Making Participation More Than A Tick Box For Your Quality Control:
Understanding the Enablers and Barriers to Client Participation

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Declaration

I certify that except where due acknowledgement has been made, the work is that of the author alone; the work has not been submitted previously, in whole or in part, to qualify for any other academic award; the content of the thesis is the result of work which has been carried out since the official commencement date of the approved research program; any editorial work, paid or unpaid, carried out by a third party is acknowledged; and, ethics procedures and guidelines have been followed.

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Abstract

This paper explores the divergent experiences of clients in receipt of social services. In both the international literature on participation, and the history of international activist contestation over the oppressive dimensions of practice, the significance of structuring social services around service user participation has been recognised at least since the 1960s.

This thesis mobilises concepts from several different theoretical approaches. The thesis draws on Goffman’s (1986, p. 3) conception of stigma as a product of the interaction of an individual and their society in the creation of the social identity of both people with disability and the experience of people receiving social services. Sennett’s (2003) ideas on respect are used as a stepping-stone to personal and professional values as a critical component of client participation. Bacchi’s (2009, p. 16) framework is used to describe the ways problem representations can create social relationships within discourses that create inequality which then underlies the experiences of service users, turning them into “subjects of a particular kind” in the eyes of their community. Schön (2013) provides insight into the behaviour of some professionals through his discussion of technical rationality, and his suggestion that professional practice has both a ‘high ground’ where practitioners make decisions based on technical solutions, and a ‘swampy lowland’ of messy problems that are difficult to specify in technical terms, but which are nevertheless present problems of greatest human concern (p. 42).

My review of the academic literature on participation focuses on what is meant by participation in the practice of social services in Australia and other countries. Drawing on both broader academic discussions of community participation, as well as the more specific appropriation and application of the concept of participation to the provision of social services, the literature review analyses descriptions and models of participation to determine the significance of this literature for service providers interested in applying the principles of participation in their work with clients.

My literature work left me with two principal questions: First, do practitioners understand client participation in ways compatible with academic discussions of the concept? And, second, how can practitioners operationalise a commitment to participation in their own practice settings? These two questions drove a qualitative research design, conducted in two stages, whose design was guided by the works of Yin (2011), Charmaz (2006) and Creswell (2007). Stage one involved interviews with a range of stakeholders – including service users with varying needs, staff and board
members at a range of social service organisations - who were asked, first, to comment on participation models, barriers and enablers to participation drawn from the academic literature on participation and, second, asked to reflect on whether they would find such models useful to help them articulate their own experiences, attitudes towards and approaches to client participation.

I then analysed this first stage of interview data, using a process developed by Boyatzis (1998), and concluded that the professional practitioners who participated expressed a reasonable understanding of what I refer to as the enablers of participation - namely: Values, Relationships, Processes, Management and Leadership - drawn from my review of the international literature on participation. At the same time, however, participants seemed much less clear about how to integrate a meaningful process for participation into their day-to-day practice with clients. These results precipitated the development of a second stage, which took the form of focus-group-based study concentrated on what appeared to be a disconnect between service providers’ understanding of client participation and their difficulty in embedding it in their practice with clients.

My analysis of the focus group data identified four specific barriers to client participation, including, notably, professionals’ fear of losing power and control to service users through their increased participation in the services they receive. At the same time, the research uncovered a diverse range of personal, professional, and systemic factors that combine to create a level of complexity that often confounds service providers when attempting the task of imbedding client participation in their practice. Some services notably remain unaware of the enablers of participation that already exist in their practice.

The research also identified that the crucial enabling factor for client involvement in social services is relationships with others – particularly with staff, but also including other clients. Such relationships appear to have the most significant impact on the quality of a service user’s experience of participation. The research also suggests that the key to incubating such relationships lies in the individual values and attitudes – both personal and professional – that determine the effort staff make to form and maintain respectful relationships with clients, which translate, for better or worse, into all systems of an organisation.
Preface

While most of the thesis will necessarily focus on the more traditional “arms-length” academic dimensions of this study – the review of the literature, original data collection, and data analysis – I want to begin by taking a step back from these academic matters, to describe, in some detail, my motivation for attempting this work. I do this in recognition that social-scientific research – particularly, but not exclusively, in qualitative investigations – has increasingly recognised the importance of self-reflection on the social location and background of the researcher (Yin, 2011, p. 264). On the one hand, this kind of reflection is important to make clearer the potential limitations of the research (Boyatzis, 1998, p.11). At the same time, self-reflection is not solely a defensive or self-limiting move: it is also a tool for gaining insight into the reliability and validity of research – particularly in qualitative studies whose investigations are situated in a time and place that may not be replicable in the traditional sense. By understanding more about the researcher, we can understand more about the principal research tool used in qualitative investigations: the researcher’s own observational and interpretive skills (Armstrong et al, 1997, p. 605). We can also better understand how the researcher’s background might enable certain forms of insight or even make possible access to a particular research field – even as it also limits or restricts other forms of insight – all of which has bearing on the confidence we might place in the research findings (Boyatzis, 1998, p. 13).

My decision to reflect on my personal background and motivations – both here in the Preface, and periodically throughout the thesis – therefore strives to meet the challenges posed by this growing literature on the importance of researcher reflexivity. It expresses a recognition that all knowledge is situated – and that this situatedness, far from undermining more general conclusions, is in fact the essential precondition for more generalised forms of knowledge that do not ride roughshod over more local experience. This distinctive understanding of how to generate broadly applicable findings from more localised studies, has proven particularly useful for studies of complex, intractable social problems – like the ‘wicked problem’ of client participation – as well as studies of traditionally under-represented social groups (Collins, P. H., 2000; Rittel & Weber, 1973). The current study hopes to operate in the spirit of these scholarly traditions.

First, I note that I was a public servant in the State of Victoria from 1977 to 2008. With the exception of approximately two years, I worked in the Department of Human Services - or the Social Welfare Department, as it was known when I started
work as an Assistant Superintendent in Prisons Division there in 1977 – spending my first week at a desk reading the Social Welfare Act, 1970. Throughout those years, I was primarily an operational manager of direct services to clients of the department. These services included prisons, community correctional services, juvenile justice institutions, disability services and institutions, including forensic services for people with disabilities, child protection and public housing, and, in the Department of Education, I was Assistant General Manager of the Program for Students with Disabilities. This experience sensitised me to the problems this thesis hopes to address, convincing me that participation has been, and remains, an essential challenge for the social services. My background also provided invaluable insights into the challenges confronting both service users and social service staff – insights that assisted me in gaining access to, and the trust of, the many participants in this research, and guided me in interpreting the feedback participants gave – and, at times, in understanding the significance of what participants left unsaid.

I have been and continue to be fortunate to be associated with some clients, students and colleagues from this time. These are people who engage with others with a level of dignity and respect that remains constant. Such relationships have taught me the value of evenness in relationships with others and have shown how little is achieved for clients or staff without this constant respect.

I have also come to know countless individuals and families who, as clients of services I worked in, trusted me with some of the stories of their lives. Their stories gave me the insight to respect and appreciate the fine, tenuous line that divides their lives from mine.

My personal intention in doing this research is to give something back to the service system. When I was working in human services, the thought I always had in my head when presented with a proposal or task was: what is this going to mean for clients; is there a tangible benefit for clients in doing this? I have approached this research with the same thought in mind, and I hope that this contribution both provides tangible benefits of its own, and assists others to build upon its findings to provide further benefits I could not have foreseen.
Chapter One: Introduction

1.1 Aims and Scope

The aim of this thesis is to contribute to the understanding and knowledge of the practice of client participation in social services, in both Australia and overseas. The thesis uses a local case study of selected social services in Victoria, Australia to build on our knowledge of the enablers of participation. These enablers are determined in the first instance by a review of the international academic literature. These insights from the literature are then further refined through a qualitative study, conducted in two stages, that solicited feedback from a range of stakeholders in social services.

In stage one, these stakeholders included service users with limited verbal communication skills (of the participating service users, few had little or no functional speech but interpreters were used in four interviews with these participants) as a result of cognitive impairment and limited capacity for decision-making, as well as staff and board members from social service organisations responsible for supporting these service users. The stage one study sought practice-based examples of the barriers and enablers of participation identified in the academic literature on participation. Analysis of the stage one data suggested that practical barriers to participation are accentuated by the apparent inability of service providers to develop a shared definition of the practice of client participation, which they could operationalise in their service delivery. This stage one finding then prompted the design of a discussion rubric, intended to help service providers explore and discuss barriers and opportunities for participation in a practical, applied setting. This discussion rubric then provided the prompt for a second, focus-group based, study that asked service providers to use the discussion rubric to reflect collaboratively on their participatory process within their organisations. The combined qualitative data from both studies has been analysed with the goal of assisting service providers to identify possible solutions to the ongoing challenges of implementing service user participation in their service provision.

1.2 Overview of the Study

The eight chapters of this thesis are presented in three main sections. The first section includes the current introductory chapter, which, together with chapters 2 and 3, is designed to assess definitions of participation in the international academic and activist literatures, and to analyse why client participation is regarded as a critical
component of the practice of social services. Chapter 2 begins with a discussion of the challenge of participation – why participation is important, why we need it, what it involves and why it is difficult to achieve. Insights from the academic literature are explored, in particular to develop an argument in support of Stoecklin’s (2012, p. 13) statement that participation is a “concept in need of an explicit theory of action”.

To set the stage for this discussion of the literature, I pay particular attention to changes in the delivery of social services, which I characterise as a shift between two ideal types (Weber, M., 1969) of social service provision – from one, which could be called a ‘positivist’ perspective, and which appealed to technocratic principles, to a second, more collaborative approach based on individual human rights. In practice, this shift is neither complete nor ‘pure’, and some combination of both ideal types can often be found in social service provision ‘on the ground’. However, the ideal types make it easier to conceptualise broad trends in the provision of social services over time – and they also make it easier to see the relationship between new frameworks of professional practice, and changes in community expectations, which were themselves influenced by activism and the social movements of the time.

Within this discussion of historical trends, services provided for people with cognitive impairments are singled out – not because the original research for the thesis focuses solely or primarily on cognitive impairment, but because the difference between positivist and more collaborative approaches can be particularly clearly illustrated by looking at changes in social service provision for this group. This clarity emerges for three reasons: first, this cohort of clients offers an explicit example of the medical model, which is still in play in some states in Australia, and is representative of the application of technocratic principles which locate the ‘problem’ within the individual, rather than in society’s failure to accommodate the needs of people; second, the changes to the delivery of services for people with cognitive impairment led to sweeping changes to service delivery across a broad range of human services; and third, my own professional experience of working within the environment of the medical model in the State of Victoria provides an additional insight into these particular historical shifts, which can cast further light on the ideal types being highlighted here.

The literature on client participation in the social services is inspired by, and draws on, an influential prior literature about civic participation among historically socio-economically marginalised groups. For this reason, the thesis reviews the literature on civic participation for the essential context it provides for understanding
the literature on client participation. Arnstein’s (1969) foundational article “A Ladder of Citizen Participation” therefore heads the discussion on the historical background to participation, as it expresses the beginnings of activism and research into participation. Parallels are drawn between the publication of Arnstein’s piece and the historical and institutional context for people receiving human services in the State of Victoria, which, at the time, made extensive use of congregate care institutions (Social Welfare Department Victoria (SWDV), Annual Report, 1972, 1976). A detailed description of the medical model is then presented, followed by a discussion of what I refer to as ‘professionalism’ – a term that draws particularly on the work of Schön (2013), which thematises how ‘technical rationality’ failed to solve a number of complex social problems. Sennett’s (2003) work on ‘respect’ is then used as a stepping-stone to ‘values’ as a critical component of the type of relationships that are necessary for the full participation of clients in the services they receive.

The task of Chapter 2, then, is to highlight the social and political forces that have generated awareness of the importance of participation as a necessary component, not just in civic life, but also within the practice of social services. Within this broad framework, I then draw on historical literature, as well as illustrative practice examples from my own professional experience, to explore what it might mean to understand the evolution of social services in the State of Victoria as a movement between the ideal-types of positivism and collaboration. Here I focus particularly on the shift from an institution-based service system, to a more engaging community-based, client-centred conception of service delivery. I present the history of the treatment of what Park and Grayson (2008, p. 1107) call “vulnerable” populations, which they identify as children, mentally disabled and educationally or economically disadvantaged persons. I draw attention to how the great harm being done to many was finally recognised, leading to a change in the treatment of the people receiving these “services”.

My review of the international literature on participation in Chapter 3 explores what is meant by “participation” for people who find themselves in situations where they are not allowed to participate in making decisions that affect their lives. Various theoretical models of participation are presented, beginning with a more detailed look at Arnstein (1969) and those who adopted her ladder metaphor (Hart, 1992), as well as those who rejected it (Treseder, 1997; Lardner, 2001). These key authors, who explore the challenge of participation in a range of different social service fields primarily in the United Kingdom and North America, are examined to distil the common enablers of the process of participation that are shared by each model. I also
assess the value and usefulness of such models for service providers who are concerned with incorporating service user participation in their practice with clients. In particular, I focus on the challenge of operationalising what are often somewhat abstract academic theoretical models for staff who must work out how to apply such models in professional practice.

This evaluation of the models and definitions of participation is followed by a discussion of the common barriers to participation. This discussion highlights the need for clarity in both stating precisely what people are being asked to participate in, for what purpose, and in clarifying who is involved, and who is not, in the participatory process. This analysis makes it possible to distil from the literature a number of enablers of participation – factors, that is, that are necessary for effective participation to occur in the practice of community sector organisations. By distilling these insights from the international scholarly discussion, my goal is to investigate how we can then help practitioners in a wide variety of social service contexts, operationalise participation – lifting the concept out of the abstract theoretical models in which it is often presented, so that service providers localise the concept and work out strategies for applying it in their everyday professional practice.

This goal then informs the next section, which includes Chapters 4, 5 and 6, in which I lay the foundation for applying the concept of participation to professional practice. Although participation has been studied for decades, there have been few attempts at developing practical frameworks that staff and service users could use to problematise and reflect on the level of service user involvement in social services (Hernandez, et al., 2010, p. 732). These chapters therefore seek to explore this question of how insights derived from the academic literature into participation are perceived “on the ground” by different stakeholders in the provision of social services.

My methodological considerations and the ethical challenges of obtaining informed consent from participants that include people with disabilities and the economically and educationally disadvantaged, are discussed in Chapter 5. I present my process for developing the qualitative coding techniques used for analysing the stage one study data in Chapter 6. In analysing the data, my focus in the stage one study was on utilising the perspectives of participants to determine the perceived validity of the barriers and enablers of participation that had been distilled from my review of the academic literature. The data from the stage one study highlighted the significant impact of the personal and professional values of staff, both on an organisation’s culture and on the experience of participation for service users. While
striking, these results were consistent with the literature on participation – which raises the question with which this chapter concludes: why, given a reasonable consensus over the principles that enable participation, does a lag seem to remain in operationalising these principles “on the ground” in professional practice? This question drives the design of the stage two study, which is discussed in the final section of the thesis in chapters 7 and 8.

One of the outcomes from the stage one study was the decision to design and construct a simple, practical discussion rubric intended to guide a professional conversation about how to apply principles of client participation in social service organisations. The design of the discussion rubric drew on both the review of the scholarly literature – particularly on the model produced by Rifkin et al (1988, p. 936) – and the stage one findings. This discussion rubric was then used as one of the prompts for, as well as an object of, discussion, in a series of focus groups conducted with staff from three social service organisations. In Chapter 7, I describe the aims for the stage two study and present my analysis of the focus group data. The questions to resolve in this chapter were: what factors make it difficult for social services to incorporate participation into their day-to-day practice with clients? And: would social service staff find a tool like the discussion rubric helpful in improving their organisation’s approach to participation?

Chapter 8 concludes by offering a summary of the key findings, and a reflection on some of the implications of these findings for the broader literature on client participation. Particularly significant here are insights into why social services might have difficulty embedding client participation into their practice – and how we might overcome the abstraction of academic models of participation and help bridge the gap between scholarly theory and professional practice. In addition, the research findings help us define more precisely, and in relation to their significance for professional practice, the most critical dimensions of the five enablers of participation originally identified in the academic literature on participation. Data from both interviews and focus groups suggest that the most important Enablers of client participation are personal and professional Values, alongside the nature of the Relationships between clients and staff. At the same time, the focus group data in particular is useful in identifying four main Barriers to participation, namely: Fear, Client capacity, Know-how and Resources. Taken together, these findings form a coherent, practical body of knowledge that can assist social service organisations in advancing their practice of participation, while also contributing to the academic debates over models of participation by offering additional insights into how to operationalise theoretical
models on the ground. I conclude chapter 8 with my reflections on the implications of this for the practice of social services and the limitations of, and future directions for, this research in client participation.

To lay the groundwork for this analysis, however, I first introduce the concept of participation and its importance in the historical development of disability services in the next chapter.
Chapter Two: Why Is Participation Important?

2.1 Introduction

The challenge of participation – why we need it, what it involves, and why it is difficult to achieve – has received extensive attention and debate in a growing academic literature in North America, Europe and Australia, dating back to the 1960s. The scholarly literature on participation, however, does not emerge in a vacuum: it is itself a response to a newly-prominent social and political contestation, which pits social movements and activists against traditional understandings of professional practice across a wide range of fields. To understand the international scholarly literature – and the implications of the literature for professional practice – it is therefore useful to discuss the emergence of this new scholarly field in tandem with a discussion of the social movements and professional trends the scholarly literature was seeking to interpret and shape. This is the task undertaken in this chapter.

One of the central challenges highlighted in the data collected for this thesis, is how social service practitioners can translate more abstract and decontextualised scholarly models into forms that are meaningful to situated practices that must be carried out in local settings. The structure of this chapter is influenced by that result, and therefore seeks to move back and forth between a general discussion of the emergence of a new scholarly field, and policy and professional practice trends on the ground in Victoria, Australia. Localising the story still further, this chapter makes recurrent reference to the transformations in service provision for clients with cognitive impairments. To avoid potential misunderstanding, I need to stress at the outset that the original research carried out for this thesis does not focus solely or even primarily on services for such clients. Instead, I have chosen this approach for this chapter for two main reasons.

Firstly, the transformation of professional practice with those with cognitive impairment captures, particularly clearly, the most significant historical trends in the delivery of services to people with disability over the past thirty-five years. These changes were achieved primarily through the international mobilisation of parent groups, who were later joined by academics who disagreed with the professional practice of the time (Dybwad & Bersani, 1996, p. 260), who began to develop new frameworks for professional practice. The activism of parents and academics also greatly benefited users of other human services, which is also discussed below.
Secondly, I wanted to be able, in this chapter, to present practice examples from my own professional experience, to illustrate some of the implications of these trends on the ground in operationalising new models of service delivery for clients in social services. In this respect, I follow Holt’s (2003, p. 20) concept of using autoethnographic observations as a useful way to examine professional experiences in a self-reflective manner. In this context, drawing on autoethnographic, as well as scholarly, resources enables me to illustrate how changes to service delivery were implemented, and to draw on my personal and professional reflections on why change was necessary and how it impacted on both clients and staff. Denshire (2014) similarly suggests that applying the method of autoethnography to professional practice has the potential to remake what she refers to as the “somewhat tired traditional professional attributes of professional expertise and professional detachment” (p. 844). In this respect, the practice of autoethnographic reflection is intended to mirror a more collaborative approach in professional practice, in that it seeks a model for the presentation of academic knowledge that opens a space for redistributing power between service users and service providers, by making the situated character of the researcher’s knowledge clearer and more explicit. It also, I suggest, mirrors the sort of reflection and translation professional practitioners will themselves be required to carry out – whatever their personal service specialisation – in order to adapt scholarly insights to the needs of their own clients and organisations. In the introductory chapter, I referred to Stoecklin’s (2012, p. 13) statement that “participation is a concept in need of an explicit theory of action”. The structure and preoccupations of this chapter are intended to model possible forms of engagement with the scholarly literature through which practitioners could draw on the scholarship to develop such explicit theories of action.

The chapter organises its discussion of historical trends, in both the literature and professional practice, with reference to a shift between two ideal types of service provision, neither of which will be realised on the ground in a pure form, but which can help highlight important features of the overall direction of key historical trends. The first ideal type of professional service provision can be characterised as an “expert driven”, institution-based model of service delivery in human services. This approach to social service provision is sometimes characterised as a “positivist” perspective, which seeks to “objectively” determine the best strategies for service delivery through the systematic application of technocratic principles. It can be contrasted to the other ideal type: an alternative, more collaborative, conception of service provision based on the human right of a person to participate in the decisions that affect their life.
Broadly, the last third of the 20th century saw a shift in the relative weight given to these ideal types, resulting in the spread of more collaborative models that reflected changes in community expectations of services, influenced legislative initiatives, and was driven by decades of activism. This shift coincided with the rise of what are sometimes called the “new” social movements – that is, movements oriented not just to problems related to material distribution, but also to problems related to mutual recognition (see Fraser, 1995), inclusion and respect.

A few definitions are useful before moving to the discussion of participation. Three models are often used to characterise services for persons with a disability: medical, social and relational. Broadly, the medical model of disability falls under the positivist, technocratic, expert-driven concept of service provision discussed above. Brisenden (1986, p. 173) thus defines the “medical model” as an approach to disability that emphasises the medical facts of clinical diagnosis. Such facts may be appropriate for determining the form of “treatment” but, under this model, medical facts tend to be used for much more, determining the form of life for the person with disability. The service user – or “patient” – remains firmly in the hands of experts, in the form of the medical practitioner and other professionals (Tarulli & Sales, 2009, p. 104). People “treated” under this model of service provision had little opportunity to make decisions and exercise control over their lives. As Brisenden (1986) notes, the medical model took control of a person’s life, in most circumstances embedding individuals within what Goffman (1961) refers to as the “total institution”. Oliver and Barnes (2012) extend this concept through their discussion of the “medicalisation of everyday life” (p. 85), which – as discussed in more detail below – offers a contemporary example of how the medical model “individualizes social problems” and continues to “encourage an ideology of victim blaming” (p. 86) as barriers to participation. I will return to these concepts later in this chapter. By contrast, the social and relational models of disability open up more potential for collaborative approaches to participation. Here I note Oliver’s (1990) depiction of the social model and emphasise the work of Shakespeare (2006, p. 58), who presents an alternative conception of disability that rejects the medical model’s focus on “impairment effects” and the social model’s “oppression” and “barriers”. Shakespeare defines disability as the outcome of the interaction of a number of factors, both personal and contextual, which are discussed in more detail later in this chapter. My analysis of each of these models, and their practice illustrations, which are drawn autoethnographically from my own professional experience, relies heavily on Bacchi’s (2009) application of Foucault to analysing problem representations, as well as on Schöns’s (2013) analysis of “technical
rationality” and its effect on professional practice. I discuss both of these frameworks in greater detail in the section on “Professionalism” below.

First, however, I turn to a brief historical background to social service provision in Victoria, as a foundation for reflecting on the practical stakes of the scholarly literature on participation.

2.2 Historical Background to the Literature on Participation

Participation emerges as a theme in the scholarly literature at a point when the substantial system of service delivery for mental health, intellectual disability, and services for children and young people in Australia was primarily institutionalisation (Social Welfare Department Victoria (SWDV), Annual Report, 1972, pp. 17-33). In Australia, many indigenous children were being taken from their families to spend their childhood in institutions (Australian Institute of Health and Welfare (AIHW), 1993, p. 6). In exploring historical trends in the everyday practices within institutions, I begin with a description of the state of services for children in Victoria before moving to concentrate on those services specifically for people with intellectual disability or cognitive impairment. As I note above, I do this for a number of reasons, the first of which is my professional experience in four of the largest of these facilities in the State of Victoria and, prior to this, my work at H.M. Prison Pentridge, Melbourne (1977-78), as well as within the State’s juvenile justice service system (1980-87). Another motivation for focusing on cognitive impairment is that achieving the genuine participation of people with cognitive impairments in the services they receive was a personal and systemic challenge in my professional work. At the time, participation for this group of mainly institutionalised people, often took the form of a walk around the grounds of the institution. Achieving and insuring their safety; having their medical and personal hygiene requirements met; and seeing them being treated, as individuals with dignity and respect: such measures were, at that time, seen as a good enough measure of an effective service. A substantial body of activism and scholarship lies behind the drive to reach beyond such measures, and this chapter seeks to schematise, and introduce a theoretical framework for understanding, the major developments in that process.

My main objective in the remainder of this section is to use my knowledge of institutional service delivery, alongside the applicable historical and theoretical material, to demonstrate why these services needed to change and, at the same time, cast light on why, in important respects, they remain unchanged. This historical
discussion thus seeks to provide an illustrative example of the institutional and social conditions that drove the emergence of a new scholarly specialisation in participation. To underscore this relationship, this section juxtaposes its discussion of the Victorian context with an analysis of Arnstein’s foundational work “A Ladder of Citizen Participation”. While Arnstein was not writing for the Australian context, nor even with the goal of promoting client participation in social service organisations, historical conditions ensured that her work resonated broadly, driving appropriations and adaptations that I will discuss in chapter 3.

2.3 The Institution Based Social Service System in Victoria

Services for children and young people, at least in the State of Victoria, have been under pressure since the early 1970s to meet the demand for community-based out-of-home care for children (SWDV, Annual Report, 1972, p. 18). In a submission to the Commonwealth Government’s Forgotten Australians: A report on Australians who experienced institutional or out-of-home care as children (2004, p. 386), the Victorian Government estimated that, from 1928 to 2003, 100,000 children, including state wards and those placed by the child protection system, were admitted to institutions in Victoria. An example was the Allambie Reception Centre for children: originally designed to accommodate 90 children when it opened in 1961, by 1976 it had a weekly holding population of 248 children, including babies, toddlers, girls under 14 and boys under 10; because of a lack of foster care placements for pre-schoolers, 45% of the population were under 5 years (SWDV Annual Report, 1976, p. 21). Allambie closed in 1990. The closure was a direct result of the release in 1986 of Community Services Victoria’s Discussion Paper on the Redevelopment of Services for Children and Young People in Allambie, Baltara and Winlaton, which were institutions for neglected children and young male and female offenders. These initiatives were the consequence of an international environment that was shifting away from an institutionally based service system to a more favored community-based system (AIHW, 2001, p. 96). The worldwide legislative changes that supported this shift in service delivery are discussed later in this chapter. Before exploring that history, however, it is helpful to discuss some key aspects of Arnstein’s work (1969) – in particular, her focus on the professional values and attitudes that influence practice, and the potential of such values and attitudes to cause further harm to service users.

Arnstein (1969) was involved in urban renewal programs in several of America’s largest cities. She was principally concerned with the apparent powerlessness of the
people, mainly among the poor and minority groups, residing in these communities. She had observed how their capacity to participate in the democracy in which they lived was severely diminished by their poverty and experience of racial discrimination. Arnstein (p. 216) referred to this group of people as the ‘have-nots’ who, despite the rhetoric and euphemisms regarding ‘citizen participation’, had few opportunities to freely participate in decision-making. What is significant for my purpose here is Arnstein’s call for action to make clear the distinction between, on the one hand, leading participants through the motions of participating and, on the other, providing them with real power to affect decisions. As an example, Arnstein presents accounts of bias in approving funding applications through numerous illustrations of community groups being manipulated, placated and victimised by those in control.

Arnstein’s anger surfaces in her description of a poverty-stricken neighbourhood of New York City with a population over 400,000: an 80% teenage drop-out rate; an infant mortality rate twice the national average; and which received no urban renewal funds in the 15 years the program had operated - she adds the comment that the unemployment rate in that community was “known only to God” (p. 224). What Arnstein (1969) describes in her examples is evidence of professionals utilising the power they hold over these communities, rather than employing their power to improve the lives of residents. In Arnstein’s view, professionals’ disrespectful treatment of the residents they were meant to serve, as though the residents were something lesser than themselves, occurs for a number of reasons. First, Arnstein argues, the racist and paternalistic views of the power holders make the sharing of their power unthinkable. The residents, or “have-nots” as Arnstein refers to them, have roadblocks of their own. These include: their lack of knowledge and understanding of the processes; their community’s poor political and socioeconomic infrastructure; inadequate numbers of residents with the capacity, time and resources to become involved; and their long-term experience of neglect, which leads to feelings of futility, alienation and distrust (Arnstein, 1969, p. 217).

How can we make sense of the implicit model of participation underlying Arnstein’s (pp. 219-222) illustrations of the disrespectful behaviour of the power holders? Bacchi’s (2009) application of Foucault to the analysis of problem representations provides a useful set of tools for addressing this question. Bacchi’s approach to policy analysis sets out a framework that scrutinises the ‘problem’ that a policy represents by first reflecting on the assumptions inherent in the representation of the ‘problem’. Bacchi refers to this as a form of Foucauldian archaeology, which identifies the logic and political rationalities in specific policies (p. 48). Bacchi’s next
step is to consider how the representation of this problem has come about, by focusing on the actions and behaviour that have led to the problem’s importance, and then asking whether the problem can be thought about differently. Finally, Bacchi (2009, p. 48) asks what effects the representation of the problem may produce.

Bacchi (p. 16) notes Foucault’s (1982, p. 208) use of the term “dividing practices”, by which she means a dynamic that divides people in terms like Arnstein’s ‘haves’ versus ‘have-not’ citizens. Arnstein’s accounts, in other words, can be seen as explicit examples of what Bacchi (p. 17) describes as the “lived effects” of dividing practices. The impoverished neighbourhoods – the subjects of the federal programs Arnstein analyses – are where minority groups live. The dividing practices of the white male power holders consist partly in their assumption that minority groups are the problem and the reason why their neighbourhoods need renewal. This definition of the problem results in the resolution that a professional in authority decides what needs to be done, rather than neighbourhood residents being able to decide for themselves. The power holders ignore the reality of a lifetime of racial prejudice, poverty, lack of employment and educational opportunities these citizens have experienced. For Bacchi (2009), the residents have become “subjects of a particular kind” through the social relationships set up and reinforced in particular ways by policies (p.16). For Arnstein, confronted by examples of professionals, some of whom may have been well intentioned but were suffering from institutionalised thinking, the problem is the powerlessness of the residents. Her solution is the transfer of power to the have-nots. This imagines Arnstein’s model – in the human services context – as pitting clients against service providers in an overt struggle for power and control (Titter & McCallum, 2006, p. 157). The initial step in addressing this unnecessary conflict is to accept and understand that some professionals do in fact behave in ways that are detrimental to their clients, staff - and inevitably to themselves.

To return to the specific example of Victoria: by the 1980s, the Victorian disability service system, like services for children and young people, began to consider policies for the closure of institutions and the movement of residents into community-based accommodation services. The preceding three decades had witnessed a number of shocking examples of the maltreatment of the residents of institutions, and many Australian states began to hold public enquiries and sponsored reports on services for people with mental health and intellectual disabilities (Molony & Taplin, 1988, p. 109; Fox, 2003, p. 39; Wiesel & Bigby, 2015, p. 180). A major criticism of 1970s government policy in Victoria had been the lack of awareness of the principle of normalisation. In the 1970s, Wolfensberger (as cited in Owen et al, 2009, p. 29)
defined the principle of normalisation as treating people with cognitive impairment in programs and environments that would allow them to behave in ways that were as normal as possible. Broadly speaking, this meant that people with mental illness and cognitive impairment should not be institutionalised, but rather supported to live normal lives in the community, with its life cycle of education, work, recreation, etc., all of which are removed when a person enters an institution. Normalisation, which provided the “ideological backbone” (Shakespeare, 2004, p. 10) for deinstitutionalisation, quickly became the guiding principle in Victoria for mental health and disability services (Fox, 2003, p. 42).

In 1985, St. Nicholas Hospital in Melbourne closed – an event which Fox (2003, p. 43) describes as “normalisation’s biggest prize”. The closure of St. Nicholas meant 98 children, with a mean age of 15, and with profound intellectual and multiple physical disabilities, were moved to alternative accommodation (Dunt & Cummins, 1990, p. 5). This marked the beginning of deinstitutionalisation for people with intellectual disabilities in Victoria and, in 1987, Community Services Victoria released their Ten Year Plan for the Redevelopment of Intellectual Disability Services, which recommended the closure of all institutions in the state where approximately 2600 people were living (Wiesel & Bigby, 2015, p. 186). The beginnings of my professional work in these institutions coincided with the initiation of the policy in Victoria of deinstitutionalisation, a policy which Wiesel and Bigby (2015, p. 182) imply is yet to be fully implemented.

The release of the Ten Year Plan caused some concern for families and staff, but the rhetoric of deinstitutionalisation in disability services had been heard for many years without being followed through with concrete action (Fox, 2003, p. 43). I note that not all families wanted institutions to remain, and some supported the idea of their family member moving to the community as long as the necessary support was provided. In discussions with families regarding the closure of the institution, many described their agony decades earlier of having to choose to care for their family members at home or institutionalise them as the only alternative. Oliver and Barnes (2012, p. 69) highlight Parker’s (1988, p. 24) suggestion that the level of demand for institutional care was dependent upon the willingness of families to care for their dependants. The experience of these families demonstrates that the lack of alternative services for some members of our community was, and continues to be, a factor in institutionalising people in Victoria and other states in Australia (Wiesel & Bigby 2015, p. 179).
Until the late 1980s a significant feature of the institutions for both mental health and intellectual disabilities was the management structure. Most had a chief executive officer or superintendent who was a medical practitioner. What was odd about this position was that it had no authority to allocate resources or employ and/or terminate employment. The senior administrator or secretary of the institution held the authority. In other words, aside from prescribing medication and designing programs for residents, the medical staff in these positions were totally dependent on the administrator for anything relating to resources, human or otherwise. This was the institutional administrative structure of the medical model for disability and mental health services as it had operated in these institutions in various forms since their creation. The power imbalance created by this structure contributed to a culture where, for decades, doctors maintained that residents were receiving “specialised medical care” (Manning, 2009, p. 164), while residents lived in “spartan, ramshackle, unhygienic buildings with nothing to do” (Fox, 2003, p. 39).

