were prevalent. In addition to educating clients around these concepts, she considered that there was a need for more education of direct support staff. In particular she would like to see an increased awareness of "how concepts [of boundaries and touching] are very different for people with an intellectual disability" as well as a greater ability to problem solve and communicate clearly when incidents first happen. However, the counsellor recognised that high staff turnover, poses difficulties for staff training. Nevertheless, with improved communication, many problems could be avoided.

> So many things come out of misunderstandings, getting the wrong end of the stick, misinterpreting something somebody has said or done. …this person's gone off with his idea of the truth and they get further and further apart and then it — when it's up here, it's so hard you know to bring two people together cos all this stuff's gone on. If it was just understood at the very beginning, clarified.

As in the previous example, as a result of working with his counsellor, Roger was able to moderate other behaviours which caused concern for those around him. However, his OCD remained present.

> He just manages it and he's quite happy to manage it the way he does. Others see it as a bigger problem than he does.

Using the principles of cognitive behavioural therapy and exposure, his counsellor has suggested various interventions to Roger.

> My idea last time, let's go with something *he* thinks he can manage a very, very specific task…. Maybe he could manage…touching the light switches, *just* light switches, not worry about the doors or anything else in life.

However, on his own, it was difficult for Roger to implement these new strategies.

> He would like rid of it [OCD].… but intellectually he really can't [pause] do what's necessary in terms of cognitive behavioural therapy. And try - trying out different behaviours and exposure, those usual things that you would try, um, he won't do by himself, doesn't want to do it.… He's too afraid of the exposure … perhaps if he was more intellectually able … he might really try and force himself to go through that barrier.

Consistent daily support might have enabled Roger to try exposure interventions. Although Roger has support from his mother and from his carers, the counsellor did not see them as being able to provide this type of support.

> [Roger's mother] sees him once a week um, so she's not with him constantly to enforce that – and staff "have better things to do."

Like Roger's mother, this counsellor considers that Roger would benefit from long term counselling. Unlike Roger's mother, she does not attribute this need to his childhood experiences, but rather perceives his counselling to be "on-going maintenance." The counsellor sees this maintenance counselling as "probably for his mum's peace of mind." Having a monthly counselling session provides Roger an opportunity to address issues as they arise.

> With the intellectually disabled clients, I've come to learn it is different…. in the early days … it was almost more of a crisis…more specific issues…. but once they were dealt with, and that took time, a long time… it's this ongoing maintenance really.

The counsellor considered that on his own, Roger would probably not have requested counselling.

7.8.4. Summary

This case raises the question, "Who is the counselling for?" Roger was referred to counselling because of the impact that his behaviours were having on other people. Roger had "all this dirtiness on [his] mind" and he wanted to be rid of that problem. He managed that dirtiness by using rituals. These rituals were a solution for him, but they were a problem for the people around him. Working with his counsellor, Roger replaced those rituals with more socially acceptable rituals. However, according to both Roger and his counsellor, the underlying OCD continued to be a problem.

As a child Roger experienced teasing and bullying. He spent several years in a boarding school which in recent years has undergone legal proceedings in response to claims of physical and sexual abuse. Convictions were made and Roger, like many other students, received a financial settlement as a result. As an adult Roger has also lived in situations

where the quality of care put him at risk. Roger began attending counselling at the request of his mother. Roger and his counsellor have established a good working alliance. Together they have been successful in modifying his ritual behaviour so that others around him are more comfortable. Indeed this was a positive outcome, particularly for the women whom he had been brushing up against.

Counselling gives Roger's mother peace of mind because once a month, someone is there to listen to any concerns he may have. But what about Roger and the dirtiness that plays on his mind? His counsellor was in the position of delicately balancing Roger's concerns and those of his mother and the staff. Roger liked talking to his counsellor and he would like to be rid of his OCD and anxiety. Although Roger and his counsellor have talked about various new strategies that he could implement, these are too difficult for Roger to implement on his own.

Although positive outcomes have been achieved in this case, most of the direct benefit was to people other than Roger. In order to increase the likelihood of Roger experiencing a direct benefit, he is in need of someone to provide daily support in implementing new strategies.

7.9. Discussion

Viewed individually the detailed case studies provide specific ideas for practising counsellors. Viewed as a whole the six cases highlight three broader themes: (a) Misinterpretations of client behaviours are common. (b) There is a need to take a broad view of counselling goals. (c) The quality of support has the potential to help or hinder the achievement of positive counselling outcomes.

7.9.1. Misinterpretation of client behaviours

In three of these cases, clients were referred to counselling for behaviours which concerned those who were supporting them. However, more in depth exploration found something different than what others interpreted.

Roger was referred for a behaviour which was viewed as sexually inappropriate behaviour. However, both Roger and his counsellor saw the problem as OCD. Interestingly, an OCD-related intervention was successful in eliciting a behaviour change. Margaret was referred to counselling for stealing. In listening to Margaret and her support person, it seemed that the job loss occurred as a result of lack of support and misunderstanding. Margaret's sweet tooth seemed to be the primary motivator for "pinching biscuits." Ian's counselling referral included mention of depression and "inappropriate" behaviours. However, of concern to Ian were his depression and suicidal thoughts. Interestingly, his counsellor considered that the inappropriate behaviours stopped in response to "being listened to" and having the opportunity to "get this other baggage out."

McMillan (2009) expressed concern about the negative impact that misinterpretation of behaviours can have on people with an intellectual disability. In his article, which discusses Asperger syndrome in particular, he discussed different types of interpretations using the narrative therapy terms of "thin" descriptions and "thick" descriptions. "Thin" descriptions narrowly label the behaviour and can "have negative effects on how others perceive us, and how we perceive ourselves" (p. 16). "Thick" descriptions allow for an understanding of the person's disability and motivations and thus, "can reduce the impact of problems as well as creating opportunities for behaviour change" (p. 17). In his article McMillan expressed considerable concern for how misinterpretation of problem behaviours can impact on young people with Asperger syndrome.

7.9.2. A broad view of counselling goals

The counsellors in this study took a broad view of counselling goals and worked in a holistic manner. As is typical in counselling, Kaye and her counsellors worked together to address her depression and hurt. Counselling goals were broadened in response to Kaye's concerns. Kaye and her counsellor worked together on issues related to her physical health and her living situation. The counsellor also supported Kaye in making connections in the community. Time was spent both inside and outside the counselling

room working on a broad range of goals. Chapter Six included descriptions of other ways that counsellors assisted clients with a broad range of personal goals.

In Roger's case, there was also a need to take a broad view of counselling goals, but for a different reason. Instead of broadening goals in response to Roger's concerns, the goals were broadened to include both Roger's concerns and the concerns of those in Roger's support network. The counsellor took time to listen to the concerns of those in Roger's support network and struck a delicate balance between responding to Roger's concerns as well as to the concerns of others. Roger's counsellor also spent time both in counselling sessions and outside of counselling sessions.

Much like the counsellors in this study, McMillan (2009) described his work as both "work inside the counselling room" and "work outside the counselling room" (p. 18). The work inside the counselling room was spent building a working alliance, affirming the clients' understandings of themselves and skill development. The work outside the counselling room was spent gathering information and passing it on to clients' families, linking clients and their families to appropriate agencies, providing information to teachers and staff who worked with the clients and fostering connections in the community.

7.9.3. Quality of support

The quality of the clients' support had a significant influence of the clients' outcomes. In a number of cases appropriate support was associated with the achievement of positive outcomes. For example, Kaye's drawing depicts how she felt buoyed up by the support of her counsellor, her case managers, her family, and other disability-related organisations. James' counsellor had worked with him over a length of time and could therefore observe turnover in the client's support workers. The addition of a "very, very good" support worker enabled James to achieve some long awaited practical goals. Achievement of those practical goals made a noticeable difference in the achievement of counselling goals. Tom credited his success in applying some new skills to having received support from his support worker.

In other cases, the absence of support at critical times was thought to create difficulties in achieving goals. In Margaret's case, a lack of appropriate support seemed to result in a job loss. Tom's support person and his counsellor expressed concern that lack of appropriate support structures could likely stall or impede his desire to move into the community. In Roger's case, the counsellor perceived that support workers would not be willing to assist with counselling interventions. Thus, there were many interventions that Roger was not able to implement.

7.10. Conclusion

Despite systemic problems, and complexities in their support network, the six clients in this study were able to achieve some positive outcomes. This chapter illustrates specific counselling practices which assisted clients to achieve positive outcomes. It also highlighted some of the complexities in determining the successfulness of outcomes. Both the identification of the problem and the determination of success are dependent on one's point of view. These six cases suggest that to accurately assess the effectiveness of counselling, multiple perspectives need to be sought in the identification of the presenting problem as well as in the assessment of the outcomes.

Chapter Eight: Discussion and conclusions

The aim of this chapter is to discuss how the findings from this thesis can be incorporated into counselling knowledge and practices and to highlight areas for future research.

8.1. Introduction

This project was initially motivated by my own desire to learn more about counselling people with an intellectual disability. I was further encouraged to pursue this topic by the high level of interest voiced by others throughout the consultation process. During the interviews with participants they, too, voiced their interest in the outcomes of this project.

> **Client:** I hope that all the other counsellors might learn something.
>
> **Counsellor:** I'll be very interested in reading your findings for your PhD…There's not a huge body of work on working therapeutically with people with an intellectual disability.
>
> **Support person:** I know a lot of people with intellectual disabilities who really need the help of a counsellor and as far as I know there aren't a lot of counsellors available…Being a part of a study means that I can tell people that there is…stuff happening.
>
> **Key informant:** I would like a copy of the key findings.
>
> **Marilyn:** All the research participants will get a copy.
>
> **Key informant:** That would be great… it's wonderful to know where that information goes and what happens to it and critically to see how you synthesize it so that we are informed as well, because we don't have all the answers either.

This chapter begins by discussing some answers to the questions which prompted me to carry out this research. Next the chapter discusses the strengths and limitations of this study. The process of searching for answers and contemplating limitations gives rise gave rise to more questions which have been presented as topics for future research. The chapter concludes with recommendations and invitations.

8.2. Questions explored in this thesis

8.2.1. What is an intellectual disability?

The literature review described three models for conceptualising the notion of disability: (a) the medical model, (b) the social model, and (c) the third movement. The medical model locates disability within the person. The social model of disability locates disability in society. The third movement locates disability both in the person and in society. The findings in this thesis indicated that the clients' concept of disability most closely resembled the medical model. That is, they located their disability within themselves. Comments from the counsellors, support people and key informants seemed to indicate that their understandings were aligned with the third movement.

The participants were in agreement that disability is understood in relation to "normal" and that people with a disability are often in need of support. Society plays a key role in their social acceptance and in the provision of support. When describing the support needs of people with an intellectual disability the participants mentioned needs for practical support, literacy support, and communication support as well a need for sufficient time to take on board new information.

Implications

When considering the differences that having a disability makes, it is all too easy to let the disability take precedence over others aspects of someone's personality. Smart and Smart (2006) urged counsellors to think differently:

> Counselors should recognize that the disability is simply one part of the individual's identity. As does everyone, the client with a disability has multiple identities and multiple roles. Disability is not the "master status." (p. 37)

While it is important to recognise a client's intellectual disability, it is equally important not to let their disability overshadow other aspects of his or her identity.

8.2.2. What is counselling?

Although many definitions of counselling abound in the literature, Wampold (2001) considered that following definition was "not controversial" (p. 2):

> Psychotherapy is primarily an interpersonal treatment that is based on psychological principles and involves a trained therapist and a client who has a mental disorder, problem, or complaint; it is intended by the therapist to be remedial for the client's disorder, problem, or complaint; and it is adapted or individualized for the particular client and his or her disorder, problem or complaint. (p. 3)

This thesis has demonstrated that the participants held a similar view of counselling to that of Wampold. The participants considered the purpose of counselling to be assisting clients to work through problems or issues. They viewed counselling to be confidential conversations between the client and the counsellor. The counsellors and the clients also noted that counselling was a working alliance. The key informants, counsellors and support people mentioned that in addition to helping with problems, counselling could also assist with personal growth and increased self awareness. The key informants, counsellors and support people considered counselling to be a professional activity.

Implications

Numerous barriers make it difficult for people with an intellectual disability to access professional counselling. However, human interactions that resemble the nature and purposes of counselling are not limited to those that occur solely between a professional counsellor and a client. Such interactions can occur in other settings as well. It would be useful to explore whether counselling-like interactions are occurring in other settings for people with an intellectual disability and if so, what are the outcomes. One of the gaps in counselling literature is "the exploration and evaluation of the use of counselling in non-counselling settings…There is very little research into counselling carried out by nurses, social workers, teachers or clergy" (McLeod, 2003, p. 190). McLeod considered that "from the point of view of the people who seek help, the quality of help they receive from nonspecialist counsellors is crucial" (p. 190). Given the range of unaddressed needs experienced by people with an intellectual disability, it would be

useful not only to improve their access to professional counselling but also to identify other possible routes for effectively addressing their counselling needs.

8.2.3. What factors influence counselling outcomes?

The findings from this study are similar to those found in literature. The findings suggest that the following factors influenced engagement in counselling and counselling outcomes:

- The availability (or lack of availability) of specially trained counsellors

- Prejudicial attitudes inside and outside the counselling profession

- The quality of support

- Physical health

- Financial resources

- Time

Exploration of these factors highlights four areas of need: (a) a need for specialised counsellor education, (b) a need for consistent and appropriate support for people with an intellectual disability, (c) a need for health education and improved healthcare for people with an intellectual disability, and (d) a need for cost effective approaches.

A need for specialised counsellor education

The key informants in this study perceived that it was very difficult to find counsellors who had the necessary expertise to work with clients with an intellectual disability. Given that the topic of intellectual disability is rarely covered in generic counsellor education (e.g., Razza, 2008), the lack of specially trained counsellors is not surprising. This study highlights a need for specialised counsellor education. Education is needed not only to enhance the counsellors' skill base, but also to counteract the prejudicial attitudes that seem to be present in both the wider community as well as the counselling community.

A need for consistent and appropriate support for people with an intellectual disability

It is well recognised in the literature that the quality of support makes a noticeable difference in the lives of people with an intellectual disability (Beaty & Perry, 1998; Test, et al., 2003). In this study all the participants referred to issues surrounding the quality of the support. Numerous instances of positive support were mentioned, and these had a positive impact on the client's well-being and on their achievement of counselling goals. However, high staff turnover and variable quality of support had negative effects. At times, when clients were lacking support the counsellors stepped in to fill those gaps. Had consistent support been available, the counsellors could have spent that time addressing the clients' specific counselling needs. This study, like many other studies, draws attention to the need for a more "capable and reliable disability support workforce" (Ministry of Health, 2008, p. 9).

A need for health education and improved healthcare

In New Zealand as well as in other countries, the health needs of people with an intellectual disability are considered an urgent priority (National Health Committee, 2003b; U.S. Public Health Service, 2002). Physical health and emotional health are interrelated. Findings from this study suggest that improvements in their physical health assisted clients to have improvements in their emotional health. These findings point to a need for better health education and improved healthcare.

A need for cost effective problem solving approaches

The key informants reported the initial engagement in counselling was often stalled due to limited financial resources. All six clients were beneficiaries; clearly they faced financial limitations. In addition to shortages of money, participants mentioned a need for more time. Clients needed more time to take on board new information. Counsellors mentioned that working with clients with an intellectual disability takes more time. One key informant clearly articulated a need for more time. The combination of limited financial resources and a need for more time points to a need for cost effective problem solving approaches.

8.2.4. Is counselling different when a client has an intellectual disability? If so, what is different and what remains the same?

The findings from this study suggest that the clients' presenting problems and hopes for counselling bear similarity to general counselling practice. The findings also suggest the following key differences:

- Counselling referrals were initiated by others. Similar findings were reported by the Royal College of Psychiatrists (2004).

- The clients were beneficiaries. According to Mirfin-Veitch (2003), low levels of income are commonplace for adults with an intellectual disability.

- The clients had multiple health needs and/or other sensory impairments. The unaddressed health needs of people with an intellectual disability are well recognised as a significant health issue (e.g., National Health Committee, 2003b; U.S. Public Health Service, 2002)

- The clients had a need for plain language and more time. This is a common need for people with an intellectual disability.

- The clients relied on others for support. This is typical for people with an intellectual disability.

Some of the key differences in counselling were directly related to the clients' intellectual disability. Others, such as poverty and unaddressed health needs, were indirectly related to their disability.

8.2.5. Whose perspectives are taken into account when assessing outcomes?

In the literature specific to clients with an intellectual disability multiple perspectives have been taken into account when assessing outcomes. However, the clients' perspective has only been sought in a limited fashion. Typically when the clients'

perspective has been sought their feedback is restricted to researcher chosen measures. There is very little research which has explored the subjective experiences of clients with an intellectual disability. Clearly, this is an area where additional research is needed.

The findings from this study and the published information regarding the clients' subjective experiences of counselling suggest that clients with an intellectual disability can provide useful information for practitioners. In these studies the clients understood counselling to be talking confidentially to a counsellor about problems. They appreciated the opportunity to talk about problems in a supportive environment and found counselling to be helpful. The clients credited counselling with helping them to feel better as well as to change their behaviour (e.g., Macdonald, et al., 2003; McGuirl & O'Reilly, 2000; Merriman & Beail, 2009).

8.2.6. How can counsellors more effectively facilitate positive outcomes for clients with an intellectual disability?

Findings from this study suggest that the following strategies may assist counsellors in their work with clients with an intellectual disability:

- Take time to establish a working alliance. This may involve time spent in social interactions such as sharing cups of tea. A warm, flexible, friendly approach was also suggested in the literature (Royal College of Psychiatrists, 2004).

- Prepare for the clients' communication and learning needs. Use plain language and adapt counselling techniques to suit the clients' learning needs. Whitehouse, Tudway, Look, and Kroese (2006), Mansell (2002), and Gallagher (2002) offer some general adaptations that can be used by practitioners. Published case studies can also provide counsellors with ways to adapt specific counselling approaches. For example, Matthews and Matthews (2005) detailed the use of narrative therapy with clients with an intellectual disability. (Refer to page 30 for other references which detail specific approaches.)