A feature of the medical model in the State of Victoria was housing people with intellectual disability and those with psychiatric conditions within the same facility, or in facilities that were located in close proximity to one another. This was seen as efficient, since it required only one medical officer to meet the needs of both facilities. Although these facilities began to be administratively separated in the late 1950s (Manning, 2008, p. 14), I have a lasting memory of having visited three of these co-located institutions still operating into the 1990s. In one, psychiatric and cognitively impaired residents shared the same dining hall. Another - which accommodated people with psychogeriatric conditions, and housed residents, mainly dressed in hospital gowns, in units evocatively named after 19th century shipwrecks that had occurred along the Victorian coast - stands out for its presentation of hopelessness and despair. Despite the Victorian Government’s transfer of the responsibility for disability services from the Health Department to the Community Services Department in 1986 - which Fox (2003, p. 43) describes as “putting the final nail in the coffin of the medical model” – the culture of these institutions continued to represent a model of isolation and exclusion that continued to harm the people who had to live and work in them into the early 21st century (Fox, 2003; Manning, 2008: 2009).

Personal experience aside, however, a strong case can be made that people with cognitive impairments represent a particularly vulnerable group of service users who continue to be excluded from discussions and models relating to client participation. An example of the perpetuation of their exclusion was the statement of a senior
representative (Name Redacted for Privacy) of the National Disability Insurance Scheme (NDIS), who revealed they had initially forgotten people with cognitive impairment for inclusion as participants in their trial site in Victoria, which commenced on 1 July 2013. This took place at the annual general meeting of the Australasian Society for Intellectual Disability (ASID) Victorian Branch, which I attended at Australian Catholic University, Melbourne, on 15 October 2014. I would not, to be clear, claim that this anecdote is representative of the views of those who work with the NDIS, which is an innovative national scheme being established in Australia for the funding of services for people with a disability. I discuss the challenges the NDIS presents for service providers and service users later in this chapter, but raise this anecdote here as an illustration of how easily service users with cognitive impairments can be excluded even in purportedly ‘model’ environments.

Success in meeting the difficult challenge of enhancing the participation of this group has proven, as I discuss later in this chapter, to have benefits for the clients of most human services programs. For this reason, people with cognitive impairments have been included as participants in this research and continue to be an important part of this discussion on participation for the remainder of this thesis.

2.5 The Rise of Professionalism

The prevailing view in the 19th century, when Australia’s first purpose-built institution for people with intellectual disability was constructed, was that the medical profession could cure the “problem” of intellectual disability and, therefore, that medical professionals were the most suitable to run these types of institutions (Manning, 2008, p. 18). For example, while intended to provide residential care and education for fifty-seven children, Children’s Cottages Kew housed adults from its opening in 1887. Fox (2003, p.38) refers to the establishment of Kew Cottages as a “moment of optimism” in the belief that children could learn and then return to the community. Fox points out this optimism soon faded as the “chill wind” of eugenics swept the world prior to World War II, and optimism was replaced with the belief that people with intellectual disability were a danger to the race and should be permanently segregated. As a result, by the late 1960s, Kew Cottages housed close to 1000 people with intellectual disabilities, becoming Australia’s largest institution for this client group (Manning, 2009, p. 151). From the beginning, the problem was understood to rest solely with the individual.
Bersani (1996, p. 260) points out that, by the 1950s, the successes of American science and technology during and after World War II created a social context that led people to believe that the application of science was the key to understand the causes and possible cures of “deficiency”. People with disability were seen as being “mentally defective” and, as the science of disability at this time was focused on prevention, they were seen as having nothing to contribute, as they represented “our failure to prevent their existence”. Bersani notes the work of American ethicist Joseph Fletcher (1972), who put forth:

An ethical argument that individuals with tested IQ scores below 40 might not be human, and that those with IQ’s below 20 were in fact not human, and did not need to be treated as such (p. 260).

The medical profession continued to promote the isolation and exclusion of people with intellectual disabilities well into the 1970s. In my experience of working with families of children who had been institutionalised for decades in facilities scheduled for closure, parents often told similar stories of being told by their doctor not to get attached to their child with disability, nor to take them home, but to get them admitted to an institution (see Manning, 2008, p. 34). To be fair to the medical profession, it is clear this advice reflected their understanding of the difficulty parents experience in caring for a child with a disability and the limited availability of community services to support families to care for their children at home. Nevertheless, Manning (2008, p. 31) speaks of the “unquestioning acceptance” of medical opinion, not as a failing of parents who placed their child in an institution, but as a reflection of the popular belief that the doctor “knew best”. This belief, in turn, should be seen as expressive of a particular concept of professionalism, to which I now turn. Used in this sense, the term professionalism reflects the belief that the application of scientific and engineering principles would solve all the problems of the world, both social and technical.

Professionalism in this sense was arguably hegemonic through to the 1970s, a period during which most disciplines - including social work, education, science and medicine - were primarily expert driven (Dybwad & Bersani, 1996, p. 259). Schön (2013, p. 38) provides insight into the success of professionalism from its beginnings in the late 19th century. In Schön’s view, the resources poured into scientific research, and the initial successful application of new technologies to many longstanding problems, led to the belief that any problem could be solved if a similar scientific approach were successfully applied, (p. 37). Schön (p.39) refers to this as Technical
Rationality, which he characterises as a positivist epistemology, which perceives professional practice as primarily a problem-solving activity in which selecting the best available solution solves problems. Schön argues that positivism concentrates on problem solving, while ignoring what he refers to as “problem setting” (p. 18). Schön describes “problem setting” as making sense of a real-world problem that initially makes no sense, and he characterises it as an important activity of professional practice. Schön (p. 42) suggests that professional practice has a ‘high ground’ where practitioners make decisions based on research and technique, and a ‘swampy lowland’ where situations are confusing messes immune to technical solutions. For Schön, the problems of the high ground are often unimportant to others and to society in general: the swamp is where the “problems of greatest human concern” are found.

In the case of problem setting, the practitioner must first name what things they will attend to and then frame the context (Schön, 2013, p. 40). Similar to Bacchi’s (2009) framework for analysing problem representations, problem setting is understood as an interactive process that the practitioner uses to define the decision to be made as well as the ends and means of the decision.

Schön (2013, p. 45) notes the work of Simon (1979; 1996) and others who have identified gaps between professional knowledge and the difficulties of real-world practice. Simon (1996, p. 150) describes the traditional definition of the professional’s role as having clear-cut and limited goals, which is compatible with what Simon refers to as “bounded rationality”. Put simply, bounded rationality states it is impossible for people to consider all existing choices and possible outcomes of decisions; therefore, rational behaviour is bounded by “people’s minds – memory content – and their processes” as well as by the real world in which they act and “which acts on them” (Simon, 2000, p. 25). Simon points out that, as knowledge grows, the role of the professional becomes more complicated, and he suggests that this complication is a by-product of the growth of knowledge. He offers the example of advances in medical technology that have given the physician “some degree of control over life and death” (1996, p.152). In Schön’s (2013, p. 46) view, it was Simon who linked this evolving predicament of professional knowledge to the “historical origins of the Positivist epistemology of practice”.

Applying Schön’s idea of problem setting to a description of the medical model of disability provides an opportunity to determine that model’s potential risks for clients. Schön (p. 41) focuses on the professional’s difficulty when the “ends” are unclear – which, to the professional, suggests there is no problem to solve. In the case of the medical model, according to Oliver (1990, p. 3) and others, professionals
located the problem in limitations that were understood to exist within the individual patient and the patient’s functional limitations, and often viewed the patient’s impairment as an unfortunate occurrence of bad luck (Finkelstein, 1980, p. 11). Oliver (1990, p. 3) rejects this notion because it places the problem of disability within the individual and understands disability to be caused by an individual’s personal functional limitations. For Oliver, by contrast, the problem of disability is instead located in society’s inability to meet the needs of people with disabilities. Here, Schön (2013, p. 42) would accept Oliver’s perspective, and understand the medical practitioner’s response to disability as a form of taking the safe “high ground” of the medical model (where the correct response is understood in terms of research-based technical expertise), instead of exploring the messy “lowland” of the social or relational constructs of disability. Professional practice for people with physical and sensory disabilities was messy enough, but the history of practice with people with what we now call cognitive impairment and developmental disabilities has complexities all its own – a point to which I return below.

Many people hold preconceived attitudes towards service users, which frequently label service users as defective or contaminated. Often these attitudes and labels have no connection to the causes of a person becoming a service user. Gupta (2015, p. 134) speaks to the experience of shame by service users and how the simple fact of using a service is humiliating. Often, such feelings of shame and worthlessness are compounded by the impact of dehumanising treatment from professionals, which suggests the importance of considering the perspective of the professional culture.

A professional culture is composed of a set of values and attitudes that determine how a specific group of practitioners approach their clients. Argyris and Schön (1974, p. 162) have highlighted the significance of a practitioner’s personal values, and of having a strong commitment to such values. However, the international literature offers a number of examples of professionals resisting change for fear of losing power and control and their perception of service user involvement as an attack on their professional expertise (Bennetts, et al 2011, p. 160). One study found that the main barriers to change in mental health services lay in the attitudes of professionals (Happell & Roper 2009, p. 578), and another reported that service users and carers often complain of not being listened to by professionals (Barnes et al, 2000, p. 190). The attitudes of professionals determine how an organisation conducts its business and how it treats its clients and staff.
Particularly problematic consequences can follow when professionals fail to see value in taking the time to gain an understanding of the experience of being a service user and appreciating what this experience has to offer them as professionals. Gupta and Blewett (2008, p. 466) describe the feelings of oppression and discrimination that families experience because of their poverty and status as service users. Gupta and Blewett offer examples of the preconceived ideas of professionals, such as the stereotype that a person is a bad parent because they are part of the family services system. Such prejudices increase exclusion from participation as members of the community and contribute to a person’s vulnerability. In the sections below, I extend these concepts about professional culture, stereotyping and shame to consider the impact of different models of disability on the way professionals and service users make sense of their social roles, and the way this sense-making process is influenced by, and finds its way into, public policy.

2.6 The Medical Model

The further exploration of the medical model that follows provides a starting point for the genealogy of participation. Here it is worth unpacking Bacchi’s (p. 16) analysis of the ways that problem representations can create social relationships through discourses that create inequality and turn people against one another.

Above, I noted Bacchi’s discussion of Foucault’s (1982, p. 208) use of the term “dividing practices”. An example might be the way an elderly woman with a cognitive impairment or mental illness is looked upon, in contrast to the elderly women at the local senior citizens club. Bacchi (p.17) refers to such contrasts as examples of the “lived effects” of dividing practices. One central aim of Bacchi’s (2009) work is to reveal the state’s part in contributing to stigmatisation, prejudice, inequality and misinformation in all aspects of policy development by providing a process for policy analysis that makes clear the way in which policies operate to frame problems – and therefore delineate the universe of available solutions. Bacchi’s (2009) approach requires first conceptualising government “policy” as a product of society’s culture, and then working through the following process: questioning the policy’s source; learning how the policy operates in the real world; gaining a sense of the implications for the wider society; and paying particular attention to the roles of experts and professionals in the process (p. ix). As Bacchi (2009) points out, when governments pass laws, write a policy or implement a program, the assumption is that a problem exists that needs to be fixed through the creation of a government policy or program.
Bacchi begins her analysis of this process by examining the implied problem to determine the intention of the policy: analysing what, according to the policy, is the problem that needs fixing (p. xi).

By following Bacchi’s lead in tracing the twists and turns of the history of participation, I suggest we can achieve a clearer understanding of how we have arrived at the current representation of the problem of participation for service users. Understanding the workings of the medical model in particular provides a number of useful insights, including: an appreciation of how service users were perceived; an understanding of why the practice of professionals had to change; and an exploration of the ways in which increasing the participation of service users reduces the risk of doing greater harm.

Bersani (1996, p. 259) details the emergence of the academic field of ‘Mental Deficiency’ in the 19th century with the founding of the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons. This was later renamed the American Association on Mental Deficiency, a name which lasted 100 years. Bersani (1996) describes this as an association of professionals, for and by professionals, who created the field of mental deficiency and determined the academic agenda in deciding which issues in the field were worth pursuing. The new discipline of “mental retardation” was born, in which the professionals consulted with one another, making all the decisions, while clients, parents and others assumed that the professionals knew what was best. According to Fox (2003, p. 48), “from the 1950s to the 1970s the only advice ever given to parents was that they should institutionalize their children”. Bersani (p. 259) writes that deciding “what was best” meant that professionals: gave out labels; designed therapy and decided who got it; determined who went to school and who could live in the community; and saw patients more as “subjects in experiments” and as the “object of studies” (p. 260) rather than as people with human rights. Oliver (1990) and Finkelstein (1980) frame these professionals’ practice as one of defining people by their disability, and Schön (2013, p. 144) would view their behaviour as seeking the safety of “Technical Rationality”, with its emphasis on the separation of research and practice, and assumption that research and science will solve the problem of disability.

Schön (2013) would suggest that the medical model left the professional without a clear sense of a “means and end” to their work and, as a consequence, they returned to what they knew best. As noted above in regard to the new discipline of Mental Deficiency, professionals created new labels, classifications and processes for
determining each classification. Such classifications provided their new paradigm with the appearance of technical expertise and rigour, which is the lifeblood of the positivist epistemology, and which also creates a dilemma in relation to what Schön (p. 42) refers to as “rigor or relevance”. In other words, the technical rigour of the professional was of little practical relevance to the client - including parents of individuals classified and labelled as ‘non-feasible’ for rehabilitation or told they would never be ready to live in the community. This point brings us to the wider community and its capacity to accept difference and reject stigmatisation.

Oliver and Barnes (2012) present a more practical application of Bacchi’s (2009) work in their discussion of the medical model. They suggest that the medical model draws much of its power from the early beginnings of industrialisation, and the medical professional’s role in legitimising the separation of those who were unsuitable for work in the new factories from those who were suitable (p. 120). They note the role of public policy in perpetuating the stigmatisation of people with disability and others who were unable to work. Goffman’s (1986, p. 3) concept of stigma is salient here: Goffman defines stigma as the product of relationships that occur as a result of the interaction of an individual and their society. This is not solely the experience of people with disability, but is a shared experience among clients of social services in general. The exclusion of a single mother, receiving welfare payments, from participation in her local community is no different from the experience of the lifetime member of the local bowling club who is banned from the club because of their occasionally erratic behaviour resulting from mental health issues. The only difference in the experience of stigmatisation between the people in these examples and a person with impairment is the impairment.

As Finkelstein (1980) and later Oliver (1990, p. 6) note, the medical model locates the “problem” of disability within the individual – who is framed as impaired – rather than within the failure of society to accommodate the needs of people with disability. Although critiques of the medical model have become increasingly common, the tendency for the social services sector to define the individual as the problem continues to underlie many professional approaches to service delivery – as we shall explore in later chapters. These approaches often limit opportunities for individual clients to participate fully and contribute to the problem of participation of clients for service providers.

Oliver (1990, p. 6) argues that one significant problem generated by the medical model relates to the lack of skills and training doctors possess to treat people with
disabilities. As a result, both people with disability and doctors are “trapped in a set of disappointing relationships”. At issue here appears to be the interplay between the doctor’s inability and unwillingness to diminish their professional authority and the expectation and past experience of the person with disability of not being listened to by professionals. Schön (2013, p. 40) would perceive this as a failure of the professional to undertake a process of problem setting. A practice example of this would be the medical professional who makes no attempt to engage with a patient with cognitive impairment, instead making eye contact with and speaking directly to the person’s carer. This interaction diminishes the patient as a person. Patients become objects within an environment supported by the medical model, which eliminates any possibility of the medical professional even establishing a “disappointing” relationship with a patient. To be clear, this critique is not a rejection of medical treatment for people with disability. It refers more to how professional practice can sometimes be damaging to the person by leaving them powerless, defining them as disabled and constructing them as impaired, rather than defining the impairment (Shakespeare, 2014, p. 65). Oliver and Barnes (2012, p.50) argue that the doctor’s role in labelling someone as impaired reflects Goffman’s view that, in accepting the label, the individual takes on the fear of discrimination, which will likely cause them harm.

Oliver (1990, p.2) declares that it is dangerous to waste time defining the medical model or the social model because it obscures the real issues in disability, which he believes are oppression, discrimination, inequality and poverty. He discounts the medical model of disability, preferring to refer to it as the “medicalisation of disability”, of which the medical model is only a component. The concept of medicalisation is underpinned by the personal tragedy theory of disability, which assumes that the person with disability is the unfortunate victim of a tragic accident. According to Oliver (p. 4), medicalisation occurs when the medical profession, as noted above, defines the problem of disability as an illness to be cured and utilises its skills and training to treat disability in this way. Oliver’s view is that doctors are socialised by their training to perceive themselves as experts. This professional socialisation is then reinforced by the broader society, which in turn bestows power on doctors to make decisions about people’s lives. When confronted with an incurable condition like disability, doctors, Oliver believes, continue to use their power as ‘experts’ to control and make decisions about treatment, which leaves the person with disability powerless to influence or make decisions about their own lives. Since its inception, the medical
model has placed someone in a position to solely determine who is “alike” and who is “different” and what forms of treatment each ought to receive (Bacchi, 2009, p. 189).

By contrast, Oliver (1990, p. 1) counterpoises the social model of disability, whose origins he pinpoints in a statement entitled “The Fundamental Principles of Disability” by the Union of Physically Impaired Against Segregation (UPIAS), which drew a distinction between impairment and disability:

In our view, it is society, which disables physically impaired people. Disability is something imposed on top of our impairments; by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1976, p. 3).

The release of the UPIAS statement occurred at a time when the policies and practices of human services, for people with impairment, were being heavily influenced by the principles of Normalisation and Social Role Valorization (Flynn and Lemay, 1999, p. 3), which are discussed in more detail in Chapter 3. Nevertheless, Oliver’s (1990, p.2) original purpose was to use the distinction between impairment and disability made by UPIAS (1976) to develop a framework that could be understood by professionals with a limited knowledge of disability issues.

In Bacchi’s terms, therefore, these critiques of the medical model of disability highlighted the potential to define the ‘problem’ of disability quite differently – locating it in society, rather than the individual, and thus opening a path for more collaborative approaches. The resulting social model of disability channelled impulses common to a range of social and political movements of the same period, to which I turn next, before exploring the social model in greater detail below.

2.7 Social Movements

In this section, I describe the historical development of a number of social movements, in Australia and overseas, that began to advance the dialogue around the right to equal participation for all members of society, without regard to their race, gender, sexual orientation or impairment. The effect of the activism of these movements was not only to enhance the lives of individuals; it also signaled the shift away from an era when the word of the professional was accepted with little question (Manning, 2008, p. 31). In proceeding with a description of the historical context for the creation of this constellation of social movements, I highlight one of the important drivers for a change in the community’s perspectives on social services. I pay particular attention to the forms of international activism that have had a significant
impact on services for people with cognitive impairments, as well as on the broader field of social services programmes.

The academic literature regarding impairment and disability in the 1950s tended to portray the parents of children with disability as needing counselling to help them deal with their guilt and denial. This view of parents was about to be challenged, as parents began to gain more of a voice for asking questions about the treatment of their children and speaking their minds. By the late 1950s in North America, the growing middle class had reached a level of economic stability and comfort that provided them with the time and resources to pursue other interests besides economic survival (Tarulli & Sales, 2009, p. 105). This led to an increase in participation in hobbies, social and recreational activities, as well as the social and personal issues that mattered to them. For some, this meant becoming more involved in the lives of their children with disabilities. Coinciding with this change in economic status for many was the era of the ‘baby boom’, with more people starting families than any other point in American history. As the population increased, so did the numbers of children with disability. This increase in the numbers of parents of children with disability coincided with the rise in time and resources to advocate and lobby government on behalf of their children for improved services. A process of mobilisation began as these mainly white, middle class parents formed support groups where they learned more about how the service system for their children with disability worked, and offered governments their own views about what should be offered by these services.

In Australia, public monies had been diverted in the 1930s to projects designed to alleviate the effects of the Depression and then, in the 1940s, to World War II, leaving both people in some Melbourne neighbourhoods and people with mental illness and impairment in institutions, living in squalid conditions (Manning 2009, p. 161). The reformist movement for public institutions led to the formation in 1957 of the Kew Cottages Parents Association in Melbourne, which “encouraged parents to maintain an interest in their children’s welfare” in spite of the child’s placement in an institution (Manning, 2008, p. 31). Bersani (1996, p. 261) refers to this as the parent movement, which came to include many academics who rejected the medical model and its method of treatment for people with impairment. The success of the disability movement was such that, by the 1970s, many states in the USA were operating services that were influenced more by the wishes of parents than by the people in receipt of these services (Tarulli & Sales, 2009, p. 104). In Australia, with many people with mental illness and impairment still institutionalised, the State Association for the Retarded (STAR), as it was originally known, was established in Victoria and became
one of a number of groups that supported deinstitutionalisation and normalisation (Fox, 2003, p. 45).

Ife (1997, p.184) suggests that social movements, both in Australia and overseas, have more potential for genuine participation and the achievement of “humanist ideals” than mainstream party politics. Ife’s (1997) view is that, in Australia, mainstream parties have moved so close together that they are becoming indistinguishable, leaving voters with very little choice. At the same time, many social movements - civil rights, and the women’s, Aboriginal rights, and gay and lesbian rights movements - have made significant achievements in the areas of both policy and public awareness. Whether correct as a generalisation, Ife’s point highlights the role social movements played in helping to incubate new concepts of participation, which extended to new concepts of disability and participation.

2.8 The Social Model

Finklestein (2001b), a spinal-cord injured psychologist, moved to the UK following his imprisonment and banishment from South Africa for opposing apartheid in 1968 (Thomas, 2007, p. 52). Finklestein describes his involvement, with Hunt (1966), in the establishment of UPIAS and the nature of the treatment of people with disabilities in the 1970s in Britain. This meant exclusion from education and employment, as well as barriers to access the built environment. Finklestein (2001b, p. 2) described a “crude but fundamental” choice: on the one hand, seeing “our” impairments as a tragedy that makes “us” incapable of social function; or, on the other, the alternative view that people with specific capabilities construct society for people with those capabilities, and it is this that makes people with impairments incapable of functioning. Finklestein (2001b, p. 2) and the other founders of UPIAS were clear that it may be a tragedy to have impairment, but it is oppression that characterises how society is structured and that prevents people with impairment from functioning.

Oliver, as a sociologist and disability activist, drew on the ideas of Finklestein and Hunt in UPIAS to coin the phrase “social model of disability” in 1981 (Thomas, 2004b, p. 24). Oliver’s writings on the notion of the social model, and in disability studies more generally, have been a significant influence on the discussion in Britain of how to define or interpret disability. Shakespeare and Watson (2001, p. 10) note that Oliver’s approach differs in important respects from the North American social approach to defining disability, which followed the civil rights tradition of seeing people
with disabilities as a minority group. The main difference between these two approaches, in Shakespeare and Watson’s view, is that the British social model makes a strong distinction between the biological impact of impairment and the impact of social oppression on disability. Shakespeare and Watson cite two major impacts of the social model on the disability movement in Britain. First, if people are disabled by the barriers society places before them, their political strategy is barrier removal. Included in this approach is the replacement of the concept of curing or rehabilitating people with disability, with a strategy of social transformation. Exemplifying this were the Victorian Government-run institutions for people with intellectual disability in the 70s and 80s that were named training centres, which implied the residents were being trained to return to the community. In reality, residing in a training centre assured lifelong institutionalisation for most. Second, people with disabilities were liberated from feeling that having impairment was their fault: now it was society’s fault. This reframing of the problem allowed them to become angry about society’s discrimination toward them and they became empowered. As the writer and activist Liz Crow (1992, p. 1) exclaimed: “My life has two phases: before the social model of disability, and after it”. Nevertheless, both Finklestein (2001a, p. 6) and Oliver (2007, p. 30) remind their critics that the social model of disability is only a model, not a definition or theory. Oliver goes on to suggest that too much time has been spent debating the usefulness and limitations of the model rather than implementing it in practice. He pessimistically states, “the social model has had no real impact on professional practice” (2009, p. 51).

According to Shakespeare (2014, p. 12), the redefinition of women’s experience of the feminist movement in distinguishing between sex and gender – or the biological and the sociocultural – influenced the distinction between impairment (sex) and disability (sociocultural). Shakespeare (1993, p. 250) also credits the consumer movement with having a positive impact by emphasising choice and promoting a presumption of distrust for the sellers of anything. Shakespeare further points to the contribution of self-help movements to the disability movement in the USA and Britain for influencing the development of the social model of disability (Shakespeare, 2014, p. 12).

Shakespeare’s account of the social model’s birth and the importance of its impact on the lives of people with disability, and on the study of disability, demonstrate that its impact has not been insignificant. Nevertheless, the tangible outcomes of the model for service users with more complex communication needs are limited for a number of significant reasons: the UPIAS statement, which led to the
development of the social model, did not include a definition of disability, which restricted it to a statement about oppression by society rather than a theory of disability; Oliver’s (2009, p. 510) revelation that the social model does not exist in professional practice, implies that the model carries no benefit for this cohort; and – significantly - only people with physical impairment could become full members of UPIAS (Shakespeare, 2014, p. 15), which suggests a primary focus on people with physical impairment. For the most part, service users, especially those with cognitive impairments, remained silent, as their families had replaced professionals as their voice. This client group continued to share a common history of changing theories and philosophies of service delivery that each failed to give them a voice.

Although the social model may not have exerted a profound impact on professional practice, it brought to the forefront the disabling aspects of society. The model, as an ideology, provided a political strategy for activism that continues today.

On the face of it, the social model of disability, like Arnstein’s (1969) model of citizen participation from more than twenty years earlier, promotes the transfer of power from the “haves” to the “have-nots”. Oliver (1990, p.4), however, expresses this distinction by attacking the “ideology of normality” which, he believes, arises from the medical profession’s quest to restore the person with disability to as close to ”normal” as possible, no matter the cost to the person in pain and suffering. To be accepted as they are, is Oliver’s vision of equality for people with disability, and his way to achieve this vision lies through the recognition of the other’s experience - as the following quote explains:

Doctors must attempt to understand why and how disabled people experience disability in the way that they do and disabled people must attempt to understand how doctors are socialised into thinking about disability in particular ways (p. 5).

Like Arnstein (1969), Oliver (1990) is trying to remedy a professional practice that turns patients/clients into objects to be told what they need and why it will be good for them. Oliver’s emphasis on seeking the knowledge of others, respecting their life experiences and understanding the impact of these experiences on their behaviour and attitudes towards others, is of critical importance in establishing effective relationships – a theme that will recur often in the chapters to come.
2.9 The Relational Model

The social model removed disability from its medical conception. This enabled a flow of ideas and discussion regarding socially constructed definitions of disability, which in turn began to define the disciplinary boundaries of disability studies, medical sociology, psychology and the rehabilitative sciences in Great Britain (Thomas, 2004b, p. 24). Thomas (2007, p. 53) focuses on Finkelstein (1980) and Oliver’s (1990) materialist analysis of society as an “oppressive disabling force” attached to the social relationships within a capitalist society. Thomas (2004b, p. 22) argues that the ideas that led to the development of the social model contained “a social relational kernel” that was overtaken by the great success of the social model and forgotten. Thomas (2004a, p. 581) proposes to recapture this kernel through a social relational definition of disability, based on a materialist approach that acknowledges restrictions that are socially caused and accepts that some social restrictions do cause restrictions of physical activity. She argues, however, that these physical restrictions are not “what is of interest in studying and combating disability”, but that disability is like other forms of social oppression associated with gender, race, class and sexuality. Her purpose was, first, to move the academic debate in disability studies from assessing the pros and cons of the social model, to a social relational conceptualisation of disability that would challenge what she called the “mealy-mouthed” stance of medical sociologists that people with impairment experience some “social disadvantage” (p. 582). Thomas’ second purpose was to shift attention from the physical external barriers of oppression, to the oppression within, which makes a person feel of lesser value than others. The social relational model thus draws attention to the interactions between the impaired and the non-impaired, within families and in dealings with educational, health and social services (2004b, p. 31). From this perspective, Thomas proposes that the impact that these interactions have on the disabled individual’s self-esteem and wellbeing can be considered, as well as the question of how power is wielded through “the words said, the decisions made and the meanings conveyed” (p. 31).

The medical, social and relational models of disability represent ways of seeing, reacting and responding to disability in a particular time and at a particular place. Similar conceptions have also been applied to other individual and social issues such as poverty, substance abuse, obesity, drunk driving and many others. Bacchi (2009, p. 26) points to the parade of professional groups and experts that play a role in shaping government programs, while the benefits of this parade for individuals in need of services and the people that deliver these services appear to receive little attention.
Bacchi’s analysis may cast light on the phenomenon that Oliver (2009, p. 51) notes, where the social model of disability has had little impact on professional practice, while the medical model remained a dominant form of professional practice in disability, mental health and aged care for many decades. At least with the medical model, we have a clear understanding of its failings, as well as examples of what forms of professional practice it engenders.

Nevertheless, I am drawn to elements of the relational model, particularly to what Thomas (2004b, p. 31) refers to as the “psycho-emotional dimensions of disability” which offer insights that may be useful in professional practice. By focusing on the outcomes of the interactions between people presumed not to be normal, and those presumed to be normal, Thomas steps back from theorising, to observe the lived interactions of disabled people with their families, professionals and others, and listens to the sometimes “hurtful” words that define and shape their sense of self (2007, p. 72). These interactions are not the exclusive experiences of individuals with impairment, but are shared with all those using social services. For example, Gupta and Blewett (2008, p. 466) describe the feelings of oppression and discrimination families experience because of their poverty and status as service users. The authors offer examples of the preconceived ideas of professionals, such as the assumption that a person is an inept parent because they are part of the family services system or they have an untidy house. Such prejudices de-value service users as people, increase their feelings of worthlessness, exclusion and isolation, make participating in their communities more difficult and contribute to their vulnerability. The message here for service providers echoes Oliver’s (1990, p. 5) advice that professionals should consider the how and why of service users’ experience of being a service user.

2.10 Legislative Change

The work of Oliver (1990), Manning (2008, 2009), Fox (2003) and Bersani (1996) underscores the powerful international influence of the medical and academic professions on approaches to the treatment of individuals who were perceived as being non-contributors to 19th century economic goals. As demonstrated in the discussion on professionalism earlier in this chapter, these professional groups defined the problem as the individual, who required removal from society to a place where they could be housed both for their own protection and, since they were also viewed as having nothing to offer as people and as exhibiting sometimes-uncontrollable, erratic behaviour, for the protection of society.
The decades of activism generated by social movements succeeded in establishing internationally recognised standards and legislation. These included the Civil Rights Act (1964) in America and the United Nations Conventions on the Rights of the Child (1990) and people with disabilities (2006). Nevertheless, as Stoecklin (2012, p. 6) observes, a person’s actual status does not change simply because they have become a ‘subject of rights’, and participation involves much more than having the right to participate. All of us are the ‘subject of rights’, but we are not all treated equally. This is determined by a diversity of factors, but one that seems to stand out is the attitude of others toward us.

The international activist contestation noted above was successful in bringing such issues to the notice of society both locally and internationally – but this success was rarely complete. The Civil Rights movement may have impacted on the attitudes of many but, tragically, race continues to be a considerable barrier to equality in America; the feminist movement had some success in their ‘equal pay for equal work’ campaign, but it failed to get the Equal Rights Amendment to the American Constitution ratified after decades of effort; and clients in human services often have few opportunities to exercise their right to participate fully in the services they receive (e.g. Balandin 2011; Concannon 2005; Cornwall 2008; Padilla et al, 2007).

In Australia, the Commonwealth Disability Services Act (CDSA) was proclaimed in 1986 and was closely followed by the Disability Discrimination Act (DDA) in 1992. The CDSA contains seven principles that, in summary, state that individuals with disability have the same rights as all other members of Australian society, no matter their degree of disability. The fourteen objectives of the CDSA concentrate on programs and services, and the emphasis is on enhancing the capacity, image and integration into the community of persons with disability. The most significant objective in regard to client participation is Objective 13, which states in part:

Services should be designed and administered so as to provide people with disabilities with, and encourage them to make use of, avenues for participating in the planning and operation of services which they receive . . .

This new legislation led to a number of significant developments for people with disability, including the transition away from the institution-based service system discussed earlier in this chapter and the movement into the community, which encompassed people with disabilities as well as service users in other human services. Legislation also provided funding for disability advocacy and resulted in changes to
mental health services in many states in Australia. Guardianship boards and Public Advocates and Community Visitor programs were also established in most states.

On 30 March 2007, Australia became a signatory, with 80 other countries (currently 161), to the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The Convention’s Article 12 clearly states that all persons with disabilities have equal recognition before the law, on an equal basis with others in all aspects of life. It also requires that signatories to the Convention ensure that: people with disabilities are provided with the support they require to exercise their legal rights; appropriate safeguards are provided to ensure people with disabilities are not subjected to abuse; all supports are tailored to the person’s circumstances and needs and are subject to review by independent and impartial authorities.

Mittler (2015, p. 79) highlights the CRPD’s potential to be the catalyst for a “radical reappraisal” of policy and practice among both government and disability organisations and services. He points out what makes the CRPD different from other UN Conventions is that it is the first to include advocacy representatives of the potential beneficiaries as “equal partners with government in negotiating all of its principles and articles” (p. 80).

Additional benefits for persons with disabilities in Australia include the way in which the Convention: strengthens the legitimacy of existing legislation such as The Disability Discrimination Act (1992) and provides a stronger context for this legislation in international law; provides a human rights framework that will raise awareness, inform laws, regulations, policy and program development; assists advocates for greater resource allocation to people with disabilities (Australian Human Rights Commission, 2007).

The impact on service providers of disability related programs in the State of Victoria was initially dependent upon whether the services they provided were located within the community services sector or within a government-run service. Government-run services were a primary target for advocates and, in most instances, this was well-deserved attention. In the State of Victoria, the Intellectually Disabled Persons Services Act was proclaimed on 11 October 1986, and later replaced by the Disability Act, 2006. Today, fewer than 300 people remain in government-run institutions in Victoria. When the original Act was proclaimed in 1986, the primary services for people with intellectual disabilities were government-run institutions, where more than 2,600 people with intellectual disabilities lived (Fox, 2003, p. 43;
The impact of these legislative and policy changes on service providers is the focus of the following section.

### 2.11 Impact on Service Providers

State funded service providers in the community services sector in Victoria find themselves in a situation where the legislation and service standards are very clear. Under the *Disability Regulations, 2007* and/or the *Children, Youth and Families Act, 2005*, all non-government organisations that provide services directly to clients are required to undertake an independent review against the *Standards* once in every three-year service agreement period, regardless of the number of departmental activities they are funded to provide. Services are also required to achieve and maintain accreditation against the Standards. The *Department of Health and Human Services* (DHHS) December 2016, p. 8) summarises the content of the *Standards* as follows:

**Empowerment:** People’s rights are promoted and upheld

**Access and Engagement:** People’s right to access transparent, equitable and integrated services is promoted and upheld.

**Wellbeing:** People’s right to wellbeing and safety is promoted and upheld.

**Participation:** People’s right to choice, decision making and to actively participate as a valued member of their chosen community is promoted and upheld.

Although the above is only a summary of the standards, there is little doubt what is required of a community sector organisation: the full participation of their clients in the services they receive. DHHS does provide descriptors to assist service providers to undertake a self-evaluation against the Standards in order to make the necessary modifications to their services to meet the requirements of the Standards and prepare for their eventual audit of their services. DHHS, in its introduction to the standards, states that their intention is not to be prescriptive, but to support service providers to be innovative in how they demonstrate compliance with the standards. How much innovation is present in the community sector service system becomes clearer in the chapters to follow, particularly those concerned with data collection and, especially, data analysis.
Human services take on many forms, but the purpose of all human services is, in some way, to advance the wellbeing of the person in receipt of the service. DHHS, for example, states their vision as “to achieve the best health, wellbeing and safety of all Victorians so that they can lead a life they value” (DHHS, 2017, p. 2.) How an organisation accomplishes this goal depends on its knowledge of the history, environment and needs of their client group – or, to put it another way, who their clients are as individuals. The task for staff in this process is to understand their client’s previous experiences in life, what their client is experiencing now and what kind of life their client imagines for themselves in the future (Kincaid & Fox, 2002, p. 30).

Frequently, people with limited communication skills are excluded from this discourse and ignored. With the right strategies, however, inclusion is possible. For example, Hewitt’s (2000) work with people with extreme difficulties in communication suggests the use of ‘life stories’ which contain the person’s wishes and preferences, documented by the significant people in the person’s life. All stories are read back to the person and their reactions monitored. Hewitt (p. 95) lists three main ways that carers used the life stories: as a means for (1) getting to know the person; (2) defining the person; and (3) displaying personality. In this way, the person’s identity is disclosed, which provides a shortcut for staff in getting to know the person, which can otherwise sometimes take years (Hewitt, 2000, p. 93). Success in these approaches is dependent upon the competence of management to select staff with the skills and capacity to create and implement actions that fully engage their cohort of clients, as well as upon external factors such as their location and environment. Building relationships with service users, including those with limited verbal communication skills, is discussed in more detail in later chapters.

2.12 Future Funding and Provision of Disability Services

The National Disability Insurance Scheme (NDIS) is the most important social policy innovation to be designed and implemented in Australian history (COAG, 2018, p. xiii). The implementation of the NDIS falls outside the period in which this research was principally undertaken and, since the scheme is not yet fully implemented at the time of writing, its full impact remains to be seen. The scheme became operational in Victoria on 1 July 2013 with a number of trial sites operating across Australia. The trial concluded in June 2016 and a transition to the full scheme commenced in July 2016 and is due to be fully operational by June 2019. As of 31 March 2018, the scheme
is operating at 21 locations, including 6 in Victoria (COAG, pp. 10-11). The NDIS has three main functions. It should:

\textit{Cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, create community awareness of the issues that affect people with disabilities and facilitate community capacity building} (Madden et al, 2014, p. 5)

In providing advice to potential users of the scheme, a major disability services provider in Victoria describes the purpose of the scheme on their website as changing the way disability services are delivered in Australia. It will do this by:

- Recognising that disability related support is an entitlement
- Acknowledging the right of all people to an ‘ordinary life’
- Matching funding to the support needed and placing control over the funding with the person and their support network
- Ensuring that providers discuss the service they will deliver with the person who will receive it through negotiation of individual service agreements
- Supporting a social model of disability support where the community sector contributes to support as they do for all community members and,
- Facilitating choice of provider in an open market (Yooralla, 2016, p. 4).

My purpose in mentioning the development of the NDIS is to note its significance for people with disability, their families, carers and service providers and to explore the intention of the NDIS to “maximise the social and economic participation of people with disability” - a phrase that appears seven times in The National Disability Handbook (Madden, et al, 2014).

My initial contact with senior staff from an NDIS pilot site, whose professional background did not include experience in the disability sector, caused me some concern. I was also troubled by my perception of the advantage a person with physical impairment has over someone with cognitive impairment in the competition for funding and services. I base this concern on two observations. First, my experience of working with persons with physical and/or sensory impairment is that they are nearly always capable of clearly articulating their needs, sometimes requiring a third person to assist with communication, but seldom requiring that person to advocate or speak on their behalf. From a service provider perspective, they come to request a specific service or equipment and, once their need is met, they generally require little further contact in the short term. Of course, there are always exceptions but, for the
most part, they have very different needs from a person with cognitive impairment who may require more intensive, lifelong support.

Mavromaras, Moskos, Mahuteau and Isherwood (2018), in their independent evaluation of the NDIS, funded by the Australian Government Department of Social Services, offer a “well informed and independent assessment of the many impacts of the NDIS trial” (p. xiii). While it is not my intention to outline the entirety of their findings, I would like, first, to note the success of the NDIS in improving the lives of many people with disability and second, to draw attention to the findings of Mavromaras et al. in regard to the key evaluation questions of choice and control, and social, economic and educational participation (2018, p.xiv). The evaluation found that the NDIS improved participants’ satisfaction with choice and control for many, but not all (p. 90). NDIS participants with “intellectual disability and/or very high needs” expressed concerns regarding their ability to have their individual choices “acknowledge and respected” (p. 118). Nevertheless, for carers of adults with intellectual disability, their satisfaction with services were the highest of any category (Mavromaras et al., 2018, p.132). Participants with intellectual disability, mental health issues or Autism noted an increase in social activities, but these were more likely to be with people with similar disabilities, rather than mainstream activities in the general community (p.177). National Disability Insurance Agency (NDIA) staff viewed participants and families who were confident, educated and articulate, as having better outcomes than older participants and those with intellectual disability, who were less capable to understand and navigate the NDIS (p. 200). NDIA staff concluded that participants more “vulnerable to poorer outcomes” included those with “intellectual disability and/or complex needs” and these staff were “not satisfied that safeguards to protect vulnerable NDIS participants were effective” (p. 199). The evaluation found that the NDIS is working well for the majority of users, but it has made some participants worse off, “particularly the most vulnerable” (p. 203). The issues that remain with the NDIS are complex and must be viewed from many different perspectives and standpoints that do not lend themselves to simple answers. Nevertheless, the implementation of the NDIS in many respects makes it even more urgent for service providers to wrestle with the meaning of client participation for their specific organisations.
2.13 Challenging the Professional-Service User Relationship

The discussion above has linked the rise of social movements oriented to recognition and respect with the emergence of a scholarly literature focused on participation, and the development of policy, legal and regulatory frameworks that place increasing emphasis on the full participation of service users. Taken together, these trends have brought to the surface a range of possible tensions between traditional understandings of ‘professionalism’, and growing social and legal expectations for recognition, respect and participation. How could these tensions potentially be resolved? Here Sennett’s work on respect provides some useful hints.

Sennett (2003, p. 3) equates the lack of respect for an individual with rendering them invisible. Most of us would confess to having experienced this insult or, more than likely, witnessed disrespect being inflicted on others. Consider the example of the adult taking their elderly parent to a medical practitioner who speaks only to the adult child and ignores the parent, because of the parent’s garbled speech resulting from a stroke. In this example, the presence of the parent/patient simply does not matter. In the eyes of the medical practitioner, the parent is no longer a human subject, but has become an object of the doctor’s expertise. Objectification is intrinsic to professionalism and, along with it, the tendency to view a person/client as an image of the professional’s own creation, viewed through lenses of prejudice, assumption and ignorance that occlude the individual sitting before them (Tarulli & Sales, 2009, p. 109).

When Sennett (2003, p. 52) speaks of respect, he is describing the basic tenet of his worldview of human relations as “taking the needs of others seriously”. Sennett acknowledges that it is not possible for us to know the needs of all others, and he concentrates on the ‘social instruments’ of laws and rituals we use to communicate. Our capacities to perform these rituals are what Sennett refers to as attributes of ‘character’. For example, Sennett (p. 53) describes our use of eye contact or body language to perform the sentence, “I will not hurt you”. Sennett regards character as the yardstick to measure other words in the “vocabulary of respect”, which includes status, respect, recognition and honour. He sums this up with the suggestion that the few examples of respectful behaviour observed in our society means that respecting others is demanding and obscure (p. 59). In spite of this, behaviour that conveys mutual respect and acknowledges others, becomes an essential ingredient in the practice of social services.
Social service organisations often declare the values that underpin their approach to practice through mission and value statements. *Respect* is a value that is often included. For some organisations, living their stated values seems effortless. Their values are observable in their interactions with staff and clients, and they appear to see value in every person who walks in their door. However, given the examples of poor-quality services and, occasionally, systemic abuse that appear in the media, it could be argued that, for other organisations, respect for clients - and frequently, also staff - is more of an aspiration than a reality. As Greenwood (1993, p. 1183) observes, people often have a reputation for not ‘practicing what they preach’ – a phenomenon that Greenwood suggests prompted Argyris and Schön’s (1974) work on the importance of a practitioner’s personal values for generating the capacity for taking action in a particular situation. Argyris and Schön (p. 162) believe that we depend on our values to assist us to form a view, in order to make decisions on how we act in real situations. The authors refer to this as a commitment to responsibility, in which the practitioner has the strength to *do the right thing* when others cannot. A recent Blackwood (2014) article draws attention to an example of a well-respected disability agency that failed in its responsibility to act in response to multiple allegations of abuse of clients in their care. It took the courage of whistle-blowers to speak out. What Blackwood found particularly galling was that, when the chief executive officer resigned, the resignation was followed by plaudits from the board, which Blackwood described as a further denial of responsibility. In this example, it appears that the people in charge failed to apply their organisational values for the benefit of the people in their care. The example is illustrative of Argyris and Schön’s (1974, p. 162) concept of a situation in which a commitment to values is not present, resulting in no one being able to take appropriate action in the situation. Fortunately for the persons in care, at least one individual – the whistle-blower - was committed and accepted the responsibility to act.

### 2.14 The Problem with Participation

In examining the importance of participation, it is clear that participation is important simply because it demands that people be treated with dignity and respect as valued individuals. Eliminating barriers to participation allows people to choose their level of participation, from a basic level of information-sharing, to participating in the development and governance of their service if they so choose.
This chapter has already pointed to the importance of Arnstein’s work in establishing the benchmark for participation, understood as the transfer of power in decision-making to non-professionals for events that affect their community and themselves as individuals. Arnstein’s (1969) “Ladder of Participation” provides a foundational model for understanding and evaluating civic participation, and the following chapter therefore takes a closer look at the specific model presented in this work, as a springboard for the analysis of other models of participation that innovate and build upon Arnstein’s work. The chapter considers the applicability and usefulness of each model of participation for community sector service providers. This analysis also addresses the challenge of contextualising what participation means to different groups of service users, and consideration will also be given to how service providers might operationalise participation to meet the particular needs of their specific group of service users.

The problem with participation is that it is an area of practice in human services that exists in what Schön (2013, p. 42) calls the ‘swampy lowland’ of confusing situations where, in this case, problems are of greatest concern to clients and the wider society. Failing to involve service users in genuine participation puts service providers at risk of doing great harm to their clients. Developing systems for addressing this risk – and understanding the barriers and challenges involved in implementing such systems – is the major concern of this thesis.
Chapter Three: What is Participation?1

In this chapter, I focus on interrogating the literature on participation to investigate what is meant by participation, particularly for people who find themselves in situations where they have limited opportunities to be involved in making decisions that affect their lives.

I begin with a discussion of the historical emergence of the term community participation and offer an explanation of why this term was adopted, with specific reference to the international context. Adapted for the purpose of this thesis, the term community participation reflects the view that members of the community should be involved in developing the primary care programs for their community (Rifkin & Kangere, 2002). Service user or client participation, which is the principle focus of this thesis, refers to the engagement of service users, by their service provider, in the services they receive.

This discussion is followed by an analysis of six key models of participation, drawn from a diverse academic literature that directly engages with the experience of participation in a number of different countries, and in diverse populations and institutional contexts. Some of the models selected were developed in the context of civic, rather than client participation, while the models specific to client participation have been drawn from studies of a wide variety of client populations, including both adults and children, and persons with and without disabilities. The range of the selected literature is deliberately broader than the scope of the empirical research in the thesis, and is intended, on the one hand, to illustrate the extensibility of the concept of participation, and its potential applicability to additional populations beyond those considered in the existing literature. On the other hand, the range is intended to help render visible elements of participation that can be regarded as common across different contexts, rather than applicable only to the single context discussed in any particular study. Bacchi’s (2009) framework, introduced in chapter 2 is once again useful for this analysis. In particular, I examine each model’s applicability for service providers in regard to their particular cohort of clients and the services they offer.

By analysing the applicability of these models, this chapter seeks to provide insight into how and why community sector organisations, sometimes knowingly but often unwittingly, can fail to ask their clients if their programs are meeting their needs.

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1 Sections of this chapter have been adapted from An Exploration of User Involvement in Service Development (Iaquinto, 2012), a paper presented at The ASID Research To Practice Conference, Wellington, New Zealand, November, 2012
and do not consistently aspire to have clients participate in the planning and development of programs. At the same time, this analysis will provide guidance on what good practice looks like on the ground, and what strategies organisations might put in place in order to operationalise the full involvement of their clients in the services they offer.

In later chapters, I then build on this analysis to explore how well these elements that appear common within the scholarly literature, correspond to service user and service provider understandings of participation. I also investigate techniques that could help service providers adapt and contextualise these common elements, to operationalise them within the situated context of their own organisational practice.

3.1 Defining Participation

Before turning to an analysis of specific models of participation, however, a brief background on the international context for definitions of participation is useful. At the most basic level, participation can be defined as a process of involving people in the decisions that affect their lives or, as Hart (2008, p.27) puts it, “the right of the individual to make their own choices”. On the face of it, Hart’s description of participation seems intuitively true and broadly acceptable. Yet, it becomes abstract when reflecting on the particulars of the individual: what is required for those ‘rights’ to be exercised in a meaningful way in practice? Similarly, from the point of view of service providers, the complexities of context and purpose come into play. Cohen and Uphoff (1980) suggest that asking "what is participation?" may be the wrong question because it "implies that participation is a single phenomenon" (p. 214). They suggest that it may be more “fruitful” to regard participation as involving people in circumstances or actions that enhance their wellbeing. For the cohort of clients with which this thesis is concerned – service users with a range of disabilities, engaging with Victorian social service organisations – the motivation is a concern with enhancing clients’ feelings of self-worth, through engagement in participatory processes built on respect for them as individuals – without inflicting greater harm.

In considering the history and evolution of participation, it is important to note the early adoption of the term community participation. This occurred at the World Health Organization’s (WHO) conference at Alma-Ata (now Almaty) in 1978 and was used in relation to the development of primary health care programs (WHO/UNICEF, 1978). All members of the WHO recognised the importance of involving the intended recipients of programs and services in their design and implementation (Rifkin &
Kangere, 2002, p. 38). According to Rifkin and Kangere, there were four reasons for this acceptance. The first was that primary care services were underutilised because the people for whom they were designed were not involved in their development. The second was the view that financial, physical and human resources existed in all communities that could be used to improve the health and environmental conditions in those communities. The third was the realisation that the greatest improvement in health was the result of what people do to, and for, themselves, not the result of medical interventions. The final reason was the belief that all people, particularly the disadvantaged, have the right and duty to be involved in decisions that affect their lives.

Ten years after Alma-Ata, Rifkin et al (1988, p. 933) reviewed a wide range of definitions of participation, and it appeared to them that three characteristics are common to all definitions. The first is that participation is active. In support of this, they refer to the WHO’s preference for the term community involvement as opposed to their original concept of community participation. Rifkin et al (p. 932) noted that this change appeared in the report on the WHO’s assessment of progress toward Health for All by the Year 2000 (WHO, 1977). They believed that the WHO’s emphasis on the word “involvement” rather than “participation” was driven by the notion that involvement implies being actively engaged in the planning, decision making and evaluation of programs, rather than being the passive recipient of services. The WHO (2001) later developed the International Classification of Functioning, Disability and Health (ICF) with the intention of providing a common language and conceptual basis to describe functioning and disability that could be used by many disciplines. According to the ICF model, a person’s level of functioning is an interaction between their health status, and environmental and personal factors. Included in this model is the concept of involvement. The ICF model considers involvement to mean a person’s involvement in all areas of life or how a person functions as a member of society and the restrictions, if any, they may experience.

The second characteristic discussed by Rifkin et al (1988, p. 933) is that participation involves choice. In order for choice to be genuine, organisations recognise the basic human right of people to make decisions that affect their lives. Rifkin makes the point that, with choice, comes the individual responsibility to participate and not be a passive recipient. Implicit in this is that people have the power and opportunity to exercise this right.
The third characteristic highlighted by Rifkin et al. is that choice is effective. For a choice to be effective there is more than one option to consider, and the individual has some degree of control over the outcome. This is achieved through the support of processes that are in place or easily created so that choice can be implemented.

In undertaking their review, Rifkin et al (1988) were making an early attempt to define participation by searching for similarities or common components in the definitions of the term. Their purpose in this work was to produce a concise list of indicators for participation so that it could be universally understood, implemented and measured. I will return to Rifkin et al. (1988) in the next chapter, and discuss my application of their work in stage two of the thesis research.

In the decades to follow, the term participation continued to have a wide range of meanings that varied according to the situation or purpose. For some, participation is simply an individual or group’s right to information and the opportunity to express an opinion (Checkoway 1998; Hart 1992; Lardner, 2001). Whether their views are considered or actually influence decisions is another matter. For Arnstein (1969), as discussed in the previous chapter, participation is a process that leads to the transfer of power and control from the ‘haves’ to the ‘have-nots’. For other authors, it is more important to consider the role of the service user. Borg et al (2009, p. 286), for example, make the point that terms such as user involvement, participation, user empowerment, control and user perspective may refer to different levels of participation, but all suggest different roles for service users. They consider participation, for example, to be less engaging and more passive than ‘empowerment’ and ‘user control’, while they view ‘involvement’ and ‘perspective’ as both non-committal and all encompassing.

Padilla et al (2007, p. 2) take the issue of defining participation further. They warn of the danger of dealing solely with definitions, and highlight their finding that identical definitions have been linked to several different practices. This point is an important warning to the researcher not to assume people have a clear understanding of what participation means when they say that their service users participate, have a choice and make their own decisions. Rather than trying to present yet another definition, the authors suggest that participation should be viewed in the broader sense of the interactions of life in general, and they offer three aspects or variations in the meaning of participation. These include:

**Its nature:** Participation as a social process valued by some; as an instrument of management; as a right by law and as a form of government.
Its aim: Participation as the way of embodying democracy in everyday life; a source of legitimacy for authority; a space for rendering high level decision making accountable; a technique for improving performance and raising efficiency; and a requisite for human development.

Its procedures: Participation processes take forms that range from the spontaneous and so-called informal encounters to the more standardised and formal (p. 6).

These three aspects offer a means to conceptualise participation in its various forms, and begin to touch on some of the important characteristics or dimensions of participation, to use the authors’ term (p. 7). Of significance are these aspects’ capacity to assist the researcher to maintain what is referred to as an ‘open notion’ when researching participation in practice. An open notion of participation, according to Padilla et al (2007, p. 13), holds that participation should be viewed as an artifact of the power and knowledge that exist in relationships that have important effects on processes for client involvement. In other words, Padilla et al are saying that processes alone do not make participation effective. Participation begins and ends with an understanding of the power imbalance in relationships and the effects of these “asymmetries” on participative processes (p. 13).

Research into the meaning of participation has continued since participation became popular within the government sector internationally, in the 1960s and 1970s (Cohen & Uphoff, 1980, p. 213). During this time many researchers, beginning with Arnstein (1969), found diversity in meaning and motivation, all leading to a variety of undefined terms and practices. Cohen and Uphoff, for example, seek “clarity through specificity” for participation in rural development projects and programs (p. 213). Pretty (1995), whose work is discussed in more detail below, speaks to the "many interpretations of participation" (p. 1251). White (1996) claims that the “status of participation as a ‘Hurrah’ word, bringing a warm glow to its users” disguises its many forms and interests (p. 143). Cornwall (2008) warns that, when exploring the meaning and practices of participation, it is vital to pay close attention to who is participating, what are they participating in and who is the beneficiary of this participation.

The models of participation discussed in the following section have each been selected in part because they provide a physical representation or visualisation of participation. Such visualisations are useful both for the clarity they bring to the model, and for the insights they provides into what is referred to as ‘participation in practice’. As discussed above, these models have also been chosen to cast light on
how the concept of participation has been adapted in different international contexts, for different populations. Together, they help demonstrate the extensibility and versatility of the concept of participation, and highlight points of disagreement and conflict over the concept. They also offer important insights into the evolution of the worldwide theory and practice of participation over the last sixty years, and provide a foundation for reflecting on common elements that span different models of participation.

3.2 Models of Participation

This section analyses the following six internationally known and influential models of participation: A Ladder of Citizen Participation, Arnstein (1969), A Ladder of Children’s Participation, (Hart, 1992), Degrees of Participation for Children, (Treseder, 1997), A Grid Model of Youth Participation, (Lardner, 2001), Five Types of Participation, (Checkoway, 1998) and Pathways to Participation, (Shier, 2001). The models address a variety of different contexts and cohorts that range from the urban poor, to children and young people. Not all are originally intended to address the participation of service users, but they each share a concern with the complexity of operationalising participation – and, in the case of the models concerned with the participation of children and young people, explicitly consider what participation might mean in a context where professional facilitation remains a central part of the process. These models highlight the lack of agreement on a definition of participation, but they also offer a pathway to investigating whether or not there are commonalities, as well as disagreements, in the practice of participation in social services.

3.2.1 A Ladder of Citizen Participation

As discussed above, Arnstein (1969) plays a particularly foundational role in the literature on participation. In this section, I delve into her model in more detail. Arnstein invites her readers to visualise a ‘ladder of citizen participation’ that takes us up a series of rungs from non-participation through degrees of tokenism, onto partnerships, shared power and, finally, citizen control. Arnstein’s (1969) field of interest at that time was urban planning, and her strongly held belief was that “citizen participation is citizen power” (p. 216). In her view, this was the key to ensuring that citizens had the power to make decisions about what they wanted in their own communities. They could only achieve this, Arnstein believed, through their
participation in the planning of their communities and through gaining the power to manage resources and make decisions. Achieving this would be beneficial, not only for those directly involved, including the power holders, but for society as a whole. Arnstein believed that capable, competent people in the community could achieve more for their communities by being empowered than by remaining powerless. Empowering community members also gave them permission to think about and try different ideas for improving their communities.

As discussed above, Arnstein focussed mainly on the power imbalance between the ‘haves’ and ‘have-nots’, which she believed was an issue both in society in general and in her area of urban planning in particular. In her view, there was much more work being done on ‘who’ the have-nots were and ‘why’ they were affected by powerlessness, than on understanding what actually constituted citizen participation. Her goal, which reflected the evolving social consciousness in America during the 1960s, was the transfer of power from the haves to the have-nots. For Arnstein (1969), enabling those excluded from political and economic processes, through a redistribution of power, was a way to achieve social reform. Arnstein was clearly more concerned with achieving broad social reform, than more narrowly improving the processes used within government-funded urban renewal programs.

Arnstein’s eight-rung ladder, which she intended to be provocative, begins by describing how many forms of participation, used by those she refers to as ‘power holders’, are simply not designed to facilitate genuine participation but are merely forms of tokenism. The bottom rungs of the ladder are what Arnstein calls manipulation and therapy. Here, the power holders are not interested in sharing power or assisting citizens to plan or manage programs. Arnstein (1969) views these bottom rungs as an attempt by the power holders to turn participation into a public relations exercise. The next three rungs are labelled as tokenism, where citizens are ‘informed’ and ‘consulted’ but their views are not heard or acknowledged. Arnstein offers examples of ‘consultation’ such as recording how many people attend a meeting, return a questionnaire or take home an information brochure. Arnstein labels the fifth rung of the ladder placation. Citizens may voice their views, but the authority of the power holders does not change. The top three rungs of the ladder represent increasing levels of actual citizen power with the top of the ladder being what Arnstein calls...
citizen control. Here citizens manage programs, make decisions and control the resources. Arnstein refers to citizen participation as a “categorical term for citizen power” (p. 216). The purpose of citizen participation, in Arnstein’s view, is the means by which power will be redistributed to people who lack the capacity to influence political and economic processes in their community. Participation or involvement without this redistribution of power become, in her words, “innocuous euphemisms” (p. 216).

The value of Arnstein’s model for this thesis is that it can readily be translated for an analysis of the recipients of social services, and, viewed in that context, it exemplifies the complexity of participation by identifying key difficulties in contextualising a form of participation for a particular group of clients in a particular service. As Cornwall (2008, pp. 271-272) discusses, providing information may be a form of manipulation for some, but sharing critical types of information may facilitate participation for others.

For Tritter and McCallum (2006, p. 157), Arnstein’s (1969) ladder represents a theoretical framework for service user involvement in health services that has outlived its usefulness for patients, policy makers and practitioners. Their critique of Arnstein’s model includes “missing rungs” that differentiate between method, type of service user and outcome (p. 161). For my purposes, the most important “missing rung” Tritter and McCallum highlight is the limited attention Arnstein pays to initiatives that build the capacity of service users to participate effectively, as well as her failure to consider the time and expertise required to develop relationships based on trust and working together to achieve shared goals (Titter & McCallum, 2006, p. 162).

Applying Bacchi’s (2009) approach to Arnstein’s ‘problem’ leads us back to the three government social programs Arnstein (1969) uses as examples for her model: urban renewal; anti-poverty; and Model Cities – beginning with the accompanying rhetoric of “absolute control” and “maximum feasible participation” (p. 216). Arnstein attempts to put meaning to these slogans by defining ‘citizen participation’ and its connection to the role of politics and the social issues of her time. Arnstein’s anger with professionals’ treatment of citizens, leads her to focus only on the citizen’s empowerment. This one-sided focus causes her to miss important rungs relating to building the capacity to participate (Titter & McCallum, 2006, p. 161), as well as the practice of professionals that inhibit participation and maintain the marginalisation of the have-not citizens (Bacchi, 2012, p. 2).
3.2.2 A Ladder of Children’s Participation

Arnstein acknowledged the limitations of applying an eight-rung ladder to describe a complex process like participation, and commented that in the real world “there might be 150 rungs with less sharp distinctions between each” (p. 217). These limitations then prompted others to develop variations of the model to describe the process of participation in practice and in specific populations, organisations or communities (Florin, 2004; Lardner, 2001; Moules & O’Brien, 2012; Wong et al, 2010). Hart (1992), for example, adapted Arnstein’s model to determine the levels of participation for services working with children when he developed his ladder of children’s participation (Figure 2). The differences between Arnstein’s model and Hart’s lie in the fact that the models were not only developed for different populations, but that Hart (1992), unlike Arnstein (1969), was not interested in the transfer of power for decision-making to children. Instead, Hart focused more on choice, empowerment and shared decision-making – in the process, implicitly extending the concept of participation to activities where the complete transfer of control might not be possible or desired.

Both Arnstein (1969) and Hart (1992) refer to the bottom three rungs of their ladders as non-participation. Hart referred to his three bottom rungs as manipulation, decoration and tokenism. Some have argued that, depending on the situation, non-participation can be a form of “self-exclusion” if there is a genuine choice not to participate for reasons known only to the individual (Cornwall, 2008, p. 279). Moreover, Hart’s first principle of genuine participation is choice, which implies the service user should have at least one option from which to choose. Empowerment implies taking control.

Hart (1992, p. 11) believed that programs should be designed to maximise a child’s opportunity to participate at the highest level of their ability. The important consideration for Hart was that children had the opportunity to decide their level of participation, and that it was not always necessary for them to participate at the highest level of their ability. More important, for Hart, was that the bottom three rungs of the ladder should be avoided.

Shier (2001, p. 110) suggests the most practical significance of Hart’s work is his inclusion of these “models of non-participation” (p. 9), which detail real-world examples of the bottom three rungs of Hart’s (p. 9) ladder. Hart’s (1992, p. 9) example of tokenism includes children doing or saying what adults suggest while having no understanding of the issues. Manipulation is asking children what they think
when their ideas have no influence on decisions. Shier (2001, p. 110) concludes that these examples may have helped other practitioners recognise non-participation in their own work.

At the same time, Hart’s model has been criticised for being rigid and hierarchical, and for the assumption the ladder metaphor implies, which is that the ultimate goal is the top rung (Lardner, 2001; Treseder, 1997, 2004; Wong et al, 2010). Such disagreements disregard Hart’s (1992) clear statement to the contrary: “it is not necessary for children to always operate on the highest possible rungs of the ladder” (1992, p. 9). Here Hart is respecting a child’s right to choose to perform at the level that they might prefer at a particular time, while Hart remains vigilant towards the child’s ability to participate (p. 11). While Arnstein (1969, p. 217) notes the “road blocks” that inhibit citizen participation for participants, Hart is instead concerned with the individual’s capacity to participate.

Moules and O’Brien (2012, p. 18) suggest that Hart’s (1992) typology, like other linear models, does not address the ways in which participation can vary depending on the circumstances. Moules and O’Brien’s disagreement with Hart, however, ignores Hart’s intent to present his model as useful for thinking about the design of children’s participation, rather than as a tool to assess the quality of any program, and it also overlooks how Hart acknowledges the “many factors” that affect children’s participation other than the design of a program (p. 11). Hart’s expectation is that his ladder may be useful when thinking about designing children’s participation – and this intention foreshadows its later actual use as a rubric to guide a conversation about children’s participation, rather than as a working model of practice.

Figure 2: Image removed prior to thesis archiving for copyright reasons. Please consult the original image at Hart, 1992, p. 8.

3.2.3 Degrees of Participation for Children

Treseder (1997) developed what can be described as a process to empower children and young people, rather than a model concerned solely with measuring their participation. He argued that children and young people should have opportunities to participate in decisions affecting policies and the delivery of services within an organisation, and therefore begins by asking, “who has control?” (Fajerman & Treseder, 2004, p. 6). Significantly, Treseder (1997) departs from the typologies of
Arnstein (1969) and Hart (1992) by offering a practical application of his ideas to the practice of service provision. Treseder acknowledged that most organisations providing services to children would not engage them in decision-making, and that creating opportunities for children to do so would impact significantly on the culture and style of the organisation. This would involve some in authority having to share their responsibility for making decisions with children. Nonetheless, Treseder does offer a process for change in which he poses questions to assist service providers in thinking through how to operationalise these changes:

- Organisations need to be clear about how decisions are made and where the power lies.
- What decisions is the organisation seeking to involve children in – what is it trying to achieve – who in the organisation needs to be involved and at what level?
- Are you proposing to involve children to improve your service delivery or are you seeking to establish real opportunities for decision-making?

With these questions, Fajerman and Treseder (2004, p. 6) are clearly focused on establishing a power-sharing arrangement between the young clients of the organisation and the professionals in authority.

What Treseder (1997) referred to as five degrees of participation are, in fact, five different forms of good practice, which he placed in a circle rather than in a ranked series of steps (Figure 3). Treseder did this because he believed the ladder metaphor used by Hart (1992) suggested a hierarchy that should always be ascended, in a structured order (Fajerman & Treseder, 2004, pp. 7-8).

For service providers, the most valuable aspect of Treseder’s model is his choice to make each of the five degrees of participation an acceptable model of participation. In choosing the right degree or degrees of participation, service providers can consider the needs of their clients, the skills of their staff and the context in which they operate.
Treseder thus offers more than an interesting conception of participation for children and young people. He provides a process that challenges professional beliefs and paternalistic assumptions – including particularly that those children and young people need to be protected, rather than empowered to participate and make decisions about the services they receive.

3.2.4 Grid Model of Youth Participation

Lardner (2001) similarly abandons the ladder metaphor, instead presenting a model that uses a grid to plot a continuum of power that Lardner believes is fundamental to the empowerment of young people. Like Treseder (1997), Lardner (2001) puts forward the view that genuine participation does not occur without aspects of empowerment. Lardner then constructs a model that builds on Treseder’s degrees of participation and includes Hodgson’s (1995) five conditions of empowerment, which she incorporates into her five dimensions of participation. Those five dimensions are (Lardner, 2001, p. 4):

- Access to those in power
- Access to relevant information
- Genuine choice between distinctive options
- A trusted independent person who will provide support and, where necessary, be a representative
- A means of redress for appeal or complaint

After researching a number of methods of youth participation, Lardner placed her six dimensions of participation on a continuum depending on who holds the power, which can be explored through the following questions:

- **Initiation of the method:** whose idea was it?
- **The agenda:** who decides what’s discussed?
- **Decision-making:** who makes decisions about how to proceed?
- **Information:** who holds the information necessary for decision-making?
- **Implementation:** who takes action on decisions?
• **Structure of participation:** how formal or informal is it; does it replicate adult ways of doing things?

Lardner (p. 5) notes that this model is proposed as a guide, not as a scientific method. Accepting this, her guide does provide a structure that would be useful for organisations interested in contrasting their approach to participation with other processes. Lardner, somewhat like the prudent parent, gives sensible advice to organisations that children and young people not be totally controlled by adults or authority, but allowed to express their views and ideas.

Lardner’s (2001) approach is similar to Treseder’s (1997) in that it first asks questions about who has control for decision-making, but also clarifies the behaviors required for implementing effective models of participation for young people. This includes being clear about the purpose of the model and the questions being asked.

**Figure 4:** Image removed prior to thesis archiving for copyright reasons. Please consult original image at Lardner (2001)

Lardner’s attempt to visualise empowerment within various methods of youth participation appears to offer a subtle progression on the approach taken by Treseder. Where Treseder confronts the power imbalance at the onset, asks direct questions and offers strategies for addressing the behaviour of those in authority, Lardner emerges from a distance to measure and compare methods. Lardner (2001, p.25) agrees that no single approach to participation is correct and that a chosen approach must meet the needs and priorities of the people involved. What is important for Lardner is that all young people have opportunities and the choice to become involved.