- Be aware of the complexities in the clients' support network. Some people with an intellectual disability have well functioning support networks; others do not. Given the high turnover in the disability workforce, with a change of worker, the quality of someone's support can change dramatically.

- Be attentive to the clients' physical health needs. Be prepared to interact with the client's GP should the need arise.

- Be attentive to clients' negative social experiences. People with an intellectual disability are vulnerable to abuse and exploitation and are victimised at a higher rate than the general population (Morano, 2001). Problems can also arise in the reporting of negative experiences. Having a disability increases the difficulty of adequately addressing such events (e.g., Lewin, 2007).

- Be aware of the pervasiveness of poverty, unaddressed health needs, social stigma and difficulties in the disability support workforce. These systemic problems invite counsellors to stretch their practice to support clients toward positive outcomes.

- Be willing to be flexible and take extra time when terminating the counsellor/client relationship. The lack of consistent support invites counsellors to think creatively about termination in order to ensure that sufficient support will be in place for the client to maintain the changes that they have made.

8.2.7. Summary: Support needed throughout the counselling process

Exploration of these questions has highlighted specific support needs throughout the counselling process. Although the presenting problems for people with an intellectual disability are similar to the general population, their emotional and mental health needs are often overlooked. More consistent recognition of common presenting problems would enable more people with an intellectual disability to have the option of using counselling to address their emotional and mental health needs.

During the referral process, people with an intellectual disability are likely to need support in finding a suitable counsellor as well as support in accessing funds to pay for counselling. This may be difficult as there is a lack of specially trained counsellors and financial options are often limited. However, some skilled counsellors work for little pay and in New Zealand there are three government schemes for funding counselling.

When engaged in counselling, there is a need for counsellors to take extra time, to modify their communication style, to be warm and caring, to consider the clients' environment when planning interventions, and at times to provide practical support. During this stage, clients would likely benefit from support between sessions from a trusted person. This person could assist the client to retain the learning from counselling and to try out new skills. And if sufficient practical support were available, counsellor could spend more time actively engaged in counselling. Just as counsellors need to take extra time, and to be warm, caring and creative during the engagement process, this study suggests that these qualities are also needed during the termination process.

In this study the counselling outcomes ranged from "feeling happier" to finding a new place to live. Counselling practice tends to focus on facilitating changes within the client, for example changes in mood, behaviour or the acquisition of new skills. Because of the complexities of their environment, facilitating changes external to the client, such as finding a new place to live, can also translate into improved client well-being. In order to promote positive outcomes for people with an intellectual disability, there is a need for both practising counsellors and researchers to consider a wide range of possible outcomes.

Figure 5 illustrates support strategies that could be implemented throughout the counselling process.

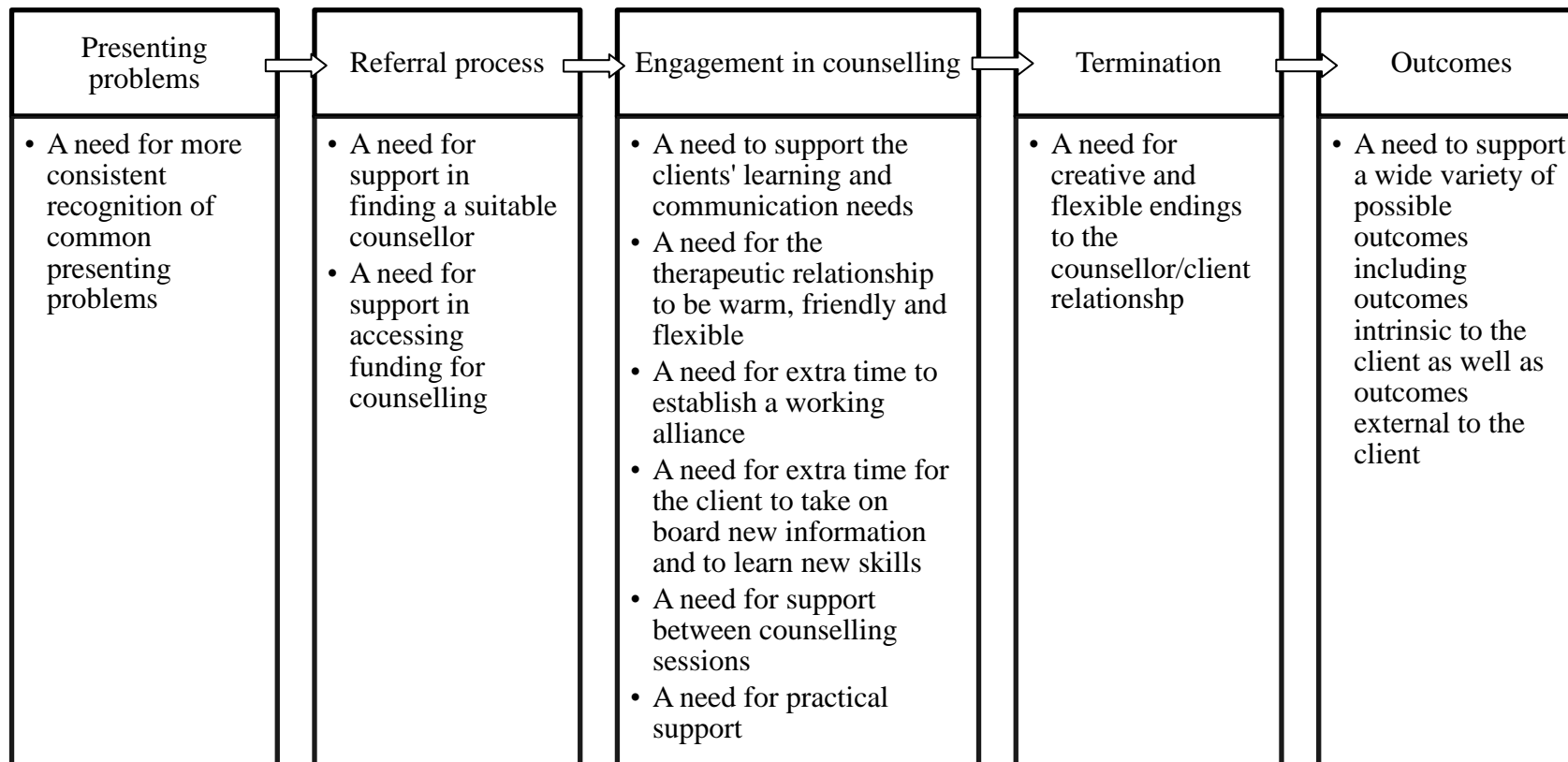| Presenting problems	Referral process	Engagement in counselling	Termination	Outcomes
• A need for more consistent recognition of common presenting problems	• A need for support in finding a suitable counsellor • A need for support in accessing funding for counselling	• A need to support the clients' learning and communication needs • A need for the therapeutic relationship to be warm, friendly and flexible • A need for extra time to establish a working alliance • A need for extra time for the client to take on board new information and to learn new skills • A need for support between counselling sessions • A need for practical support	• A need for creative and flexible endings to the counsellor/client relationshp	• A need to support a wide variety of possible outcomes including outcomes intrinsic to the client as well as outcomes external to the client

Figure 5: Support needed during the counselling process

8.3. Strengths and limitations

This thesis is based on a multiple case study which relied on interviews exploring the subjective experiences of the 19 participants. The interviews were conducted over a period of several months in an English-speaking western country. Within the confines of its scope, this study offers contributions to counselling practice. Beyond its scope, it is open to misinterpretation. Therefore I wish to be clear about the parameters of this study.

A common criticism of case studies is that they lack generalisability "to a broader clinical population" (Roth & Fonagy, 2005, p. 25). Studies suited to that type of generalisation begin by finding a statistically representative sample from a population and then generalising the findings to that population. This is referred to as "statistical generalization" (e.g., Yin, 2003, pp. 10, 32-33). As pointed out by Roth and Fonagy (2005) and Yin (2003) case studies are not designed to be generalised to populations. However, case studies can be used to make "analytic generalizations" (e.g., Yin, 2003, pp. 10, 32-33) which allow researchers and readers to make "a reasoned judgment" about how to apply findings from one study to another similar situation (Kvale, 2007, p. 127). By providing "rich specific descriptions" and "arguments about the generality of his or her findings" the researcher provides the reader with sufficient information so that the reader can make an informed decision about the appropriateness of applying the findings to another similar situation (Kvale, 2007, p. 127).

Case studies are also useful in linking theory and practice (Ragin, 1992). Case studies play an important role in learning about a particular discipline because they serve as exemplars (Flyvberg, 2006). In counselling research case studies have served as "starting points for subsequent research" and have the potential to contribute "information that is immediately applicable to the counselling relationship" (McLeod, 2003, p. 99). This thesis is not intended to demonstrate statistical generalisability. In keeping with the strengths of case study research this thesis is intended to: (a) provide exemplars which allow counsellors to make reasoned judgments about similar cases

they may encounter, (b) link theory with practice, (c) highlight areas for future research and (d) generate findings which are easily applicable to counselling practice.

Another limitation of a case study approach is that, although case studies can highlight the presence or absence of particular factors, they are less able to determine the relative importance of each factor (Vaughan, 1992, p. 184). Because this was an exploratory study, the intention was to identify a range of factors that influenced engagement in counselling. This thesis has not attempted to determine the relative importance of each of these factors.

These factors were identified from data gathered during qualitative interviews which took place over a period of several months. Qualitative research is often criticised for being subjective rather than objective. This criticism centres on the notion of researcher-bias. A study is seen as less valid or trustworthy if the researcher has had undue influence on the results of the research. Results can be influenced in the selection of participants, in the collection of data and in the data analysis and presentation. Some studies strive to reduce researcher bias by randomising participant selection, collecting data using standardised measures and analysing the data following specific procedures. Other studies such as this one, address the notion of bias by being candid about how participants were selected, how the data were gathered and analysed, and by describing other issues that may have influenced the study.

The research interviews took place over a period of several months. The interviews provided opportunities for both the clients and the counsellor to reflect on the counselling process. Having regular opportunities to reflect on the counselling process is likely to have had some influence on the clients and counsellors engagement in the process. This was a natural consequence of this type of study.

Another limitation is that discussion of the clients' outcomes is based on self-report measures which are "vulnerable to distortions by participants" (Heppner, et al., 1992, p. 254). This vulnerability was mitigated by exploring their outcomes from multiple perspectives.

This thesis presents the data primarily in verbal form. However, the research interviews included both verbal and non-verbal communication. Because of their communication difficulties people with an intellectual disability are often at a disadvantage when communicating their views to others. By reducing the breadth and richness of their non-verbal communication to written transcripts, I have risked further disadvantaging their communication. Although unavoidable, this is a limitation. The inclusion of two drawings is representative of my desire to convey the richness of human communication.

Lastly, this project is situated in the context of an English-speaking western country. I readily acknowledge that counselling and counselling research take place across the globe.

> While counselling has been evolving into a profession in selected parts of the world, it can be asserted that the process associated with this profession is universal. Every culture has traditionally had ways of dealing with human crises and psychological distress. (Bond et al., 2001, p. 246)

8.4. Recommendations

This thesis has drawn attention to the need for specialised counsellor education. It has also highlighted four systemic problems that complicate the delivery of effective counselling services: (a) poverty, (b), health inequalities, (c) difficulties in the disability support workforce, and (d) social stigma.

In order to facilitate positive outcomes for their clients, the counsellors in this study generously extended their practice to include voluntary service and the provision of help with practical matters. For the clients in this study, the counsellors' generosity resulted in positive client outcomes. However, their generosity tended to mask the difficulties that these systemic problems create for counsellors and clients. Addressing these systemic problems is likely to result in more positive counselling outcomes for more people with an intellectual disability.

Changes which promote prevention and early intervention tend to be less costly and more effective. Therefore, I recommend that attention be paid to both counsellor education and to the education of the disability support workforce.

Currently there are gaps in counselling education with respect to intellectual disabilities (e.g., Razza, 2008). I suggest that counsellor educators consider making changes to curricula so that counsellors are better informed about how to work effectively with clients with an intellectual disability. It would be useful for curricula to include information about the nature of an intellectual disability, useful strategies for working with clients, and the influences of systemic problems on counselling practice. With increased knowledge counsellors are likely to feel more competent and therefore would be more likely to engage with clients with an intellectual disability (e.g., Mason, 2007; Raffensperger & Miller, 2005).

This thesis has drawn attention to the difficulties in the disability support workforce and how these difficulties impact the emotional and mental well-being of people with an intellectual disability. According to New Zealand's Ministry of Health (2008) one of the strategic priorities for 2008-2010 is to promote a "capable and reliable disability support workforce" (p. 9). It would be beneficial if implementation of this strategy included educating the disability support workforce about "emotional and mental health problems" of people with an intellectual disability (Royal College of Psychiatrists, 2004, p. 48). A greater awareness could potentially assist in prevention of some problems and earlier identification of other problems.

In addition, it would also be useful if relevant members of the disability support workforce could receive specific training regarding government benefits, so the people with an intellectual disability could receive specialised support. Although case managers are sometimes available to assist with forms, not all case managers are familiar with working with people with an intellectual disability. Alternatively, a consistent programme of disability awareness training could be provided to government workers to ensure that a larger number of workers would be better prepared to assist people with an intellectual disability.

8.5. Invitations to practising counsellors

Attempts are being made to address the systemic problems of poverty, health inequalities, and difficulties with the disability support workforce. Meanwhile many people with an intellectual disability are living with unaddressed emotional and mental health needs. A case could be made for specialist counsellors to be trained to meet those needs. However, given the limited financial resources currently available in New Zealand, it seems unlikely that a specialist counsellor could financially sustain a practice solely for clients with an intellectual disability. Instead I invite mainstream practitioners to examine their beliefs about disability, to learn some new skills and to include one or two clients with an intellectual disability within their caseload.

8.5.1. An invitation to engage rather than exclude

One of the stumbling blocks for clients with an intellectual disability is counsellors' reluctance to engage with them. A counsellor may lack of confidence in his or her ability to interact with clients who have *different* communication and learning needs. A counsellor may have a belief that people with an intellectual disability cannot benefit from a "talking therapy." Any number of reasons may prevent a counsellor from choosing to engage with clients with an intellectual disability. These reasons stem from our responses to difference. It is, indeed, difficult to negotiate difference.

> We are who we are not because we are separate from others who are next to us but because we are *both* separate and connected….What then is exclusion? … First exclusion can entail cutting the bonds that connect….The other then emerges as … a non-entity … that can be disregarded or abandoned. Second, exclusion can entail erasure of separation…. The other then emerges as an inferior being who must be … assimilated by being made like the self. (Volf, 1996)

Differentiating without excluding means that we as counsellors must first recognise the human connection that we share with clients with an intellectual disability. The nature and purposes of counselling for those clients are the same as for all other clients. Yet we must not erase the communication and learning differences that exist. We need to work differently on account of those differences and on account of the systemic problems that many people with an intellectual disability encounter in their daily lives. I invite my

fellow counsellors to engage with difference rather than use perceptions of difference as a means to exclude.

8.5.2. An invitation to be creative

Choosing to engage in the presence of resource shortages is an invitation to be creative. Tallman and Bohart (1999) have suggested "that it is the mobilization of client resources which is therapeutic and not the application of a technique to a problem" (p. 119). Instead of assuming the presence of resources which may be problematic for people with an intellectual disability, counsellors are invited to creatively mobilise a broader range of client resources. Although a client's support network may be small, it should not be overlooked; family, friends, and paid support workers can be an asset in the counselling process.

8.6. Future research

This thesis has highlighted the overall need for more counselling research involving clients with an intellectual disability. As Willner (2005) has pointed out, the literature base is "astonishingly small" (p. 74).

- Research is needed to identify more effective ways of responding to the emotional needs and mental health needs of people with an intellectual disability. Research could either focus on finding ways to improve the accessibility of professional counselling services or by identifying alternative ways to suitably address those needs.

- There is a need for further exploration of the many factors that influence the outcomes of clients with an intellectual disability. A study with a larger number of participants might yield useful information regarding the relative importance of these factors.

- There is also a need for research exploring cost effective ways to increase counsellors' education about intellectual disabilities and to improve the overall quality of life for people with an intellectual disability.

- In particular, this thesis has drawn attention to the need for further research exploring the counselling experiences of people with an intellectual disability. The counsellors in this study used a range of communication strategies in their counselling sessions to enhance communication with their clients. When exploring the subjective experiences of clients with an intellectual disability, researchers could enhance their data collection by using other strategies in addition to verbal interviewing. Riia's paintings and Kaye's drawings illustrate how artwork can enhance clients' ability to communicate about their experiences.

8.7. Closing remarks

In 1970 Lott reviewed articles published from 1940 onwards which examined counselling outcomes for people with an intellectual disability. One purpose of his review was to counteract the prevailing assumption that "people with 'backward minds' cannot be responsive to 'talking or relationship' therapy" (p. 234). In his review Lott concluded that counselling "can be of assistance" to people with an intellectual disability and that "it is a mistake to assume that mental retardation…is a firm barrier to the use of psychotherapy" (p. 227). Nearly forty years later there seems to be more openness to offering counselling to people with an intellectual disability. However, many people, including some counsellors, still assume that having an intellectual disability precludes one from gaining benefit from counselling. This thesis challenges that assumption and invites practitioners to engage in a rewarding, albeit complex, area of professional practice. This thesis invites researchers to engage with the question of counselling's effectiveness by exploring the subjective experiences of clients with an intellectual disability and the many factors that influence their counselling outcomes.

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Appendices

Appendix A: Review of four therapy approaches

Cognitive-behaviour therapy

Rose et al. (2008) examined the effectiveness of cognitive-behavioural interventions for clients who were "experiencing problems with aggression which included physical assault on other people and/or repeated damage to property and/or repeated verbal aggression" (p. 100). The content of the sessions centred on teaching about "anger as an appropriate and normal emotion" and helping clients to recognise their emotions and the relationship between their environment and their emotions and to learn new ways to cope with anger (p. 102). The content was presented in a variety of ways including "worksheets, mood diaries…behavioral relaxation…photographs…line drawings… [and] problem solving" (p. 102).