### 3.2.5 Five Types of Participation

Checkoway (1998) also adapts Arnstein’s ladder in his “Eight Rungs on the Ladder of Youth Participation” (p. 769), which relates to the practice of youth participation in neighbourhood development. Checkoway includes Arnstein’s examples of non-participation at the bottom rungs and the goal of ‘Youth Control’ at the top rung of the ladder. In his discussion of the meaning of participation, Checkoway (p. 768) notes that participation is often viewed in terms of scope, where the analysis of participation involves measuring the frequency of activities and the number of people participating, while ignoring the attribute of *quality*. For Checkoway, participation
quality occurs when particular decisions are influenced, the participation has some effect and a favourable outcome is achieved (p. 768).

Checkoway drew on a national study of exemplary youth programs to help him visualise the integration of youth participation and neighbourhood development by focusing on two key objectives. First, he sought ways to encourage young people to participate in decisions that affected their lives and neighbourhood. A prerequisite for this to occur, according to Checkoway, was for agencies to have a commitment to viewing youth as a resource. Second, he sought ways to integrate the participation of young people into youth and neighbourhood development programs. He achieved this by distinguishing five types of participation practiced by youth development agencies and neighbourhood development organisations (Figure 5 – on the next page). The first two types of participation include *youth action* and *citizen action*. Participation in this sense is achieved when people take the initiative and organise themselves to take action (p. 788). Integration with neighbourhood development is achieved when people, including youth, come together and organise themselves regarding specific community or neighbourhood development issues. Checkoway (1998, p. 788) refers to his third form of participation as *youth development*, which concentrates on developing youth’s potential instead of focusing on their deficits. *Neighbourhood development* occurs when residents take action to implement programs relating to neighbourhood issues. *Neighbourhood-based youth initiatives* combine neighbourhood development with youth participation and become integrated with neighbourhood development. Checkoway’s fifth form of participation involves youth-initiated programs that help to improve education and employment opportunities for neighbourhood youth. Checkoway’s approach presents a progression from general community engagement, to more specific neighbourhood and youth participation that includes opportunities for the personal development of individuals as well as the broader community.

Two factors distinguish Checkoway’s model from the others already discussed in this chapter: first, his attempt to integrate participation into existing youth and neighbourhood development programs; and second, his emphasis on the importance of viewing youth as a resource that can take responsibility and work to make a difference in their communities. This contrasts with a view of young people as vulnerable and requiring protection. Checkoway’s five types of participation suggest how a young person could progress from youth action, which may be the first step toward developing the confidence to become involved in youth/community issues, to citizen action where youth contribute to change in the broader community.
Although Checkoway does acknowledge the development of relationships (p. 781), he does not provide a description of the nature of the relationship between the young person and the adult neighbourhood residents and individuals who are likely to be responsible for running the community agencies and institutions. Implicitly, it would seem the relationship would have to be in the form of a youth-adult partnership. Checkoway (1998, p. 775) does, however, offer examples of some service providers that engage former service users as workers, but he notes that this does not necessarily mean this worker will have any influence on the organisation’s decision making.
The strength of Checkoway’s approach is his focus on the value of what youth have to offer as competent, as opposed to passive, participants. This focus reflects a possible response to the issues raised in chapter 2, which highlighted the challenge of shifting professionals away from viewing the individual client as a passive recipient of services determined by professional staff. In this case, youth are portrayed in the media as being alienated from their communities, and professionals view them as deficient, rather than building on their strengths to provide opportunities to empower young people by promoting their right to participate in decisions that affect their life and their community (Checkoway, 2010, p. 341).

### 3.2.6 Pathways to Participation

Although similar in structure and purpose to some of the models already described, particularly those of Arnstein (1969) and Hart (1992), Shier’s (2001) model (Figure 6) differs from the others in a number of ways. Firstly, Shier does not include the lower rungs of Hart’s ladder, which are described as *non-participation*. Shier (2001, p.110) acknowledges that many practitioners found this the most useful component of Hart’s model because it offered examples of poor practice, which they could use to assess their own. However, Shier is more concerned with the empowerment of children and youth and bases his model on five levels of participation:

- Children are listened to
- Children are supported in expressing their views
- Children’s views are taken into account
- Children are involved in decision-making processes
- Children share power for responsibility for decision-making

Unlike some of the authors noted above, Shier observes that individuals and organisations may have differing levels of commitment to the process of empowerment. Shier attempts to clarify the level of commitment by identifying three stages of commitment – which he refers to as *Openings, Opportunities* and *Obligations* – that occur at each of his five levels of participation (Figure 6).
For example, if an organisation were to implement participation at level one of the model, workers would have to ask themselves the question: ‘are you ready to listen to children?’ and then make a personal commitment (‘opening’) to do so. This level of participation, however, only requires listening to occur when a child decides to express a view. At the ‘opportunity’ stage the question is: ‘do you work in a way that enables you to listen?’ For example, workers might attend listening skills training or construct their roster in such a way to allow a worker the time to talk to a child. Listening to children becomes an obligation when the organisation makes it policy that the duty of all workers is to listen carefully to what children have to say.

One criticism of Shier’s (2001) model is that his questions are framed and responded to by adults, which, for some, perpetuates the power of adults over children and young people. However, Shier does provide a way to approach the concept of adults and youth working together to define their roles to improve opportunities for shared responsibility for decisions (Wong et al., 2010, p. 103).

Shier (2006, p. 16) suggests that his model can be used as the first stage of a planning and evaluation tool to enhance children’s participation in various types of organisations working with children. It is also a model that can be adapted by organisations in many social services programs. By including the three stages of commitment, Shier helps organisations to operationalise his model by offering a tool for workers and organisations to measure their ‘degree of commitment’ at each level of participation. In doing this, Shier provides a structure that can be used to examine the culture of the organisation and provide an opportunity for workers to reflect on their attitudes and values regarding their work with service users. The capacity of workers to reflect on their work with service users will determine whether they are willing to enter into genuine partnerships with service users. They do so with the understanding this would most likely lead to shared decision-making and some loss of power and control. This would seem to be a critical factor in implementing and sustaining genuine service user involvement and one that may provoke resistance from staff reluctant to relinquish power.

Figure 6: Image removed prior to thesis archiving for copyright reasons. Please consult original image at Shier, 2001; 2006)

Each of the six models of participation summarised above, although grounded in empirical work, offer perspectives on participation that remain in the realm of
academic studies. While this is not a criticism of the valuable insights they offer, my primary concern is with how to translate and apply these insights for social services, in their day-to-day practice with clients.

In the section to follow, I probe each model from the standpoint of Bacchi’s (2009) framework for policy analysis, introduced in Chapter Two. The conception of the ‘problem’ that each model was designed to address is considered. Applying Bacchi’s framework, I reflect on the commonalities and disagreements between the models presented above, and I outline my apprehensions from a service provider’s perspective.

3.3 Discussion - Six Models of Participation

The “core idea” (2009, p. 181), to borrow Bacchi’s words, for each model is to develop a means to address the problem of limited opportunities for vulnerable and/or marginalised groups to influence decisions that affect their lives. For Bacchi, the core idea is open to interpretation. She points to the key concepts and practices, as well as to who holds the power that shapes their meanings. The supposition in Arnstein’s (1969) ladder is that the discrimination towards minority groups in the communities targeted for renewal, contributes to the suppression of their right to influence any decisions. This became obvious to Arnstein when she observed the discriminatory behaviour of the professionals involved and their ignorance of the impact of racism and poverty on the residents. This professional behaviour led to the residents being manipulated, placated and informed through activities that amounted to non-participation, which resulted in them having little or no control of, or influence over, outcomes.

Roger Hart’s (1992) conception of participation is more concerned with children and young people being empowered to decide their level of participation, and therefore it foregrounds that it is not always necessary for service users to participate at the highest level of their ability. Hart is saying children and young people should be treated like adults, which brings the principle of equality into play. Bacchi’s (2009) difficulty with the principle of equality is that it is subject to interpretation by the powerholders (p. 182). Treseder (1997) focuses his representation of participation on the need to support service users in the decision-making process by providing opportunities to practice decision-making - he places the responsibility for achieving this on service providers who, Bacchi (2009) would say, have the power to define the discourse. Checkoway (1998, p. 341) cautions about viewing participation in terms of the
frequency of participation activities, rather than the quality of the outcomes for service users, which he defines as having “real influence” over decisions. Like Arnstein (1969), Checkoway speaks to the power of young people as a group to influence and shape opportunities for the wider society. Bacchi would agree with Lardner’s (2001) view that aspects of participation depend on who holds the power. Shier (2001) provides us with a model that asks both the individual worker and the broader organisation to define their level of commitment to each step in the model.

In Table 1 below, I present each author, their model, and a summary of the author’s purpose in developing the model. The table provides a means to compare and reflect on the underlying premise of each model:

**Table 1: Six Models of Participation**

<table>
<thead>
<tr>
<th>Author</th>
<th>Model</th>
<th>Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sherry Arnstein, (1969)</td>
<td>A Ladder of Citizen Participation</td>
<td>Arnstein’s goal was to give children a choice to participate in the social order of communities by giving people the power to make decisions</td>
</tr>
<tr>
<td>Roger Hart, (1992)</td>
<td>A Ladder of Children’s Participation</td>
<td>Hart’s purpose was to examine giving children a choice to participate at the level they choose</td>
</tr>
<tr>
<td>Phil Treseder, (1997)</td>
<td>Degrees of Participation</td>
<td>Treseder focused more on systems, processes, that empower children to participate</td>
</tr>
<tr>
<td>Barry Checkoway, (1998)</td>
<td>Five types of Participation</td>
<td>Checkoway was interested in finding the value and skills within each youth opportunities for young people to have to say</td>
</tr>
<tr>
<td>Clare Lardner, (2001)</td>
<td>A Model of Participation</td>
<td>Lardner’s priority was to examine methods that improve opportunities to what children have to say</td>
</tr>
<tr>
<td>Harry Shier, (2001)</td>
<td>Pathways to Participation</td>
<td>Shier’s model empowers staff to listen</td>
</tr>
</tbody>
</table>

Although each of these models is developed for a distinct population and environment, the comparative discussion of the models overall touches on the major debates and types of conceptual frameworks that underpin the academic study of participation. These concepts will be useful for the discussions in chapters 4, 5 and 6. For our purposes here, however, it is important to note one significant commonality that all these models share: they do not describe how to manage the complexities
that arise when trying to contextualise any of them. Cornwall (2008, p. 269) highlights how models appear straightforward, starting from limited or non-existent forms of participation and leading to genuine participation. The difficulty arises when a model is contextualised. The individual as well as organisational factors that act to inhibit participation are insufficiently thematised in the construction of the model. This thesis seeks in part to act as a corrective and a contribution to this gap, by looking more closely at how individual and organisational values and cultures might influence the capacity to operationalise ideals of participation. The literature attests to how professional groups will approach their cohort with values and attitudes unique to their profession that may influence opportunities for participation on the ground (Arnstein, 1969; Brownlea, 1987; Oliver & Barnes, 2012; Schön, 2013): the impact of such values and attitudes, however, is at best incompletely built into many otherwise influential models of participation.

Another issue, incompletely addressed in the models discussed above, are the more complex and varied barriers to participation that arise for populations in receipt of social services, including particularly individuals with impaired decision-making. I have commented above on my professional experience with people with limited communication skills and those with limited decision-making capacity, which informs my interest in what it means to operationalise participation in the delivery of social services. These individual barriers interact complexly with obstacles generated by the behaviour and attitudes of professionals, as discussed in the following section.

3.4 Barriers to Participation

As previously discussed, a significant objective of this research is to advance the participatory practices of social services. This section addresses two significant issues that require clarification before the results of the research can be presented. The first issue is the ambiguity of the term participation. Cornwall’s (2008) statement that participation is “an infinitely malleable concept, ‘participation’ can be used to evoke – and to signify – almost anything that involves people” (p. 269), is an example. In this section, I draw on the academic literature to provide evidence that will assist me in identifying practice-based means that begin to address this problem. I highlight in particular the work of Pretty (1995) and White (1996) in order to note their influence on Cornwall’s discussion of the need for clarity about exactly what people are being asked to participate in, to what purpose, and who is involved (and who is not) in this
process. As Cornwall (2008) puts it, “being involved is not equivalent to having a voice” (p. 278).

The second issue is a consideration of the factors that inhibit participation. I examine these factors through the application of what Hickey and Kipping (1998) refer to as four broad “categories of constraints” to participation in decision-making (p. 86). Each of these categories is presented and examined in order to provide more contextualised understanding of the factors that inhibit client participation in the practice of social services.

When Cornwall (2008, p. 278) observes that being involved does not mean having a voice, she is referring to one of the common barriers to participation, which is the tendency for some participatory processes to be ambiguous. This is often unintentional on the part of the organisation, since what it frequently demonstrates is a lack of understanding as to what participation in practice should look like. Nevertheless, this ambiguity may sometimes be intentional - designed to meet other organisational agendas. Cornwall (2008, p. 269) builds on the work of Pretty (1995) and White (1996) to ‘unpack’ the meanings and practices of participation: a brief summary of their work is therefore useful here.

Pretty (1995), in his work on sustainable agriculture, considers the term sustainability to be a multifaceted concept, which makes establishing its precise definition “impossible” (p. 1247). Pretty, like Schön (2013), points to the failure of the scientific paradigm of positivism to solve problems of uncertain contexts, as well as problems that can be interpreted in various ways. He suggests that problems such as defining sustainability can only be solved with broad scientific and public participation, which, in turn, confronts Pretty with the problem of defining participation - a term he describes as “fashionable”, with many interpretations. Pretty’s response (p. 1252), borrowing from Hart’s (1992) work, is to set out a Typology of participation: how people participate in development programs and projects. In presenting his typology, Pretty (1995, pp. 1250-51) offers five alternative means to think about solving problems, other than the positivist paradigm:

- Attempts to precisely define concepts (such as participation) are fundamentally flawed
- Problems are always open to interpretation
- The resolution of one problem inevitably leads to another problem-situation
• The capacity of actors (professionals) to learn continually becomes the key feature to acting quickly to transform existing activities.
• Systems of learning and action are needed to seek the multiple perspectives of the various interested parties and encourage their greater involvement.

While all five are noteworthy, Pretty’s final two are the most significant for this thesis. Namely: all actors require the capacity to learn continually and adapt swiftly to change; and, it is necessary to ensure the perspectives of all concerned are sought and their involvement encouraged.

White’s (1996) work with Bangladeshi NGO leaders examines their dilemma that attending a planning meeting was no guarantee that plans would be implemented. If they chose not to attend, however, they would have no grounds to complain. As White put it: “plans are left untouched but their names remain” (p. 142). This and similar experiences led White to develop a framework that mainly considers the different interests which form different types of participation, which she refers to as: *nominal*; *instrumental*; *representative*; and *transformative*. Cornwall (2008, p. 271) suggests that White’s (1996) typology (p. 144) is useful for determining why and how participation is being used.

Of value for this thesis is that Cornwall (2008), Pretty (1995) and White (1996) all propose a typology that may assist service providers to determine what is actually happening in their practice with clients. Cornwall’s typology of interests, in which she merges Pretty’s ideas with White’s framework, offers a means of clarity for service providers by focusing on the conditions in which participation occurs. It does this by asking three questions: who is participating; what are they participating in; and, who is the beneficiary of this participation? Cornwall’s (2008) typology is useful in that it puts forward “clear and unambiguous” (p. 274) questions that attempt to address the complexity of participation in practice. In the table below (Table 2), Cornwall sets out White’s (p. 144) forms of interests in participation and provides descriptions for each form under her three practice-based questions. For example, for the service provider under the ‘nominal’ category, participation is designed to legitimise their participatory process, in order to meet the requirements of their funder, and thus the so-called participation of their clients is enacted for display purposes only.
Bacchi (2009) offers an alternative framework that sidesteps defining client participation in decontextualised terms, by adopting a strategy for investigating the following: the meaning client participation has acquired in the context of the organisation’s practice with clients; how this meaning shapes the roles played by both staff and clients within their relationships; and the impact of these relationships on program outcomes for clients. Following this path may provide service providers with a clearer understanding of the perceptions, interests and intentions of all participants, and an appreciation that these various perceptions may lead to outcomes for clients that are both planned and unplanned.

While Bacchi (2009) suggests policies “give shape to problems” (p. x), Heffernan (2006) concentrates on the use of language as a means of power, and suggests, “language is an indirect means of repressing those without power” (p. 140). Heffernan, not unlike Bacchi (2012, p. 2), points to changes in public policy that seem to perpetuate divisions between people. Heffernan highlights the public sector’s shift in the 1990s, to the ideology of managerialism, adopting its language of private sector market principles, which replaced the term client with consumer and service user (p. 141).
The term service user involvement, considered passive and non-committal by Borg et al. (2009, p. 286), is nevertheless a concept widely promoted by social services. Yet, Heffernan (2009, p. 375) found that there are still many service users who remain uninvolved, and there is a notable lack of research on what involvement actually means to this group. Heffernan’s study attempts to address this significant concern by engaging uninvolved service users in focus groups to determine their attitudes toward and perceptions of service user involvement. Heffernan (2009, p. 380) found that, of 24 participants in five focus groups, only two said they preferred the term service user, while 40 per cent preferred the term client. Heffernan (p. 381) notes in conclusion that most of the participants in her study never had the opportunity to become involved with the services they use, and many reported having negative experiences with professionals.

Although only a small sample was used, Heffernan’s work is valuable because it provides examples of two significant barriers to service user involvement: first, the knowledge and experiences of service users are often ignored, instead of being appreciated for the potential value they offer; and secondly, the attitude of some professionals impacts on the service users’ opportunity to participate. Heffernan’s (2009) work also underscores the need to engage the service user in a conversation about their life experiences as a person as well as a service user.

Hickey and Kipping (1998, p. 85), analysing what they call a participation continuum of user involvement in the provision of mental health services, describe four categories of ‘constraints’ to participation in decision-making. These constraints refer to those factors that inhibit the transfer of power in decision-making from service providers to service users. Although Hickey and Kipping (p. 86) suggest that there are many possible constraints, they group them into what they consider four ‘important categories’, namely: ‘user issues’; ‘organisational culture’; ‘professional culture’; and ‘wider society’.

In considering this grouping of constraints, Hickey and Kipping’s category of ‘wider society’ stands out for its presentation of the views and attitudes of our society towards marginalised populations. This category is also reflective of Bacchi and Beasley’s (2002) views, discussed later in this chapter, that some social policies are designed to keep marginalised individuals under control. Hickey and Kipping (p. 87) note that society’s lack of understanding of mental health has been influenced by certain policies and practices, such as incarcerating people with mental illness and intellectual disabilities in institutions as discussed in Chapter Two.
In the following discussion, these broad categories will underpin the analysis of what might be the significant barriers to participation for service users highlighted in the academic literature. The first step in developing an understanding of what forms service user participation takes, is identifying and analysing both the processes and attitudes that determine what service users are participating in. Only with this understanding will service providers begin to determine how their organisation’s practice of client participation might be implemented and evaluated (Cornwall, 2008, p. 272).

3.4.1 Service User Issues

The responsibility of the individual service user to make the choice to participate has been raised by a number of authors, particularly Hart (1992) and Shier (2001), and the view that choosing not to participate can be a form of participation (Lardner, 2001) has also been noted above. Nevertheless, the attitudes and perceptions of service users toward seeking help in the first instance, reveal another initial barrier for service users and service providers to overcome. In their study of rural adolescents’ attitudes toward seeking help for mental health issues, for example, Francis et al (2006, p. 44) found that the ideas and attitudes young people exhibited toward seeking help could be significant barriers to their participation. A particular influence was the culture of self-reliance in their rural community, which contributed to a perception of themselves as weak if they sought help (Francis et al, p. 45). Francis et al (p. 47) also discovered that “self-stigma” was a significant barrier to seeking help. The authors ascribe this to the rural environment where people’s lives may be more visible, and youth may experience less privacy than in urban settings. The concept of ‘self-stigma’ is reminiscent of Gupta’s (2015) discussion, as noted in the previous chapter, of feelings of shame and humiliation described by service users, and foreshadows two important aspects of service user issues in the context of this research.

The first and most significant for my purposes is the participation of the “seldom heard” (Begum, 2006, p. 2) service users with cognitive impairment who are the most likely group of service users to be excluded from participative processes (Beresford, 2007, p. 310). Ward et al (2016, p. 3) draw on Green and Featherstone (2014) to highlight the ‘normative violence’ which occurs through relatively benign activities such as not allowing particular people to be heard because what they have to say is not considered legitimate. Ward et al (p. 3) argue that people with profound and
multiple disabilities are regularly subjected to ‘normative violence’ “by not having their voices heard or legitimated”. They suggest that the concept of normative violence may be a useful one to apply when reflecting on participative processes, as it prompts questions about which voices are heard and which are omitted.

The second notable ‘user issue’ is the need for service providers to consider the diversity of service users, particularly given the various demographic, economic, social statuses and personal characteristics service users present. The concept of intersectionality applies when the individual characteristics (identities) of service providers’ clients, such as disability, mental illness, poverty, race, gender and other characteristics overlap, causing multiple and compounding experiences of discrimination and exclusion (Crenshaw, 1991). Intersectionality also requires services to consider the adaptability of their method of service delivery to meet the various needs of their diverse clients.

As Hickey and Kipping (1998, p. 86) are interested in user involvement in mental health services, their description of ‘user issues’ refers to people receiving these services and the impact their mental health may have on their capacity to become involved in making decisions about their own treatment. Some service users may recognise that they need help in making decisions and allow service providers to take on that responsibility. Others may be inhibited by their prior experience as a service user, their low-socioeconomic status and their inexperience in participation (Evans, 2004, p. 23). While it is possible, as Checkoway (1998, p. 769) suggests, that the lack of participation by some service users might be due to the fact they have other things to do with their time, the diversity among service users raises two important considerations for service providers.

First, as detailed in the previous chapter, professionals often focus on one aspect of a person’s identity, such as their impairment or their specific need for a social service, without looking beyond this aspect to discover the life experience of the person before them. Butt’s (2006, p. 2) study of social care agencies that promote diversity first examined what is meant by the term diversity, and found that the term is often used to mean different things such as ‘cultural diversity’ or ‘gender diversity’ and is sometimes used interchangeably with other terms like race equality for example. Butt determined that diversity meant taking account of the complexities of a person’s life and the impact of these complexities on the person’s experience of discrimination and disadvantage. Beresford (2013, p. 14), who builds on the work of Butt, argues that services should consider focusing on the interplay of all the aspects
of a person’s identity such as age, sexuality, ethnicity, race, faith, etc. that contribute
to a person’s lived experiences of oppression and inequality.

The second consideration for service providers is to reflect on the diversity of
their organisation and how its culture, structure and practice come together to support
client participation. Hernandez et al (2010, p. 716) recommend organisations adopt a
“whole-systems approach” first proposed by Wright et al (2006, p. 6) as a practice
model when affecting change and improving service provision. Briefly, the whole-
systems approach names four parts of service development that: begins with
organisations developing a culture of participation; then moves to organisational
structures that support participation; then focuses on effective practice of
participation; and ends with developing effective systems for review of participation
(Wright et al, pp. 6-8). I return to the whole-systems approach later in this section,
but first I want to illustrate a situation in which this approach could be applied, with
reference to the example of persons with cognitive impairment.

People with a cognitive impairment, for example, frequently require assistance
to make choices. Often, the default position for a service user with a cognitive
impairment is complete dependence on the service provider for assistance in decision-
making and, as Balandin (2011, p. 210) notes, people with lifelong disability, including
those with complex communication needs, are seldom included in discussions about
participation. As an example, Balandin notes a study of the factors that influence the
concept of integration that did not include those with intellectual disability or those
with little or no functional speech. Balandin suggests there may be a variety of reasons
for this position, including: a poorly defined understanding or definition of participation
by service providers and clinicians; speech pathologists working with this cohort have
not been able to fully explore their role in the context of participation; a lack of funding
to support communication systems, and a limited focus on people with complex
communication needs by advocates at a political level. She highlights the ICF as
providing a framework that can assist professionals to view clients holistically, and
include them in assessment and invention processes, and functional goal-setting (p.
208). Nevertheless, Balandin (p. 209) states that although the ICF emphasises
participation and is relevant to anyone in the community with or without a disability,
and important to speech pathologists, it cannot make them a ‘client centred’
practitioner. Balandin also points out that, in spite of many decades of rhetoric about
inclusion, people with life-long disabilities, including complex communication needs,
remain a presence in the community without being part of it – a situation already
describe a number of legislative changes and policy initiatives introduced in Great Britain over the previous decade, which require the participation of service users and those with cognitive impairments in particular. In spite of this, the ‘seldom heard’ groups of service users, which include people with communication impairment, continue to remain excluded and marginalised (Hernandez et al, p. 716).

The United Nations Convention on the Rights of Persons with Disabilities (2006) is clear that people with disabilities must be provided with the support they need to exercise their legal rights (Schulze, 2009, p. 61) and promotes the use of supported decision making “in lieu of substitute decision making” (Watson et al, 2017, p. 1022). Disability Services in the State of Victoria pursue a policy of self-directed approaches that are designed to “enable people with a disability to identify, design and oversee the support and resources they require” (Department of Human Services (DHS), 2012, p. 4). In practice, these goals are achieved through supported decision making, which entails the following steps: a person makes decisions on behalf of an individual with a disability; the decision-maker believes the individual would have made the same decision if they were able to do so; the decision-maker does this in the ‘best interests’ of the individual; and the decision remains the decision of the person with a disability (DHS, p. 10). Bigby, Whiteside and Douglas (2017, p. 2) point out, however, that supported decision making has not been formally recognised for people with intellectual disability in Australia and is often provided informally by significant others, paid carers or formally appointed guardians. Both Watson et al (p. 1023) and Bigby et al (p. 5) support the notion that supported decision making is a process that utilises key people that know the person concerned. Nonetheless, as Concannon (2005) suggests, the difficulty with this approach is determining who are the best persons to make the decision. This begins with service providers confronting this and other service user issues in an applied, practical sense. To describe how this may be achieved by social services, I now return to the whole-systems approach first presented by Wright et al (2006) and draw on a practice model developed by Hernandez et al (2010).

Hernandez et al (pp. 716-717), relying heavily on Wright et al, present an “integrated model of participation” that both adapts and departs from the customary ladder metaphor used by Arnstein (1969) and Hart (1992), as well as other models of participation presented earlier in this chapter. In an integrated model, participation activities are conceived on an equal footing, where none is given a higher status and participation is not seen as an activity that is ‘added-on’ to day-to-day service delivery.
Participation here merges with the four main aspects of an organisation, namely: culture; structure; practice; and review.

For Hernandez et al, a whole-systems approach shapes the organisation’s culture into one that enables two-way conversations between staff and service users. Here, staff: hold the primary belief that participation is fundamental to policy and practice; are sensitive to the needs and circumstances of service users; work to assist service users to build the confidence to discuss and criticise services and influence decisions that affect their lives; and engage in joint problem-solving with service users (Hernandez et al, 2010, p.722).

As in Arnstein’s (1969) work, in order for this approach to be effective, one prerequisite is a power shift in the relationships between staff and service users. The organisational aspects of structure and practice need to be designed to enable the everyday participation of service users in all aspects of decision-making. This shift should provide opportunities for service users to do things such as: participate at the level they choose (Hart, 1992); be empowered to participate (Treseder, 1997); be valued for their skills and experience (Checkoway, 1998); and achieve a commitment from practitioners to listen to what children have to say (Shier, 2001). This kind of shift is no small challenge, however, and the likelihood of success can be heavily influenced by organisational culture, which I discuss in the following section.

### 3.4.2 Organisational Culture

As Volti (2008) points out, workplaces are not solely a place to earn a living, but exist with values, attitudes, norms and accepted ways of operating. In other words, workplaces have a culture. Volti goes on to suggest that, despite the many definitions of culture, most include two broad components of culture, the *material* and *nonmaterial*. Volti emphasises that the material does not operate independently of the nonmaterial components of organisational culture, because they are “uniquely human” and can be created, manipulated, interpreted and understood in different ways (pp. 215-216).

This variability in how even material dimensions of organisational culture can be interpreted, is one of many reasons that what is described as ‘participation’ often varies greatly in practice (Cornwall, 2008, p. 269) and that, as Padilla et al (2007, pp. 1-2) suggest, despite more than 30 years of research into the study of organisations, *participation* continues to have a variety of meanings. Balandin (2011, p. 209), for
example, questions whether leisure activities such as going bowling are examples of being an active member of the community or merely the presence of people with disability in the community (see Bigby & Fyfe, 2010). Robson et al (2003) offer illustrations of how involvement means different things to different people in the same service. One staff member thought involvement meant helping service users “tidy up their beds” (Robson et al, 2003, p.1), while one service user thought involvement meant making friends and another thought it meant, “being able to voice an opinion, being heard and acted upon” (p. 2).

What these authors suggest is that service providers may have a view of themselves as being good at involving their service users in decision-making when, in reality, their practice does not justify this belief. To achieve meaningful participation, an organisational commitment is required to work in partnership with service users, which might need to extend from the direct service delivery staff all the way up to the wider management of the organisation (Hickey & Kipping, 1998, p. 86).

As Heffernan (2009, p. 382) noted, genuine participation begins at the first contact between service user and service provider. Dearden-Phillips and Fountain (2005, p. 201) point out that the commitment to partnership also comes from service users but in order for this to occur, service users need to be empowered to become involved. The conditions for service user empowerment, may themselves rely on an organisational culture that can incubate this empowerment.

In their work with voluntary organisations, Robson et al (2003, p. 4) usefully distinguish between two approaches to user involvement, which they name as ‘user-centred’ and ‘management-centred’ user involvement. For Robson et al, user-centred user involvement means that service users are able to pursue their own objectives and priorities; this has individual benefits for service users, as well as benefits for service providers in terms of effectiveness and relationships with funding agencies. Management-centred user involvement, by contrast, occurs when management defines priorities, agendas and structures. Reflecting on this distinction, Robson et al (2003, p. 22) acknowledge that a user-centred approach may be stating the obvious and that the usefulness of a management-centred approach for service users is contradictory. In their view, these two approaches may help to illuminate what user involvement is and what it is not (Robson et al, p. 23). Robson et al conclude that meaningful involvement occurred when: the agenda for involvement was influenced by service users; and an organisational commitment to user involvement was supported by facilitative leadership that engaged senior managers, such that the
process placed an emphasis on the importance of developing strong relationships between people in decision-making roles and service users (p. 4).

In practice, statements that describe how agendas are being ‘influenced’ by service users, or by having senior staff ‘engaged’, and that highlight relationships between decision-makers and service users, seem to imply that power for change remains with managers. Robson et al (p.26) concede that the problem is that managers may say they facilitate and support user involvement, when they are essentially giving service users permission to become involved.

Another significant aspect of ‘organisational culture’ relates to whether or not the leadership of the service provider, in the first instance, understands the attitudes and feelings of the staff toward service users and the organisation itself. Carr (2007) states that an “open dialogue” between clients and staff becomes part of the practice of the organisation because, in her view, “staff involvement is a prerequisite to user involvement” (p. 272). Nevertheless, the literature provides considerable examples of professional behaviour that make staff involvement difficult to achieve. Burns and Pope (2007), in their study of negative workplace behaviour in the health sector, found that the common effect on staff who experienced or witnessed negative workplace behaviour was decreased job satisfaction and motivation (p. 295). Spence et al (2009) suggest that the power imbalance inherent in supervisor incivility resulted in feelings of powerlessness in employees, which impacted on their jobs and turnover intentions in particular (p. 308).

Such research suggests that staff may need to feel empowered themselves before they can empower others. An organisation whose culture does not include the empowerment of their workforce may not be able to expect workers to build positive relationships with service users. As Robson et al (2003) and others (Barnes et al, 2000, p. 191; Carr, 2007, p. 13; Hernandez et al, 2010, p. 730) point out, a strong commitment to user participation within an organisation influences attitudes and behaviours and assists in the establishment of positive relationships between workers and service users, as well as among colleagues and supervisors.

Of primary concern is the capacity for workers to act effectively within the constraints of the organisation in meeting the needs of service users. Research suggests that workers who are able to take action to achieve results for their service users are empowered. An empowered worker has the confidence and determination in themselves to maintain a consistent approach to establishing productive relationships with service users. This empowerment of staff can potentially be
bolstered by staff understandings of their own professional status – but the impact of professional culture is ambivalent: it can serve as a source of confidence, and yet also potentially work against collaborative relationships with service users. To explore this ambivalence, I therefore turn to the question of professional culture below.

### 3.4.3 ‘Professional’ Culture

The previous chapter used the work of Schön (2013) and Simon (2000) to problematise the concept of ‘professionalism’ and examine the rise of forms of activism that contested expert-dominated models of service delivery. My main purpose in this section is to differentiate between ‘professionalism’ in that sense, which is contingent and can be contested, and organisational cultures more broadly, in which staff with various kinds of professional training participate.

For purposes of this thesis, what distinguishes a ‘professional’ culture from an organisational culture is that a professional culture is created by a specific occupation that asserts its expert status to apply its specialised knowledge to a specific group of service users – sometimes creating a distinct professional subculture within the overall organisational culture (Bloor & Dawson, 1994, p. 287). More than one professional subculture may exist within an organisation, and each may respond to service users in different ways. Some groups may be more influential or outspoken than others, and each will relate to other occupational groups in their own particular manner. Bloor and Dawson conclude that the degree to which the interplay of this behaviour shapes the dominant organisational culture is dependent upon the latter’s stability, so that the influence of the professional subculture may not become evident until the dominant culture becomes unsettled (p. 291). In such an unsettled environment, professional groups who view themselves as knowing what is best for service users can act to limit the opportunities for service user involvement in that organisation – asserting the dominance of specific professional expertise, over more collaborative arrangements, even if the broader organisational culture might have been open to greater service user participation.

While this remains a risk, there is increasing evidence that the active involvement of service users in the education of human services and health professions can influence the attitudes of professionals. For example, Happell and Roper (2009) suggest that opportunities for service users to influence the behaviour of professionals are greater in an academic environment, which they believe offers more intellectual freedom than the service delivery context (p. 579). Ward et al (2016)
propose that the engagement of service users with profound and multiple disabilities is a “foundational requirement of social work education” (p. 2), and describe their success in challenging the attitudes and beliefs of social work students through their engagement with a person with profound disabilities and their family (p. 9).

In order for service users to become involved in decision-making beyond academic settings, however, it is necessary for professionals to recognise that service users have knowledge and experience and are capable of having an opinion and making their own decisions. As Happell and Roper (2009, p. 575) note, professional attitudes remain a significant barrier to participation, and consumers of mental health services in particular require opportunities to influence the attitudes of mental health professionals through their direct involvement. Bennetts et al (2011, p. 160) similarly point out that some managers view participation by consumers as a loss of control and fear having their expertise challenged, while Hickey and Kipping (1998, p. 87) warn health care workers not to underestimate the impact the ‘professional culture’ may have on their practice. In other words, a professional subculture that works to inhibit user involvement may exist in some organisations, and it is therefore important for professionals to reflect on their practice and examine their beliefs regarding user involvement in order for these barriers to be avoided. If not, an outcome for service users can be a view of themselves as powerless.

3.4.4 Wider Society

The final group of barriers to consider is what Hickey & Kipping (1998, p. 87) refer to as ‘wider society’. Here, the authors express their view that attitudes formed in the wider society toward people with mental illness, influence service users’ opportunities for involvement in decision-making. Shier et al (2011, p. 368) refer to such attitudes as socicultural factors, which are a combination of the collective values and beliefs of a society, its social interactions, and the dynamics of its institutions. The authors describe how these factors impact on service users by not only creating, but helping to maintain, their vulnerability because of their ability, age, gender, sexual orientation, ethnicity and socioeconomic status.

The experience of discrimination by people with mental health issues and disabilities is well documented; however, many individuals in receipt of services from other types of human services report similar experiences of discrimination. Gupta and Blewett (2008), in their work on involving service users in training social workers, acknowledge the common characteristics of poverty and social exclusion among
families involved in the child protection system. Although they focus primarily on the impact of poverty, they provide examples of prejudice and pre-conceived ideas toward this group of families. One example is the notion that, if you are part of the social care system, then your capacity to be a good parent is questionable (Gupta & Blewett, p. 466). They also present examples of being judged on things that have nothing to do with child protection matters, such as a badly decorated house. These prejudices, and the fact that these families’ children are now part of the child protection system, would seem to increase their exclusion from participating in their community with the normal respect of their peers.

Finally, the impact of the wider society needs to be recognised as potentially the most important of the four barriers to participation, because of how it shapes the other three. For example, people with disabilities and mental health issues are meet with discomfort and avoidance from members of their communities. Similar reactions may also confront service users in general, at times. A young mother seeking family assistance, for example, may be excluded from participating in the community because she is most likely poor, probably receiving benefits, viewed as inexperienced and therefore seen as not having as much to contribute to her community. A person attending a drug treatment program may also be looked upon with mistrust because they were participating in an illegal activity. For many, the experience of discrimination would lower their self-esteem, increase feelings of inadequacy and reduce their confidence in being able to participate effectively. As Shier et al (2011, p. 371) explain, exclusion from participation is not only about the individual behaviours of service users, but also about how society views – or projects assumptions about - the behaviours imputed to service users.

3.5 Confronting Barriers

At first glance, identifying service user issues as a barrier to participation appears to blame the service user for their failure to participate. Confronting the barriers to participation first involves stepping back from the present to take a historical view of the treatment of service users since the 19th century. Participation, choice and community – given popular characterisations of service users in terms like ‘the menace of the feebleminded’ - remained optimistic ideals until the middle of the 20th century (Fox, 2003, p. 38-39). Even after this period, and despite the awakening of a human rights perspective in the 1960s, 100 years of stigmatisation left a legacy of
the apprehension of difference in the wider community, as well as a fear of discrimination in the service user.

As the discussion of professionalism illustrated, professional practice can sometimes be damaging by asserting a version of expertise that leaves clients powerless, defining them as an object and constructing them in relation to their problem or impairment, rather than first seeing them as a person (Oliver, 1990; Oliver & Barnes, 2012; Shakespeare, 2014). Taking my cue from Bacchi (2009), I have argued that social services, often unwittingly, define the service user as the problem – a definition that often begins with, and is guided by, public policy. Bacchi and Beasley (2002, p. 325) advise that assumptions about bodies in Australian social policy have led to a differentiation between citizens who are understood to be in control of their bodies, and those who are constructed as being controlled by their bodies. Bacchi and Beasley imply that this lack of control is used to justify forms of regulation and constraint for those seen to be controlled by their bodies and thus constructed as a “lesser citizen” (p. 325). Bacchi and Beasley suggest that this mind/body dichotomy operates as a political framework that “marks a boundary between full and lesser citizens” (p. 326). This in turn rationalises the continued influence of professional knowledge in forming public policies that affect the status of individuals (p. 327). This process of mutual reinforcement between public policy and professional knowledge then becomes a Catch-22 that restrains the potential for change in professional and organisational cultures. Policies that construct differences between people will always place someone in the position of determining who is different, as well as shaping what form of treatment each group will receive (Bacchi, 2009, p. 189). My earlier discussion of Oliver’s (1990) conception of the medicalisation of disability is an applicable example. Oliver’s social model offers an alternative to framing disability primarily in terms of the biological and the individual, and yet – according to Oliver himself – this has failed, since the 1970s, to gain significant traction in professional practice (Oliver, 2009, p. 51). Nevertheless, the social model, through its materialist analysis of society as oppressive and disabling, was successful in beginning to shift disability from its medical conception. By doing so, the social model established disability studies as a discipline and provided a conceptual framework for scholars to pursue a disability rights agenda (Thomas, 2004b, p. 22).

Yet the limited success of the social model to date suggests the continuing importance of asserting alternative ontologies of disability, including the social and relational models discussed above, not just for academic analysis, but for the everyday practice of social services. In the remaining paragraphs of this subsection, I want to
underscore this point by drawing attention to some notable insights into the lived experiences of people with impairment, as well as into the attitudes of professionals and others toward this cohort and service users in general.

Nearly four decades ago, Finkelstein (1980) wrote of the significant growth of professional expertise in the field of disability since the early 20th century, which helped to build the professional’s role in creating an “absolute monopoly in defining and articulating the problems of disability” (p.1). Finkelstein’s view is that this growth shaped the construction of people with disabilities as passive, objects of research, and dependent on others. This, Finkelstein suggests, created the presence of disability as paradoxical - a personal tragedy in one respect, and a form of discrimination by society in the other. This understanding of disability as a paradox, places people who work for and with people with disabilities as participants in the “total disability paradox” (p. 5). Finkelstein believes that it is only within this framework that attitudes toward people with a disability can be truly uncovered - attitudes that emerge from the ‘helper’ side of the relationship, and focus exclusively on the ‘helped’. As the ‘helper’ is perceived as the disability expert, their articulated attitudes are presumed to be the accepted attitudes toward disability (p. 6).

Finkelstein’s work is applicable in many situations and relationships where one side is the ‘helper’ and the other is being ‘helped’, such as that between a professional and their client in a social service. This work is specifically important for highlighting that the quality of the relationship may depend on the ‘focus of attention’. If the focus remains solely on the ‘helped’ individual, Finkelstein suggests, negative attitudes will be facilitated. If the focus is more holistic in nature, including the ‘helped’ individual’s lived environment, social relationships and any external situations and problems, Finkelstein believes more positive attitudes will result (p. 16).

Shakespeare and Watson (2001, p. 20) point out the dilemma involved in having to identify and participate as a disabled person in order to participate in one’s own management – despite any unwillingness to identify as disabled in either the political or medical sense, preferring to be ‘ordinary, not different’. Professionals who continue to describe people by their impairment or their need of social services, perpetuate the stigmatising effect of difference. In each of these respects, confronting barriers are analysed both as essential, and as a paradoxical mechanism through which barriers are ironically confirmed and reproduced.

Although the preceding discussion of barriers to participate may sound discouraging, research also suggests that these barriers are not insurmountable.
Gupta and Blewett (2008), among others (Beresford, 2013; Robson et al, 2003; Wright et al, 2006), offer suggestions for workers and services to improve their practice. Gupta and Blewett (2008) offer the following list of such practical strategies for overcoming barriers to participation:

- Demonstrate an understanding that society as well as individuals can create neglect
- Respect people enough to explain things - be honest and open
- Have good accountability and complaints procedures (and assist families to use them)
- Don’t label and pre-judge people - get to know the individual
- Listen to what families think would help
- Provide support at an early stage, before crises occur
- Treat people with courtesy and respect - don’t be over-intrusive or abuse your power
- Don’t offer people in poverty a poor service because they are not in a position to challenge you
- Offer a human touch - don’t be a robot just carrying out procedures and filling in forms
- Recognise and develop people’s strengths and aspirations - what they have done to survive and what they want for the future
- Be true to social work values and treat families with dignity and respect, and recognise the importance of building a trusting working relationship based on both parties having the child’s best interests at heart (Gupta & Blewett, 2008, p.466).

My intent in highlighting barriers to participation is therefore not to suggest that nothing can be done, or to present a pessimistic view of the possibilities for change. Rather, my intent is to explore the lessons from the academic literature for service providers wanting to improve their practice of participation. In addition, I want to foreshadow the concerns of the later chapters of this thesis, which explore a method for social service organisations to identify barriers to participation in their day-to-day practice with service users.

Recognising barriers, however, is only half the job: at least as important is identifying and supporting enablers of participation – a topic to which I turn in the concluding subsection of this chapter below.
3.6 Enablers of Participation

In this subsection, I draw on the academic literature to begin to develop the notion that there exists a core group of pre-conditions for participation that are critical to success in operationalising client participation in social services. I outline these below.

3.6.1 Values

Ife (1997) offers support for the notion the practice of social services operates from a “clear and explicit value position” (p. 11). As suggested earlier in this chapter, an individual, working within the context of the social services, may suggest they possess a set of personal values that includes things like compassion, a commitment to social justice and service to others, equality and respect for human rights. Given the behaviour of professionals as described in Blackwood (2014), however, this is sometimes an inaccurate self-perception. Bacchi (2009) would recommend searching for the deep-seated values, which she refers to as a “kind of social unconscious” that often underpin problem representations (p. 5). For example, Bacchi refers (p. 168) to the Australian Values Statement requirement for visa applications as another example of how problem representations can be used to establish social relationships that create inequality and turn people against one another – in her example, in the form of framing some persons as potential problems or threats and others as acceptable for life in Australia.

Argyris and Schön’s (1974) work, as noted in the previous chapter, highlights the importance of taking seriously a practitioner’s personal values because the decisions practitioners make are guided by these values (p. 162). Schön’s (2013, p. 234) later work implies that practitioners have a choice on how they wish to frame their role by making public their private assumptions and having the personal strength necessary for taking action in a particular situation. According to Schön, these actions are taken with an awareness of the values at stake in the decision and a commitment to the action because it is “intrinsically satisfying”, not subject to external rewards or punishments (p. 231).

Volti’s (2008) view is that an organisation’s “collectively held values” underpin the behaviours that influence, if not determine, the success or failure of an organisation, no matter what its endeavour (p. 216). Ife (1997, p. 11) notes that social service organisations cannot operate in a depersonalised, bureaucratic value-
neutral fashion, if they are to offer services that meet the needs of clients and ensure their participation. They first establish a valid commitment to participation through a system of values and beliefs, based on the principles of humanism and democracy (Bennis, 2009, p. 106).

Hernandez et al (2010, p. 721) argue that a commitment to “everyday participation” ought to be instilled in both the direct service delivery staff and the broader organisation. They suggest that everyday participation begins with organisational practices that build an ethos where staff and clients work together, recognising the value of participation and providing and nurturing opportunities for clients to participate. The factors that enable everyday participation, according to Hernandez et al (2010), are the “beliefs and values that embrace participation” (p. 721). Without this commitment at all levels of the organisation, any approach to initiating user involvement has little chance of being meaningful. It follows that any plan to operationalise participation in social services must first consider the organisation as a whole (Wright et al, 2006, p. 6) and include the recognition of organisational values and beliefs, as well as the role these basic tenets play in developing and sustaining, on the one hand, meaningful relationships with clients and, on the other, the potential to cause clients greater harm.

3.6.2 Collaboration-Knowledge-Education

As discussed above, the participation literature offers numerous examples of tokenistic processes portrayed as the meaningful involvement of service users. Nevertheless, the involvement of service users remains crucial in the practice of social services. Schön (2013), for example, presents his notion of reflective practice as built upon the quality of the collaboration between all actors, which is underpinned by mutual accountability (p. 295).

Webb (2008) offers a means to build relationships in practice that includes actions such as: talking, listening, sharing information; implementing processes that build relationships and involve service users in setting agendas, building relationships and making decisions; and having a set of values that are underpinned by notions of human rights, democracy, inclusion and differences in power (p.270). In other words, collaboration is a component of relationships. It is built on trust and is reciprocal and respectful. Collaboration forms relationships that challenge the power imbalance between the service user and the service provider, creating a partnership: a
partnership where the focus is on empowering the service user to share their lived experiences and to frame problems (Beadle et al, 2012, p. 353).

Lardner (2001, p. 4) asks the question: who holds the knowledge necessary for decision-making? This question may be answered from the perspective of both the service user and the service provider. The service provider or professional practitioner is assumed to have expert knowledge regarding the services, treatments and therapies available, but the professional also makes the effort to engage with the service user to gain the benefit of the users’ life experiences, their particular needs, and their previous experience with other service providers. In spite of this, some service providers often perceive a client’s knowledge and experience as having little value, and therefore make a limited attempt to engage with the service user to find out who they are and what they think (Carr, 2007; Bradshaw, 2008; Borg et al, 2009; Happell & Roper, 2009). Bennett et al (2011) found, for example, that managers of mental health services felt they would like “having their voices heard” if they became clients. Managers that disclosed personal experiences noted that those experiences now underpin everything they do in their work, and that an understanding of client participation involved being able to gain sufficient knowledge of the client to imagine standing in their shoes (p. 158).

Appreciating the relevance of service user experiences would seem to be a key enabler of client participation for three significant reasons. First, a client’s previous experience with service providers may leave them with attitudes and beliefs that inhibit their capacity to engage with their current service provider, which needs to be acknowledged and addressed by the current service provider. Alternatively, this previous experience may contribute to an organisation’s participative processes in positive ways (Hickey & Kipping, 1998; Beresford, 2007; Gupta & Blewett, 2008; Happell & Roper, 2008). Finally, as Borg et al (2009, p. 287) and Bradshaw (2008, p. 675) have noted, the experience of service users may assist service providers in meeting the challenge of resolving the varying perspectives of practice held by professionals, with the real-life experiences of service users. Solbjør and Steinsbekk’s (2011) work supported Borg et al (2009) and Bradshaw’s (2008). They found that service user knowledge provided an alternative viewpoint to professional knowledge and, in some instances, supported professional knowledge. Solbjør and Steinsbekk (p. 144) also found that, although some professionals valued service user knowledge, they limited its influence on their professional practice.
In completing this discussion on the enablers of participation, I focus on what Schön (2013) describes as one of the most important functions of a manager, which is the education of their staff. With this analysis, Schön refers to a manager’s education of staff on the “phenomena of organisational life”, which includes the cumulative knowledge, attitudes, experiences and identity of the organisation (p. 242). For Schön, the characteristics of interpersonal relationships within the organisation represent its ‘behavioural world’. This behavioural world, combined with organisational structure, creates what he calls the “learning system” of the organisation. Schön suggests that an organisation’s learning system can limit or strongly support a manager’s practice with clients and staff. As noted in the previous chapter, challenging the learning system of an organisation requires a professional to have a strong commitment to their personal values (Argyris & Schön, 1974, p. 162).

Although Schön’s views on professional practice, particularly in relation to the medical model of disability, were presented in the previous chapter, here I want to highlight another dimension of Schön’s work: his analysis of how reflective practice can be used to link the enablers of participation presented above. Schön (2013) is concerned with the relationship between the professional and the client - a relationship that, he believes, is underpinned by values and mutual accountability (p. 295). Accountability in the relationship between professional and client is what links the enablers of participation. In Schön’s (2013) approach, the professional first recognizes the limits to their expertise and seeks the knowledge held by the client through their engagement in conversation. The authority of the professional is not assumed or acknowledged by the client. Instead, the client is asked to “suspend disbelief in it” (p. 296) until the professional’s expertise emerges through a process of collaboration. In other words, the professional and client engage in a two-way conversation where the professional listens to what the client has to say, and demonstrates interest in the client’s life experiences as a person, as well as in what they seek from the service (Hernandez et al, 2010; Heffernan, 2009). I will return to these enablers of participation again in later chapters.

3.7 Chapter Three Conclusions

This chapter engages with the international literature on participation to address the question of “What is participation?”. I take a pragmatic approach to examining a variety of models of participation. My purpose is to explore what these models might
offer service providers attempting to implement participatory processes in their service delivery.

This chapter first presents a discussion of what the academic literature offers as the common characteristics of participation. Each characteristic is important to all definitions and models of participation presented in this chapter. Each of the six models of participation is analysed using Bacchi’s (2009) framework first, and then assessed in terms of how applicable it is for service providers to operationalise them in their service delivery. The ambiguity and complexity of the term participation is also addressed from a number of different perspectives, including Cohen and Uphoff’s (1980) suggestion that asking ‘what is participation?’ assumes that participation is a single phenomenon, when in fact it is multifaceted. Finally, a number of barriers to participation are identified.

The academic literature on the enablers of participation, presented in this chapter, attempts to identify the elements required for service providers to become aware of the necessities of client participation. Elements discussed here include: Argyris and Schön’s (1974) emphasis on the importance of the practitioner’s personal values, which guide their decision making; Bacchi’s (2009) notion of searching for the intrinsic values that underpin problem representations; Ife’s (1997) conviction that social service organisations cannot operate in a value neutral fashion; and the experience of Hernandez et al (2010) that everyday participation is at the heart of service delivery in all facets of an organisation.

This review of the academic literature on participation draws attention to the growing international scholarly consensus on the importance of participation, and also mines the academic literature for insights into barriers to, and enablers of, participation. At the same time, the review highlights the difficulties of translating abstract academic models into more practical measures that can be applied more directly in the provision of social services. In the following chapter, I explore a possible solution to this problem, by examining selected scholarly works oriented to producing more applied tools for thinking about participation in the provision of social services. By adapting and building on the insights from this literature, I suggest, it becomes possible to translate abstract models more effectively into the practical requirements of social service provision.
Chapter Four: Applying the Concept of Participation in Professional Practice

My analysis of the international literature on participation presented an assortment of models of the professional practice of participation, and identified both barriers and enablers to the full participation of service users in the social services they receive. This literature review led me to conclude that, although there is agreement in the international academic analysis of the importance of participation, this emerging consensus remains difficult to implement on the ground in international practice. This raises two principal questions that are examined in the research to follow: first, do practitioners understand participation in ways compatible with academic discussions of this concept? Second, how can practitioners operationalise a commitment to participation in their own practice settings? These two questions drove a two-part research design, conducted in two stages, which I describe in detail in chapters 5 and 7. In this chapter, however, I first explore whether the academic literature might already contain a tool that service providers could use to gauge the level of service user participation in their services, which could perhaps help service providers translate between more abstract academic models and the requirements of everyday practice. Regrettably, my reading of the literature on measuring client participation yielded few examples, none of which were applicable directly and without modification in the practice of social services. Studies mainly included participants with physical and sensory disability (see Velde et al., 2017), with few having participants with cognitive impairment. O’Halloran and Larkins (2008, p. 24) in their work with people with limited verbal communication skills, point out the many ways participation has been defined in the research literature. They list various methods of data collection, including: surveys and questionnaires; focus groups; and qualitative interviews. However, a substantial body of work that focused on Individual Program Plans (IPPs) offered some particularly productive methodological insights into how it might be possible to investigate the problem of participation discussed in previous chapters. It is therefore to this literature that I now turn.

IPPs are based on the principles of normalisation noted in Chapter Two and are a mechanism for planning and developing individualised services, exclusively for service users with cognitive impairment (Alexander & Hegarty, 2001, p. 17). In Victoria, the Intellectual Disabled Persons Services Act, 1986 (IDPS) included the requirement for every person receiving a disability service under the Act to have a case plan (General Service Plan), to be reviewed every five years for persons in
congregate care institutions and every three years for persons in the community. Prior to the proclamation of the IDPS, there was no legal requirement for any form of service planning for people with intellectual disability in Victoria. As I noted earlier, the majority of people receiving a disability service in Victoria at that time, resided in large institutions. The 1987/1988 Victorian Department of Community Services, Annual Report states that in June 1988 there were 134 staffed community residential units with an average of approximately five residents per CRU (p. 43), which equates to 670 people with cognitive impairment living in the community. The report also notes that there were 11 State Training Centres operating at that time, housing 2700 residents with cognitive impairment. As a professional employed in one of those large facilities, my view was the IDPS was written to facilitate the movement of people out of institutions and into the community. Twenty-one years hence, the IDPS was replaced with the Disability Act 2006 which commenced on 1 July 2007 and most of the large institutions for people with intellectual disability, in Victoria, were closed or were in the process of being closed. Under the new Act, disability service providers must: ensure planning is directed by the person with the disability and is individualised; consider support services generally available to anyone in the community; maximise the choice and independence of the person; and facilitate the goals and needs of the person with a disability.

Alexander and Hegarty (2001, p. 18) reflect on what in fact constitutes client participation and how can it be evaluated and, if necessary, increased. They confront this issue in their review of evaluation studies on the effectiveness of individual program planning, which, consistent with the literature review in the previous chapter, points to the lack of commitment of professionals and staff problems as barriers. These factors result in staff setting ambiguous goals, which create difficulties for evaluating the outcomes of these goals. Nevertheless, Alexander and Hegarty (2001) conclude that the most valuable consequence of IPPs is the core requirement for IPPs to involve the client in the process of planning for their future and the goal of the IPP to “ensure services are made to fit clients rather than clients fit services” (p. 18). Alexander and Hegarty (2001) note that some studies refer to client attendance at an IPP meeting as an indicator of client participation in IPPs. Similarly, Arnstein (1969) and Checkoway (1998) offer examples of organisations counting the number of people attending a meeting as evidence of participation. This body of work seemed a good starting point for identifying examples of the difficulties in measuring the participation of clients, and offered a possible means to compensate for the paucity of concrete examples elsewhere in the literature. IPPs imply the presumption that clients will be
involved in planning their future. My personal experience of attending IPPs, however, often involved people who were, then, long-term residents of large institutions, many with little or no family support, who were limited in their choices and given few opportunities to move into the community. In such circumstances, although the person was always in attendance, they were not supported to participate fully. In other words, the legal requirement to conduct a planning meeting for the person was met, but the moral obligation to ensure they participated fully, was not. The literature specifically concerned with IPPs has itself needed to wrestle with this problem.

Rifkin’s (1986) work in evaluating the effectiveness of community participation in primary health services is particularly notable here. Rifkin (p. 240) highlights the declaration by the WHO, at their conference at Alma-Ata in 1978, that primary health care, together with community participation, would become “the means by which radical health improvements would be made for the majority of the human race”. Rifkin (1986) intended her work to support this shift in the focus of health care, which at the time was dominated and controlled by the medical profession, to the community. Rifkin’s purpose was to draw on the emerging lessons from the previous eight years of primary care programs that focused on community participation, and to use this base to assist both health professionals and funding agencies to build support for health programs that were based on community participation, so that they could become self-sustaining programs into the future (p. 240). Rifkin began with an analysis of practice examples in approximately 200 case studies dating back to the early 1970s. From her analysis of the case study experiences, Rifkin (p. 241-245) identified a number of major lessons relevant to the ways in which professionals develop community participation in health programs. The ones most pertinent for this thesis are as follows.

Rifkin’s first lesson is that a universally acceptable definition of community participation is not possible or even useful. This lesson echoes similar views in the literature surveyed in the previous chapter, which suggested that participation could take many forms. Rifkin (p. 241), like Bacchi (2009), argues that the critical factor is how professionals define program objectives. Rifkin presents three approaches to community participation, each of which rests upon the way professionals define health, as well as how professionals think the community will respond to this definition of health. Rifkin (1986) refers to the first approach as the medical approach, where health is defined as the absence of disease and community participation is defined as activities undertaken by people in the community under the direction of a medical professional. The second is the top down and bottom up approach, in which top down
reflects the positivist assumption, described in previous chapters, that professional experience and current medical technology will solve existing health problems. For the bottom up component, what is important are the changes in attitudes of both professionals and community people. This attitude change is the belief that professionals will relinquish their control, while community people will slowly begin to carry out basic health interventions formerly performed by professionals. The third approach, which Rifkin names variations between people and over time, suggests that the difficulty with defining community participation is that professionals often perceive the problem of participation as “they do the solution of a disease problem” and “try to identify it in terms of cause and effect” (Rifkin, 1986, p. 242). This third approach, it should be noted, resembles Schön’s views on the positivist epistemology (2013, p. 39).

Rifkin’s work, although conducted more than three decades ago, is consistent with examples found in the current literature – highlighting how some professionals seldom seek their clients’ feedback or provide opportunities for clients to discuss their expectations of a program. This observation, alongside two further aspects of Rifkin’s work, is of particular importance for this thesis.

Given my interest in the practical application of participative processes in social services, the next aspect of Rifkin’s work that is important for this thesis relates to how the work is underpinned by a decade of experience in practice. From this experience, Rifkin et al (1986) builds what I consider the third valuable aspect of her work: a framework for planning and implementing community participation in health services that asks three broad questions: “why participate, who participates and how do they participate” (p. 246)? Rifkin (1988) suggests thinking about the answers to these questions as “corresponding to points along a continuum” (p. 247), with management concerns that view community participation as a program component at one end and, at the other end, community development activities that prioritise community decision-making over efficiency. Rifkin also makes the point that asking these three questions can assist professionals in clarifying and implementing program objectives, which reflects the current challenge facing social services that want to increase the involvement of their clients.

In the following section I detail Rifkin’s later work, especially Rifkin et al (1988), which puts forward a method for measuring participation that relies on Rifkin’s (1986) earlier analysis of case studies, as well as fieldwork carried out by Muller et al (1988, p. 935). Additionally, the authors offer conceptual and methodological approaches
that contributed a number of key features to the design of the stage one study. Below, I discuss this work and contrast it to the models of participation presented in the previous chapter, to explain its importance for the doctoral research design.

Rifkin et al (1988) addressed the problem of finding a measure for community participation by developing a set of indicators (Figure 7) for community participation in health care programs. Specifically, Rifkin et al (p. 931) were interested in finding ways to measure what they considered the two major principles of primary health care: equity and participation. Concentrating on participation, they first put forward a methodology to define five indicators they believed influenced community participation in health care programs.

For each indicator, a continuum was developed which had ‘wide participation’ at one end – with service users planning, implementing and evaluating primary health care programs while receiving advice from professionals – and ‘narrow participation’ at the other end of the continuum – where professionals make all the decisions (Rifkin et al, p. 933). The authors utilised a ranking scale (p. 936, see Figure 7 below), to mark one of five points along each of the five indicators across a continuum from one to five, with one being nothing or no participation (narrow) and five being significant participation (wide). Each mark across the continuum was the point that most closely resembled participation in the health program being assessed.
These points are visualised in a spoke configuration where each arm represents one of the five indicators. By placing the appropriate mark along each continuum, the authors are able to show the breadth of participation. In Figure 8 below, a baseline has been taken which sets the level of participation at the narrow end. This offers the opportunity for comparison with other assessments at a later date or assessments completed by other assessors (Rifkin, et al, 1988, p. 934).

A series of questions were provided for each of the five indicators to assist evaluators in developing their own questions for each program, although they were not intended to be a checklist for marking each indicator (Rifkin et al, 1988, p. 938). Rifkin et al acknowledged the difficulty in obtaining and analysing the answers, and they advise that the point to be plotted is comparative and does not have to be precise. Rifkin et al also state that these tasks should become easier with experience.

These indicators were utilised by the authors to compare differences in participation across a number of different scenarios, including: in the same program; at a different time; by different assessors; and by different participants (Rifkin et al, 1988, p. 934). The authors suggest that their framework has value in that it can be used as a marker that illustrates how wide or narrow the level of participation is at a particular moment in time. Their assumption in undertaking this work, is that an understanding of the process of participation will increase service user involvement, which will in turn lead to better outcomes for service users (p. 937).

Although the methodology described above has some limitations, it offers a number of advantages over more academic models of participation. First, it starts with a clear description of what the authors mean by community participation (Rifkin et al, 1988, p. 933). It uses a set of process indicators for community participation drawn from the practice experiences of service users, planners and managers, obtained through fieldwork undertaken by the authors (p. 935). Questions for each indicator are constructed for the specific program being assessed, and its purpose is to provide a snapshot or baseline of an organisation’s ‘wide’ or ‘narrow’ levels of participation. This can provide a way to assess changes in the program at a later date. Establishing
this baseline for a given health service would present opportunities to compare observations by different assessors and perceptions of participants in the same program at a different point in time (p. 931).

Rivkin’s work has been further developed in more contemporary scholarship. Draper et al (2010), for example, revisited this methodology in an attempt to continue the development of an instrument that describes community participation and its influence on program outcomes in health services. The significant differences in this later methodology were changes to the process indicators and the values used to score each indicator along the participation continuum. I note Draper et al (2010) here particularly as an example of how Rifkin et al (1988) use process indicators that may be adapted to different settings. Pérez et al (2009) further enhance Rifkin’s framework by the addition of criteria that differentiate between target-oriented and empowerment frameworks. These include capacity building, leadership characteristics, documentation processes and ethical issues regarding participation. These indicators align closely with the enablers of participation discussed in the previous chapter - values, knowledge, collaboration and education – which are formative for the stage one study. These more recent appropriations of Rivkin’s work suggest the extensibility and adaptability of her approach, and map out a literature to which the current thesis makes a further contribution.

My reading of Rifkin’s methodology - in particular her use of the lived experiences of participants to build process indicators – solidified the methodological decision to focus the current study on developing a method for social services practitioners to begin a reflective conversation on their practice of participation. Utilising Rifkin’s approach, in combination with the concept of barriers and enablers of participation from my literature review, I set out to produce a structured discussion rubric that would provide a concrete, grounded, specific framework for anchoring a conversation on the professional practice of participation that avoids abstract discussions that could sound like ‘motherhood’ value statements.

In the chapter to follow, I present a detailed description of the steps I took to adapt a ranking scale developed by Rifkin et al (1988, p. 936), beginning with the construction of five indicators based on the barriers and enablers of participation. My use of indicators in this qualitative study is initially confined to those found only in the academic literature, with my initial stage one – described in the following chapter – intended to explore whether the indicators drawn from the academic literature were regarded as appropriate by a range of stakeholders, and also whether these indicators
needed to be supplemented with others that might emerge from the stage one study. Following the example set by Rifkin et al (1988), I undertook the stage one study, consisting of 29 semi-structured interviews with service users, staff and board of management members at three social services in the State of Victoria. My process for deciding on the use of a staged research design is documented in the following chapter. Nevertheless, my purpose was to construct the indicators contained in my adaptation of the ranking scale with real life examples of the practice of participation, in the three participating social services, which sought the experiences and perspectives of service users, workers and management. In order to achieve my goal of creating a structured tool to guide an in-depth qualitative conversation about the practice of participation, it was crucial to make the indicators real. Failing to achieve that practical resonance risked confining the study to the more abstract realm of the academic literature on participation. My goal, instead, was to enable a translation of these concepts into professional practice.

With this overarching goal in mind, the stage one study, whose design is outlined in the following chapter, had an interim, primarily methodological, goal: the study sought to inform the creation of a discussion rubric that would be both a discussion prompt and an object of analysis for the stage two study.
Chapter Five: Stage One: Validating Concepts² (Aim and Method)

As discussed above, the doctoral research was divided into two main stages. This chapter outlines the data collection method and goals of the stage one study, while chapter 6 discusses the data analysis method and major findings, including particularly the implications of those findings for the stage two study, which will be described in chapter 7. As stage one was the only portion of the research project to directly involve service users, I was determined not to exclude any service user participant because of their intellectual, physical and/or sensory impairment or limited decision-making capacity. This chapter therefore discusses the procedures followed to ensure that all participants were able to give their consent, along with a discussion of the ethical and methodological motivations underlying the details of the stage one design.

5.1 Aim of Stage One Study

The aim of the stage one study was to examine whether practitioners have an understanding of participation that is compatible with the academic literature, and also whether the barriers and enablers of participation derived from my academic literature review were appropriate and sufficient when applied to the specific context of social service delivery. The study also sought to define the context in which these barriers and enablers of participation exist, as well as to identify which, if any, barrier or enabler is viewed as having greater significance to service users and to service providers.

5.2 Stage One Ethics

The RMIT University College Human Ethics Advisory Network of the Science, Engineering and Health College approved the stage one study, which was then carried out from September 2011 to November 2011 and from February 2012 to May 2012.

5.3 Methodological Considerations

² Sections of this chapter have been adapted from Making Participation Accessible for Vulnerable Clients, (Iaquinto, 2015) included sections from this chapter, paper presented at the Disability Support Symposium, UNSW, Kensington Campus, November 2015.
As discussed in chapter 3, the scholarly literature on participation provides a number of suggestive typologies of participation, but offers few practical examples of how service providers would go about operationalising client participation in their services. Although most would agree that the full participation of clients in the services they receive is important, necessary and a basic human right, how we realise this goal remains elusive. This is particularly true among service providers offering social services to people who have historically been excluded or who have complex communication needs. A second feature of the literature is the paucity of attempts to pinpoint the level of service user involvement in the applied context of programs and services provided by these organisations, which led me to supplement the review of the literature on participation from chapter 3 with a more targeted review of the literature on selected research in IPP in chapter 4. The latter literature provides a key methodological model for the stage one study, which was informed by the concern with how to operationalise conceptions of participation and keep these concepts grounded in practical terms that are relevant to service users, and the staff and board members of social service organisations.

In addition to the more specific method models provided by Rifkin’s work, my research design was informed by collaborative, participatory and action research models - including the format for planning and conducting qualitative research put forward by Kemmis and Wilkinson (1998) - which operate from what Creswell (2007, p.21) describes as an “advocacy/participatory” perspective. This approach concerns itself with focusing on changing real practice, and Kemmis & Wilkinson suggest that it provides a means for the researcher to engage with participants, in a practical and collaborative manner, by providing participants with opportunities to first understand and examine their own knowledge, values and interactions and, secondly, encouraging participants to interpret how their knowledge impacts on their behaviour in regard to their experiences and in their practice. In adopting this participatory approach, the research is done with participants as active collaborators (Creswell, (2007, p. 22). This methodological approach is consistent with the substance of the literature on participation, and therefore offered the potential for the form and the approach of the research to express its substantive questions and concerns.