This study compared 20 people (13 men and 7 women) who were receiving counselling with 21 people (16 men and 5 women) who were on a wait list. Assessments were carried out "on referral, prior to treatment, on completion of treatment and at follow up, three to six months after the treatment had finished" (p. 99)[25]. The counselling sessions were "usually weekly" and the "overall length of treatment" was 3 to 4 months (p. 101). The people on the wait list were assessed on referral and then three to four months later.

The findings suggested that these counselling sessions were helpful "in reducing levels of expressed anger" p. 104). The authors noted a number of limitations with their study and suggested a number of ways that future studies could be improved. They invited further research, saying "much remains to be done…" (p. 106).

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[25] Assessments consisted of a structured interview with the client, an interview with a carer, the British Picture Vocabulary Scale Second Edition, a test of Receptive Hearing Vocabulary, and an adapted Anger Inventory.

Psychodynamic psychotherapy

Beail, Warden, Morsley and Newman (2005) carried out an exploration of the effectiveness of psychodynamic psychotherapy "in normal clinical practice" (p. 246). Psychodynamic therapy seeks to help clients make connections between early life experiences and present day relationships. As described in this article, sessions began by inviting the client to free associate, that is, "to say whatever is in their mind and whatever comes to mind" (p. 248). The counsellor listened and observed as the client told his/her story. The counsellor attended to the content and language used and to the client's mood. The counsellor also attended to his/her own responses to the client's story; this is referred to as counter-transference. The counsellor sought to understand the "latent or unconscious meaning of the client's communications" (p. 248) with the aim of understanding how the client's feelings and/or relational patterns were being relived in the present; this is referred to as transference.

> Transference is the term for interaction with the therapist based on the transfer of feelings from past relationships; countertransference is the therapist's corresponding interactions based on feelings from the therapist's past relationships (Levitas & Gilson, 2000, p. 53).

According to Beail et al. (2005) understanding the client's feelings from past relationships allows the counsellor "to identify interpersonal issues and deal with them … in the here and now." These "interpersonal issues" are often linked to "early traumatic experiences and empathic failures on the part of parents and other caregivers (p. 248). Counselling allows these experiences to be "relived and corrected" (p. 248).

Beail et al. approached 35 clients to participate in this study. Five "could not consent" and "10 dropped out of treatment" (p. 246), leaving a total of 20 participants who completed both treatment and follow-up. The treatment consisted of once a week meetings with a counsellor. Research data were gathered via questionnaires at the beginning and end of treatment and also at a three month follow- up[26]. The treatment consisted of once a week meetings with a counsellor. The findings suggested that

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[26] The following questionnaires were used: the Symptom Checklist 90-Revised, the Inventory of Personal Problems-32 and the Rosenberg Self Esteem Scale.

counselling was helpful. Outcomes included reductions in distress, improvements in interpersonal skills and increased self esteem (p. 249).

They considered that this study was "beset with limitations" because it was a "naturalistic" study rather than a "controlled" study (p. 249). However, I, as a practitioner, considered this to be a strength, rather than a limitation. For example, in this study some clients attended 5 sessions, some 8 sessions, some 16 session and so on up to 48 sessions. While this variety in treatment length may pose challenges for controlled studies, it resembles actual counselling practice. Beail et al. concluded this article by discussing issues that arose during their study and by highlighting the need for further research.

Person-centred therapy

Flitton and Buckroyd (2002) described a qualitative study which was "concerned with the provision of counselling for children with a moderate learning disability and the evaluation of its effects on the child's self concept" (p. 164-165). They described the outcomes of four children with an intellectual disability who had participated in "a 14 week person-centred counselling intervention using person-centred art therapy as an adjunct" (p. 166). These four children were selected by the head teacher because he thought they "might benefit from counselling" (p. 167).

In order to create starting baseline, the children were invited "to visualize an animal or object that they felt represented them" (p. 169). They were given access to a wide variety of art materials and asked to put that image on paper. The children's classroom teacher also filled out a questionnaire regarding "the child's self concept and the teacher's perception of the child" (p. 169). The children were then offered 14 person-centred counselling sessions. Illness, family schedules and children's personal choices meant that none of the children attended all 14 sessions. One attended 8 sessions, one 9 sessions, one 12 sessions and one 13 sessions.

Outcomes were discussed in reference to Rogers' seven stage process of counselling. Outcomes were viewed from the perspectives of the children, the researcher/counsellor

and the classroom teachers. From the viewpoints of the children and the counsellor, some forward progress was made. However, "on the whole the staff did not identify the changes in self-concept that the individual children demonstrated and the counsellor witnessed" (p. 173).

Buckroyd and Flitton were candid about the ethical issues that arose during their research as well as their hopes for their article. The researchers demonstrated sensitivity regarding the vulnerability of children with an intellectual disability in their careful consent process. Although they were clearly attempting to approach the children carefully and sensitively, they did not realise that one of their strategies would upset the children. Their plan had been to have a research assistant conduct the mid-term interview; however this plan was abandoned when it became apparent that the presence of a stranger was upsetting the children. One of the original five participants dropped out of the study because "meeting with a stranger was too arduous" (p. 175). Because the research assistant could no longer be used in the researcher role, the counsellor then took on that role with the children. This change in role caused some confusion for the children, but the children continued to co-operate.

> This project highlighted many difficulties not only in researching this client group but in offering counselling to such children. Counselling and researching with learning disabled children is in its infancy; the researcher hopes this article will create discussion (p. 176).

Narrative therapy

Matthews and Matthews (2005) begin their article by providing a brief description of narrative therapy. The process of narrative therapy involves "(1) Listening to and understanding the person's story, (2) deconstructing the problem stories, (3) Re-storying, and (4) sustaining the change" (para. 9). They then describe the use of narrative therapy with two young people with an intellectual disability. For purposes of brevity I will summarise just one case.

Kelly began counselling when she was 15 ½ years old. The reason for seeking counselling was "support in coming to terms with high levels of "self-talk" that were interfering with her social integration" (para. 22). The first session with Kelly and her

family lasted nearly two hours. During that session the counsellors used language which externalised Kelly's self talk. They also noticed that during the session "the self talk had not been present even once" (para. 25). In that session they described Kelly as being "delighted to hear that her family and the authors all wanted to be on Kelly's side in her struggle with the 'self-talk' " (para. 26).

During the second session Kelly identified two of her "awesome skills" (para. 27). "Over the following year, regular meetings were held with Kelly in order to help her identify a preferred story and gradually move toward this" (para. 27). The authors listed several questions which helped Kelly to "focus her thinking" (para. 28) and to "identify skills… and put self talk in an appropriate context" (para. 29). Here are two of the questions that were listed:

> What kinds of things does the self talk steal away from your life?

> It was an amazing story that you told me about the time that you set the toaster on fire when you were cooking the pancakes. Has that happened since you've been using the awesome skills in the kitchen?

Kelly's outcome was described from her mother's perspective. Kelly's self talk had significantly decreased, and her attention during cooking had improved. As with the previous article, the authors hoped that this article will "stimulate interest and research into this approach" (para. 1).

Appendix B: Copyright permission letter

From: Driven T [email address]
Sent: Tuesday, 2 February 2010 12:58 p.m.
To: marilyn@snap.net.nz; Robin Friedlander; [email address]
Subject: Hello Marilyn this is Riia
Importance: High

From: rfriedlander@cw.bc.ca
To: marilyn@snap.net.nz

Hello Marilyn,

Yes I would be hounored for you to use my image for your thesis. I have one question is there any way of emaling me a copy of your work ,so that I could have a copy.

Thank you very much for chosing one of my art pieces.

Sincerly Riia Talve
website www.rtalve.com

> Hi Marilyn,
> I am copying both Riia and Eva her support worker.
> I suspect Riia will be just delighted to be included in your work.
> All the best with your project.
> Robin.
>
>
> Robin Friedlander MB. FRCPC.
> Clinical Director, DDMHS, Vancouver Coastal & Fraser.
> Program Director, Developmental Disorders Program, Dept. of Psychiatry, UBC.
> Chair, DD section of Canadian Psychiatric Association.
> BC Childrens Hospital,
> Neuropsychiatry, P4, Box 141.
> 4480 Oak street,
> Vancouver, B.C.
> V6H 3V4.
> Canada.
> tel. 604 918-7542; fax. 604 918-7550.
>
>
> This message contains confidential information and is intended only for the individual named. If you are not the named addressee you should not disseminate, distribute or copy this email. If you have received this message in error, please delete it and notify the sender
>

Appendix C: Ethical approval letters

**Health
and
Disability
Ethics
Committees**

5 October 2006

Ms Marilyn Raffensperger
School of Education
University of Canterbury
Private Bag 4800
Christchurch 8140

Dear Ms Raffensperger

**Exploring Counselling for Clients with a Mild intellectual Disability from
Multiple Perspectives
Ms Marilyn Raffensperger
URB/06/08/058**

Thank you for your response to the Committee's comments. The above study has
now been given ethical approval by the Chairperson of the Upper South B Regional
Ethics Committee under delegated authority.

Approved Documents
Information sheet and consent form Counselling Clients version (see attached)
Information sheet and consent form Counsellors version (see attached)
Information sheet and consent form support people version (see attached)
Questionnaire for Counselling Clients (see attached)
Questionnaire for Counsellors (see attached)
Questionnaire for Support People (see attached)

*For administrative clarity, please include a version number on all future versions of
the above mentioned documents.*

Accreditation
The Committee involved in the approval of this study is accredited by the Health
Research Council and is constituted and operates in accordance with the
Operational Standard for Ethics Committees, April 2006.

Progress Reports

The study is approved until 30 April 2008. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project on 5 October 2007. The report form is available on http://www.newhealth.govt.nz/ethicscommittees. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.
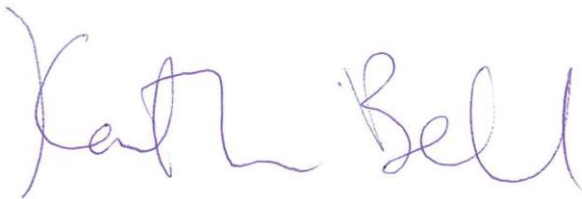
Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation e.g. advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

Katherine Bell
Upper South B Ethics Committee Administrator
Email: katherine_bell@moh.govt.nz

HEC Ref: 2006/118

20 October 2006

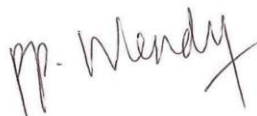Marilyn Raffensperger
Education
UNIVERSITY OF CANTERBURY

Dear Marilyn

The Human Ethics Committee advises that your research proposal "Exploring Counselling for Clients with a Mild Intellectual Disability from Multiple Perspectives" has been considered and approved.

Yours sincerely

pp- Wendy

Dr Alison Loveridge
Chair, Human Ethics Committee

Appendix D: Information sheets and consent forms

Counselling Study Information Sheet

Information for Clients

You are invited to take part in a study about counselling and people with disabilities. This study is being carried out by Marilyn Raffensperger. Marilyn is a Ph.D. student at the University of Canterbury in Christchurch. A Ph.D. student is someone who has taken a lot of classes at university and is now working on a research study.

What is a study?
A study is a carefully planned project to learn new information. The person who plans and carries out the study is called a **researcher**.
My name is Marilyn Raffensperger. I am the researcher in this study.

I am a student at the university. Students have people who watch over their projects. These people are called **supervisors.** I have three supervisors.

The people who help with the study are called **study participants**. You are invited to be a study participant.

When the study is finished, the new information will be shared with the community. The information from the study is shared by giving talks or by writing reports.

This study is private. Study participants' names will not be used in talks or reports about this study. No information which could personally identify study participants will be used in any reports on this study.

What is this study about?

This study is about counselling and people with disabilities. Counsellors and clients work together in counselling. Sometimes clients bring a support person with them to counselling or have support outside of counselling.

To learn more about how counselling works, I would like to talk to clients, counsellors and support people chosen by clients.
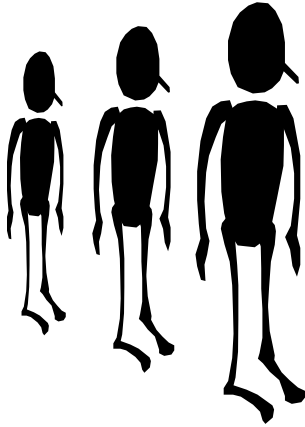
Clients

Counsellors

Support people

The aim of this study is to get some new ideas about counselling.

I want to know about the counselling experiences of people with an intellectual disability, their counsellor and people who support them.

I want to know about what things help clients feel better and

what things make clients feel worse.

I want to know about how clients and counsellors work together. For example: What do you do in counselling? How well do you and your counsellor get along?
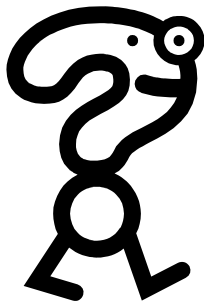
What do you do?

I want to know how what is happening in your life makes a difference in counselling.

For example: How do you get to and from counselling? What support do you get from family and friends? How is your general health?
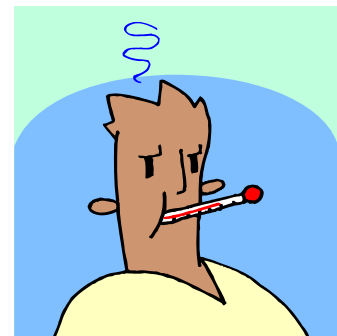
Who can be included in this study?

I want to talk to people who have an intellectual disability and are in counselling. I also want to talk to their counsellor and their support person.

This study is about clients and counsellors. If your counsellor doesn't want to take part in this study, then you cannot take part in this study.

It is your choice whether or not to take part in this study.

All people who take part in this study must be adults over the age of 18.

Feel free to take your time to think about whether or not you want to help with this study.

You do not need to hurry with this decision. Please think about it for a few weeks.

What happens if I want to take part in this study?

 If you want to take part in this study, you can phone me or you can ask your counsellor to introduce me to you. My phone number is 364 2987 extension 4817.

If you say yes, we will meet and talk about the study. The first thing we will do is fill out a consent form and some questionnaires. After that, I will meet with you four or five times throughout a one-year period. We will meet somewhere that is easy to get to and is suitable for private talking. Our talks will last about one or two hours each time. Our talks will be recorded.

In the middle of the study, you and your counsellor will be invited to have one counselling session videotaped. You and your counsellor can choose whether or not you want to be videotaped.

During the study we will talk about what we are doing and how it is going. At the end of one year we will talk about how the study has been and share with each other what we have learned.

What happens if I change my mind during the study?

You can leave the study at any time.
From time to time during the study I will check with you to make sure that you are still comfortable helping with the study.
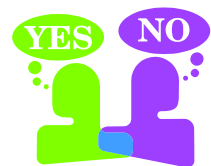
What happens if I don't want to take part in the study?

NO If you don't want to take part in the study, you will continue working with your counsellor just as you have been.

What do I do if I want to learn more about this study?

If you want to learn more about this study,
contact Marilyn Raffensperger.

Phone: 03 364 2987 ext. 4817

Email: mra45@student.canterbury.ac.nz
Mailing address: School of Education
                University of Canterbury
                Private Bag 4800
                Christchurch 8140

If you would like to know more about your rights as a participant in this study you may want to contact the Health and Disability Consumer Advocate. This number for Christchurch is:
377 7501

This study has been approved by the Upper South B Regional Ethics Committee and the University of Canterbury Human Ethics Committee.

Counselling Study

Information Sheet for Counsellors

You are invited to take part in a study about counselling clients with an intellectual disability. This study is being carried out by Marilyn Raffensperger, a do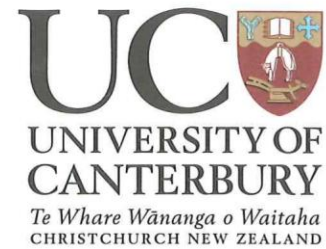ctoral student at the University of Canterbury in Christchurch. This information sheet is provided to help you decide whether or not you wish to participate in this study.

What is the study about?

This study is about how counselling works for people with an intellectual disability. This exploratory study will look at the counselling process from the viewpoints of counsellors, clients and their nominated support people.

The aims of this study are to:

* explore the counselling experiences of people with an intellectual disability, their counsellors and people who support them

* identify factors that help or hinder the counselling process

* explore the therapeutic relationship

* identify other life experiences that may affect the counselling process (extratherapeutic factors)

In keeping with the New Zealand disability strategy this projects seeks to contribute to "an aware and responsive public service" [27] by increasing the knowledge base of counsellors and other mental health professionals.

Who can be included in this study?

This study includes people with an intellectual disability who are in counselling, their counsellors and their support people.

It is your choice whether or not to take part in this study.

* All people who take part in this study must be adults over the age of 18

---

[27] Dalziel, L. (2001). The New Zealand disability strategy: Making a world of difference, whakanui oranga. [Electronic version]. Wellington: Ministry of Health. page 7.

What do I do if I want to take part in this study?

If you want to participate, contact Marilyn Raffensperger:

Phone: 364-2987 extension 4817

Email: mra45@student.canterbury.ac.nz

We will meet and discuss the study. If you decide to take part in the study, the first step is to fill out a consent form and a questionnaire. After that, I will meet with you four or five times for an hour or so throughout a one-year period. During the study we will talk about your work with your client and how your work is going. In the middle of the study you and your client will be invited to have one counselling session videotaped. You and your client can choose whether or not you want to be videotaped. At the end of one year we will conclude the study and share what we have learned.

What happens if I change my mind during the study?

You can leave the study at any time.

From time to time during the study I will check with you to make sure that you are still happy to continue participating.

What happens if I don't want to take part in the study?

If you don't want to take part in the study, your role as a counsellor will not change. You will continue working with your client just as you have been.

What if I want to learn more about this study?

If you want to learn more about this study, contact Marilyn Raffensperger.

Phone: 03 364 2987 ext. 4817

Email: mra45@student.canterbury.ac.nz

Mailing address:　　　　School of Education
University of Canterbury
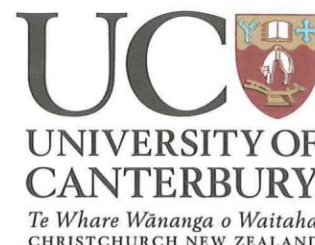Private Bag 4800
Christchurch 8140

If you or your client would like to know more about your rights as a research participant, you may want to contact the Health and Disability Consumer Advocate. This number for your area is 377 7501.

This study has been approved by the Upper South B Regional Ethics Committee and the University of Canterbury Human Ethics Committee.

Counselling Study

Information Sheet for Support People

You are invited to take part in a study about counselling and disabilities. You are being invited to participate in this study because _____ has nominated you to be his/her support person. Your knowledge about _____ and his/her experience with counselling is an important part of this study.

This study is being carried out by Marilyn Raffensperger, a doctoral student at the University of Canterbury in Christchurch. This information sheet is provided to help you decide whether or not you wish to participate in this study.

What is the study about?

This study is about how counselling works for people with an intellectual disability. This exploratory study will look at the counselling process from the viewpoints of counsellors, clients and their nominated support people.

The aims of this study are to:

* explore the counselling experiences of people with an intellectual disability, their counsellors and people who support them

* identify factors that help or hinder the counselling process

* explore the therapeutic relationship

* identify other life experiences that may affect the counselling process (extratherapeutic factors)

In keeping with the New Zealand disability strategy this projects seeks to contribute to "an aware and responsive public service"[28] by increasing the knowledge base of counsellors and other mental health professionals.

Who can be included in this study?

This study includes people with an intellectual disability who are in counselling, their counsellors and their support people.

It is your choice whether or not to take part in this study.

* All people who take part in this study must be adults over the age of 18.

---

[28] Dalziel, L. (2001). The New Zealand disability strategy: Making a world of difference, whakanui oranga. [Electronic version]. Wellington: Ministry of Health. page 7.

What do I do if I want to take part in this study?

If you want to participate, contact Marilyn Raffensperger by phone on 03 364 2987 ext. 4817 or by email at mra45@student.canterbury.ac.nz

We will meet and discuss the study. If you decide to take part in the study, the first step will be to fill out a consent form and a questionnaire. After that, I will meet with you four or five times for an hour or so throughout a one-year period. During the study, your role will be to provide your perspective on how counselling has made a difference for _____. At the end of one year we will finish the study and share what we have learned.

What happens if I change my mind during the study?

You can leave the study at any time.

From time to time during the study I will check with you to make sure that you are still happy to continue participating.

What happens if I don't want to take part in the study?

If you don't want to take part in the study, this will not impact _____'s access to counselling services.

What if I want to learn more about this study?

If you want to learn more about this study, contact Marilyn Raffensperger.

Phone: 03 364 2987 ext. 4817

Email: mra45@student.canterbury.ac.nz

Mailing address: School of Education
University of Canterbury
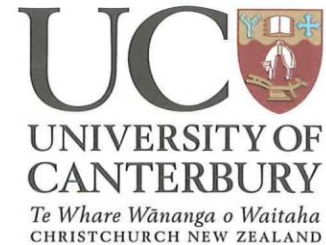Private Bag 4800
Christchurch 8140

If you or your client would like to know more about your rights as a research participant, you may want to contact the Health and Disability Consumer Advocate. This number for your area is 377 7501.

This study has been approved by the Upper South B Regional Ethics Committee and the University of Canterbury Human Ethics Committee.

Counselling Study
Information Sheet for Key Informants

You are invited to take part in a study about counselling for clients with an intellectual disability. This study is being carried out by Marilyn Raffensperger, a doctoral student at the University of Canterbury in Christchurch. This information sheet is provided to help you decide whether or not you wish to participate in this study.

What is the study about?

This study is about how counselling works for people with an intellectual disability. This exploratory study will look at the counselling process from the viewpoints of clients, counsellors, and support people.

In order to better understand the context in which this counselling takes place, the researcher will also be interviewing key informants who are knowledgeable about disability services and mental health services for those with intellectual disabilities.

The aims of this study are to:

* explore the counselling experiences of people with an intellectual disability, their counsellors and people who support them

* identify factors that help or hinder the counselling process

* explore the therapeutic relationship

* identify other life experiences that may affect the counselling process (extratherapeutic factors)

In keeping with the New Zealand disability strategy this projects seeks to contribute to "an aware and responsive public service" [29] by increasing the knowledge base of counsellors and other mental health professionals.

Who can be included in this study?

This study includes people with an intellectual disability who are in counselling, their counsellors and their support people. This study also includes people with an intellectual disability who have had counselling and key informants.

It is your choice whether or not to take part in this study.

* All people who take part in this study must be adults over the age of 18.

---

[29] Dalziel, L. (2001). The New Zealand disability strategy: Making a world of difference, whakanui oranga. [Electronic version]. Wellington: Ministry of Health. page 7.

What do I do if I want to take part in this study?

If you want to participate, contact Marilyn Raffensperger:

Phone: 364-2987 extension 4817

Email: mra45@student.canterbury.ac.nz

We will meet together twice. The meetings will take approximately one hour each time.

What happens if I change my mind during the study?

You can leave the study at any time.

From time to time during the study I will check with you to make sure that you are still happy to continue participating.

What happens if I don't want to take part in the study?

If you don't want to take part in the study, you don't need to do anything.

What if I want to learn more about this study?

If you want to learn more about this study, contact Marilyn Raffensperger.

Phone: 03 364 2987 ext. 4817

Email: mra45@student.canterbury.ac.nz

Mailing address: School of Education
                          University of Canterbury
                          Private Bag 4800
                          Christchurch 8140

If you would like to know more about your rights as a research participant, you may want to contact the Health and Disability Consumer Advocate. This number for your area is 377 7501.

This study has been approved by the Upper South B Regional Ethics Committee and the University of Canterbury Human Ethics Committee.

UC

UNIVERSITY OF CANTERBURY

Te Whare Wānanga o Waitaha

CHRISTCHURCH NEW ZEALAND

Counselling Study

Consent form for recording conversations

The researcher and I are meeting on _____ 2007 at _____ to talk about the project.

I agree that our talk can be recorded.

I can ask to have the recorder turned off at any time.

I can change my mind about the recording at the end of our talk.

Signature

Date and time

****

Our talk finished at _____ o'clock on _____.

I am still happy to have our talk recorded

OR

I have changed my mind about the recording. The researcher will erase the recording.

Signature

Date and time

(Copies were given to the participant and to the researcher.)

Counselling Study

Consent form for counselling clients

If you want to take part in this study please read this form very carefully. It outlines your rights as a study participant.

1. I have read or have had read to me the information about this study.

2. I understand the information I have been given.
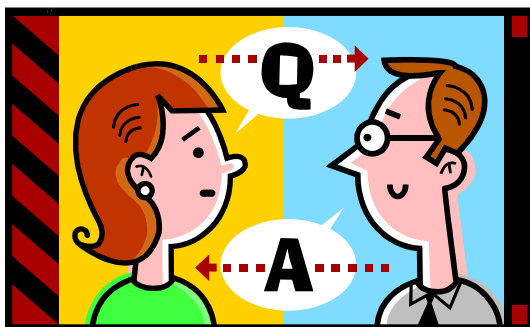
3. I have had a chance to talk to the researcher about this study.

4. I have been able to ask questions and I am happy with the answers I have been given.

5. I have been able to use family or whanau or a friend to help me ask questions and to understand the study.

6. I understand that taking part in this study is my own choice.

7. I know that I can stop taking part in the study at any time.

8. If I do stop taking part in the study, my work with my counsellor will not change.

9. Information about my counselling is private. The researcher needs my permission before she can ask other people about me and my counselling. The researcher will ask me to sign a form before she asks anyone questions about me.

10. I understand that the researcher wants to talk to my counsellor about me and about my counselling. I give the researcher permission to ask my counsellor questions about me and my counselling.
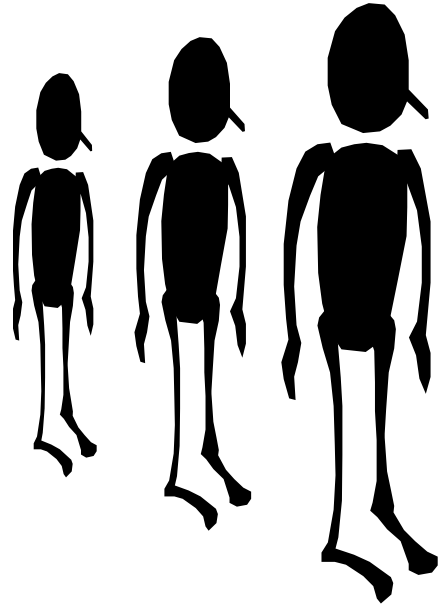
11. I understand that the researcher wants to talk to my support person about me and my counselling. I give the researcher permission to ask my support person about me and my counselling.

12. I understand that the researcher needs to talk to her supervisors about things people say in this study. I give permission to the researcher to talk to her supervisors about things I say.

13. The information that I give during the study is confidential. I understand that confidentiality may be broken if I am in danger or if someone else is in danger.

14. This study is private. My name will not be used in reports on this study. No information that could personally identify me will be used in reports on this study.

15. I have had enough time to decide whether or not I want to participate in this study.

16. I understand that I will be interviewed.

17. I understand that these interviews will be recorded.

18. I understand that I can ask to have the recorder turned off at any time during the interviews.

19. The recordings of the interviews will be typed out.

20. I understand that I will have a chance to check what I have said during the interviews. I can make changes at this time.

21. I know that the researcher may take notes during the interviews.

22. If I give written responses to interview questions I understand that these answers will be used as information for the study.

23. I understand that I will receive a copy of a report on the findings of this study. I understand that there will be a delay between my taking part in the study and receiving the final report.

24. I know that if I have any questions or concerns about my rights as a participant in this study that I can contact a Health and Disability Services Consumer Advocate. The telephone number is 377 7501.

25. I know that I can contact Marilyn Raffensperger if I have any questions about this study. I can ask questions at any time.

Researcher:	Marilyn Raffensperger
Mailing address:	School of Education
	University of Canterbury
	Private Bag 4800
	Christchurch 8140
Phone:	364 2987 extension 4817
Email:	mra45@student.canterbury.ac.nz

Please complete the following section

I _____(full name)
want to take part in this study on counselling.

Date: _____

Signature _____

This section will be completed by the researcher at the time of the interview.

Researcher: Marilyn Raffensperger
Phone number: 03 364 2987 extension 4817
Email: mra45@student.canterbury.ac.nz
Mailing address: School of Education
                  University of Canterbury
                  Private Bag 4800
                  Christchurch 8140

Date: _____

Signature: _____

Counselling Study
Disclosure Consent form

I, _____, want to take part in this counselling study.

I give my permission for the researcher, Marilyn Raffensperger, to talk to my

counsellor, _____, about me and about my counselling.

_____
Date

_____
Signature

****

The information disclosed by the clients and counsellors in this study will be kept confidential. No information that could personally identify research participants will be used in reports on this study.

This study has been approved by the Upper South B Ethics Committee and the University of Canterbury Human Ethics Committee.

_____
Date

_____
Signature of the researcher

(Copies were offered to the counselling client and his or her counsellor.)

Counselling Study
Disclosure Consent form

I, _____, want to take part in this counselling study.

 I give my permission for the researcher, Marilyn Raffensperger, to talk to my support person,

_____, about me and about my counselling.

_____
Date

_____
Signature

****

The information disclosed by the clients and counsellors in this study will be kept confidential. No information that could personally identify research participants will be used in reports on this study.

This study has been approved by the Upper South B Ethics Committee and the University of Canterbury Human Ethics Committee.

_____
Date

_____
Signature of the researcher

(Copies were offered to the counselling client and the support person.)

Counselling Study
Disclosure Consent form

I, _____, want to take part in this counselling study.

I give my permission for the researcher, Marilyn Raffensperger, to talk to her supervisors and her research mentor about all the information I give during this study.

_____
Date

_____
Signature

****

The information disclosed by the clients and counsellors in this study will be kept confidential. No information that could personally identify research participants will be used in reports on this study.

This study has been approved by the Upper South B Ethics Committee and the University of Canterbury Human Ethics Committee.

_____
Date

_____
Signature of the researcher

(Copies were offered to the counselling clients)

UC
**UNIVERSITY OF
CANTERBURY**
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Counselling Study

Consent form for Counsellors

If you want to take part in this study please read this form very carefully. It outlines your rights as a study participant.

1. I have read and understand the information about this study.

2. I have had a chance to talk to the researcher about this study and get answers to my questions.

3. I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

4. I understand that taking part in this study is voluntary. I can stop taking part in the study at any time.

5. If I do stop taking part in the study, I understand that this will not affect my role as a counsellor in any way.

6. I understand that the researcher will talk to her supervisors about information gathered in this this project.

7. This study is confidential. The information I give during this study will be disclosed only to the researcher, her supervisors and parties nominated by me. I understand that my participation in this study is private and that no information that could personally identify me or my clients will be used in reports on this study.

8. I understand that the researcher may break this confidentiality agreement if she learns that I am in danger or someone else is in danger.

9. I understand that the researcher will talk to my client about his/her perceptions of the counselling process and about his/her relationship with me. Information gathered from my client will be disclosed only to the researcher, her supervisors and parties nominated by the client.

10. I understand that the researcher will also talk to my client's support person about my client and about the support person's perceptions of the counselling process. Information gathered from the support person will be disclosed only to the researcher, her supervisors and parties nominated by the support person.

11. I have had enough time to decide whether or not I want to participate in this study.

12. I understand that my participation in this study will involve me being interviewed and that these interviews will be recorded and transcribed.

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13. I understand that I can ask to have the recorder turned off at any time during the interview.

14. I know that the researcher may also take notes during the interviews.

15. I know that I will have a chance to check what I have said during the interview and that I can make changes at this time.

16. If I give written responses to interview questions, I understand that these answers will be used as information for the study.

17. I understand that I will receive a copy of a report on the findings of this study. I understand that there will be a delay between my taking part in the study and receiving the final report.

18. I know that if I have any questions or concerns about my rights as a participant in this study that I can contact a Health and Disability Services Consumer Advocate. The telephone number is 377 7501.

19. I know that I can contact Marilyn Raffensperger at the University of Canterbury if I have any questions about this study. I can ask questions at any time. Marilyn's phone number is 364 2897 ext. 4817.

Please complete the following section

I _____(full name)
want to take part in this study on counselling.

Date: _____

Signature _____

This section will be completed by the researcher at the time of the interview.

Researcher: Marilyn Raffensperger
Contact phone number: 03 364 2987 ex. 4817
Email: mra45@student.canterbury.ac.nz
Mailing address: School of Education
                   University of Canterbury
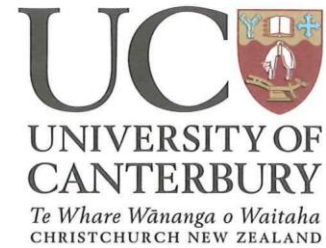   Private Bag 4800
                   Christchurch 8140

Date: _____

Signature:_____

UC
UNIVERSITY OF
CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Counselling Study

Consent form for Support People

If you want to take part in this study please read this form very carefully. It outlines your rights as a study participant.

1. I have read and understand the information about this study.

2. I have had a chance to talk to the researcher about this study and get answers to my questions.

3. I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

4. I understand that taking part in this study is voluntary. I can stop taking part in the study at any time.

5. If I do stop taking part in the study I understand that this will not affect me nor will it affect the person who nominated me as a support person.

6. I understand that the researcher will talk to her supervisors about information gathered in this this project.

7. This study is confidential. The information I give during this study will be disclosed only to the researcher, her supervisors and parties nominated by me. I understand that my participation in this study is private and that no information that could personally identify me or the person I support, will be used in reports on this study.

8. I understand that the researcher may break this confidentiality agreement if she learns that I am in danger or someone else is in danger.

9. I understand that the researcher will talk to _____ about his/her counselling and about his/her relationship with his/her counsellor. Information gathered from _____ will be disclosed only to the researcher, her supervisors and parties nominated by _____.

10. I understand that the researcher will also talk to the counsellor about _____ and about his/her counselling. Information gathered from the counsellor will be disclosed only to the researcher, her supervisors and parties nominated by the counsellor.

11. I have had enough time to decide whether or not I want to participate in this study.

12. I understand that my participation in this study will involve me being interviewed and that these interviews will be recorded and transcribed.

13. I understand that I can ask to have the recorder turned off at any time during the interview.

14. I know that the researcher may also take notes during the interviews.

15. I know that I will have a chance to check what I have said during the interview and that I can make changes at this time.

16. If I give written responses to interview questions, I understand that these answers will be used as information for the study.

17. I understand that I will receive a copy of a report on the findings of this study. I understand that there will be a delay between my taking part in the study and receiving the final report.

18. I know that if I have any questions or concerns about my rights as a participant in this study that I can contact a Health and Disability Services Consumer Advocate. The telephone number is 377 7501.

19. I know that I can contact Marilyn Raffensperger at the University of Canterbury if I have any questions about this study. I can ask questions at any time. Marilyn's phone number is 364 2897 extension 4817.

Please complete the following section

I _____(full name)
want to take part in this study on counselling.

Date: _____

Signature _____

This section will be completed by the researcher at the time of the interview.

Researcher: Marilyn Raffensperger
Contact phone number: 03 364 2987 extension 4817
Email: mra45@student.canterbury.ac.nz
Mailing address: School of Education
                    University of Canterbury
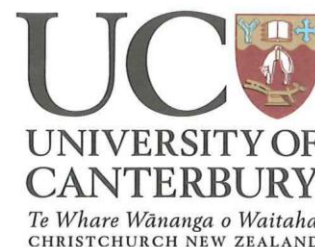   Private Bag 4800
                    Christchurch 8140

Date: _____

Signature:_____

UC UNIVERSITY OF CANTERBURY
Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Counselling Study

Consent form for Key Informants

If you want to take part in this study please read this form very carefully. It outlines your rights as a study participant.