Specific method design decisions were driven by several key goals. First, I was interested in identifying examples of the barriers and enablers of participation in what was considered good practice for service user involvement. However, as noted above, the literature warned that what is described as participation by service providers often varies greatly in practice (Arnstein, 1969; Padilla et al, 2007; Cornwall 2008). This
finding, which matched my own professional experience in human and social services, greatly influenced my decision to adopt an exploratory and open-ended data collection process, with an emphasis on a collaborative and participatory relationship with participants. McNiff (2013, p. 30), like Schön (2013), views research into practice as taking the form of action research through collaboration with professional practitioners. Second, I sought an approach that would best enable me to collect examples of good practice that could serve as contextual, situated models for services to consider in improving their practice. Third, I wanted a method consistent with the goal of promoting the right of service users to have a voice in the development of their services and the right to participate fully in the services they receive. Fourth, I decided that a collaborative approach would lessen the risk of further marginalising individual participants (Creswell, 2007).

A purposive sampling method, aimed at generating a diversity sample, was chosen for the stage one study as the best method to ensure participants would be able to provide relevant data for assessing the prevalence of the barriers and enablers of participation (Yin, 2011, p. 88; Creswell, 2007). Purposive sampling also operated at the level of organisational recruitment, ensuring that the organisations selected could offer diversity in their size, program type, service delivery and in particular, service user attributes. Of the three organisations recruited, one organisation had a small group of staff and approximately 50 service users and primarily provided counselling and emergency accommodation to adolescents; a second, medium-sized organisation offered case management services to children and families; and the third setting was a very large service, primarily for people with disabilities, operating in three states across Australia.

The participants recruited from this range of settings would likely be able to offer a diverse variety of knowledge and experience of service user involvement, and each would view it from one of three organisational perspectives. At the same time, the choice of participants within organisations was informed by a desire to achieve a diversity of perspectives from within each organisation, with service users, staff members and members of the board of management expected to potentially offer different accounts of service delivery, roles, and experience of participation (cf. Yin 2011). This approach conforms to Creswell’s (2007) definition of purposive sampling as selecting individuals and sites because they can “purposefully inform an understanding of the problem or phenomenon” being studied (p. 125). In other words, participants were selected because they could potentially provide the data that was
unavailable elsewhere. The next consideration was the question of how large a sample was required.

In designing the stage one study, the primary objective was not only to obtain sufficient data to answer the research questions, but also to give participants the opportunity to elaborate on their experiences. However, given that some of the participants required support from staff and interpreters, and others were at their place of employment, it was important to keep the number and length of interviews to a reasonable level. There was also the need to balance the sample size with the concept of data saturation. While the stage one research design did not follow a formal grounded theory approach, it did benefit from key concepts from that research tradition, including the concept of data saturation, which Glaser & Strauss (1967) characterised as the point in the inquiry when no new data is collected that contributes to existing or new theories. Their concept of data saturation has since been amended and supplemented by many others (Glasser, 2001; Charmaz, 2006; Creswell, 2007). Dey (1999), for example, suggests categories that emerge from partial coding are better described as “suggestive” (p. 116) and new data that does not extend a theory as ”theoretical sufficiency” (p. 117). No matter what label you attach to the decision to stop collecting further data, Dey would consider the decision a well-informed guess, rather than an exact science.

Consistent with the concept of data saturation, data collection was ceased in the stage one study when the interviews did not produce additional data for answering the research questions. Creswell (2007) suggests the exact number required to achieve this goal is highly variable – offering 20 to 30 or 50 to 60 interviews to fully develop (or saturate) a model (p.67). As described earlier in this section, my priority was to understand the service users’ experience of participation. For this reason, interviews with service users continued until I was confident no new data would be gained by continuing to interview. This resulted in service users representing 55% of the 29 interviews completed for the stage one study.

In the stage one study, two factors influenced the number and location of participants. As stated above, the study was conceived with an advocacy perspective in mind (Creswell, 2007). This put the primary focus on service users, with the result being that service users formed the majority of the participants in the stage one study. The second factor was that, since the analysis of the data commenced immediately after the first interview, the sample size was determined as the analysis progressed,
resulting in saturation being achieved prior to the point when the number of service user participants potentially available for interview was exhausted.

The stage one study was itself divided into two parts. An initial pilot test – in the form of a collaborative conversation about the draft research method – was conducted to solicit feedback that could inform the development of the research instrument, which for the stage one study took the form of schedules of interview questions. This pilot test consisted of conducting discussions with both service users and social services professionals and was designed to test whether the interview questions were understandable and sensible to service users, particularly those considered vulnerable as described below. The second purpose was to consider the matter of consent for service user participants. Finally, the third purpose was to engage social services professionals in a practice-based conversation about the draft indicators to obtain their views on the indicators as representative of practice in social services. This approach allowed the commitment to collaboration and participation to be incorporated into the research design, as both service users and social service professionals were given an opportunity to provide feedback on the preliminary research design.

In the section to follow, I present a brief discussion on the purpose and use of pilot studies, discuss the method for the pilot test, and then discuss its impact on the final stage one study design.

5.4 Method – Pilot Test

Polit et al (2006, p. 56) suggest that researchers use the term Pilot Study to refer to a study done to prepare for a larger undertaking. Turner (2005, p. 1) makes the point that, although pilot studies are often used and their outcomes reported, there is little present in the literature about the concept of pilot studies. Nonetheless, Turner goes on to suggest that the purpose of pilot studies is mainly to avoid risk and reduce uncertainty. Teijlingen and Hundley (2002, p. 33) support the view that one of the advantages of doing a pilot study is that it might reveal some of the potential risks to the study, but they also point out that some issues might not appear until the study commences. The authors also raise the further concern of contamination. They explain that contamination may occur when the main study includes data from the pilot study or when new data is collected in the main study from participants included in the pilot study (p. 34).
The decision to pilot test the stage one method was influenced by my examination of both the extent to which service users are empowered to make decisions and how organisations apply the requirement of informed consent. In addition, the purpose of the pilot within the stage one study was to: first, assess the content, clarity and order of the interview questions and determine any gaps; construct and trial a process to obtain consent from vulnerable participants; test the concept and feasibility of the indicators of participation; and finally, facilitate a collaborative approach to the overall research design.

5.4.1 Pilot Test Procedures

The method used in the pilot test consisted of three semi-structured group discussions and one semi-structured interview, followed by a qualitative analysis of the group discussion and interview notes. Two of the group discussions were held with social service practitioners and the third with service users. The intention of the group discussion with practitioners was to examine the enablers of client participation as determined by the literature review. The group discussion with service users was to test the service user interview questions (Appendix A) for clarity and, especially, for understanding by service users with cognitive impairment, and to consider a process to obtain formal consent from this cohort of participants. The purpose of the interview with a service user of aged care services was to obtain feedback on the interview questions from a service user without impairment who was receiving social services and living independently.

The service user interview questions were adapted from Brafield and Eckersley’s (2007, pp. 116-117) work on service user involvement in supported housing. My aim in this pilot test was to determine the potential usefulness of the interview questions when interacting with service users with and without cognitive impairment, and to include service user input into the development of the interview questions.

Two group discussions were conducted, one with twelve and the other with sixteen social services practitioners. I moderated these discussions with the assistance of a note taker. All participants were students of vocational training courses I was teaching at RMIT University. The purpose of the course was to increase their knowledge of program management and possibly improve their career opportunities. Participants were selected by asking if they would like to volunteer to attend an after-class activity related to my PhD research. Approximately 50 percent of students participated. All participants were experienced in social services delivery and ranged
in age from mid-twenties to late sixties. Approximately 90 per cent were female, which is representative of this sector. The services provided by the organisations that employed these students included disability services, aged care, family services and mental health programs. Each participant also received a copy of the Plain Language Statement (Appendix B). It was made clear to all participants that their participation in the group discussion was voluntary and each participant was advised that no personal details, including their name or the name of their organisation, would be kept on file or reported in any subsequent publications. Notes were taken but no audio recordings were made. All records were de-identified at the point of collection and identities of participants could not be reconstructed from the notes.

I began by presenting a brief verbal summary of the aim and purpose of conducting a pilot test. A copy of the draft indicator below (Table 3) was presented to the participants and was used as a prompt to describe what might be considered an enabler of client participation:

**Table 3: Draft Pilot Test Indicators**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Insignificant-1</th>
<th>Limited-2</th>
<th>Fair-3</th>
<th>Good-4</th>
<th>Very Good-5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Forming Relationships</strong></td>
<td>One-sided, staff maintain control of day to daily living</td>
<td>Some acknowledgement of importance of good relationships between staff and clients</td>
<td>Users are actively encouraged to participate and make choices</td>
<td>Staff actively represent views and needs of service users</td>
<td>Users views are fully represented in all organisational processes</td>
</tr>
</tbody>
</table>

Participants were asked to use this table as a guide to develop an additional four to five indicators the group thought would enable the participation of service users in social services. My emphasis was on obtaining their direct professional experiences as practitioners in social services. Other prompts encouraged participants to consider: their personal values and how these may impact on their work; their relationships with colleagues and clients and how these relationships develop and are maintained; how organisational processes support or limit client participation; the management’s contribution to participation and their experiences of the influence of leadership on participation. Each group was given a supply of blank tables to record their indicators and descriptors, and given approximately 30 minutes to complete the task. The table below summarises the service providers’ results, which were transcribed from handwritten tables:
Table 4: Pilot Test Summary of Results

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Insignificant-1</th>
<th>Limited-2</th>
<th>Fair-3</th>
<th>Good-4</th>
<th>Very good-5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information access</td>
<td>Not informed or consulted about processes, no “road shows”</td>
<td>Staff received training. NSW Dept. of Planning/Housing key areas of implementation, <em>should there be two definitions here?</em></td>
<td>Presence limited &amp; led to decisions, family involvement process driven</td>
<td>Clients consulted &amp; actively involved, implementation &amp; review process</td>
<td></td>
</tr>
<tr>
<td>Values</td>
<td>Plan without input, tokenistic</td>
<td>Basics being implemented</td>
<td>Education and discussion on process with all concerned</td>
<td>Analysis and discussion on process with all concerned</td>
<td></td>
</tr>
<tr>
<td>Sub-Category</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change in service delivery</td>
<td>Person does not voice what would like to participate in</td>
<td>Client voices interest in different activities</td>
<td>Client chooses which activity they do, with assistance from staff</td>
<td>Client decides their own programming</td>
<td>Client decides their own programming and explores new options</td>
</tr>
<tr>
<td>Change in service model</td>
<td>Rollout of model &amp; match with service delivery, causing friction</td>
<td>Client and service having collaboration</td>
<td>Basic training, Support Team developed and evolving</td>
<td>Fundamentally understood And commitment given</td>
<td>Support services working together and all involved committed and trained ownership taken</td>
</tr>
<tr>
<td>Leadership</td>
<td>Team fragmented and high turnover, limited structure</td>
<td>Learning as we go – rehash of IPP</td>
<td>Commitment from staff and board</td>
<td>Attendance And involvement</td>
<td>Clients embrace, Lead have knowledge</td>
</tr>
<tr>
<td>Family response</td>
<td>Staff decides what family needs to know to be involved.</td>
<td>Family, staff and client are involved</td>
<td>Client in consultation with staff</td>
<td>Family are involved in PWS life</td>
<td>Clients make informed decisions about what they disclose</td>
</tr>
<tr>
<td>Communication</td>
<td>Clients – limited communication with peers</td>
<td>Client initiates communicatio n with peers</td>
<td>Client initiates communicatio n with peers and staff</td>
<td>Client initiates communicatio n with peers, staff and community</td>
<td>Client communicates well with peers, staff and community</td>
</tr>
</tbody>
</table>

While the groups were completing the task, I circulated among the groups listening to their discussions. One particular group argued strongly for family response to be listed as a separate indicator. Another thought communication should also be included. Once the groups had completed the task, we discussed the language used, such as using collaboration instead of communication, as well as some of the descriptors used for
indicators, such as change in service model and change in service delivery were actually forms of collaboration.

The sessions concluded with my circulation of a copy of what I referred to as a draft rubric, which is presented below (Table 5). Once the groups had an opportunity to study the draft rubric, most participants thought it adequate. Suggestions relating to the descriptors included proposals for reframing indicators and some further discussion on the language used. One group focused on the relationships indicator, pointing out that it was limited to relationships between staff and service users only. This group proceeded to comment on the importance of service users being assisted in maintaining relationships with family and friends.

As a result of this discussion, additional questions were added to the interview schedules for service users and staff. Generally, the participants agreed that their suggestions could be addressed in the semi-structured interviews through properly formed questions, and I became more confident of the potential usefulness of my adaptation of the ranking scale from Rifkin et al (1988, p. 936).

The third group discussion involved five adult male service user participants, who had previously lived in large congregate care facilities for many years before moving to their home. The session took place in their staffed group home in suburban Melbourne. The house supervisor was a former student who arranged permission for me to visit their home. The supervisor discussed my visit with the residents to determine if there were any objections. This group home was chosen because of the capacity of these adult participants to confidently make choices. As an example of their capacity to participate: I had a previous professional association with one of the residents, who remembered me and asked about my children who he had played with as a child living in a residential unit next door to where we lived. This was at a facility for people with cognitive impairment where I was employed as Chief Executive Officer from 1987 to 1995. My personal view of these participants is that, given their level of functioning, they would not be institutionalised as children in today’s service system for people with cognitive impairment.

In general, I informed them that my intention was to study the program (accommodation services) that they were receiving, and that I was interested in hearing about all the good and any bad things about living in their house. I informed them that they could leave at any time if they no longer wished to participate, and that I would not be angry or upset if they decided to leave. They were asked if they were willing to continue the discussion to which they all agreed.
Note that no written consent form was used in this situation, but the willingness of all participants was assessed verbally and through close observation of body language. All appeared to be eager to participate in the discussion. All seemed perfectly capable of making their own decision about participating. I followed my list of questions for service users (Appendix A), testing to see if they understood the question and were able to answer. Questions included: “Do you like living here; do you feel safe; do you get on with staff; do the staff ever ask you what you think about living here; whom do you ask if you have a problem; do you see your family much; who’s the boss here; and, is there anything you’d like to change here?”

This session, which lasted 30 to 40 minutes, resulted in minor alterations to improve the clarity of the wording, some changes to the order of questions and the inclusion of additional questions. For example, “did you choose the program you attend?” was changed to “how did you find out about the program you attend?”, “did you get to choose this program?” and “were there other programs you wanted?”

The final pilot session was held at the home of a woman receiving in-home aged care services from a community service organisation in a rural community in Western Victoria. The program manager of this service was a former student at RMIT University, who arranged organisational approval for access to this service user. Also, this participant was capable of choosing whether to participate or not. The purpose of this session was: to test the schedule of questions for comprehension by a service user without impairment; to see if they provided responses that were in line with the research questions relating to the study; and to determine whether or not there were additional questions to consider. The client was able to understand the content and purpose of the questions asked, but they did not offer any suggestions for additional questions.
Table 5: Draft Rubric

<table>
<thead>
<tr>
<th>Leadership</th>
<th>Management</th>
<th>Processes</th>
<th>Values</th>
<th>Attitudes and Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintain status quo changes in management positions</td>
<td>Not inclined to consider the importance of participation of some personnel</td>
<td>Non-existent</td>
<td>Limited: 1</td>
<td></td>
</tr>
<tr>
<td>Some personnel to obtain user views and opinions</td>
<td>Some participation encouraged to meet short-term and long-term objectives, participation is role modeled</td>
<td>Limited: 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active seek input from service users</td>
<td>Participation is role modeled because it contributes to outcomes for service users’ roles</td>
<td>Limited: 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service users views are incorporated into mission and values</td>
<td>Users’ views are always included as part of normal practice</td>
<td>Limited: 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Processes for user participation in service user role</td>
<td>Participation is role modeled because it contributes to outcomes for service users’ roles</td>
<td>Limited: 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Forming and Maintaining Relationships

| One-sided staff acknowledgement of day to day living needs, client needs, individual choices, relationships | Good: 1 |
| Some acknowledgement of the importance of information only | Good: 2 |
| Some acknowledgement of the importance of the staff, clients and their needs | Good: 3 |
| Staff actively seek to understand and represent views of service users | Good: 4 |
| Views of service users are actively sought, and then incorporated into day to day operations | Very Good: 5 |

5.5 Stage One Study - Indicators

After the pilot study was completed, final indicators were selected for the stage one study, and the Draft Rubric displayed in Table 5 was developed. For this stage of the research, the Draft Rubric was not shared directly with research participants, but was rather explored through a conversation organised as an open-ended, but semi-
structured interview that explored the meaning and usefulness of several indicators drawn from the analysis of the academic literature on participation, including: attitudes and values; relationships; processes; management; and leadership. Informing the research design in this stage was the professional judgement that the practice of participation would be an area known to and directly experienced by participants, as contrasted with the more abstract realm of the scholarly literature on participation. In the subsections below, I briefly discuss the meaning of each indicator.

5.5.1 Attitudes and Values

The individual attitudes and values of the people within an organisation underpin the culture of the organisation. This culture influences, if not determines, how service users are treated. For staff and board member participants, the intention of this indicator was to encourage them to describe their personal values: what they believed were the values of the organisation, and, if they perceived a conflict between their values and the values of the organisation, what action if any, they would take. Participants were also asked to describe what it was like being part of the organisation and to give examples of how service users made choices. Questions for service user participants were targeted at understanding their experience of attending/living at the organisation: did the organisation help them feel safe, did they feel able to have friends and were they assisted in maintaining their connections to family and friends external to the organisation? This indicator also attempted to determine whether staff and board members possessed values and displayed attitudes that supported or restricted service user involvement.

5.5.2 Relationships

The focus of this indicator is the importance of establishing productive relationships between service users and staff, among direct services staff and between management and staff. The literature suggests that, without these relationships being established and maintained, service users are unlikely to be successful in meeting their goals. Participants were asked to describe their relationships with staff and service users and how these relationships were formed. The data sought in this indicator related to being treated, or treating people, with dignity and respect, as well as establishing trust. Also examined was whether service users knew to whom to
speak if they had a problem, and whether they were ever questioned about what they thought of the services they received.

5.5.3 Processes

This indicator examined the organisation’s processes in an attempt to determine if the established processes within the organisation inhibit or facilitate participation by service users. The intention was also to gain an understanding of the organisation’s approach to involving service users in their individual planning processes, and to describe their formal and informal feedback mechanisms for service users. Service users were asked: about having some form of a plan that described what actions would be taken and what goals were expected to be achieved; about being involved in the construction of their plan; and to describe how they choose what programs they attended. Staff participants were asked to describe the decisions a service user would make in the course of a typical day.

5.5.4 Management

The management and leadership styles of individuals can have a significant impact on the performance of an organisation. The intention of this indicator was to determine the impact of management’s approach on service user involvement. Questions were designed to determine the frequency and significance of the interaction between management and staff, and management and service users, and the impact of management structure on participation.

5.5.5 Leadership

Leadership communicates the vision and direction of an organisation and how leaders model the appropriate values and behaviour for people within the organisation. The intention of this indicator was to determine the impact of leadership on the organisation in regard to participation for service users, and to describe how the leadership of the organisation responds to the needs of service users.

5.6 Data Collection Method - Stage One Main Study
The main stage one study was conducted at three community sector social service organisations, with two located in the Melbourne metropolitan area, and one in a large regional centre in the State of Victoria. A total of 29 individuals were interviewed, which included sixteen service users, seven staff members, mainly at team leader status, and six board of management members. The recruitment procedures, characteristics of participants and the process used to assess their capacity to give informed consent to participate in the study are discussed in the following section.

5.6.1 Recruitment - Organisations

The recruitment of these organisations was assisted by my familiarity and prior personal contact with all of the organisations that participated. I had gained this knowledge through many years of employment in the Department of Human Services Victoria (DHS). However, at the time the study was undertaken, I was no longer employed by DHS and had no relationship in a professional or formal association with any of these organisations. Neither the organisations, nor I, stood to benefit from the inclusion of any specific organisation in the research.

In approaching potential organisational participants, my preference was for a level of diversity in size, geographic location, program type, service delivery type and service user attributes, across the participating community sector organisations. Collectively, the five organisations I originally approached met these criteria, as well as offering potential opportunities for links to other social service organisations.

To initiate the recruitment process, I emailed an invitation to participate in the stage one study, along with a copy of the Plain Language Statement (Appendix B), to the Chief Executive Officers at five CSOs whom I had met in my professional work. They were asked to express their interest in participating in the study by responding by email or direct contact by telephone. The result was that all five CSOs expressed their interest in participating, but two noted that, due to organisational processes they were currently undertaking, they would be unable to commence their participation within the study timelines. The remaining three were contacted by telephone and emailed additional information regarding the study. This information included the service user consent form (Appendix D) and plain language statement for service user participants (Appendix C) with and without cognitive impairment, and staff and Board of Management participants’ plain language statement (Appendix B). The remaining two organisations were advised that they would be contacted at the time they were
available if further data collection were required. The participating organisations did not receive advance copies of the schedules of interview questions, to eliminate the possibility of participants being coached prior to interview. Finally, I arranged a meeting that included the Chief Executive Officer, senior staff and at least one member of the Board of Management.

At this meeting, I described the purpose of the study, emphasising the fact that this was a staged study and including a discussion of the research questions (see Appendix B). The participants were also informed of my requirement of a minimum number of two staff members in leadership or management positions with direct contact with service users, two service users currently in receipt of services from the CSO and two board of management members. The numbers of participants could vary, but this was the minimum requirement for the CSO to participate in the study. The significant factor in determining the number of participants utilised was my dependence on: the numbers of volunteers; the need for all participants to have the capacity to give their consent; and the suitability of the data collected. The process for recruiting participants was discussed, and it was suggested that notices be posted on bulletin boards, and included in newsletters to families and the research project placed on the agendas of staff and service user meetings. The participants were also informed that interviews for all participants would take place at the location where the participant attended their service or place of work. I also discussed the procedures for managing any unforeseen circumstances and the availability of staff to provide assistance to participants if required.

A 'snowball technique' was also used at this meeting. Yin (2011, p.312) defines a snowball sample as a source of participants that have been referred by another source. This was achieved by asking those present if they knew of organisations that, they believe, have effective participative processes in place that might be interested in participating in a further study. As a result, two additional CSOs were noted as possible participants for stage two.

The characteristics of the three organisations who participated in this stage of the study are as follows. (CSO1) is small in size with less than 100 service users and located in a regional centre in the State of Victoria. Its cohort of service users consisted of young people (12-25 yrs.) receiving services that included emergency accommodation, family mediation, and counselling and referral. I considered it crucial to include this cohort’s experiences and views of participation in the study, since they would represent a large proportion of service users in community service
organisations. Also, my experience working with this cohort in various services assisted me in establishing relationships with these participants. Making the participant comfortable is the first step required to facilitate conducting interviews in a relaxed, non-threatening and respectful manner (Yin, 2011, p. 125). Although familiar with this cohort, I had no direct experience of the services provided by this CSO which include a youth refuge and family counseling services. Another advantage of including CSO1 was their maintenance of strong links with other youth and health services in their region. It was hoped this fact would contribute to my use of the snowball method to obtain participants for the further study. CSO1 would be considered typical of a small, newly established community service organisation providing adolescent services.

(CSO2) primarily focused on families rather than adolescents; these service users include children and their families, including some families with children with a disability. This organisation provides a wide variety of family support programs to more than 500 service users. Their services include support for children with special needs, family relationships, and disability support.

This organisation was included mainly for its focus on families and my interest in learning how an organisation involves families in their services. A second consideration was the organisation’s long history of providing services to families in their community. Less significant, but also a factor in an effort to have some balance in the participating organisations, was the size of CSO2, which would be considered a medium sized organisation.

(CSO3) is representative of services that were founded by a group of families with children with a specific condition for which there were no specialist services. Many community service organisations in existence today, particularly those providing services to people with disabilities, were founded by individuals, usually parents, seeking assistance for their child when the only option available was institutionalisation. This organisation was also of interest because of how it has evolved over time. It had recently repositioned itself as a major provider of services to children and adults, some with multiple disabilities, across a number of states in Australia in anticipation of the introduction of the NDIS. A second feature of this organisation is that, unlike the other organisations in the study, it provides permanent accommodation to a large number of service users, with a range of physical, sensory and intellectual disabilities.
This is also a large organisation providing services to approximately 3000 children and adults, some with multiple disabilities in more than one state in Australia. In addition to permanent accommodation, they also provide respite services for children and adults as well as day activities and specialist services. They have been a provider of these services for more than 50 years.

5.6.3 Recruitment - Service Users

Service user participants received information about the study in different ways. Some attended regularly scheduled service user meetings where the study was discussed. Others would have seen information flyers posted on bulletin boards at the community service organisation they attended, and the remainder were told about the study from another service user or staff member. All service users were 18 years or older, and all expressed their interest in participating in the study through a caseworker or direct care worker who made contact with me by email or phone.

Thirty-eight service users at the three community service organisations volunteered to participate. The selection process for choosing service user volunteers for interview was dependent upon their days of attendance at the CSO, since some service users did not attend every working day. I attempted to schedule as many interviews as possible on the same day. When I attended a CSO to conduct interviews, staff would advise me which service user volunteers were present. Staff member and Board of Management participants were also scheduled for interviews on these days.

Service users participated in four different styles of interview format. These included four service users in a group interview, three at individual interviews, five with a support person present and four with an interpreter present. All interviews were held at the community service organisation’s premises, which were familiar to participants and provided a safe atmosphere for the interviewees. These locations also provided easy access to support staff if required during interviews of service users. However, no unforeseen circumstances were experienced during any of the interviews. I ceased conducting interviews with service users when sixteen service users had participated in interviews.

5.6.4 Obtaining Consent – Service Users

As noted above, it was my intention to not exclude any service user from participating in the study on the basis of their having an impairment or limited
decision-making capacity. This raised the ethical issue of obtaining their consent to participate.

Arscott et al (1998) adapted an Ability to Consent to Treatment Questionnaire, developed by Morris et al (1993), to assess whether the five questions could be used to determine the ability of people with cognitive impairments to consent to research. The results of their study were that participants had the most difficulty with questions regarding the advantages and disadvantages of their participation, and nearly half of the participants understood they could withdraw from the research if they wished. This process was adapted for use in the stage one study.

The explanation process utilised in the stage one study for some service user participants consisted of my reading of a statement based on the Service Users' Plain Language Statement (Appendix C) to the participant prior to commencing the interview. The summary included the following:

I am going to speak to you for about half an hour; I want to help make better programs at this CSO; I want to know what you do when you come here; I want to know who decides what you do; you can stop talking to me at any time.

Participants were then asked if they were happy to keep talking to me and if it was OK for me to use my recorder. The recorder consisted of a pocket-size digital recording device. Participants were also reminded they could stop talking to me at any time. The summary was read once and repeated again if necessary. This procedure was approved by RMIT ethics committee.

The work of Cameron and Murphy (2007, p. 115), who outline a number of ‘positive’ and ‘doubtful’ indicators for giving consent, was also applied, as was my professional experience with this cohort. Positive indicators included: high engagement, such as eye contact and body language; positive verbal and nonverbal responses indicating a willingness to participate. Doubtful indicators were: low engagement such as lack of eye contact, indifference; agreeing but not understanding; and ‘ambivalent nonverbal responses’ such as negative facial expressions and body language. If part of a participants’ response, such as their pronunciation of a word, was difficult for me to interpret, participants were asked to repeat their answer or I turned to carers for assistance if appropriate. My assessment was that each of the service users available for interview had a reasonable understanding of what was taking place.
The questions incorporate three elements of information, competence and voluntariness, and seek to determine the extent of the participant’s ability to consent to participating in the research (Arscott, et al, 1998).

Once this process was completed and I was satisfied that the participant could give consent, the consent form (Appendix D) was read to or by the participant; they were asked if they understood and if they were willing to sign the consent form and continue with the interview. If their impairment prevented them from making their signature or mark on the consent form, their verbal and/or nonverbal responses were noted. Watson (2016, p. 72) refers to this as acknowledging a persons’ expression of preference.

Table 6: Service User Attributes

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Service Users</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Mean Age</td>
<td>39</td>
<td>41</td>
</tr>
<tr>
<td>Age Range</td>
<td>18-57</td>
<td>18-74</td>
</tr>
<tr>
<td>Service Users with Physical and Sensory Impairments</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Service Users with Cognitive Impairments</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Service Users in Residing in Group Homes</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Total Service Users Accessing Disability Services</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Accessing Youth Support</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Accessing Family Services</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Parent of Service User</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

5.6.5 Recruitment - Staff

The primary criterion for staff participants was that they held a position as a supervisor or team leader, and that this position included a daily component of time
where they provided direct service delivery to service users. I was also conscious of ensuring a gender balance of staff participants.

A total of fifteen staff from the three CSOs volunteered to participate after either seeing the notice or attending a staff meeting where the study was discussed. All staff that volunteered to participate were emailed a *Plain Language Statement* (Appendix B) prior to scheduling their interview.

The process used for selecting staff for interview was dependent on their days at work, their availability for interview on that day and the number of service user interviews I was conducting on that day. All staff member participants were contacted by email or telephone to schedule the time and date for their interview. All participants were asked if they had any questions or concerns at this time and were asked this again at the interview. Individual interviews were conducted with all staff and these were held at their place of work during business hours. Also, all staff participants agreed to the recording of their interview. Interviews for staff participants ceased after seven interviews had been conducted. The seven staff participating in the study included two males and five females. All were at manager or team leader level, and none had less than three years’ experience at their CSO.

**5.6.6 Recruitment - Board of Management Members**

The board member who was present at the initial meeting I organised with the CEO and senior staff, ultimately volunteered to participate in the study and provided me with a list of board members. All board members contacted agreed to participate in the study as long as they were able to attend the interview at a time convenient to all concerned. For all but one board member participant, the most convenient time was prior to their monthly Board of Management meeting. One board member participant was interviewed at their place of work. The remaining board member participants were interviewed at the CSO’s premises. The first face-to-face contact with all except one board member participant, occurred at the time and place of the interview. I previously knew a male board member as a former colleague, but I had not had any contact with him for more than ten years. All board member participants agreed to the recording of their interview.

Six interviews were conducted with Board of Management participants. Of these, four were males and two were females. Their experience as board members ranged from two years to more than twenty years, but not all board member participants had
previously been on the board of a community service organisation providing human services.

5.7 **Semi-Structured Interviews**

The interview questions were grouped under five categories, which were based on the indicators described earlier in this chapter. These included *Attitudes/Values, Relationships, Processes, Management* and *Leadership*. Two schedules of interview questions were used: a schedule for staff and board members (Appendix E), with slight variations in phrasing at interview depending on whether the participant was staff or board member; and a schedule for service users in general with slight variations to accommodate service users with limited communication skills (Appendix A). Although the questions in all three schedules were grouped into the five categories noted above, they differed in wording according to the participant’s role in the organisation and their ability to comprehend the questions.

All participants agreed to the recording of their interview, and this was noted on the signed consent form. A digital recording device was used to record all interviews with the exception of one service user interview, which was not recorded due to a technical issue. Detailed notes were taken instead. Recordings were transferred into NVivo 10, and I transcribed all recordings as soon as possible.

A table of the interview formats used, the format type and the number of participants in each format of interview is included in Table 7 below.

<table>
<thead>
<tr>
<th><strong>Table 7: Summary of Interview Formats</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Format</strong></td>
</tr>
<tr>
<td>Group</td>
</tr>
<tr>
<td>Individual</td>
</tr>
<tr>
<td>Individual with support</td>
</tr>
<tr>
<td>Individual with interpreter</td>
</tr>
</tbody>
</table>

115
This chapter has described the data collection method and methodology for the stage one study. The following chapter presents the data analysis method and methodology for this study, discusses the results, and analyses their implications for the design of the stage two study, which will be discussed in chapter 7.
Chapter Six: Stage One Study Results

The previous chapter outlined the methodology, and described the data collection method, for the stage one study. Even where the data collection process follows a semi-structured form, as in the stage one interviews, the open-ended and exploratory nature of qualitative interviewing generally requires a further process to structure and interpret the raw data. This chapter presents the data analysis method used in stage one, describing the techniques used to code and interpret the raw interview data to create what Boyatzis (1998) describes as the "structure of a useful, meaningful code" (p. 31). The chapter then presents an overview of the coded data, in the form of illustrative quotations and stories that have been organised thematically, using the five themes presented in the previous chapter: Values; Relationships; Processes; Management; and Leadership. The data under each theme is explored for what it suggests about the barriers and enablers of participation. In conclusion, the chapter analyses the implications of the stage one data for the questions and methods of the stage two study, which is the subject of chapter 7.

6.1 Method and Methodology of Data Analysis

The data analysis involved coding the raw interview data into the five themes discussed above: Values; Relationships; Processes; Management; and Leadership, which represent the barriers and enablers of participation discussed in previous chapters. Table 8 presents a list of these themes along with their descriptors.

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Table 8: Five Themes and Their Descriptors

<table>
<thead>
<tr>
<th>Themes</th>
<th>Descriptor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Values</td>
<td>Personal and organisational values influence an individual’s approach to their work and how an entity conducts its business.</td>
</tr>
<tr>
<td>Processes</td>
<td>Processes that support client choice by providing opportunities to influence available choices and exercise the right to make decisions and/or to practice and learn decision-making.</td>
</tr>
<tr>
<td>Management</td>
<td>Management decisions are based on the principles of equity, fairness and the acknowledgement of client needs.</td>
</tr>
<tr>
<td>Relationships</td>
<td>Relationships between all actors are built on dignity, respect, honesty and trust.</td>
</tr>
<tr>
<td>Leadership</td>
<td>Role models organisational values and behaviours and provides the vision for continuous improvement.</td>
</tr>
</tbody>
</table>

While quantitative researchers often enjoy a reasonable consensus over the methods required to establish validity and reliability, qualitative researchers must often navigate a range of competing approaches for thinking about validity and reliability. In coding the data from the stage one study, I navigated these concerns by: mapping a process for analysis of the interview information that reflected Boyatzis’ (1998) advice on developing codes and avoiding projection; adopting Creswell’s (2007) suggestions on validation and reliability; and adopting Charmaz’s (2006) method for coding. I discuss each of these decisions briefly below.
Methodologically, I have drawn particular value from Boyatzis’ work, because his methods of thematic analysis have their roots in the world of organisational behaviour and the social psychology of people in management (p. ix). Boyatzis begins by stating that learning how to use thematic analysis is assisted if the researcher has a background in the field being examined. As noted in the Preface, I have training and experience in managing human services, and this experience has provided me with insight into where to look, and what to look for, which Boyatzis (1998, p. 11) refers to as *what to see* - when analysing the raw data from the interviews. Nevertheless, Boyatzis warns that being overly familiar with the material may cause the researcher to provide responses, rather than interpretation. I believe I was able to lessen this risk through my use of autoethnographic reflexivity, as discussed in Chapter Two, as a check on projection and as a means to bring together participant and practitioner reflections.