1. I have read and understand the information about this study.

2. I have had a chance to talk to the researcher about this study and get answers to my questions.

3. I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

4. I understand that taking part in this study is voluntary. I can stop taking part in the study at any time.

5. If I do stop taking part in the study, I understand that this will not affect my current role in the health/disability sector in any way.

6. I understand that the researcher will talk to her supervisors and her research mentor about information gathered in this project.

7. This study is confidential. The information I give during this study will be disclosed only to the researcher, her supervisors, her research mentor and parties nominated by me. I understand that my participation in this study is private and that no information that could personally identify me will be used in reports on this study.

8. I understand that the researcher may break this confidentiality agreement if she learns that I am in danger or someone else is in danger.

9. I have had enough time to decide whether or not I want to participate in this study.

10. I understand that my participation in this study will involve me being interviewed and that these interviews will be recorded and transcribed.

11. I understand that I can ask to have the recorder turned off at any time during the interview.

12. I know that the researcher may also take notes during the interviews.

13. I know that I will have a chance to check what I have said during the interview and that I can make changes at this time.

14. If I give written responses to interview questions, I understand that these answers will be used as information for the study.

15. I understand that I will receive a copy of a report on the findings of this study. I understand that there will be a delay between my taking part in the study and receiving the final report.

16. I know that if I have any questions or concerns about my rights as a participant in this study that I can contact a Health and Disability Services Consumer Advocate. The telephone number is 377 7501.

17. I know that I can contact Marilyn Raffensperger at the University of Canterbury if I have any questions about this study. I can ask questions at any time. Marilyn's phone number is 364 2897 ext. 4817.

Please complete the following section

I _____(full name)
want to take part in this study on counselling.

Date: _____

Signature _____

This section will be completed by the researcher at the time of the interview.

Researcher: Marilyn Raffensperger
Contact phone number: 03 364 2987 ex. 4817
Email: mra45@student.canterbury.ac.nz
Mailing address: School of Education
                 University of Canterbury
                 Private Bag 4800
                 Christchurch 8140

Date: _____

Signature:_____

Transcriber's Confidentiality Agreement

TITLE OF STUDY: Exploring Counselling for Clients with a Mild Intellectual Disability from Multiple Perspectives

PRINCIPAL INVESTIGATOR: Marilyn Raffensperger

CONTACT PHONE NUMBER: 03 364 2987 ext. 4817

As a transcribing typist of this research study, I understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement.

I hereby agree not to share any information on these recordings with anyone except the principal investigator of this project. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

I agree to return all files and documents pertaining to this study to Marilyn Raffensperger once the transcribing is complete. At this time, I will also delete any electronic copies of these interviews from my computer.

This study has been approved by the Upper South B Regional Ethics Committee and the University of Canterbury Human Ethics Committee.

_____   _____
Signature of Transcribing Typist   Date

_____   _____
Printed Name of Transcribing Typist   Date

Appendix E: Questionnaires and interview schedules

Questionnaire for Counselling Clients

(Note: This questionnaire was handled as a structured interview. The researcher read the questions to the participant and wrote down their answers. The interview was also recorded.)

I am going to ask you some questions. I will ask about you, your home, your school, and your work. I will also ask for your ideas about counselling and disabilities.
Some questions will be about your life now. Some questions will be about you as a child.
If you do not want to answer a question, please tell me and we will skip that question.
First I will write down your name_____
and that you are a man/woman.

Now I have some other questions about you.

Questions about you.

How old are you?
Which country were you born in?

Maybe you have already guessed that I am not a New Zealander. I am an American. Sometimes I may not understand your Kiwi words. I will ask you to tell me again. Sometimes you may not understand my American words. Please ask me to tell you again.
I am an American. My ethnic background is mixed. A long time ago my relations came from Europe, ---from England, Ireland, Scotland, and Germany. Some of my relations were Native Americans.

I will read a list of ethnic groups, and you tell me which ones apply to you.
Which ethnic group do you belong to?
___New Zealand European
___Maori
___Samoan
___Cook Island Maori
___Tongan
___Niuean
___Chinese
___Indian
___other (Such as Dutch, Japanese, Tokelauan.) Please state _____

Are you a part of any groups?
(If yes) What groups are you a part of?

Questions about your home.
Who do you live with?
Where do you live?
What kind of place is that?
How long have you lived there?
Where did you live when you were a child?

Questions about school
What schools did you attend as a child?
Did you get any awards or prizes at school?
Have you taken any classes as an adult?
(If yes) What classes did you take?
Did you get certificates from those classes?
(If yes) What certificates did you get from those classes?

Questions about your work?
What do you do during the day?
Do you have a job?
(If yes) What is your job?
Do you get paid for your work?
(If yes) How much do you get paid?
Are you on a benefit? _____
(If yes) What benefit do you get?

Questions about disabilities
What is a disability?
Do you have a disability?
(If yes) Tell me about your disability
How do you know you have this disability?
What is a medical condition?
Do you have any medical conditions?
(If yes) Tell me about them

Questions about counselling.
What is counselling?
When was the first time you went to see a counsellor?
How many counsellors have you talked with?
How long have you been seeing (insert Counsellors's name here)?
What is (insert Counsellor's name here) helping you with?
What do you hope to gain from going to counselling?

Do you have any questions about this study?

Interview Schedule for Counselling Clients

Preliminary conversations (unrecorded) were conducted to discuss the study.

Initial recorded interview consisted of filling out the consent forms.

Second interview was a structured interview using the Questionnaire for Counselling Clients.

Subsequent unstructured interviews covered the following sorts of topics:

The story of how you started to go to counselling. There was a time when you did not go to counselling. Now you go to counselling. How did that happen? How you get to and from counselling? (This topic explores accessibility to counselling, personal choice and the counselling referral process.)

The story of about what you do in counselling. (This topic explores the relationship of the client and counsellor.)

Your opinions about counselling. What do you like about counselling? What do you wish was different? (This topic explores factors that help or hinder the counselling process.)

The story about your life outside of counselling. How are things going for you in general? (This topic explores other life experiences that may affect the counselling process.)

Because the interview style was informal and unstructured, clients also initiated discussion on other topics which were relevant their lives.

Questionnaire for Counsellors

If you do not want to answer particular questions, feel free to leave them blank.

Name _____
Gender: _____
Age: _____
Are you a member of a professional organisation? _____
If yes, list the professional organisations

_____

_____

Years of counselling experience: _____
Years of experience counselling clients with an intellectual disability _____

Which ethnic group do you belong to? Mark the space or spaces that apply to you.
___New Zealand European
___Maori
___Samoan
___Cook Island Maori
___Tongan
___Niuean
___Chinese
___Indian
___other (Such as Dutch, Japanese, Tokelauan.) Please state _____

Circle the answer which best describes your current workplace
a. A generic counselling agency
b. A counselling agency for a specific target group (name target
group_____)
c. Private practice
d. A social service agency which provides counselling as a part of its services
e. A secondary school
f. A tertiary institution
g. Other   (please describe_____)

What are your tertiary qualifications? _____

_____

What are your counselling qualifications? _____

_____

What is counselling?_____

_____

_____

How would you describe the type of counselling you offer to clients? _____

_____

How long have you been counselling (insert Client's name here)? _____

Has (insert Client's name here) received counselling prior to working with you? _____

How would you describe (insert Client's name here)'s presenting problem?

_____

What is a disability? _____

_____

_____

Does (insert Client's name here) have a disability? _____

If yes, how would you describe (insert Client's name here)'s disability? _____

_____

How did you come to know about (insert Client's name here)'s disability? _____

_____

Does (insert Client's name here) have any medical conditions that require on-going support? _____

If yes, please describe the condition and the support needed. For example: vision problems/glasses, hearing problems/hearing aid, epilepsy/medication, etc.)

_____

_____

How did you come to know about (<u>insert Client's name here</u>)'s medical conditions?

_____

_____

Do you have any questions about this study? _____

_____

_____

Interview Schedule for Counsellors

Preliminary conversations (unrecorded) were conducted to discuss the study.

Initial recorded interviews included: Filling out the consent forms
Questionnaire for Counsellors
Discussion on one of the topics listed below.

Subsequent unstructured interviews included the following sorts of topics:

How did you come to be working with clients with an intellectual disability? How has your education helped prepare you for this work? Do you receive on-going support for this work? (This topic explores counsellors' experiences of the counselling process. It also explores accessibility of on-going education and support for counsellors. Gaps in counsellor education and on-going support, limit counsellors' accessibility to specialised training which in turn limits clients' accessibility to specialised counselling services.)

What do you do in your work with your client? How would you describe the counselling method you use? Do you do any activities besides talking? (This topic explores the relationship of the client and counsellor.)

What do you think is particularly helpful for your client? What do you think might hinder the counselling process for your client? (This topic explores factors that help or hinder the counselling process.)

What factors in the client's life do you think impact on the counselling process? (This topic explores other life experiences that may affect the counselling process.)

Because the interview style was informal and unstructured, counsellors also initiated discussion on topics which were relevant their practice.

Questionnaire for Support People

If you do not want to answer particular questions, feel free to leave them blank.

Name: _____

Gender: _____

Age: _____

Occupation: _____

Qualifications: _____
_____

Which ethnic group do you belong to? Mark the space or spaces that apply to you.

___New Zealand European

___Maori

___Samoan

___Cook Island Maori

___Tongan

___Niuean

___Chinese

___Indian

___other (Such as Dutch, Japanese, Tokelauan.) Please state _____

How long have you known (insert Client's name here)? _____

What is your relationship to (insert Client's name here). _____

Do you provide on-going support for (insert Client's name here)? _____

If yes, please describe the type of on-going support you provide _____

_____

What is a disability? _____

_____

_____

Does (insert Client's name) have a disability? _____

If yes, how would you describe (insert Client's name)'s disability? _____

_____

How did you come to know about (insert Client's name)'s disability? _____

_____

Does (insert Client's name) have any medical conditions that require on-going support? _____

If yes, please describe the condition and the support needed. For example: vision problems/glasses, hearing problems/hearing aid, epilepsy/medication, etc.)

_____

_____

How did you come to know about (insert Client's name here)'s medical conditions?

_____

_____

How long has (insert Client's name) been receiving counselling from (insert Counsellor's name)? _____

What is counselling? _____

_____

_____

Do you know why (insert client's name) began going to counselling with (insert counsellor's name? _____
If yes, how would you describe the issues that caused (insert client's name) to seek counselling from (insert counsellor's name)?

_____

_____

Has (insert Client's name) received counselling prior to working with (insert Counsellor's name)? _____

If yes, how many other counsellors has (insert client's name) worked with? _____

Do you have any questions about this study? _____

_____

Interview Schedule for Support People

Preliminary conversations (unrecorded) were conducted to discuss the study.
Filling out the consent forms

Initial Interview included: Filling out the consent forms
Questionnaire for Support People
Discussion on one of the topics listed below.

Subsequent unstructured interviews included the following sorts of topics:

How did you come to know (insert counselling client's name)? How did he/she come to be involved in counselling? What is your impression of the purpose of counselling for him/her? Does he/she talk to you about counselling? (This topic explores the support person's experiences of the counselling process and the accessibility of counselling.)

What is your impression about how well he/she gets along with the counsellor? (This topic explores the relationship of the client and counsellor.)

Do you think counselling is helpful for (insert counselling client's name)? What do you think is particularly helpful for him/her? What do you think might hinder the counselling process for him/her? (This topic explores factors that help or hinder the counselling process.)

What factors in the client's life do you think impact on the counselling process? (This topic explores other life experiences that may affect the counselling process.)

Because the interview style was informal and unstructured, support people also initiated discussion on other topics which were relevant them.

Questionnaire for Key Informants

If you do not want to answer particular questions, feel free to leave them blank.

Name _____

Gender: _____

Age: _____

Are you a member of a professional organisation? _____

If yes, list the professional organisations _____

_____

Years of experience working with people with an intellectual disability _____

Which ethnic group do you belong to? Mark the space or spaces that apply to you.

___New Zealand European

___Maori

___Samoan

___Cook Island Maori

___Tongan

___Niuean

___Chinese

___Indian

___other (Such as Dutch, Japanese, Tokelauan.) Please state _____

What are your tertiary qualifications? _____

_____

Do you have tertiary qualifications specific to working with people with intellectual disabilities? _____

If yes, what are those qualifications? _____

What is counselling? _____

_____

What is a disability? _____

_____

Do you have any questions about this study? _____

_____

Preliminary conversations (unrecorded) included discussions about this study either in person, by phone or by email.

Interview included:

1. Filling out the consent forms
2. Questionnaire for Key Informants
3. Discussion around the following sorts of topics:

> Please describe your workplace, i.e. how the organisation is structured, how it is funded, criteria for service recipients, how are outcomes measured, how many clients do you serve, etc.

> Does your workplace track the "unmet needs" of your clients?

> Can you provide me with any written documents about your workplace?

> Please describe the counselling referral process that would typically be used in your workplace.

> What factors in a person's life do you think have an impact on the counselling process? (This topic explores other life experiences that may affect the counselling process.)

Because the interview style was informal and unstructured, key informants also initiated discussion on other topics which were relevant them.

Appendix F: Sample interview summary

Summary of our meeting on [date]

Here is what we talked about in July, after I came back from my trip to the USA.

First, I gave you an update on the study. You gave me permission to talk to my research mentor, Brigit.

Then, I read you a summary of our other meeting.

We talked about a lot of different things in this meeting.

I asked you what the word "special needs" means.

You talked about workshops. You said, "People have wheelchairs. Lots of people have sticks. Like two sticks. I've got the one stick." What does your stick look like?

I asked you how you decided to go for counselling with [name]. You told me the long story about losing your job. It was hard to talk about this. Please tell me if I got your story right.

You worked with old people at [name of rest home]. Your Auntie [name] lives in [rest home]. You did jobs in the rooms. You emptied the rubbish and stuff like that. The manager was named [name]. Some things belonging to the residents went missing. You were caught taking some biscuits. That made people think that maybe you had taken the personal items. Then they told you that you couldn't work there anymore. This was embarrassing.

[Support person] thought there was a breakdown in communication and support. [Support person] said that the person who found you the job should have been keeping in touch. "When the initial problem was found, they didn't really know who to speak to. So no one did anything. The whole system really fell down at that point."

[Support person] said that you have always had a sweet tooth. When you lived at home you would sometimes get up at night and raid Mum's cupboard. You were like a little mouse.

You and [support person] told me that you were not very good at hiding the crumbs from the biscuits.

You sometimes pinch biscuits and lollies, but [support person] doesn't think you took personal items from the old people.

You went for counselling with [counsellor's name] because you lost this job.

Your counselling with [counsellor's name] finished up many months ago. But you still see [counsellor] because she visits your house sometimes. When was the last time you saw [counsellor]? What did you and [counsellor] do?

Someday maybe you will get a new job. [name] is helping you to look for another job. You will wait a while before getting a new job. If you do get a new job, you said, "I like to be different." You would try hard not to sneak biscuits. You said, "I wish…but I can't." I think that means that you want to eat the biscuits, but you know that you should not eat them.

Then you told me about taking buses.

[name] is a bus driver. You talk to him to find out which bus to take. You look at a map.

Then we turned off the recorder and had a cup of tea.

Appendix G: Sample research update

School of Education

College of Arts
Tel: +64 3 364 2987 ext. 6209, Fax: +64 3 364 6418
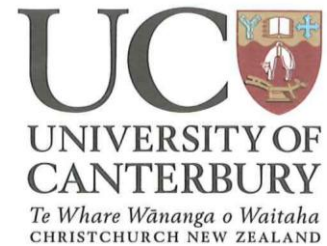
Counselling Study Information Sheet

Second Update for Research Participants.

Thank you for taking part in this study about counselling and people with disabilities. Thank you to counselling clients, counsellors, support people and key informants. I want to give you an update on the study.

First of all, I want to give you an update on my supervisors.

My supervisor named Bob is going to retire.

Bob Manthei

So I will be getting a new supervisor. Her name is Judi.

Judi Miller

I have been busy with this project. I have talked to lots of people and I have lots of interviews that are recorded. The next part of my work is to type out all these words on to paper.

This work is called **transcribing**. So far I have done the transcribing by myself. Many times researchers hire people to do this work for them. People who do this kind of work are called **transcribers.** They are professionals. Their work is private and confidential.

I will be asking each participant for permission to ask a professional transcriber to type out their words. You can say yes or you can say no. If you say yes, then if I need help, I will pay a transcriber to type out the words of our interviews. If you say no, then I will type out our interviews myself.

Once again, thank you very much for your help with this project.

Appendix H: Data analysis diagrams

Organising the data using the counselling process framework

Figure 6 illustrates how the data were analysed using the counselling process framework. I began by reading through all the transcripts and then organising relevant data into the five content areas related to the counselling process: (a) presenting problems, (b) the referral process, (c) engagement in counselling, (d) termination, and (e) outcomes. Next each content area was further subdivided into themes.
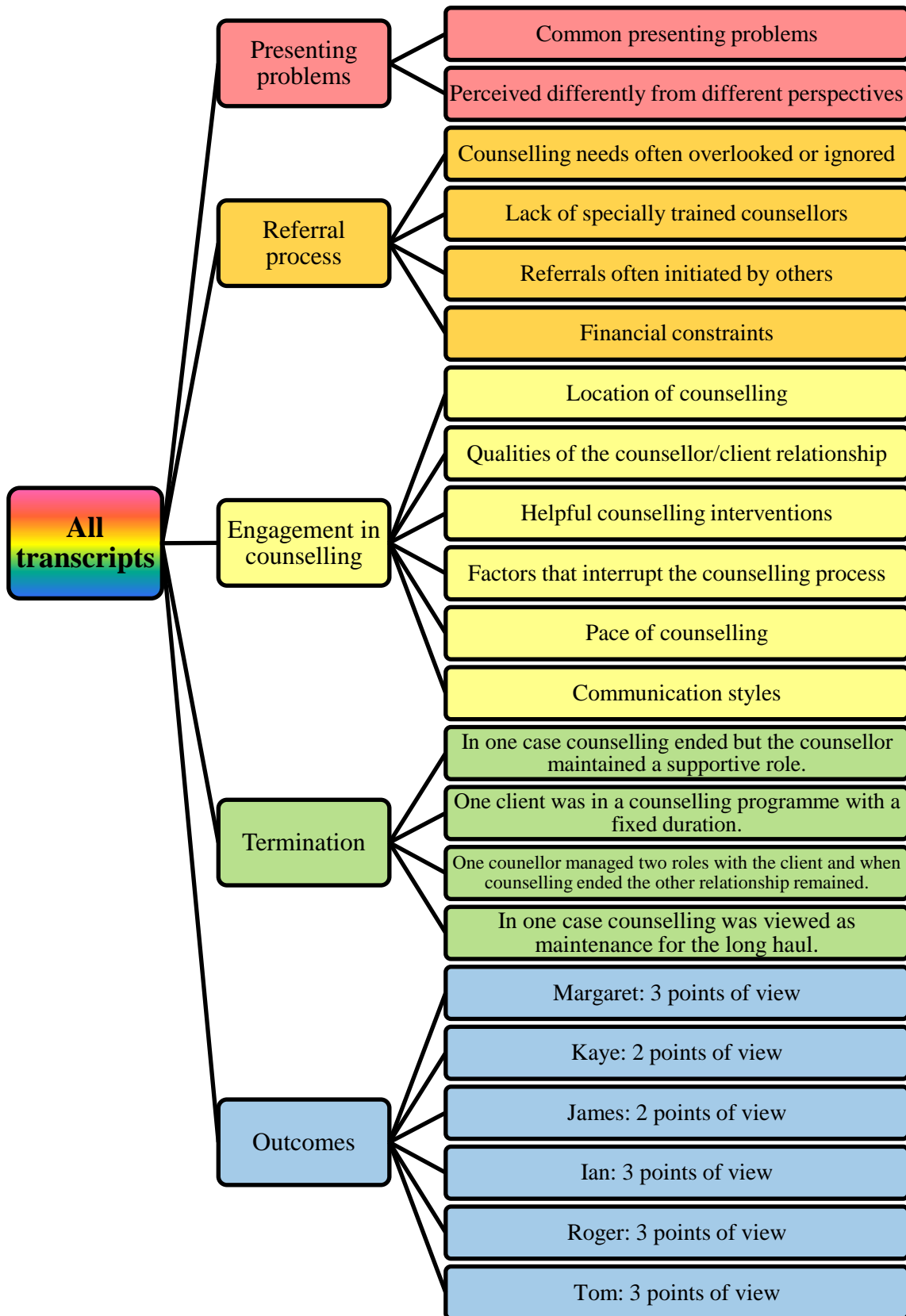
Figure 6: Data analysis: Organising using the counselling process framework

Organising the data using two research questions

Figures 7 and 8 illustrate how the data were analysed according to the research questions: (a) What is a disability? and (b) What is counselling? I began by reading through all the transcripts and organising relevant data into these two content areas. Next the content areas were subdivided into the four different participant groups and then further subdivided into themes.

Table 3 provides a coding example of the process used to generate themes. I read the through a content area (e.g., Clients' comments related to "What is counselling?") and looked for "meaning units" (Graneheim & Lundman, 2004, p. 106). These meaning units were then condensed into themes.
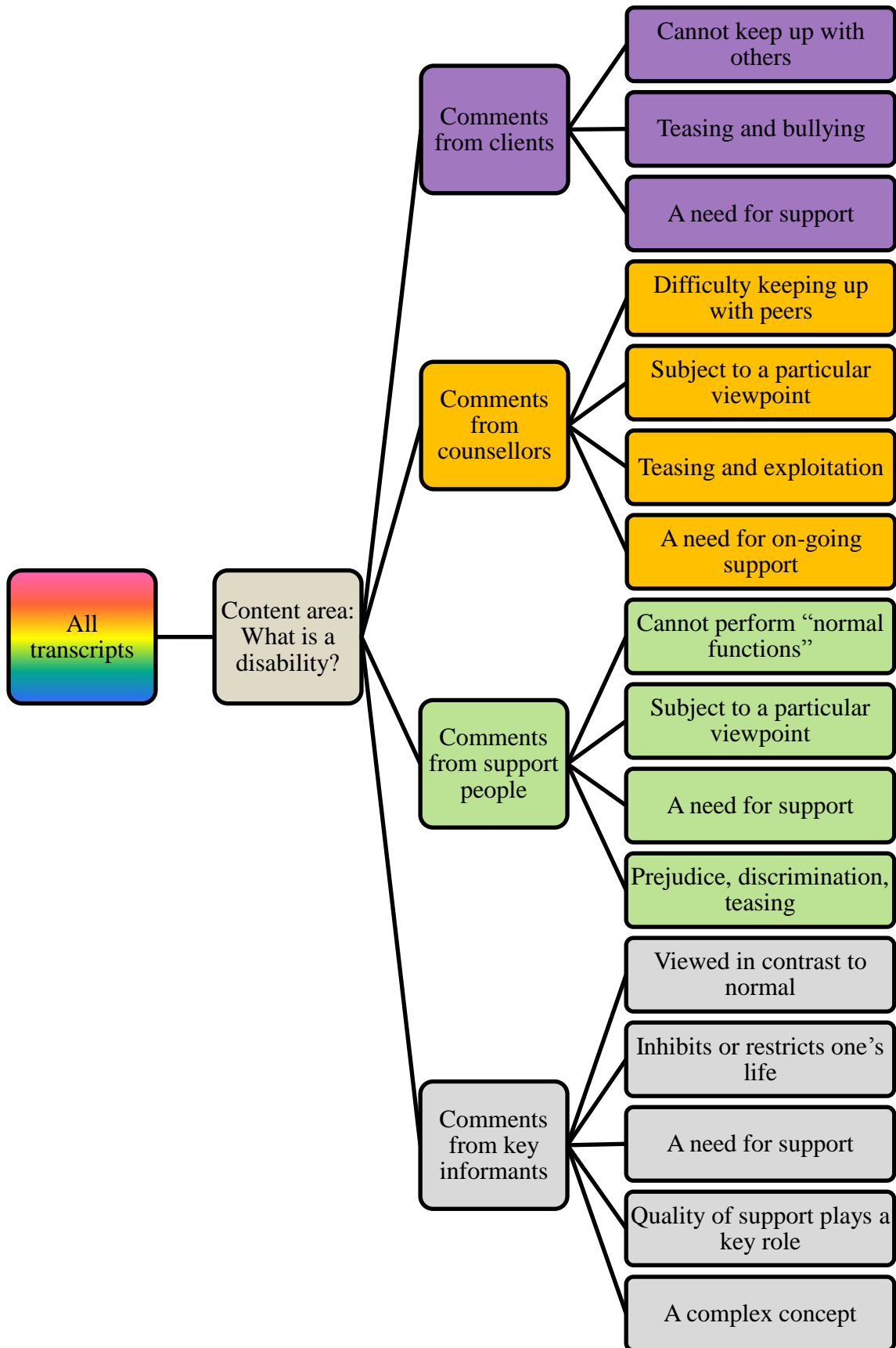
Figure 7: Data analysis: What is a disability?
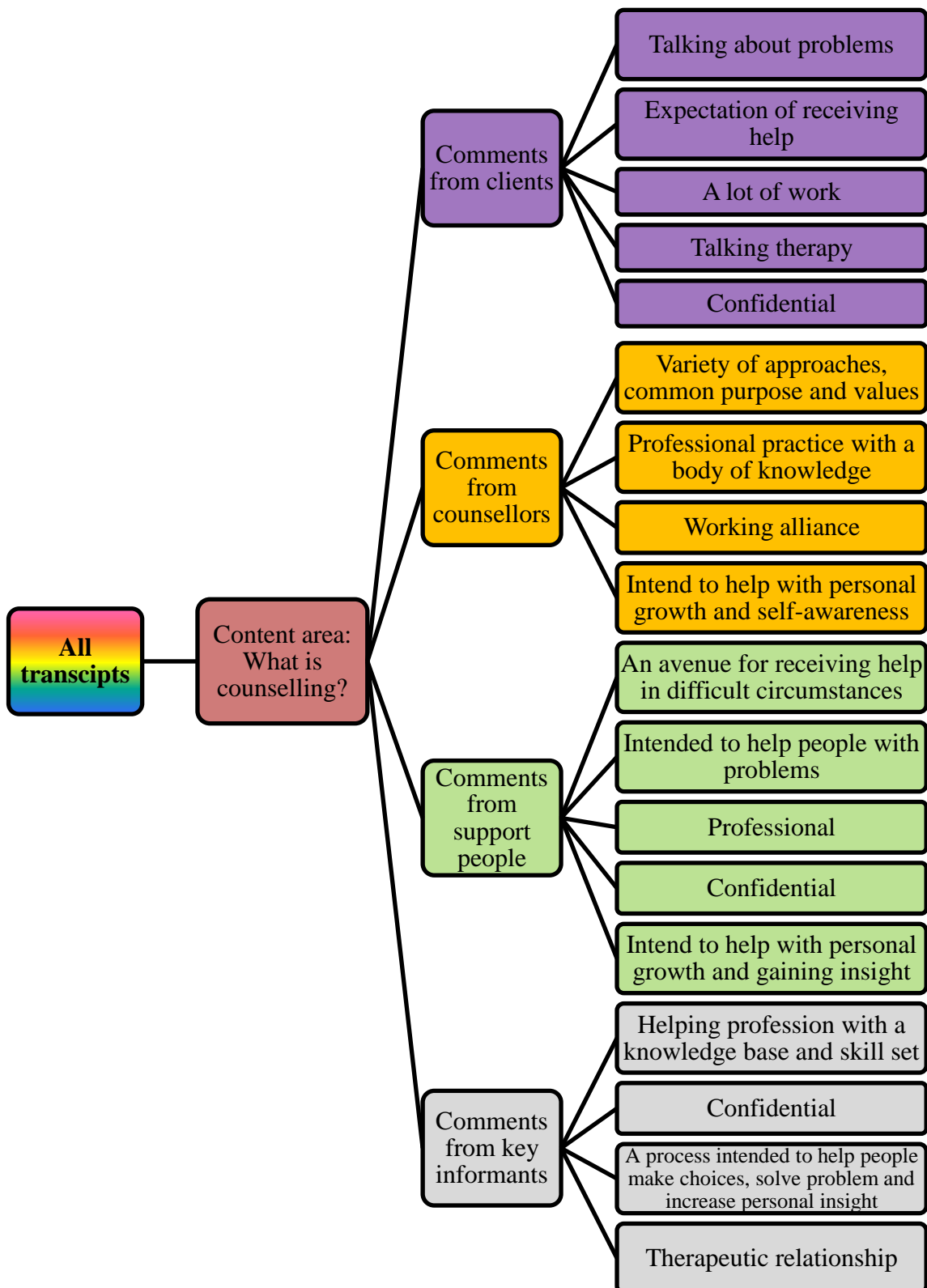
Figure 8: Data analysis: What is counselling?

Table 3: Coding example

Content area: What is counselling? Comments from clients		
Meaning units	**Condensed meaning units**	**Themes**
Client 1: Just talking to someone about your problems…what sort of advice you want	Advice for problems	Getting help to solve problems
Client 2: Where people go see someone to talk about problems	Talk about problems	
Client 3: To help you deal with a problem	Deal with problems	
Client 4: To get help and sort out a lot of stuff in your life… to keep you from going off the rails	Get help with stuff	
Client 5: …[counsellor's name] helped me a lot	Getting help	
Client 6: If you got anything worrying you or stressing you out, it is easier to talk to someone else than your family…If I got anything worrying me, I can tell my counsellor	Help with worries and stress	

Organising data according to the four participant groups

Figures 9, 10, 11, and 12 illustrate how the data were organised according to the four participant groups. I read through the transcripts of each participant group and organised the data from each group into content areas. Each content area was then subdivided into themes.
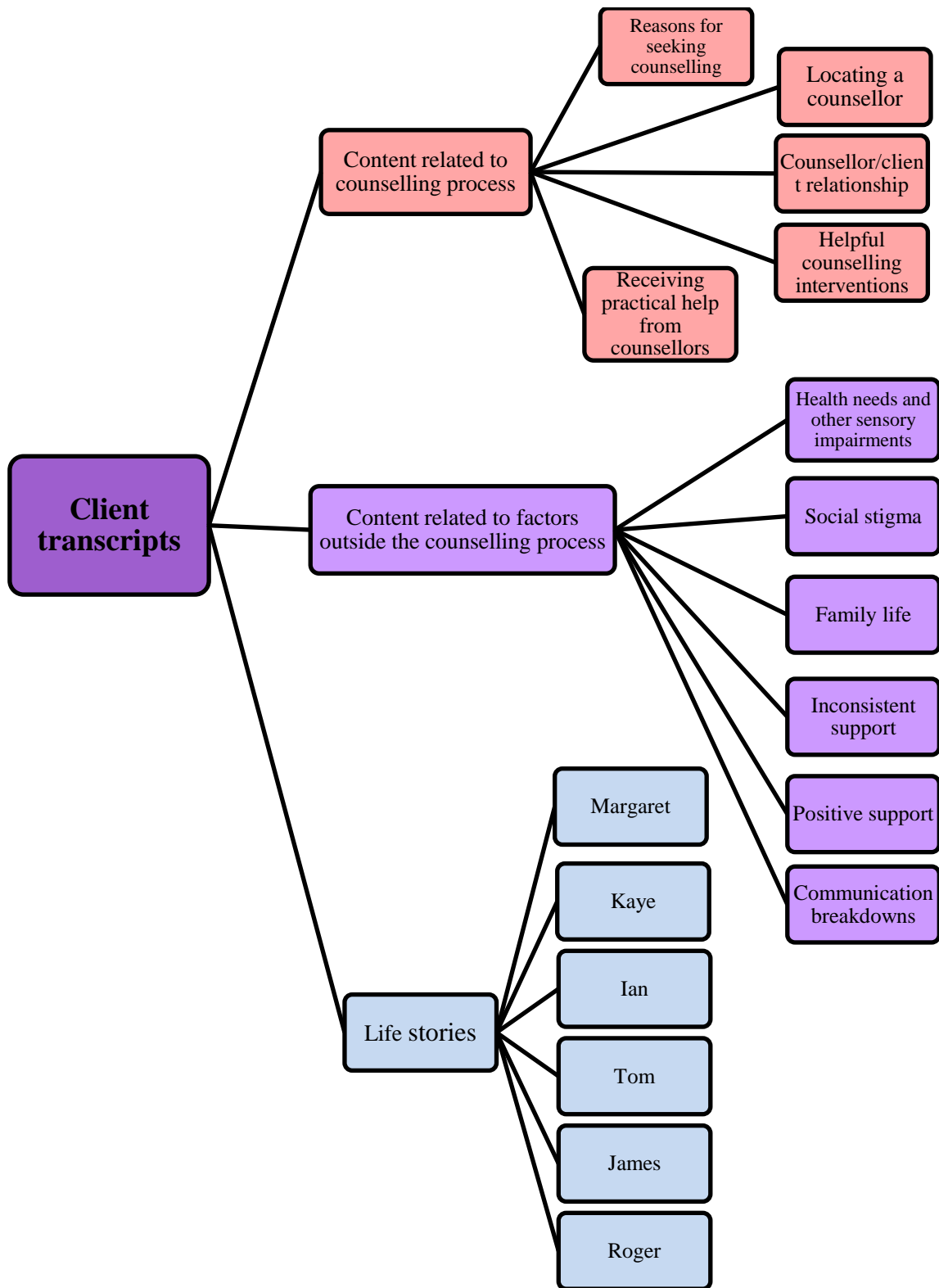
Figure 9: Data analysis: Organising the clients' transcripts

Clients' personal qualities

Clients' presenting problems

Clients' social networks and social experiences

Clients' health needs and other sensory impairments

Clients' disabilities

Described specific interventions and their outcomes

Accommodated the clients' learning and communication needs

Shared some of their emotional responses to their work with these clients

Described how complexities in the clients' environment affected their intervention

Described how establishing trust and making progress takes time

Private practice counsellors often worked for less money.

Private practice counsellors often provided practical support for clients with an intellectual disability.

Described their model of counselling practice

Sometimes their practice caused colleagues to "raise eyebrows."

Worked collaboratively with other professionals

Three of the counsellors worked in settings other than counselling offices.