Boyatzis (1998) describes the philosophical debate that the topic of *reliability* evokes, specifically in relation to postmodernist critiques that sometimes view the concept of *reliability* as tainted with positivist ‘bad values’ (p. xiii). In Boyatzis’ view, however, *reliability* is simply “consistency of judgement” and need not carry strong positivist associations (p. 146). Boyatzis advises that researchers can prevent or avoid projection by applying consistency of judgement, developing explicit codes, using several people to encode the information and focusing on the raw data in developing codes.

Creswell (2007) further suggests that validation is an attempt to assess the ‘accuracy’ of the findings and views it as a clear strength of qualitative research, regardless of its type. He bases this assessment on the time spent in the field building relationships with participants and understanding the culture of the organisation, which adds value and accuracy to the study (p. 207). My knowledge and experience of the participants and their services placed me in an advantageous position as a credible person to conduct research in these services. This enabled me to conduct interviews, with vulnerable service users in particular, in a thoughtful, sensitive manner.

As the coding proceeded, copies of the coded transcripts, including the applied schedule of codes, were forwarded to my supervisors (lead researcher) to check for the relevance of the codes to the research questions and consistency in regard to coding decisions. Creswell suggests discussing and confirming an agreement between the parties on exactly what is being checked. One of the few studies on inter-rater
reliability at the time of Creswell’s (p. 210) work was conducted by Armstrong et al (1997). The study found there was not a divergent range of views, but consensus among the analysts in regard to how themes were mapped against the data. The authors suggest that this study showed that qualitative data analysis enables a conversation between the researcher and the data, where the views of the researcher greatly affect the interpretation (Armstrong et al, 1997, p. 605). In spite of this, the study showed a significant level of consistency among analysts. This lends support to Boyatzis’ (1998, p. 13) view that a diversity of perspectives contributes to the reliability of the analysis.

Although no formal agreement was completed between my supervisors and myself, we did agree that coding decisions were my responsibility. Only my supervisors and I had access to the transcripts and coding schedules during the data analysis stage of the stage one study. Although their advice was constructive, I decided to adopt a strategy that closely resembled Charmaz’s (2006, p. 3) advice to study my initial interviews and begin to sort this data by labelling each piece with a code that represented an area I was interested in pursuing. As Charmaz describes, I would link these codes to the next interview and then the next for comparison, to gradually build a better understanding of the data I was collecting.

As the number of codes increased, I returned to the interview recordings and transcripts in order to determine from where in the data a particular code had emerged. I did this, not only to immerse myself in the data, but to also decide whether certain codes had similar meanings and could be merged. An example of this process was the initial decision to add a sixth theme - Organisational Structure - after the initial coding, which I then reversed when I later determined that the code Service Delivery Style could incorporate any references to organisational structure. Returning iteratively to the recordings and transcripts also allowed me to check whether my data and coding connected to my original research questions, and determine if I had missed potentially useful insights within the data. Yin (2011) refers to this as the compiling phase of data analysis, which he suggests differs significantly from data collection. In the compiling phase, the researcher is able to embrace the information in a more “thoughtful” and “measured” pace (p. 183).

By the end of the iterative coding process, I had decided that the initial schedule of fifty codes included some duplication of codes and some required their descriptors to be edited in an attempt to achieve an improvement in the level of clarity for each code. Other codes, which emerged only in early interviews, were either deleted
because of a lack of any further comments or merged with other codes. The results presented in this chapter rely on the final, settled list of codes, and use selective, illustrative quotations and stories to communicate how the data support the interpretations.

For transparency, however, Table 9 in Appendix K provides a detailed description of the changes I made to the themes and coding schedules over an eighteen-month period, as well as a comprehensive presentation of the analysis of the data, with applicable quotes from all participants. The descriptor for each code, and all deleted and merged codes, are included. Identical codes were used for staff and board member participants.

In the sections below, I discuss each theme in turn, interspersing illustrative examples from the data with preliminary interpretations, before panning back to analyse the findings overall toward the end of the chapter. Note that this presentation differs somewhat from the more traditional thesis convention of first presenting the findings in one consolidated section, and then offering interpretations in a separate, subsequent section. I have organised the presentation in this way to recognise how ‘thick’ qualitative data (Geertz, 1973; Ryle, 2009) is often difficult to present separately from its interpretation; I have followed the common qualitative research convention of intertwining findings and analysis (Rhoads, 1995; Sidel, 2006; Trujillo, 1992; Yin, 2011).

6.3 Values Theme

The Values theme captured comments from participants that disclosed the personal values of participants and the organisational values of the service provider. Argyris and Schön (1974), along with others noted in Chapter Two, support the notion that personal and professional values can have a significant influence on organisational values in both positive and negative ways, which may support or impede the development of effective relationships with service users. This theme sought to explore whether there were a set of specific values or beliefs that impacted on service user participation within the social services in the stage one study.

Interestingly, of the service user participants interviewed, only one made any reference to the theme of Values: a service user who was an adolescent in a residential program said, “staff treat us with respect”, when asked what it was like to live at the service. In other words, this service user was stating their satisfaction with the
relationship they have with staff at this service. This service user has family intervention orders against his family, which in the State of Victoria protects this service user from a member of their family who has been violent towards them. This comment may therefore suggest that the service provider is meeting the service user’s need to have a safe place to live, and therefore this may not have any direct relevance to the Values theme as defined for purposes of this research, or to a service user’s level of involvement in the service. Nevertheless, the comment may imply something about how the personal and professional values of staff influence their approach to service delivery and their interactions with service users. The values of staff most likely influenced how service users were treated, which impacted on whether or not the needs of service users were being met. Staff and board member quotations relating to the Values theme, which are outlined below, support this interpretation.

In contrast to the service user data, staff and board member interviews often referred directly to their personal values in discussing their experiences in the field, as well as the manner in which they approach their work. Many responses could be interpreted as representing their intrinsic motivations for working in social services. For example, when asked if they thought there was a good match between their personal values and the values of the organisation, typical responses from staff participants were:

_I think if there was a big mismatch I wouldn’t stay; that’s why I left (CSO)_

_I really love working here, it comes through so much that everyone believes in it and sees value in every person that walks through that door_

_Yes, absolutely because I couldn’t work for an organisation that didn’t. That’s why I left (CSO) and why I won’t go back. It’s ‘an incongruence’. You can have organisational values but how do people in the organisation actually live them?_

These quotations support the notion that shared values within an organisation contribute to a positive work environment that may benefit service users by supporting their right to participate. They also highlight that shared values do have some significance for staff, as the quote below suggests:

_Having gone through the exercise of putting together our mission and our values which some people see as just one of those corporate things but the pride everybody took coming to our mission really was just a clarification that staff and board members, everybody, have that same set of values, it’s really interesting putting the clients first._
This manager expressed the significance of shared values from their perspective of recruiting people with similar values:

_We realised when trying to decipher which are the important key areas to put into a position description. We said well, that’s a value, are we recruiting to values? I think we should recruit to values. How do they become our values, my values, unless I am recruited to them?_

When asked about their personal values, however, board member participants from one CSO responded in a manner that suggested they did not appreciate the difference between personal values and experience:

_For me it’s the 36 years of experience of working with people with disabilities. The empathy I have for people with disabilities. I didn’t have a clue about people with disabilities. I was an engineer by trade. I jumped at the chance to be on the board here._

A second board member from the same CSO made a similar comment: “I suppose my greatest attributes are my years of experience, knowledge and participation”, and then went on to say:

_No family makes a choice to have a child with a disability. So these clients that we work with have never been the great joy and celebration in life that our children have been._

This disturbing comment captured a sense of moral superiority over service users, rather than a concern for their dignity and human rights. Further reflections from these board members reinforced this impression. In particular, when asked to describe their relationship with service users, the response was, “we have a very high respect for them” and a comment from another board member regarding their motivation to be on the board because they “have a genuine commitment to people that are less fortunate”. Another mentioned receiving financial support: “It was only last year after all the years we’ve been on the board that we’d get some financial compensation for being on the board”. The implication here is that board member behaviour needs to be applauded and rewarded, while the life experiences of service users are less deserving of respect. Such values might be expected to generate barriers to service user participation, for reasons discussed in previous chapters: the literature suggests that staff or board members who are positive about their work and respectful of the people they work with, have a greater potential for achieving
meaningful relationships with service users, which in turn contributes to service user participation (Argyris & Schön, 1974; Spence Laschinger, et al, 2009, p. 303).

Strikingly, the board member participants from this CSO seemed to hold values and beliefs that differed greatly from the staff participants from the same CSO. The comments below are reflective of different perspectives on who merits respect:

The (CSO’s) values are treating (service users) with respect. Providing them with information they need to make choice and assisting them with resources. Validating what you believe in and what the young person is telling you.

It (CSO) certainly has the view that relationships are important and the staff should be working to establish relationships that are respectful and have dignity with (service users).

It depends on the quality of the relationship you establish with the (service user), but you also need to have a degree of respect.

These comments may represent an organisational culture that first empowers their workforce, which in turn facilitates building positive relationships with service users (Spence Laschinger, et al, 2009, p. 303).

Participants were asked to articulate their understanding of what the organisation is trying to achieve with service users. Staff and board members presented as being very clear about what they were trying to achieve with service users. What was significant for these participants was whether or not this aligned with their belief of how this should be achieved. This seemed to be more of a reflection of their personal and professional values: “I suppose I see myself as an advocate for young people” and “being a voice for a child”. The corporate values from mission statements and strategic plans seem to only become significant to staff when they are not evident in their service delivery or conflict with their own values and attitudes as a professional.

In discussing the purpose of this research with staff and board member participants, I noted that the human rights of the individual service user to be involved in all aspects of the services they receive is now recognised in state and federal legislation in Australia. All staff and board member participants acknowledged their respect and support for the fundamental human rights of services users and the requirement to involve them fully in services. One staff participant said, “I have a social justice streak. I do this because I really believe in social justice, it’s my life and it’s my work”. A board member said, “It is the right of the individual to make decisions
about their own life”. However, no staff or board member participant articulated specific examples of how they would ensure the rights of service users were addressed in the day-to-day practice of their organisations.

To sum up, the data coded under the Values theme, from which the illustrative quotes above were drawn, was consistent with the international literature on participation, which predicts that an individual’s personal values will influence their behaviour and treatment of service users. Values underpin how staff approach their work and, in particular, can support or hinder their practice of establishing relationships with service users. Moreover, having values that are shared with colleagues and with the entire organisation in general, seemed to strengthen the resolve of all staff to work together for a common purpose. In the case of the participants in this study, their common purpose was to meet the needs of the service users.

Both staff and board member participants described instances of how the values and the leadership style of individuals impacted on the organisational environment for both service users and staff. In one example, a participant referred to management as “genuine” and “out to do the right thing”, which the participant described as being “contagious”, as all staff began to behave in that way. In another organisation, one worker initially viewed management as being “risk averse” in their approach to service delivery. In the mind of this staff participant, this approach limited opportunities for service users by inhibiting the problem-solving initiative and creativity of staff. A change in management brought about an emphasis on creating a collaborative and less restrictive environment, which resulted in what that staff member viewed as a more reasonable approach to risk taking.

These issues are examined further in the stage two study, whose design is guided, in part, by the work of Agbényiga (2011) into the influence of values on organisational culture and how the culture of the organisation impacts on its service delivery. The stage two study was therefore designed to enable further investigation into the effect of organisational values on service users particularly, exploring questions such as: (1) what are the articulated values of the organisation; (2) how do staff and service users perceive these values; (3) do the values of the organisation influence the recruitment and retention of staff; (4) in what ways do these values influence service delivery; and (5) how are service users valued in this organisation? The data coded under the Values theme was not the sole influence, however, on the
stage two study design. To capture the other influences, I will summarise the findings from the data coded under other themes.

6.4 Processes Theme

The Processes theme captured data concerned with the establishment of organisational processes that provide opportunities for service users to express their own perspectives on what support they need and offer their own interpretations of the services they receive. Processes can facilitate establishing relationships between service users and staff, among staff, and between staff and management, within the operational environment. They underpin an organisation-wide commitment to supporting service users to reach the level of participation they wish – from information sharing to co-design of services.

Within this theme, trust emerged as a key factor in establishing or destroying relationships between service users and staff. Although not articulated in these terms by service user participants, service users implied an expectation that their confidentiality will be maintained. The statement included below is an example of how a breach of trust can impact on the well-being of the service user and their continued involvement in the service:

*I'd spoken to other counsellors about a year ago but it didn’t work out. They gave me up to my parents when I told them something I didn’t want my parents to know about. They (counsellors) always told me I was doing something wrong. So, I gave up on counsellors.*

The need for trust in order to establish relationships with service users was highlighted by the majority of staff and board member participants. The importance of maintaining a professional relationship with service users is raised in comments such as the following, from a staff member participant: “if there is a risk, you still treat the young person with respect, while you’re watching out for your own safety”. This reflection is a reminder of the complexity for staff in building trusting, supportive and helpful relationships with service users while maintaining appropriate boundaries to avoid unnecessary risks to themselves and others.

Service users were asked if they knew who the boss was at their service, and to whom they would speak if they had a problem. Each service user participant responded with the name of their case manager or direct staff member as their first point of contact. It is the strength of this relationship that contributes to successful
outcomes for service users. For the service user participants in the stage one study, senior management and board members are generally regarded as being of no significance to service users. As an example, “We talk to the Manager, I think sometimes if you go higher up people don’t really listen”. In another example, the service user’s complaint appears to have not been taken seriously, but the details of the complaint or how it was expressed is unknown:

I tried to make complaints. I got told off by the team leader, ‘we don’t want to know any of that we just want you to get better’. In another reference from this service user, the same team leader “has been a good support to me, especially last year when I lost my parents.”

Although the statement from this service user is contradictory, the fact remains that at least one person in the organisation had a meaningful relationship with them, and that person is generally the one that has the most regular contact and has made the effort to establish a relationship.

However, a service user participant with hearing and vision impairment complained that “agency staff don’t sign” and then proceeded to name all the regular staff that work with this service user who can and cannot sign or fingerspell, and continued with their complaint:

I can’t hear, I can’t hear. It’s hard if people don’t sign. I don’t know who works here with me. It’s better if they sign. It’s hopeless when they do this little signing.

The fact that only a small number of staff who work with this service user are able to communicate with her, confines her to her own world, where choice and decision-making are severely restricted.

The response from one staff member regarding complaints, displayed feelings of frustration and a sense of helplessness in trying to provide a better experience for service users:

In disability it is always happy, there is no language for complaining. Everyone is so worked up about behaviour and his or her lives (service users) are so impoverished and everybody is so desperate for it all to be good, there is no option to complain.

Secondly, participants were asked to describe their organisation’s approach to measuring the quality of their work. Some responded with comprehensive approaches to staff supervision and obtaining feedback from service users (see Appendix K), while
one board member said “there is no mechanism (for client feedback) that I am aware of other than there’s a suggestion box that sits in the foyer of the building”.

Of the board member participants from the three CSOs in the stage one study, participants from one CSO stood apart from the others in the views and attitudes they expressed. In regard to receiving information useful in judging the quality of their services one board member responded with, “We get very comprehensive reports” and a second board member from this CSO suggested that detailed information is being presented to the board of management regarding operational issues such as the “welfare of staff” and “grassroots reporting from the clients” that would be the responsibility of the CEO and senior management. Another concern is the description of the advisory committee, particularly the time spent meeting and the frequency of meetings. A service user participant, however, adds a different perspective of the operation of “grassroots reporting from the clients”:

I was involved with a group that was supposed to enable you to bring forward issues but in practice I didn’t find it all very good. I found it wasn’t a very good environment. It takes you a couple of meetings before you get anywhere near understanding what people are saying.

Comments from board members that describe the lack of formal feedback from service users regarding the services they receive represent lost opportunities. Their assumption that comprehensive reports at board meetings can substitute for giving service users a voice, limits choices for both service users and staff. Ignoring the knowledge and experiences of service users restricts opportunities for improving services.

What became clear in the stage one study was the dependence of the Processes theme on the relationships between service users and staff. Service users know who to speak to if they have a question or a problem because that individual: has assisted them in the past; actually did what they said they were going to do for them; or had taken the time to establish a relationship. The formal structure of the organisation, or an individual’s official position in the organisation, is, by comparison, of little significance to service users.

The contribution of Processes as an enabler of participation is thus dependent upon the manner in which actors engage with each other, which presents challenges for service providers, who must resolve the varying professional views of staff with the lived experiences of service users. The data suggest that participation can only be fully enabled through the engagement of service users, which itself is dependent on
the quality of the relationships between service users and key staff. Success in building such relationships in turn appears to be the product of the values of staff and their capacity to collaborate with service users. This prompted me to investigate, in the stage two study, what steps an organisation may take to build processes that support professional relationships between staff and service users.

6.5 Management Theme

The data captured under the Management theme derive from comments that describe how the ways in which the management approach of a service provider facilitated or hindered the participation of its service users. Perhaps not surprisingly, in light of the background on Victorian social services discussed in chapter 2, the data coded under this theme centred on the limited choices and decision-making opportunities for service users: this issue featured prominently in the data from all three organisations participating in the stage one study. This finding is significant because, as Smyth and Bell (2006, p. 227) point out, choice impacts on a client’s potential for success in achieving their program goals and contributes to a person’s quality of life. Choice for clients is achieved by providing opportunities and experiences for them to make choices. Without choices, clients may feel that they have no control over what happens in their life, which may lead to feelings of powerlessness. My reading of Ife (1997, p. 16), discussed later in this chapter, implies that it is the responsibility of management to establish structures in which choice, access, control and processes that support client participation can occur – interview data around choice, or the lack thereof, is therefore coded under the Management theme.

The data overall therefore provide a number of examples of the lack of choice among service users with disabilities, particularly those with physical and cognitive impairment. Service users with disabilities were more likely to experience difficulties in accessing the usual activities outside the home, which persons without disabilities can often take for granted. Furthermore, the more severe a service user’s impairment, the fewer choices they generally have. The quote below illustrates one staff participant’s frustration with the reality of choice for service users with communication support needs:

*What I find is that so often there is no concept of choice actually, so it is a foreign concept.*
As noted above, access to community activities is often limited by the availability of staff. A female service user with hearing impairment commented, through an interpreter, how delighted she was with her supported access to the community: “Mondays, Wednesdays and Fridays I come here. Today I go walking to the shops for coffee and cake. Wednesdays I go to city by train”. Later, the person in charge of her program provided this insight into this service user’s life:

_The program that she did really like and she did choose was going for coffee and cake and going into the city. Every person here needs one to one but no person here has one to one funding. She can go out as often as she can but not every day because she doesn’t have the funding for it. Every time she is here she might do other things, reading, art but I always make sure she goes out for coffee and cake because she is totally isolated in her life._

The statement above is an example of how some staff make a genuine attempt to facilitate community access and improve the quality of life for service users, in spite of limited resources. It also highlights the plight of service users with sensory impairment and their risk of isolation with little choice, as the following quote from a staff participant suggests:

_We’re (staff) the main social contact they have, we’re the only social contact they have, people with communication difficulties can’t really become friends with the other clients since they don’t sign, it’s staff or nothing, but that’s what the program is all about, offering social opportunities. Where else? They’re not going to get it at the café._

Service users seemed to rely more on the relationships they have with key staff members to respond to requests, answer questions and meet their needs. A factor that influences the opportunities for choice is that programs often operate within a long-established structure, and sometimes only in a particular geographic location. These factors all contribute to reducing choice for service users. Nevertheless, the quote below highlights the impact that a simple difference in a staff member’s approach can have on their success in achieving their goals:

_Yes, we didn’t do a completely new plan, which just broke it down a bit better. The things that I want to get done and we just make our way through them. It’s not really a schedule it’s just what we do, appointments, routines, we’re pretty much flying through these things where with the other case manager it took quite a while._
No staff or board member participant described a process in place at any of the three CSOs in the stage one study that provides service users with opportunities to make choices. The comments below from a board member and staff at the same CSO describe the situation in regard to service user choice:

**Some young people will come in; they have made a choice in what they want to do. They’ll come and say, “I want to get a place to live, my mates and me.” I’ll say, this is how it is and they go away and I know they’ll come back because it isn’t going to work; these are some of the things you can do, here are your options. Sometimes I ask myself, what am I doing here because there aren’t any choices.**

**To some extent service users don’t have many choices; if you want to do a certain program and you live in a particular place, you do it with us.**

Participants were asked what decisions a service user would make in the course of a normal day, how staff find out what a service user wants and what the organisation does about getting service users to participate. The initial three quotes below are common examples for staff working with people with disabilities. The service providers that participated in the stage one study were genuinely concerned with providing their service users with real choices, but struggled with how they would implement this approach. A common question to me was, “how do we do this?”

The following quotes describe how a staff member often decides on behalf of the service user. As one staff member participant stated, “The move to Person Centred Planning has made us think a bit more but I have people with severe sensory disabilities and for them we’re still assuming”. Another staff participant said, “they tell us through their parents” – yet this, again, is someone else speaking for the service user.

The quotes below provide illustrative examples of situations where a staff member makes an effort to improve the opportunities for service users with limited capacity to make choices:

**We do have A at the moment (service user) is high care. She does 150 signs but I’ve started speaking to her without signing and after a year she’s responding, setting the table with placemats. I think she didn’t use it for so long she just became withdrawn. She’s very much communicating.**

**With my client group it’s really about getting to know them. When a staff first comes here they (Service users) aren’t physically talking to you with language,**
the staff actually have to get to know them and that happens by getting to know them individually, just by spending time with them. It’s a long process.

These cases underscore the importance for staff to take the time to get to know and establish a relationship with service users.

Board member and staff participants from one CSO offered conflicting views regarding service user choice and decision-making. The staff participants quoted above commented on their attempts to support users with limited decision-making capacity to have and make choices. Board member responses, by contrast, reflected a paternalistic attitude toward service users making choices – for example:

The changes to the legislation... giving people their individual packages. My concern is that some clients don’t have the level of insight as to how to judge which service has more to offer.

This paternalism, however, should not be taken as representative of board members as such. One board member participant from a different CSO, when asked what choices service users would make in a normal day, provided a complex response that highlighted the critical importance of decision making for a group of adolescent service users:

I think the role that some of our staff take on; the role of a mentor in helping young people make decisions about their life, will I go to school, will I go to work, will I get some counselling, will I get help with my substance abuse problem? So, a lot of options being presented to them by staff in a supporting role. These are the decisions you could make to help you move forward. It is such an underrated area, because they are not two-year-olds that could be beaten to death by an adult, they are not seen as vulnerable but, in my opinion, it is the crossroads of their life and it is the most underfunded area and the most significant point in their lives.

To sum up: the individual efforts demonstrated by some staff participants in attempting to provide their clients with genuine choices, illustrate the importance of staff knowledge of clients in providing opportunities for choice and decision-making. Failing to provide these opportunities simply because of a person’s limited capacity does not meet current community expectations or ideals of participation expressed in the scholarly literature.

Although the analysis of this data implies a significant lack of choice for service users in the types of services they may receive, the fact is that all the service user
participants in stage one study were in receipt of a service. The data from service user interviews did not include any comments stating they desired a different service. What service users said they required, aside from being treated fairly and with respect, was enough flexibility in the delivery of the service to meet their needs.

The results suggest that a measure of a CSO’s effectiveness is whether choices exist and are able to be implemented, as well as their capacity to use their processes in flexible ways that meet the needs of service users. The data suggest further aspects of choice to be examined in the stage two study, and in future research, including: what are the examples of choice in service provision; how are service users supported to make these choices; are there structural factors in the design of services that inhibit choice; and what are the expectations of service users regarding choice?

6.11 Relationships Theme

The data coded under the Relationships theme captured comments on building and maintaining relationships between service users and staff, and also reflects what I have referred to earlier in this thesis as an evenness of relationships. The concept of evenness captures the way in which interactions between all players, within and external to some organisations, are conducted with a level of dignity and respect that remains constant.

In constructing positive relationships with service users, the data suggests some capacity for an individual staff member to tailor their approach to suit the needs of their client is often critical to the relationship. The statement below is included as an example of a number of similar comments that describe the respect staff demonstrate to their clients by considering the client’s circumstances and needs in how they deliver the services required, which can enhance the client’s chances of success (Beadle et al, 2012; Webb, 2008):

*I don’t actually come to the office. I have my caseworker come to me, which is really convenient. She comes to my home. I tend to miss appointments so I prefer her coming to my home and I have two young children.*

Although most service users expressed a dislike for formal planning processes, for some, “it’s nice to have help working out what you can do” and for others it is a ‘to do’ list that provides the structure and support they require.

There were more than a dozen quotes relating to Relationships from staff and board members. These comments all supported the notion that the quality of the
The relationship between the staff member and the service user has a direct impact on the effectiveness of the services being provided. The first reference is another example of the importance of staff taking the time to get to know their clients. This is highly significant for staff working with service users with communication support requirements. Without this effort, the relationship will be one sided and of significantly less value to a service user. The following quotes illustrate the need for staff to maintain limits in their professional relationships, while the final quote reinforces that the relationship is the first step in achieving a successful result with a service user:

> I think I have a great relationship with most of my clients. I take the time out to spend time with them. I’d say I am not an office bound manager. I know paperwork has to be done and that’s my responsibility and I have to keep that turning over. My responsibility to my staff and my clients here is to really get to know them. I have a good knowledge of all my clients because I spend time with them.

> You are supposed to keep or not supposed to be that close to them. You’re supposed to keep your distance but you’ve been around people for so long, they make you happy.

> The relationship is fundamental to being able to get anywhere with the intervention you want to put in place.

A significant contribution to the results of this theme was the service user’s point of view that a relationship between a service user and at least one individual staff was the one that mattered. As many authors have noted, participation is a form of a relationship, and participation does not occur without a relationship (Padilla et al, 2007; Checkoway, 1998; Shier, 2001).

The data coded under this theme suggest that a sound relationship between a service user and a least one staff member enhances a service user’s chance of success and empowers service users to make choices. As discussed previously, service users’ social status and sense of themselves may inhibit their willingness to ask questions, and some might find making decisions and choices difficult because of their lack of experience. This can be overcome through their relationships with staff, where the service user is supported and encouraged to ask questions and given appropriate choices. Simple considerations of a service user’s practical needs such as preferring visits at home rather than travelling to the office give service users the sense that staff value and care about them first as a person and their success in reaching their
goals. These findings led to the stage two study question of ‘how are service users valued in this organisation?’

6.12 Leadership Theme

Although the formal leadership of the organisation is to provide the vision and model the behaviour, attitudes and values that contribute to the organisation’s culture, the data coded under the Leadership theme capture a more expansive understanding of what leadership involves and who can engage in leadership activities. This theme therefore captures data that reflects how actions and values are modelled at any level of the organisation.

Service user data suggested that it is often the approach of the individual worker that made the difference for some service users. One male adolescent service user, for example, made the comment that his counsellor did not have to say much, “it’s just the fact there’s someone there that actually cares, you start feeling a lot better”. When asked what the counsellor did to let them know they actually cared, the service user responded in this way:

“They’re always supportive, he says, "if you need me, call me, these are the days I work, if you need someone to talk to just come in and talk to me." They are taking time out of their day to talk to me, to talk about things that don’t really have anything to do with what they’re doing. If you’ve got someone to talk to, it’s a great help.

The following quote illustrates how a more action-oriented approach by a caseworker can assist a service user, when contrasted to a more arms-length approach of just telling the service user what they should do:

My other caseworker used to say; “you need to make this appointment.” Now the new caseworker says; "you need to make this appointment, here’s the phone, call them now”.

Some staff data also suggest the importance of this kind of local, client-specific, leadership approach. The following staff member quote, for example, simultaneously illustrates a number of important practices, including that: (1) people seeking help are treated with respect; (2) people are heard; and (3) people leave knowing what to do next. The final point - that people “never leave with uncertainty” – is both a clear expression of a model of frontline leadership, and also demonstrates the care this individual takes in providing assistance to people in need of information.
This is a reflection of not only this individual’s professional values, but also the culture of the organisation:

*We get a lot of people walking in the door and most of them are fairly desperate since most of our work is outreach. I make sure they are heard. I am very careful and clear they have a hearing. They never leave with uncertainty, they’ve got the next step; a phone number or we’ve often made the appointment while they’re still here.*

In spite of these suggestive quotations, however, staff and board member participants in general provided little evidence of how leadership contributes directly to service user participation. When starting this stage of the research, my expectation was that effective leadership would lead to an improvement in services to clients, but this actually remains unclear from the data collected. What the data did provide was evidence of how a change in leadership influenced a change in the style of service delivery. This change, at least in one of the participating organisations, led to a shift toward a more client-focused approach. The responsiveness of management to the needs of clients, noted by staff participants, also appeared to reflect the leadership’s role in building a culture that puts the needs of clients first. The inconclusive nature of the data coded under this category, meant that this theme factored less into the design of the stage two study than some of the other themes. However, the limited size and scale of the stage one study leaves open the potential to investigate the specific question of leadership and its impact in a more sustained way in the future. For present purposes, I have concluded my thematic synopsis of the stage one data, and therefore pan back to an overview of the implications of the results overall in the following section.

### 6.15 Stage One Study: Summary of Overall Results

The results of the stage one study suggest that the most influential enabler of participation would be *Values* – a conclusion arising both from the strength of the data coded specifically under that category, and for the way in which organisational, personal and professional values appear to be implicated even in enablers of participation coded under other themes. On one level, this finding is not surprising: intuitively, and also according to the literature discussed in chapters 2 and 3, personal and professional values are what we use to measure what is important to us. The decisions we make in this regard determine how we behave and form relationships. Staff participants described the process of building relationships with service users in
terms of: (a) listening; (b) being respectful of their views and opinions; (c) having a sense of curiosity for each individual; and (d) being responsive to their needs. These points are practical examples of the influence of the personal values of participants. Participants likewise noted the importance of the first contact with service users in forming these relationships. This was achieved by: clearly explaining what the service offered; asking service users what they thought they needed; and ensuring service users left the first contact knowing what their next step was going to be. Service user data thus supports Heffernan’s (2009, p. 376) claim that participation begins at the first contact between service user and service provider.

Participants also described the importance they placed on having shared values among the staff and management of the organisation. Comments singled out examples where management appeared as “genuine” and “out to do the right thing”, which one participant described as being “contagious” as all staff began to behave in that way. Having the appropriate shared values builds an organisational culture that bonds the enablers of participation together.

Shim (2010, p. 848) has defined organisational culture as the way things are done in an organisation. In the case of one CSO studied here, however, there was an apparent mismatch between the articulated values of the board of management participants and those of the staff participants. This was unlike the two other CSOs, where there was a sense of excitement and satisfaction with the idea that all staff shared similar values. As a result, the role of board members and their motivation for being on a board of management may be considered more closely in the research to follow.

An example of how Values influence Relationships can be found in the staff participant descriptions of the effort they make to first consider the practical needs of the service user in how they might deliver services. Simple considerations like this demonstrate to the service user that staff value and care about them as individuals, and are interested in helping them to achieve their goals. The determination demonstrated by staff in establishing productive relationships with service users, including those with physical and sensory impairment, is a further example of the connection between Values and Relationships.

Statements from participants applied to the Relationships theme provide three important factors that contribute to service user participation. The first is trust, which applies to all participants and is inclusive of any positive relationship. This is consistent with the work of Webb (2008, p.280) and others who list trust as a necessary factor
for satisfaction with a relationship that facilitates participation (Beadle et al., 2012; Gupta & Blewett, 2008). The second concentrates on providing opportunities to give feedback and discuss their needs and experiences, which is in turn dependent upon the third element, which requires service providers to take note of and manage the professional attitudes and culture within the organisation. This means that professionals understand that they do not necessarily have all the knowledge required within themselves to assist a service user and therefore learn to take the time to reflect on their assumptions.

In answering the question of whether any of the enablers of participation were of greater significance to service users, the results clearly indicate that Relationships are the most important in the minds of service users. The emphasis service user participants placed on their relationship with at least one staff member whom they could trust and depend on to assist them, demonstrated this.

From Values and Relationships comes an approach to Management and the subsequent Processes that pays attention to the principles of fairness, equity and the human rights of service users. As noted previously in this chapter, the responses from participants did not suggest a significant availability of choices for service users. For some service providers, however, their flexible style of service delivery both generated some choices for service users, and partially compensated for the lack of broader choice - but this result appeared primarily to derive from an individual staff member’s level of confidence in management to back staff decisions, combined with staff knowledge of the service user’s needs. This exemplified the personal values of participants and the organisational values that underpinned the client-focused culture of the service provider.

Ife (1997, p. 16) notes the trend (which continues today) in social services toward ‘managerialism’, which is the belief that management is a generic skill that can be applied to any organisation without regard to the nature of its business. What is significant for Ife in this trend, is the change in perspective of senior managers from a personal and professional identity based on the values of a human services professional, described in previous chapters, to a view of themselves as the managers. Having experienced the beginnings of this shift toward managerialism in Victoria in the late 1980s, I am reminded of a colleague’s remark, which described our experience of managerialism in human services as “behaving like we’re making toasters”. The findings of the stage one study imply that a management focus on efficiency without effectiveness, at least in some organisations, ignores the appropriate personal and
professional values that enable respectful relationships to be formed with clients. Relationships that are critical to the success of service users in achieving their goals.