Shared their emotional responses to their work

- **Figure 10: Data analysis: Organising the counsellors' transcripts**
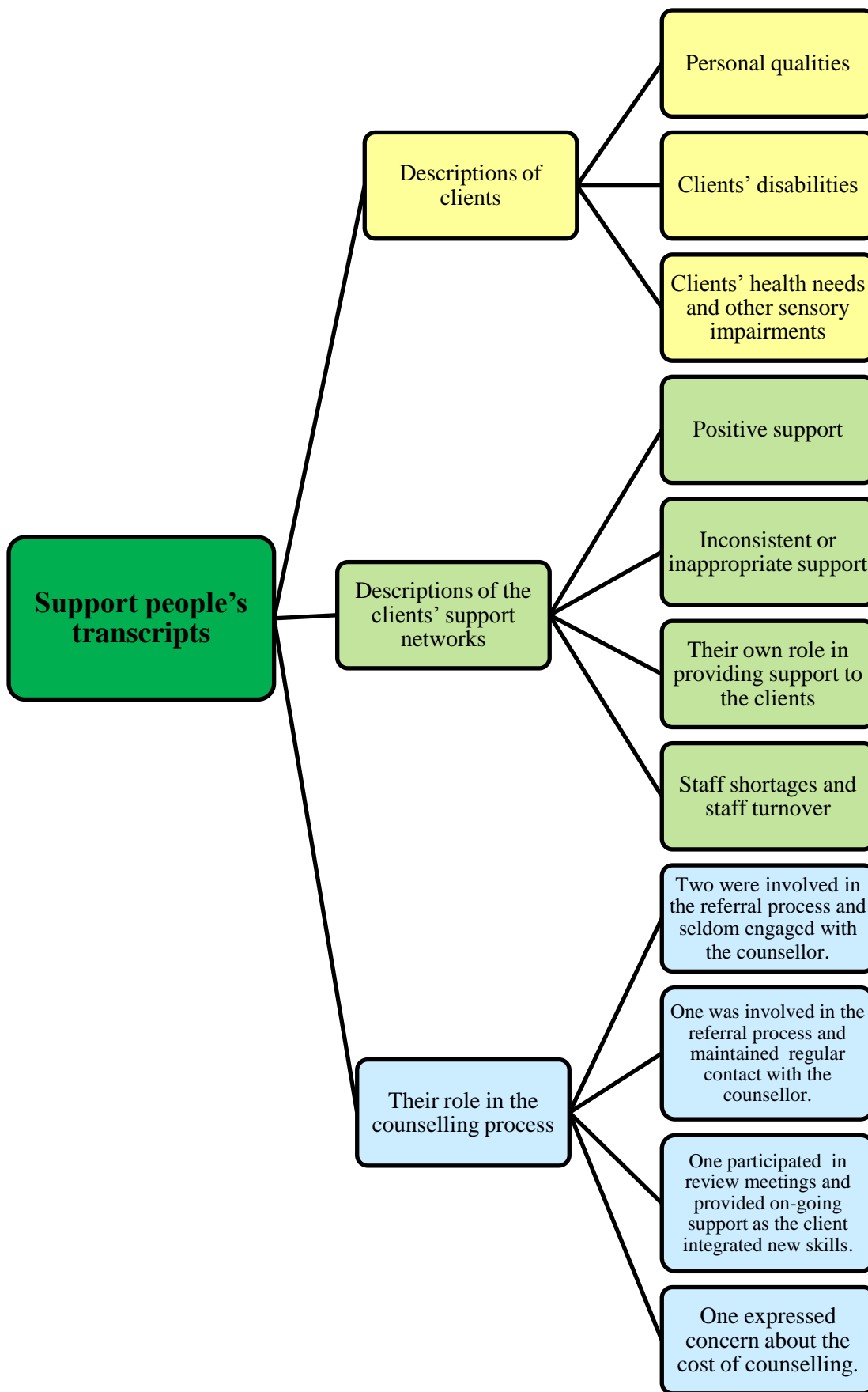
Figure 11: Data analysis: Organising the support people's transcripts
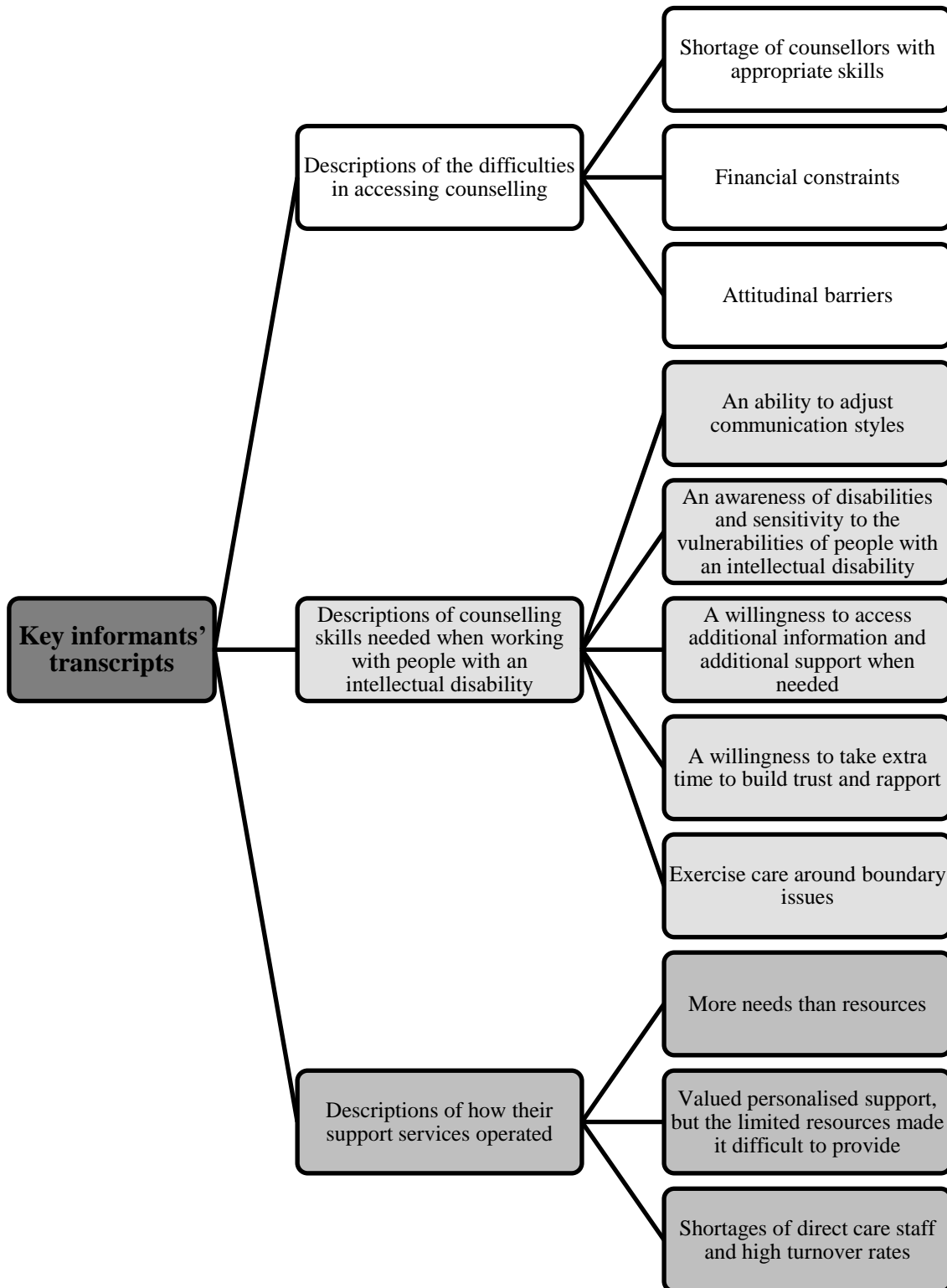
Figure 12: Data analysis: Organising the key informants' transcripts

Pulling together content areas and themes

Figures 13, 14, 15, and 16 illustrate how content areas and themes were pulled together to write up the participant descriptions and Chapters Five, Six and Seven.

Figure 13: Data analysis: Pulling together topics for participant descriptions

Content area: What is counselling? Comments from counsellors

Content area: What is a disability? Comments from key informants

Content area: What is counselling? Comments from clients

Content area: What is a disability? Comments from support people

Chapter Five: Participants' understandings of disability and counselling

Content area: What is counselling? Comments from support people

Content area: What is a disability? Comments from counsellors

Content area: What is a disability? Comments from clients
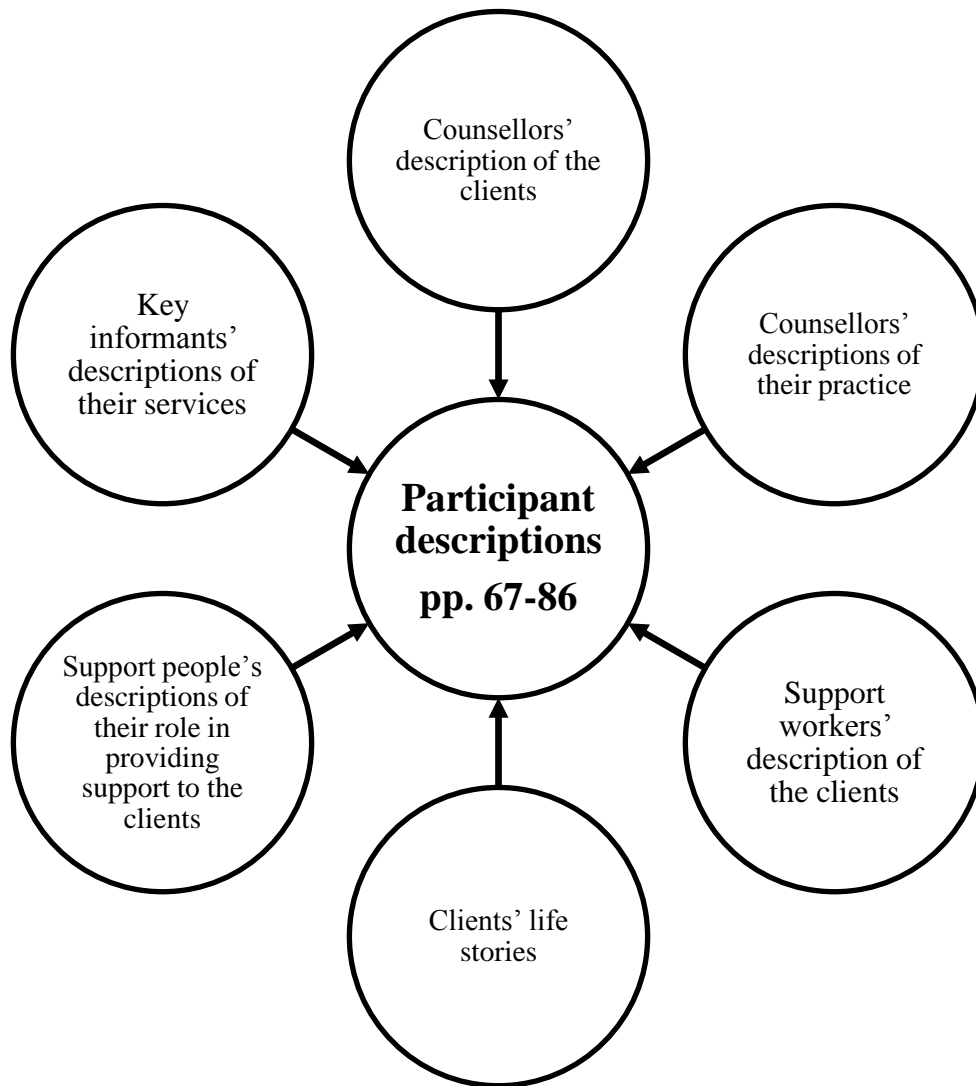
Content area: What is counselling? Comments from key informants

Figure 14: Data analysis: Pulling together topics for Chapter Five

Figure 15: Data analysis: Pulling together topics for Chapter Six

Counsellors'
descriptions of
their work
with these six
clients

Support
people's
descriptions of
the clients and
the clients'
support
network

Support
people's
descriptions of
their role in
the
counselling
process

Counselling
process:
Presenting
problems

**Case studies
in Chapter 7**

pp. 138-162

Clients'
descriptions of
the
counselling
process

Counselling
process:

Outcomes

Clients' life
stories

Clients'
descriptions of
factors outside
of counselling

Counsellors'
descriptions of
the clients

Figure 16: Data analysis: Pulling together topics for Chapter Seven

Appendix I: Published article

Routledge
Taylor & Francis Group

Factors that influence outcomes for clients with an intellectual disability

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Is counselling effective for clients with an intellectual disability? This question hovers in the minds of busy practitioners who question not only the ability of these clients to derive benefit from counselling but also their own ability to provide an effective service. However, this simplistic binary question does not do justice to the complexities of either the counselling process or the lives of those with an intellectual disability. A more useful question would be, 'What factors influence the counselling outcomes of these clients?' This review invites practitioners to refrain from questioning abilities, but rather to reflect on their practice in light of this latter question. Researchers are invited to broaden the scope of their inquiry to further assist practitioners' reflections.

Keywords: counselling; intellectual difficulties; outcomes; leaning difficulties

Introduction

An abundance of research indicates that 'counseling, in general, is effective' (Lambert & Cattani-Thompson, 1996, p. 602). Interestingly, disagreement remains regarding the effectiveness of counselling for clients with an intellectual disability (e.g., Beail, 2005; Hurley, 2005; King, 2005; Sturmey, 2005, 2006; Taylor, 2005).

Since 2003, several reviews examined the literature and arrived at different conclusions (e.g., Beail, 2003; Benson, 2004; Prout & Nowak-Drabik, 2003; Sturmey, 2004; Willner, 2005). Though the reviewers' conclusions regarding effectiveness differed, similar themes were reported. For example, they noted the pervasiveness of behavioural interventions used in such counselling. They also noted methodological problems in the research which included a lack of randomised controlled trials, and insufficient descriptions of the clients, the interventions used or the outcomes achieved. The reviewers noted the relative lack of counselling effectiveness research for this client group, in contrast to the wealth of general counselling effectiveness research.

General counselling research also has a wealth of research exploring the numerous factors that influence outcomes (e.g., Hubble, Duncan, & Miller, 1999; Norcross, 2002). In contrast, very few studies have explored the influence of these factors on the outcomes of clients with an intellectual disability (Willner, 2005). This lack of research is problematic. Not giving due consideration to these factors significantly restricts the profession's ability to assess the effectiveness of counselling.

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Numerous factors influence client outcomes, – client factors, levels of social support, outside events, therapist attributes, hope, and specific techniques. Significant attention has been paid to the 'effectiveness of specific techniques with particular groups of psychiatric disorders' (Roth & Fonagy, 2005, p. 447). Such research provides useful evidence in support of various techniques, however, on its own, it is unable to account for a 'substantial proportion of the variability in therapeutic outcomes' (Roth & Fonagy, 2005, p. 447). To account for the complexities inherent in counselling, attention must be paid to other factors as well. Fortunately, general counselling literature is replete with outcome studies exploring specific techniques as well as studies exploring the numerous other factors which are shared across different theoretical models (e.g., Clarkin & Levy, 2004; Lambert & Barley, 2001; Roth & Fonagy, 2005). When using research to inform their practice, counsellors can readily locate their work with non-disabled clients within this vast expanse of research.

In contrast, when working with clients with an intellectual disability, counsellors are likely to encounter difficulties in using research to inform their practice. First of all, locating applicable research is difficult. Counselling studies which focus on clients with an intellectual disability are not centrally located in the counselling domain. Currently, this knowledge rests primarily in the disability sector and is published in journals such as *Journal of Intellectual Disability Research, Intellectual and Developmental Disabilities, British Journal of Learning Disabilities,* and *Disability and Society.* Additionally, counselling literature specifically focused on clients with an intellectual disability is relatively sparse and is largely focused on the exploration of specific techniques. Very few studies have focused on the number of other factors that influence outcomes. Therefore, on its own, this relative small, narrow body of research is unable to account for 'the variability in therapeutic outcomes' (Roth & Fonagy, 2005, p. 447), and counsellors are left to question not only the ability of these clients to derive benefit from counselling but also their own ability to provide an effective service. However, when viewed alongside general counselling research, this body of research can provide practitioners with valuable insights.

The purpose of this review is to explore the broad range of factors that are likely to influence outcomes for clients with an intellectual disability. Specifically this review explores client factors, counselling factors and environmental factors. This review also identifies gaps in existing research. This review is intended as an invitation for practitioners to reflect on their practice in light of these factors and for researchers to broaden the scope of their research.

Definition of terms

Counsellor

Counselling is a multifaceted profession. Counsellors work with individuals, couples or groups. They work with a broad range of issues such as relationship difficulties, career choice, anger management, grief and mental health (e.g., Manthei & Duthie, 2003, p. 90). They may also be involved in preventative education, advocacy and research (e.g., Manthei, 1997; Tyler, 1969). They work using a wide variety of approaches; in fact, well over 400 different therapies have been identified (Kazdin, 1986, p. 96; Roth & Fonagy, 2005, pp. 5–6). Counsellors refer to their work using a

range of terms including counselling, therapy, psychotherapy, psychological interventions, and psycho-social interventions.

In this article, the term 'counsellor' will be used to refer to those whose work:

> ...involves the formation of professional relationships based on ethical values and principles. Counsellors seek to assist clients to increase their understanding of themselves and their relationships with others, to develop more resourceful ways of living, and to bring about change in their lives (New Zealand Association of Counsellors, 2002, p. 26).

The author acknowledges that the single term 'counsellors' actually refers to a heterogeneous group of individuals.

Counselling

The term 'counselling' will be used to refer to the work engaged in by counsellors and their clients. This work is:

> ...primarily an interpersonal treatment that is based on psychological principles and involves a trained therapist and a client who has a mental disorder, problem, or complaint; it is intended by the therapist to be remedial for the client's disorder, problem, or complaint; and it is adapted or individualized for the particular client and his or her disorder, problem or complaint (Wampold, 2001, p. 3).

The author acknowledges that the term 'counselling' refers to a wide variety of approaches which share a common purpose.

Intellectual disability

The term 'intellectual disability' will be used to refer to:

> ...a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development (Department of Health (United Kingdom), 2001, p. 14).

The author wishes to alert the reader that 'many different names are still used for the same phenomenon [i.e., intellectual disability]. Names change over time, particularly when their connotations or stigma become so derogatory in common usage, that they are no longer acceptable' (Bray, 2003, p. 1). For example, the term 'mental retardation' is being replaced by more socially acceptable terms such as 'intellectual disability' or 'developmental disability'. Names also vary from country to country and in different countries the same term can be applied to significantly different disabilities. For example, in the United Kingdom the term 'learning disability' refers to the same disability as the term 'intellectual disability' as defined previously (Department of Health (United Kingdom), 2001). However, in the United States of America the term 'learning disability' refers to a significantly different group of disabilities (National Dissemination Center for Children with Disabilities, 2004). In spite of the multiplicity of terms that the reader will encounter in the referenced articles, the author has chosen to write using a single term, 'intellectual disability', throughout the review.

The author wishes to remind the reader that the single term 'clients with an intellectual disability' actually refers to a heterogeneous group of individuals.

Client factors: utilising client resources

Although this client group is typically identified by shared common impairments, they also share common personal assets such as strengths in concrete thinking, including a 'sophisticated manipulation of visible and tangible reality' (Levitas & Gilson, 2000, p. 49), and a tendency to follow an idea rigorously to its conclusion (Wolfensberger, 1988, p. 67). Recognition and utilisation of a client's personal resources is a key factor in promoting change. Tallman and Bohart (1999) have suggested 'that it is the mobilization of client resources which is therapeutic and not the application of a technique to a problem' (p. 119).

Unfortunately, the recognition of a client's low cognitive ability often takes precedence over the recognition and utilisation of that same client's personal resources. Low cognitive ability has frequently been cited as a factor which reduces one's ability to benefit from counselling (Benson, 2004, p. 353) and such clients 'are rarely offered the full range of psychotherapeutic options' (Mohr, 2007, p. 13). However, 'over the past decade this assumption has been increasingly challenged' (Willner & Hatton, 2006, p. 1) both explicitly and implicitly. Literature specific to clients with an intellectual disability challenges this assumption explicitly by exploration of adaptations to specific techniques, by identifying the specific skills used in those techniques and by accurately assessing the necessary skill level needed to benefit from cognitive therapy (e.g., Joyce, Globe, & Moody, 2006; Oathamshaw & Haddock, 2006; Willner, 2006). This notion is implicitly challenged in general counselling literature by the assertion that it is a focus on client's resources, not their deficits, which promotes positive change (Tallman & Bohart, 1999).

Although there are many client factors which are likely to influence the outcomes of this client group, low cognitive ability still remains a key focus in outcome research. Very few other factors have been explored. Rose, Loftus, Flint, and Carey (2005) explored five variables and their influence on outcomes for clients with an intellectual disability. Three of the variables considered were client factors – the participants' receptive vocabulary, age and gender. The study included 50 participants and 36 people from a waitlist control. After an initial assessment, the participants attended a 16-week group session focused on anger management, and were assessed 3–6 months later. The findings suggested that group interventions for anger management for people with intellectual disabilities are effective (pp. 313–315). The findings also suggested that a higher receptive vocabulary improved outcomes. These findings supported findings by Willner, Jones, Tams, and Green (2002) who conducted a study on the efficacy of anger management for people with intellectual disabilities. This study did not have a special focus on variables that influenced client outcome; however, the researchers noted that improvement during treatment appeared to be strongly correlated to verbal IQ (p. 232).

Implications for researchers and practitioners

The existing research on the influence of client factors is limited and narrow in focus. The narrow focus on low cognitive ability and the accompanying lack of exploration

of other factors perpetuates, perhaps unintentionally, the notion that one's disabilities take precedence over one's abilities and resources. This review invites researchers to explore the broad range of client factors that have been well recognised in general counselling literature (e.g., Clarkin & Levy, 2004, pp. 194–226); client factors such as age, gender, ethnicity, socio-economic status, and personal assets affect counselling process and outcomes. In particular, this review invites researchers to explore the personal assets and resources of a client group whose abilities and strengths often go unnoticed.

The need for this wider research focus is supported by Rose *et al.* (2005) who stated that 'there is a considerable amount of variance unexplained'. They suggested that 'a larger number of variables need to be taken into account', i.e. 'more comprehensive measures of individual characteristics', numerous 'staff characteristics', and other environmental factors (p. 315). A broader research focus would better inform practitioners as they reflect on their work with clients with an intellectual disability.

Because these clients have limited verbal and cognitive abilities, it is crucial that counsellors recognise these limitations and seek to mobilise a broader range of client resources. Counselling is primarily practiced as a talking based therapy, often relying on the client's ability to understand and implement abstract concepts. Although clients with an intellectual disability have expressed that talking is helpful (Macdonald, Sinason, & Hollins, 2003, pp. 439–441), counselling interventions need not be exclusively verbal. Potential resources to mobilise are a client's hobbies and skills, a client's personal qualities such as resilience, generosity and good humour, and supportive family and friends. For example, precise needlework done by a client with significant co-ordination difficulties is more than just an interesting side-note; it is a concrete demonstration of that client's resourcefulness. Also, although a client's support network may be small, it should not be overlooked; family, friends, and paid support workers can be an asset in the counselling process.

Counselling factors

Inside the counselling room, both the client and counsellor contribute to the quality of the working alliance. Client attributes, such as active participation and attachment style, influence the quality of the working alliance (Bachelor & Horvath, 1999). Counsellor attributes such as interpersonal skills, communication skills, experience, and attitudes influence the quality of the working alliance (Horvath & Bedi, 2002) and the quality of the alliance influences client outcomes (Bachelor & Horvath, 1999; Horvath & Bedi, 2002). Schoen (1995) has suggested that these factors are important to consider for clients with an intellectual disability.

When researching outcomes for clients with an intellectual disability, several therapist attributes could be examined, e.g. personal qualities, training, experience, and attitudes. Personal qualities such as warmth, empathy, genuineness and unconditional positive regard are considered essential when working with this client group (Schoen, 1995). Counsellors' training and experience have an influence on counsellors' perceptions of their ability to work effectively with this client group (Raffensperger & Miller, 2005). Counsellors' 'perceived competence' appears to influence the provision of services to clients with an intellectual disability (Mason, 2007, p. 246). Counsellors' perceptions of themselves as well as their attitudes toward their clients have an influence on potential outcomes, at times preventing engagement

in the counselling process. Such attitudes include 'therapeutic disdain', the reluctance of therapists to engage with clients with an intellectual disability, and 'diagnostic overshadowing,' the tendency to attribute negative symptomology to an intellectual disability (e.g., Kroese, 1998, pp. 315–316; Mason & Scior, 2004, pp. 85–90; Williams & Heslop, 2005, p. 237).

Although general counselling literature includes numerous studies which have explored the influence of these common factors on client outcome in the general population, only a few studies have explicitly explored the influence of common factors on the outcomes of clients with an intellectual disability (Rose *et al.*, 2005; Strauser, Lustig, & Donnell, 2004; Williams & Heslop, 2005). Interestingly the findings from these few studies have mirrored the findings from numerous studies involving the general population. That is, the quality of the working alliance and the presence of outside support impact counselling outcomes (Bachelor & Horvath, 1999, pp. 137–139; Beutler *et al.*, 2004, p. 292; Clarkin & Levy, 2004, p. 213).

Rose *et al.* (2005) explored two therapeutic variables, the experience of the therapist and the presence of a support person for the client during the group sessions. They found that the presence of a support person during the sessions contributed positively to the outcomes (p. 315). Similarly Willner *et al.* (2002) found that 'the clients who did best overall were accompanied to the group by carers' (p. 234).

Strauser *et al.* (2004) confirmed the importance of the therapeutic relationship. When describing the background to their study, they stated that 'no research has addressed the impact of the working alliance on the counselling relationship with individuals with mild mental retardation' (p. 217). In this study, former clients of a vocational rehabilitation service were invited to respond to a telephone questionnaire designed to explore the relationship between the working alliance and outcomes. Although this study has some serious limitations, the results supported the importance of the working alliance on client outcomes.

Implications for researchers and practitioners

To facilitate positive outcomes for these clients, it is important for both researchers and practitioners to take into account the quality of the working alliance and the presence of outside support. This review invites researchers and educators to provide practitioners with specialised education, thereby increasing their 'perceived competence' and thus their willingness to engage with this client group. Researchers are also invited to assist practitioners by providing evidence-based practice research regarding how to cultivate and maintain strong working alliances and how to effectively utilise the client's support network.

An example of how one might cultivate a strong working alliance can be found in an article by Brooks and Davies (2008). They are currently involved in a participatory research project with people with an intellectual disability, which, among other goals, 'is trying to see if counselling and therapy helps people with a learning disability feel better'(p. 128). They discussed some of the steps they took to establish a working alliance with their co-researchers. Building this alliance took time, patience, and an awareness of 'roles, boundaries and power differentials' (p. 130). 'Ownership grew with time' (p.130) and as one of their co-researchers, a person with an intellectual disability, said, 'You've got to be more patient with people with learning disabilities, it takes time to learn' (p. 131).

In addition to providing ample time, patience, and relational sensitivity, counsellors can enhance the likelihood of positive outcomes by utilising techniques specific to their clients' needs. Unfortunately, the broad scope of this review does not permit discussion of each of numerous techniques found in the literature. Because relevant articles are often difficult for practitioners to locate, the author has chosen to make reference to a range of presenting issues and counselling models and invites the reader to refer to the relevant literature for further information. Following this passing glance is a brief discussion of adaptations which can be generalised to a range of techniques.

As is typical in counselling, clients with an intellectual disability present with a variety of issues and counsellors work using a variety of theoretical models. There are examples in the literature of presenting problems such as couple counselling (Larkin, 1992), challenging behaviour (Berry, 2003; Bissell, Phillips, & Kroese, 2005), depression (Jahoda, Dagnan, Jarvie, & Kerr, 2006; Lunsky & Palucka, 2004), anxiety (Dagnan & Jahoda, 2006), anger/aggressive behaviour (Rose, Dodd, & Rose, 2008), self-harm (Jones, Davies, & Jenkins, 2004), grief (Stoddart, Burke, & Temple, 2002; Summers, 2003), psychosis (Haddock, Lobban, Hatton, & Carson, 2004), adjustment disorders (Levitas & Gilson, 2001; Levitas & Hurley, 2005), offending behaviour (Lindsay & Taylor, 2005), nightmares (Kroese & Thomas, 2006; Willner, 2004), and trauma/sexual abuse (Cederborg & Lamb, 2008; Hollins & Sinason, 2000; Mansell, 2002; Mansell & Sobsey, 2001). Practitioners may also be called upon to work with families whose children have intellectual disabilities (Hornby, 1994; Lindenbaum, 2000), and in some families both the children and the parents have disabilities (Taube-Schiff & Serbin, 2006).

Although counsellors use various theoretical models, the majority of published articles have described the use of behavioural interventions, cognitive-behaviour therapy or psychodynamic psychotherapy. A few articles describe the use of other models, e.g., person-centred counselling with children (Flitton & Buckroyd, 2002), person-centred play therapy with adults (Demanchick, Cochran, & Cochran, 2003), narrative therapy (Matthews & Matthews, 2005), rational emotive therapy (Schneider, 2001), group therapy (Tomasulo, Keller, & Pfadt, 2004), family therapy (Haddock *et al.*, 2004), brief therapy (Anger & Hawkins, 2000), and solution focused therapy (Stoddart, McDonnell, Temple, & Mustata, 2001).

Practitioners using a variety of models may find it useful to adapt their current techniques when working with this client group. Whitehouse, Tudway, Look, and Kroese (2006), Mansell (2002), and Gallagher (2002) offer some useful general accommodations/adaptations that have been used by practitioners. 'In working with those with learning difficulties we will *usually* need to slow down, both in our communication and in the speed with which therapy proceeds' (Gallagher, 2002, p. 207). It is helpful to use concrete, plain language and provide ample time for the client to respond in conversation. The counselling style may end up being more directive, i.e. structured, including more prompts, suggestions, and activities. Counsellors may need to allow more flexibility with session length and location. The involvement of the client's support network was helpful.

Interestingly these adaptations are remarkably similar to suggestions made by direct care staff in a 2004 New Zealand study.[1] The following quotes were provided by support workers in response to the question, 'What specific issues should a counsellor consider when working with an adult with an intellectual disability?'

Have a good understanding of the persons support network. Being flexible in the meeting place to ensure person is relaxed.

Councillors [sic] need to be familiar with the effects of institutional living on people.

The level and kind of support available to that person for on-going progress.

Gain some background information on the specific problem from families, caregivers, etc. Have an interest in intellectual disability.

Supports client receives. Possible repercussions following session.

Using visual cues and physical way of representing situation.

Think in pictures rather than use words. Use more body language.

Regular liason [sic] with clinical team. Being creative in developing practical strategies.[2]

Counsellors are encouraged to remember that 'all people (especially children, the elderly, the less educated, non-English speakers, and those with mental illness or disabilities) understand more than they are able to communicate or demonstrate' (Gallagher, 2002, p. 209).

Outside the counselling room: environmental factors

Outside the counselling room there are many factors that can impact on a client's outcome. Issues of power and self-determination are likely to affect a client's ability to actively engage in the counselling process (Kroese, 1998). Social support is often limited (National Health Committee, 2004, pp. 117–128), possibly because of the social stigma attached to having an intellectual disability (Jahoda & Markova, 2004). People with an intellectual disability are vulnerable to abuse and exploitation and are victimised at a higher rate than the general population (Morano, 2001). 'Having a disability can pose as a major problem for achieving redress after abuse' (Lewin, 2007, p. 170). They often have physical or sensory impairments and often live with unaddressed health needs (National Health Committee, 2004, pp. 53–66). They often have limited income (Mirfin-Veitch, 2003) and difficulties with transportation. 'Accessible and affordable transport has been highlighted as a key service gap for people with disabilities in New Zealand' (National Health Committee, 2003, p. 7).

Although researchers acknowledge the impacts of this social context on the well being of this client group (e.g., Dagnan & Jahoda, 2006; Dagnan & Waring, 2004) and appear to be 'moving beyond individualistic cognitive models of mental health problems to the development of integrative models of mental health problems incorporating issues such as stigma, self-determination and socio-economic status' (Willner & Hatton, 2006, p. 2), outcome research which considers the influences of environmental factors is extremely limited. Considering the numerous environmental factors which could influence counselling outcomes, the author was disturbed by the difficulty in finding articles which explicitly explored the influences of environmental factors on counselling outcomes for clients with an intellectual disability.

Although such counselling articles were noticeably absent, numerous related studies have explored the influences of life events, living conditions and social

support on the well being of those with intellectual disabilities (e.g., Hastings, Hatton, Taylor, & Maddison, 2004; Heller, Miller, & Hsieh, 2002; Lunsky & Benson, 2001; Lunsky & Havercamp, 1999; Williams & Heslop, 2005).

Hastings *et al.* (2004) gathered information regarding recent life events and psychiatric symptoms from 1131 adults with intellectual disabilities. They found that 'exposure to one or more [stressful] life event in the previous 12 months was associated with an increased risk for affective disorder' (p. 44).

Heller *et al.* (2002) examined the impact of various environmental factors on the well-being of adults with intellectual disabilities. Findings from this eight-year study suggested that environmental factors such as opportunities to make choices, the physical attractiveness of the residence, and involvement with family 'influenced the long-term well-being of adults with mental retardation' (p. 372). Williams and Heslop (2005) explored the mental health support needs of young people with intellectual disabilities.

In this study, the young people considered friendship to be an important mediator of stress and a source of support. At the same time, they 'expressed a degree of tension in the establishment of friendships: several people had been bullied ...' (p. 239). Similar themes were discussed by Lunsky and Havercamp (1999) and Lunsky and Benson (2001). Findings from their studies suggested that the relationship between social support and well-being for those with intellectual disabilities is similar to the general population; that is, the quality of social support has significant influence on well-being.

The importance of attending to environmental factors was described by Kroese and Thomas (2006) and Willner (2004) in their case studies of clients who were having recurring nightmares. Kroese and Thomas (2006) pointed out that their intervention 'stresses having control over one's safety, it is essential that the client's home life is stable and without danger' (p. 79). Similarly, Willner (2004) commented on the positive influences of caring staff in his client's living place. Willner also noted the influence of a good working alliance; the intervention 'was built on a foundation of pre-existing good relationships with the therapist and supporting care staff' (p. 462). Given the high turnover of staff in the disability sector (e.g., Test, Flowers, Hewitt, & Solow, 2003), the frequency of relationship disruptions (Runnion & Wolfer, 2004) and the high incidence of crime and abuse experienced by people with an intellectual disability (Horner-Johnson & Drum, 2006; Wisconsin Coalition Against Sexual Assault, 2003), it is imperative that more attention be given to the influences of a client's home life on counselling outcomes, particularly in regards to relationship stability and personal safety.

Implications for researchers and practitioners

The complexity of these environmental factors along with the dearth of counselling studies is an invitation for new exploration. Clearly such research is likely to be complex and time consuming. Nevertheless such research could provide valuable insights for practitioners who wish to consider how these environmental factors are likely to influence their day to day practice. Currently these practitioners must rely on knowledge gleaned from sources other than evidence based counselling research.

A heightened awareness of the environmental factors that can interfere with the counselling process and a willingness to creatively work around these barriers is a necessity for practitioners working with this client group. In the first instance,

accessing counselling services is not easy for this client group (Raffensperger & Miller, 2005). Such barriers may be as simple as finding one's way to the counselling office. For example, a client with a low income may wish to take a bus to the counselling office. However, a limited reading ability and a lack of familiarity with the new location pose challenges that require extra support. Such a client may benefit from verbal instructions supplemented by a pictorial map. Alternatively, the counsellor may choose to meet the client in an appropriate location that is more convenient for the client.

Remaining actively engaged in the counselling process is likely to be difficult if a client has limited social support, transportation difficulties, limited finances or unaddressed health needs. If a client is having difficulty making forward progress in counselling, it may be that factors outside the counselling room have interrupted the counselling process. A counsellor's awareness of relevant environmental factors and subsequent creative responses can enhance the forward progress of their clients.

Conclusion

Achieving positive outcomes is at the crux of the debate regarding the effectiveness of counselling for clients with an intellectual disability. By taking into account the many variables that influence outcomes, counsellors may discover more ways to assist clients to achieve positive outcomes. This review echoes the voices of Ayers and Duguay who in 1969 suggested that counsellors consider factors such as:

> ... the emotional problems, the level of intellectual functioning, personality characteristics (motivation, self-concept and temperament), communication factors, learning ability, parental influences, and environmental factors. Regardless of the particular theoretical counseling technique or mode of therapy employed, all of these variables directly and indirectly influence the overall adjustment of the retarded [*sic*]. Hence, it is imperative that counsellors become aware of them (p. 50).

Researchers are invited to help increase counsellors' awareness of these variables by broadening the scope of outcome research. Such research would enable counsellors to reflect more effectively on their practice.

Notes

1. For a description of this study and previously published data, see Raffensperger and Miller (2005).
2. These previously unpublished quotes were taken from data gathered in the 2004 New Zealand study which is detailed in Raffensperger and Miller (2005).

Notes on contributor

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