6.19 Summary of Chapter 6

The stage one study data supported the importance of personal values as the foundation of organisational culture, a theme which has been covered extensively in earlier chapters. Values therefore stood out as an enabler of participation in the stage one results, and the data generated a number of explicit examples of good practice with clients, touching on actions like:

- The effort made by staff to give a voice to people with profound communication needs
- Maintaining a sense of hope and curiosity about clients as people
- Understanding that some clients feel unworthy of asking for help
- Putting the needs of clients over the needs of staff in operationalising programs
- Taking on the role of mentor in assisting clients to make choices
- Making sure clients are informed and are given a chance to speak for themselves
- Establishing relationships with clients that are respectful and dignified

My analysis of the interview data suggests that the professional practitioners who participated in the study appeared to be fully aware of the importance of the participation of clients in their services, and they also agreed, with reasonable coherence and understanding, with what I refer to as the enablers of participation. At the same time, however, although no specific questions regarding operationalising participation were asked at interview, professional practitioners did not appear to be able, when responding to questions that would benefit from reflection on this issue, to briefly articulate an explicit understanding of practice principles for how to integrate a process for client participation into their day-to-day practice with clients. This appeared paradoxical to me, given the number of descriptions of what I would consider good practice with clients noted above. The data suggested a gap between actual practice, which practitioners often spontaneously reported, and practitioner capacity to synthesise these practice examples into a more reflective self-understanding of the implications for the complexities of client participation. This gap suggested a productive target for further investigation, which I pursued in the stage two study.
This second stage of the research was carried out through a purposive sample of Victorian social service organisations, the details of which I describe in the following chapter. Completing the stage two study enabled me to obtain a view of how experienced professional staff in contemporary social service organisations understand the current barriers and enablers of participation, and to further explore the question of how to improve the capacity to put principles of participation into applied professional practice.

In the chapter to follow, I return to the sector and concentrate on examining, through qualitative focus group data collection techniques, what appears to be a disconnect between service providers’ understanding of client participation and their difficulty in imbedding it in their practice with clients. Given the apparent influence of personal and professional values on organisational culture, as outlined in the stage one results, I investigate the current perceptions of values in social services from a number of different perspectives. Guided by the work of Agbényiga (2011, p. 1776), I consider the ways in which an organisational culture, in acting out its values, influences the day-to-day work with clients in social services. The stage two study was therefore designed to consider the current understanding of client participation in Victorian social services, and to investigate in what ways organisational values influence the four remaining enablers of participation, namely: relationships; processes; management; and leadership.

I also undertake to determine the usefulness of a discussion rubric – based on the review of the participation literature and the data from my stage one study – that seeks to provide a simple, concrete, practical method for social services that wish to self-evaluate and carry out useful, professional conversations about their practice of participation within the organisation. This rubric seeks to provide a guide for collective and individual self-reflection on participation, and to assist practitioners in more easily linking ideals with concrete practice examples. The stage two study uses this rubric both as a prompt for discussion, and also as one of the objects of study, evaluating the potential usefulness of such a tool for practitioners concerned with integrating processes for client participation into their everyday practices.
Chapter Seven: Stage Two - Focus Group Study

7.1 Introduction

In the previous chapter, I found a reasonable conformity between the academic literature and the views of participants: in other words, participants expressed no significant disagreements with the academic literature over the importance of participation, or over the factors that enable or hinder participation. In spite of this agreement, however, participants described a lack of capacity to fully operationalise a process to realise participation in their service delivery. Stage one therefore left open the question of how to understand the lingering barriers to participation in social service organisations in Victoria today.

To pursue this question, I conducted a series of focus groups with professional staff from selected social service organisations in Victoria. In recruiting organisations to participate in this stage of the study, my goal was to obtain additional qualitative data that reflects a diverse range of experiences, regarding different organisations that have each confronted the current challenges of client participation. My purpose was, first, to obtain professional staff members’ perspectives on what the barriers and enablers of participation might be in the sector at the present moment in time, as well as their views on how client participation is understood and enacted in these services. Second, I wanted to explore more deeply the question of why social services do not seem to be managing to incorporate participation more thoroughly into their practice. Third, I sought to determine the ways in which organisational values may propagate into: establishing and maintaining client/staff relationships; the development and implementation of organisational processes; and organisational management approaches and leadership styles.

Given the recognition of the enablers of participation by participants in stage one, the barriers to participation did not appear to be driven to any significant degree by disagreement with, or lack of understanding of, principles described in the academic literature. The problem, instead, seemed to centre on how to put this knowledge to use in everyday practice. This problem informed the decision to develop a discussion rubric for service providers, intended to provide a structured guide for a professional conversation on approaches to client participation in the context of their specific organisation. This discussion rubric served as one of the prompts for the focus

4 Sections of this chapter were published as ‘A Conversation Between Normal and Abnormal’ by L. Iaquinto in Oke, Sonn & Baker (2018) Places of Privilege, Interdisciplinary Perspectives on Identities Change and Resistance, 67-84. Boston: Brill
group discussions, and focus groups were also asked specifically to provide feedback on the potential usefulness of the rubric as a means for bridging the gap between academic principles and the application of these principles in realistic scenarios in professional practice.

In the sections to follow, I first present a summary of the development and use of focus groups from market research to becoming “part of the collective consciousness of the qualitative research community and the public imagination” (Kamberelis & Dimitriadis, 2013, p. 1). Prior to moving onto a presentation of the procedures used for the recruitment of participants and the preparation and conduct of the focus groups, I offer an overview of the methodological basis of my decisions to utilise focus groups as a method of data collection and the process I used in the construction of the discussion rubric. In the final section, I present my detailed analysis of the focus group data. Indicative examples of direct quotes from participants are included. This is followed by my presentation of the results, which draws heavily on Cyr’s (2015) analysis of the reporting of focus group data in academic journals, over the past ten years.

### 7.2 Historical Background of Focus Groups

Krueger and Casey (2009) outline the history behind the use of focus groups, which, according to the authors, began with the concern of some social researchers that common interviewing techniques of the 1930s meant that the preconceived ideas of the researcher could greatly influence the response of the subject (Krueger & Casey, 2009, p. 2). In considering strategies to diminish the perceived dominance of the researcher conducting one to one interviews, Merton and Kendall (1946), followed ten years later by Merton et al (1956), published their work on the focused interview. Kamberelis and Dimitriadis (2013) consider the main advantage of the focused interview to be the way it provides a means to obtain pertinent, applicable information from large numbers of participants quickly. The approach to focused interviews and early focus group research was, according to Kamberelis and Dimitriadis, “rooted in positivist or post-positivist epistemologies” which assume that “truth is out there” to be found and is “independent from human interactions” (p. 3). The authors go on to make the point that data generated from the focused interview could be analysed using the same techniques as those used for one-on-one interviews.

Although Merton is now considered to be the father of the focus group, his work was neglected in the social sciences for decades (Krueger & Casey, 2009, p. 3). At the
time, according to Krueger and Casey and noted by Kamberelis and Dimitriadis (2013), qualitative methods such as focus groups were neglected in academic research, which tended to favour quantitative procedures, in line with the dominance of the positivist perspective discussed in earlier chapters. Kamberelis and Dimitriadis (p. 8) suggest that it took the world of research methods five decades – until the development of “mixed methods” - to catch up with Merton and Kendal. Yet, the authors point out that Merton and Kendall’s writings on the focused interview made no mention of groups or interaction among participants as units of analysis. Merton and Kendall (1946) were more concerned with the interviewer’s skills as a moderator and with the “focus” of the interview (pp. 8-9). In spite of the neglect of the method in academic research, the booming post-war economy led market researchers to quickly realise the usefulness of focus groups with consumers (Krueger & Casey, 2009, p. 3). This use of focus groups remained within the area of sponsored corporate market research – only to re-emerge in social sciences the 1980s in the form of ‘audience analysis’ research (Kamberelis & Dimitriadis, 2013, p. 31).

Realising that some of the market researchers’ practices were not appropriate in academic research, academic researchers distinguished several approaches: a market approach, which was not constrained by academic rigour; an academic approach which initially encountered resistance at the thought of participants in studies speaking to one another; a public/non-profit approach, whose purpose was to improve or design a policy or program; and a participatory approach, which involved volunteers in conducting research rather than professionally trained researchers (Krueger & Casey, 2009, pp. 143-149). Krueger and Casey point out that, although each approach is unique in itself, all contain the common features of a focus group - namely: people who possess certain characteristics and provide qualitative data in a focused discussion to help understand the phenomenon or issue under study (Krueger & Casey, 2009, p. 6).

Liamputtong (2011) cites Morgan’s concept of two broad types of focus groups: the market research type and those used in social sciences. Liamputtong notes the differing role of the moderator in each. In market research, the moderator is an active participant in the group whose most likely purpose, according to Liamputtong, is to seek specific answers for a client. In the social sciences, the moderator takes a more facilitative role, asking questions and encouraging participants to speak to one another, rather than directing the discussion. Each type requires selecting the “right moderator” who, Krueger and Casey believe, is the one who respects the participants (p. 85). In earlier chapters I referred to Sennett’s (2003) work on respect and
emphasised its importance as a critical factor in underpinning the values required to enable the relationships necessary for the full participation of clients in the services they receive. In addition to respect for participants, Krueger and Casey (pp. 85-88) suggest that the qualities for the right moderator require someone who: understands the purpose and topic of the study; communicates clearly; is open, not defensive; and gets the most useful information. For Krueger and Casey, the most significant attribute of the moderator affecting the quality of focus group results is respect for participants, followed by the “critical qualities” of empathy and positive regard (Krueger & Casey, 2009, pp. 85-86).

In the section below, I discuss the factors that influenced both the design of the stage two study and my choice of focus groups for data collection.

### 7.3 Why Focus Groups?

The focus group offers a number of advantages as a data collection method, in particular by obtaining and understanding knowledge through a structured discussion, utilising well thought out questions and prompts, in an efficient manner, in a safe and nonthreatening environment. Moreover, it is also a method that appealed to my personal values and suited my particular skills and experience – and, by extrapolation, I expected it to also appeal to the skills and experience of the professionals of similar backgrounds with whom I intended to engage. In my professional work, I always preferred face-to-face contact with key actors as the best method for solving problems and clarifying goals and expectations. McNiff (2013, p.31) points out that work is something done in relationship with others. Through McNiff’s reflections on her own practice, I came to realise that, when I think about my professional practice, I am actually reflecting on the relationships I had with other people. I began to view conducting focus groups as ‘large interviews’, and became mindful of the differences between individual and group data gathering strategies noted above and by Kamberelis and Dimitriadis (2013, p. 2). For me, conducting a focus group appeared similar in many ways to my experience of the relationships I had with clients, their families/carers, my superiors, and staff, in a variety of circumstances that assisted us to solve problems and make decisions. The sum of these experiences, as both a practitioner and student researcher, has inculcated in me the notion that problems are best solved through engaging in a dialogue with others which provides opportunities to discover the deep-seated assumptions underpinning these views. This approach finds resonances with Schön’s (2013) view, noted in chapter 3, that
professional expertise emerges through a process of collaboration with the client (p. 296), as well as Bacchi’s (2009, p. 171) notion of examining the intrinsic values within problem representations. Kamberelis and Dimitriadis (2013) view the three primary functions of focus groups as, inquiry, pedagogy and political effectivity. These functions combine to “refract and reflect” the focus group content back to the researcher in different ways (p. 20).

Inquiry, in Kamberelis and Dimitriadis’ (2013) view, has long been associated with "hard science" (p. 37), or what Schön (2013, p. 39) would see as an example of the positivist epistemology that he would refer to as “technical rationality”. Here, Kamberelis and Dimitriadis’ orientation blends with Schön’s, as they describe the emergence of focus group research as a way to answer the “messy, dirty” how and why questions left unanswered by “positivistic quantitative methods” (p. 37).

Kamberelis and Dimitriadis see the pedagogic function of a focus group as promoting a dialogue to achieve higher levels of understanding of the issues by asking and answering questions. In this second study, my questions are structured to engage participants in a reflective conversation around their experiences, interests and values, inherent in their approach to their work with clients, in order to determine in what ways they respond to the ‘problem’ of client participation in their services. This approach was also supported by RMIT ethics approval.

Kamberelis and Dimitriadis also see focus groups as having a political function, which is to “transform the conditions of existence for particular stakeholders” who are typically marginalised and oppressed and by making their conditions more “democratic” (p. 36). The appeal of this function is that it is reflective of my primary goal in undertaking this work, which is to initiate a conversation on the experience of client participation in social services for clients and service providers. The purpose of this conversation is to precipitate a process of reflection that can bring about change in the practice of participation in the delivery of these services.

Schön (1995, p. 30) believes that we all have some capacity to reflect “on what we know as revealed by what we do”. Schön’s (2013) ideas have been referred to frequently in previous chapters. In the second stage study, I apply Schön’s concept of reflection-in-action to the practice of participation. Schön (1995) would view client participation as a “new category of scholarly activity, which takes the form of action research” (p. 31). McNiff (2013, p. 30) suggests that Schön’s concept of reflection on action is the core assumption of action research. Like Schön (2013), McNiff refers to a time when practice was seen as something to observe in processes remaining
separate from practitioners. McNiff suggests that Schön’s ideas, by contrast, only apply when “practice is seen in relation with others” (p. 31), and argues that improving practice begins with improving knowledge and learning which can occur at a personal, social or community level (p. 73).

Fook (2002) discusses what she refers to as an inclusive approach, as a method to use for theorising from practice. In her work, Fook (2002) dismisses the idea of “collecting data”. Instead, Fook (2002) prefers to speak about “accessing experiences”, since it is the experiences themselves that are being sought (p. 86).

In summary, the suitability of focus groups as an experience collection method, from an action research perspective, offers an opportunity to utilise the knowledge I value – and expect other professionals to value - in professional practice in social services. This, combined with my understanding of the specialised nature of operationalising participation in social services, and what I have learned from participants in the first stage study, enabled me to further develop the ‘what I value and what I know’ of client participation in social services, into a form that could facilitate a productive group discussion among professional practitioners about what they value and know about participation (McNiff, 2013, p. 73).

The limitations of utilising focus groups are discussed later in this chapter.

7.4 Ethical Considerations

The Design and Social Context College Human Ethics Advisory Network, a sub-committee of the RMIT University Human Research Ethics Committee, approved the stage two study. All procedures followed in the stage two study were not varied in any way and complied with the ethics approval. The study is classified as low risk in accordance with the National Statement on Ethical Conduct of Human Research. All participants provided written consent (Appendix L) prior to the collection of data and consented to the groups being recorded. Participants were made aware that their participation was voluntary, and that they could withdraw from the session at any time without prejudice (Appendix I).

7.5 Aim of the Stage Two Study

To begin, I state that the stage two study is of a solely qualitative nature. My principal aim in this study is to extrapolate, from the experiences of participants, an
understanding of why there is an apparent disconnect between their conceptual awareness and knowledge of client participation, and the difficulty they have implementing this knowledge in practice.

7.6 Study Design

Cyr (2015), in her meta-analysis of focus group use over the previous decade, found a scarcity of published works that analysed how, and for what purpose, focus groups are used in research practice. Cyr also noted that few published works present descriptions of how the data collection method was prepared for publication (pp. 232-233). Cyr’s goal was to rectify this situation and put forward a set of guidelines that I have applied to my results section later in this chapter.

My study design is based on what Cyr (2015) refers to as three norms for maximising “the transparency of the method” (pp. 250-251). Using focus groups:

- allowed me to obtain the views, opinions and experiences of professional practitioners within a relatively short period of time;
- disclosed a broad consensus among participants on the existence of the enablers of participation;
- provided evidence of barriers that prevented service providers with the knowledge of what’s required for client participation from putting it into practice; and
- revealed fear, as one significant but unanticipated barrier to participation.

Cyr (2015) highlights the importance of clearly articulating the unit of analysis and specifies three potential units that can be used for focus groups. These are the group, the individual, where the reported findings are focused on an individual member of the group, and the interaction, which is the interaction between group participants (p. 240). For Cyr, a lack of specificity in regard to the unit of analysis makes evaluating the quality of the data analysis difficult (p. 251). For my purposes, the unit of analysis is the group. However, one notable interaction, discussed further in this chapter, also contributed to the findings of the second study.

The following section presents the procedures used to recruit participants, as well as ethical considerations and the development of a set of questions to guide the focus group discussion.

7.7 Data Collection Procedures
In considering the disadvantages of utilising focus groups, the possibility of the group dynamics inhibiting data collection and the interpretation and analysis of the data were my main concerns. Stewart et al. (2007, p. 43) note that a particularly dominant participant may bias the group and highlight the difficulty of summarising and interpreting results due to the fluid nature of responses.

My initial concerns regarding the group dynamics inhibiting data collection, particularly the potential for a dominant participant to take over, were addressed through adequate planning and well thought out questions and prompts, which kept the participants engaged. My professional experience assisted me to create a respectful, safe, nonthreatening atmosphere in which to conduct the discussion. Also, it seemed that all participants understood the issues services have with operationalising participation and, as such, were interested in improving their practice. My final concern was the time involved in transcribing the focus group audio recordings. With repetition, I became comfortable with recording and transcribing each focus group. The process I adopted for analysing the data and presenting the information is described later in this chapter. The results suggest that I was able to minimise the potential problems described above to such an extent that they did not affect my results.

7.7.1 Recruitment

The advice of Kruger and Casey (2009, p. 64) in the selection of participants is to let the purpose drive the study. In undertaking the stage two study, my purpose was, first, to understand the causes of the disconnect between the sound knowledge of participation displayed by service providers, and their professed inability to fully operationalise participation in their service delivery. Second, the study was motivated by my interest in exploring whether the appropriate values are the catalyst that binds all aspects of an organisation together to enable or inhibit participatory processes. Third, the study was designed to investigate the possibility of using a discussion rubric for self-evaluating client participation by social service organisations.

My requirement for participants was that they possess a breadth of knowledge and experience in human services programs. In selecting this group of participants, I contacted, by phone, a selection of social service organisations that I had previously known through my professional work in human services and/or RMIT University, but with which I had no professional relationships. I then met with the CEO or their representative to discuss my proposal and walk them through the Focus Group
Running Sheet (Appendix G). If they agreed to participate (none declined), I requested that they nominate a minimum of six staff members, at team leader level or above, to participate in a focus group of approximately 90 minutes duration. I also requested that participants not be included in a focus group with their direct line manager, and I asked if the focus group could be held at the organisation’s premises during normal working hours. Requesting participants be at the minimum level of team leader insured they would possess an adequate level of experience in social services. My assumption was that they would also have insight into the issues and challenges inherent in social services more broadly, beyond their current organisation.

None of the organisations that participated in the stage one study were recruited for the second stage. This ensured a lack of “contamination” between the two parts of the study, and prevented the possibility of confusion due to the additional knowledge about the study that stage one participants might possess.

I facilitated all focus groups personally and commenced by going through the participant information sheet (Appendix I), and ensuring that each participant had signed a consent form prior to starting the focus groups. The focus group interview questions (Appendix G) were presented in four segments. The initial questions were intended to create a comfortable, relaxed, non-threatening atmosphere. The introductory questions were designed to lead a discussion on the participants’ history and experience with client participation in their working lives. Participants were probed to describe their personal and professional definitions of client participation and to offer their views on the current and past issues of operationalising client participation in the services they managed. The discussion then turned to their specific views and opinions on client participation in the context of their current cohort of clients and service provider.

The next segment sought feedback on the design and content of the rubric, pictured below in Table 10, which began with each participant being handed a copy of the rubric and given time to read it carefully. The rubric in Table 10 was used for discussion and comment in all focus groups, and is adapted from Rifkin et al. (1988, p. 936), which was discussed in earlier chapters. I ensured that each participant had finished reading before presenting an explanation of the content and a description of the background and intended purpose of the rubric. I also included a statement on my typology of client participation as a continuum that ran from providing service users with information on the services available to them, to involving them in the services’ approach to case management, through to service user co-design of services. This
was followed by conversational prompts on the indicators of participation, with a particular emphasis on prompting participants to offer tangible examples of each indicator from their practice with clients.

**Table 10**: Discussion Rubric – Version One
(Adapted from Rifkin et al., 1988)

<table>
<thead>
<tr>
<th>Leadership</th>
<th>Management</th>
<th>Processes</th>
<th>Relationships</th>
<th>Values and Attitudes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whammin starts up</td>
<td>Participation is short</td>
<td>Policies</td>
<td>Documented and used to inform and guide process</td>
<td>Org-acrossional process always the same</td>
</tr>
<tr>
<td>Some management makes some effort to</td>
<td>Improved objectives</td>
<td>Process</td>
<td>Understood, primary focus of process is imposed by service users,</td>
<td>Day to day living</td>
</tr>
<tr>
<td>(Adapted from Rifkin et al., 1988)</td>
<td></td>
<td>also and</td>
<td>documented</td>
<td>Maintenance oriented</td>
</tr>
<tr>
<td></td>
<td></td>
<td>services</td>
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</tbody>
</table>
The third segment of the focus group session considered the five descriptors presented for each of the indicators of participation. Again, this segment aimed to draw participants out on concrete, specific examples of good practice from their own practice and past professional experience. Participants were also asked their views on having a numbered ranking scale.

The fourth segment concentrated more on the usefulness and practical requirements of the discussion rubric. This segment included questions such as whether and how participants might use the rubric, and what processes they currently use, or would potentially use, to observe, document and gather evidence of good practice.

Audio recordings were made for all focus groups. None of the participants of any group were uncomfortable with being recorded, and all were clearly informed of their right to withdraw from the focus group at any time without prejudice. Only the researcher (myself) and supervisor have access to the raw audio recordings and transcripts.

I have previously noted that I have more than thirty years professional experience in the management and delivery of a broad range of human services programs. The majority of this experience was gained as a senior executive in the Department of Human Services Victoria and included, at various times, operational management responsibility of juvenile justice, disability services, child protection and public housing programs. This experience provided a solid basis for understanding what sorts of information organisations and professional staff members would not wish to disclose or to have published. In transcribing each focus group, the omission of data, which mainly consisted of the names of individuals and organisations withheld for confidentiality purposes, did not adversely affect the results of this study.

The focus group questions were not designed to prompt for any financially or professionally sensitive information, and I was able to draw on my experience to recognise if the focus group conversation was steering in a direction that could result in information being disclosed that the organisation or staff would not wish recorded. I used that experience to prevent any such unintentional disclosure, and I was ready to stop recording if necessary. If any such information were to end up on the recording, I had committed to not transcribing or otherwise disclosing it. In the course of conducting the focus groups, it did not become necessary to make use of any of these contingency plans.
Any uniquely identifiable details about organisations or individual participants were edited out at the time of transcription. Original recordings are confidentially stored in a secure online drive, dedicated to research data storage, at RMIT University. Documents that may link codes with participant and organisational identities are stored electronically on this secure drive, where they are encrypted and password protected.

### 7.7.2 Participants

Five social service organisations representing a broad range of programs and client groups participated in the stage two study, which consisted of seven focus groups with a total number of 35 participants. Focus group participants were representative of the following services: drug and alcohol; advocacy and peer support services; family services; homelessness; family violence; emergency accommodation; disability services and specific religion based family welfare services. Each focus group included participants who all work within an individual organisation and already knew one another. Since they knew the other participants in their sessions, they could individually decide what they were prepared to share with the group. Participants were addressed by their first name only. No personal or identifiable details were recorded with the exception of a voice recording of each focus group.

So far this chapter has concentrated on the rationale, design and procedures used to conduct the stage two study. A brief history and background on the use of focus groups has been included in support of my decision to utilise focus groups as a method of data collection. The next section presents the results of seven focus groups conducted in the stage two study. As in the previous chapter, and for the same reasons, immediate findings are juxtaposed with interpretive analysis so that the implications of the qualitative data are clear. I then pan back later in the chapter, and in the conclusion to the thesis, to reflect on the overall implications of the stage two study as a whole.

### 7.8 Data Analysis Method

Just as determining the purpose of the focus group is the first step in planning one, Krueger and Casey (2009, p. 114) remind us that purpose also guides the analysis. The authors warn the novice analyst of the risk of becoming overwhelmed by the amount of data collected, by pointing out that “not everything is worthy of
analysis” (p. 124) – a caution that reminds me of my own initial experience of confronting the stage one interview data (see Appendix K). Following the direction of a number of authors (Cyr, 2015; Krueger & Casey, 2009, p. 118; Stewart et al, 2007, p. 116), I proceeded with the analysis of the focus group data through a systematic approach. First, the focus group interview questions were grouped in segments that represented the following research questions:

- How is client participation defined in the context of service delivery in participating social services?
- What are the barriers to including client participation in service delivery and how can these be addressed?
- Are the building blocks necessary for client participation included in the rubric?
- Do the descriptors for each indicator provide clear examples of limited, adequate and good practice in social services?

The process I chose for analysing the focus group data was the classic analysis strategy (Krueger & Casey, 2009, p. 118), which is also referred to as the cut-and-paste method (Stewart, et al, 2007, p. 116). Given the depth of material provided in each transcript, this approach appeared similar in nature to the process I used to analyse the interview data in the stage one study. As noted above, the source of data for analysis were the recordings and typed transcripts, and the unit of analysis was the group. Each recording was first transferred into NVivo 10 where they were transcribed as soon as possible after completion of the focus group.

As in the stage one study, I focused first on becoming as familiar as possible with the focus group transcripts, and I repeatedly returned to the recordings to ensure clarity in my interpretations of the data. Krueger and Casey (2009, p. 125) offer examples of a number of analytic frameworks including: Constant Comparative which, for example, is useful for identification of trends and patterns; Critical Incidents, which is suitable for theory development and identifying factors relating to the success or failure of an organisation or concept; and the Key Concepts framework, which appeared similar in nature to the methods of qualitative data analysis noted in my earlier work in this thesis. For this sort of data, Cyr (2015) states that, when using the group as the unit of analysis, focus groups “generate information that is not easily replicated by other data collection methods” (p. 250). Another advantage of focus groups that attracted me to this method of data collection is Munck’s view that the social nature of focus groups (as cited in Cyr, 2015, p. 250) is their unique ‘value
added’. The important task for me as moderator, according to the Key Concept framework, was to engage participants in identifying the experiences, ideas and preferences participants believed important to the phenomena being discussed, thus safeguarding the contribution of the data to answering the research questions. Being present in the focus group, listening to recordings and reading transcripts all increased my capacity to identify these concepts. The specific factors or key concepts that emerged from the data included: participants’ experiences of both good and bad practice of client participation and the consequences of each for clients and staff; values and attitudes of staff towards clients; confusion on how to operationalise participation; and the general agreement of participants on the usefulness of the discussion rubric as a conversational prompt.

My presentation of the results of the stage two study is modelled on Cyr’s (2015) recommendations for establishing guidelines for presenting focus group data. One of Cyr’s concerns was the considerable variation in how scholars present focus group data in publications (p. 249). Cyr’s (2015) first two points regarding the purpose of the focus group and being clear about the unit of analysis were discussed earlier in this chapter. Her third recommendation is to provide the focus group questions that inform the results of the focus group (p. 251). In Cyr’s view, approaching the presentation of the data in this way serves two purposes. First, I demonstrate that the questions I have asked in the focus group are measuring what I had intended them to measure (p. 244); and, more importantly, I show that I have met the goals of my data collection method.

The analysis is first presented in four broad themes and three sub-themes, which are based on the research questions noted above. The themes are: the participants’ Experience of Client Participation (values and relationships, operationalising participation, fear and client capacity); their views on the Content, Structure and Use of the Rubric; the Rubric Indicators; and the Rubric Descriptors. I discuss each of these in turn below, before retuning to each of the research questions outlined above, to evaluate the data in relation to each of these questions.

7.9 Enablers of Participation – Data Analysis

7.9.1 Experience of Client Participation

In seeking their detailed practice experiences of client participation, participants were asked to describe: what client participation meant to them; the approach to
client participation in their current service; and to elaborate on their experiences, both past and present, of client participation. Initial responses included: “engagement; identifying the things they (clients) want to work on and then actually doing the work to achieve those things; be active rather than passive; being involved in whatever is happening”.

My intention here was to gauge the participants’ level of knowledge and experience in regard to the history, issues and barriers of client participation, and to prompt participants to reflect on what client participation means to them and how they make it part of their day to day practice with clients. These questions also provided an opportunity for participants to display their attitudes toward client participation.

One group articulated a clear approach to engaging with clients, while another suggested that social services were not good at learning from one another:

- We identify three factors for engagement: motivation, readiness and confidence. The belief that, ‘I can do this’. If those three factors are in play; then, it’s a pretty good chance the client will stay here and do a good program.
- There are practical living examples of organisations that exist with high levels of consumer participation. What we don’t do in community services is to look for those living, breathing examples. What they did and how they did it and what didn’t work and what did and why.

The first quote, which indirectly refers to a method that may contribute to client participation, is actually grounded in good practice through establishing relationships with clients, and then supporting clients in building their confidence to succeed. This response appears to reflect the view of participants that client participation is something services do outside of their normal everyday practice with clients. This approach presents participation as an activity that is added on to their current practice with clients, not inclusive of it (Hernandez et al, 2010, p. 717). This conclusion on the part of participants suggests a possible cause of the confusion between understanding participation and operationalising it.

7.9.2 Values and Relationships

The notion of fear, presented in detail later in this chapter, is noted briefly here because it arose from three distinct standpoints of participants. All three perspectives appear to originate from, and are sustained by, the internal beliefs and values of the
leadership/management that set and maintain the environment of an organisation. Such beliefs stem from a lack of respect for clients in the practice employed by some professionals. Their lack of respect for clients is illustrated in their disinterest in the knowledge and life experience that clients hold, and in their limited understanding of what this experience has to offer them as professionals in establishing mutual relationships with their clients. Treating others with respect, as suggested by Sennett’s (2003) analysis of the value of respect, is a stepping-stone to building relationships. The results of my initial study highlighted the importance of the personal values people bring to their work in establishing relationships with clients. Participants also noted that shared values, within social services, contribute to a more productive workplace and better experiences of participation for clients. The following quotes reinforce the necessity of collaborative relationships in client participation:

The development of relationships is the key to participation and holding people.

When people (clients) leave here they say, ‘these friendships are what helped me and kept me here’. ‘I’ve never had a friend in my life and now I’ve got a friendship group’. That’s what the program is based on, relationships.

It takes a bit of giving of yourself and opening up; relationship building is probably around how much they (clients) are willing to trust and how trustworthy are they?\(^5\)

Bacchi (2009) points out that problem representations can sometimes develop relationships that create inequality. Nevertheless, the nature of the relationships professionals establish with clients is a matter of choice for the professional. How professionals frame their role, as well as their capacity to take action in difficult circumstances, are both guided by their values (Argyris & Schön, 1974, p. 162). When a practitioner states that relationships are the key to “holding people”, they are offering a practice example of what they value in their work, which, in the case above, is the importance of establishing balanced relationships with their clients.

Schön (2013) takes this further when he suggests that a commitment to take action by a practitioner should be “intrinsically satisfying”, not for external rewards (p. 231). In the quote above, “giving of yourself” expresses the participant’s acknowledgement of the importance of trust in relationships, which comes from both the client and the professional.

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\(^5\) For further discussions of the complexities of the staff/client relationship, see Stamp (2003), Moses (2000), Morris (2012), & Kendrick (2013).
7.9.3 Operationalising Participation

The quotes to follow reflect a common assumption, expressed in all but one focus group, regarding the difficulty of operationalising participation. I believe that this assumption is the result of two main influences: the first is the complexity of constructing a definition for participation in itself. As discussed in chapter 3, the inability to construct a definition that would be universally acceptable has been a feature of the international literature on participation for the past fifty years. Secondly, when service providers confront the task of operationalising client participation in the context of their practice, to meet the needs of their clients and the skills of their workforce, the level of difficulty appears insurmountable. The quote below is an example of this view:

*I think we don’t do it very well at all. I don’t think it has been an active part of our program but it has become more so in terms of the kind of environment we want to create but there is no real consistent format for including clients in all sort of stages of that.*

The second quote touches on a second influence, which are the attitudes of workers towards clients:

*Another thing that stands out for me is that a lot of organisations don’t understand what consumer participation is. Some are also scared of it because if you share power with consumers it will harm the business.*

The quote above expresses the participant’s view that some organisations are unclear on what client participation actually means in the context of their service delivery. It also suggests an awareness of the potential for staff to mistrust clients.

7.9.4 Fear and Client Capacity

Beginning with Arnstein (1969), the literature on participation offers numerous examples of the resistance that professionals and powerholders display toward sharing power or changing professional attitudes that sometimes damage clients’ self-esteem (Gupta, 2015; Bennetts et al, 2011; Happell & Roper, 2009). Schön’s (2013, p. 42) conception of the features of professional practice that inhabit the ‘swampy lowland’, rather than the ‘high ground’ of technical rationality, applies to the aspects of fear and client capacity presented here. The fear is that sharing power with clients will harm
the business, and the quote that follows suggests that, for some services, resistance to implementing client participation remains for this reason:

When we talk to organisations about auditing their consumer participation we really need to talk with them about their fears. We learned that with one organisation where we hadn’t done that initial work and had this huge resistance and when I unpacked it we found that it was fear.

Ours was a grassroots organisation, which started by consumers 25 years ago. I don’t know if I had to do it (operationalise participation) now that I would be brave enough to do it.

It appears from such comments that a common reaction to fear, is for the leadership and management of an organisation become risk averse in their approach to service delivery, a point to which I return in a moment.

Other quotes highlighted the potential for workers to underestimate the capacity of clients to participate, a phenomenon which also features in the literature. For example, Tritter and McCallum’s (2006) suggest that Arnstein’s (1969) work has outlived its usefulness, because they believe Arnstein (1969) neglected to include capacity building of clients, in order to enable them to participate effectively. Perhaps more fairly, we can acknowledge that Arnstein did provide examples of a professional culture that seemed determined to obstruct the participation of the citizens of the neighbourhoods being redeveloped.

The quotes below illustrate two common approaches that fail to recognise the capacity of clients to participate fully. The first is an example of the professional culture, as described by Arnstein, that assumes clients have nothing to contribute. This would include whether or not the service is meeting their needs, which would seem the most basic and important feedback a client could provide to a service provider. The second and third quotes note the importance of participation to clients, and the potential damage to clients through the use of tokenistic approaches to participation:

I think for a lot of it is also that they (organisations) feel they (clients) don’t have the capacity to contribute and that is a personal judgment. If there are communication issues you can include a carer but by offering them that opportunity to participate we’re not putting our judgment on consumers about whether they can or cannot contribute. I think that’s a failure of a lot of the
community health sector is they feel consumers can’t offer expertise but often they can.

We involve our consumers in our strategic planning day as an organisation. Most of them don’t turn up which is good because it would be unmanageable but the ones that are there want to give their time and feel empowered to have a contributory role. I think that is a fear of some organisations that consumers will turn up and speak up and things will go in the wrong direction.

In trying to develop capacity for consumer participation is that people’s good will is that we want to involve our consumers but it actually becomes disempowering to collect data and shelve it. You create a disheartened consumer base that feel disempowered and they wasted their time doing this and they never see any fruit of their input.

The three quotes presented here also illustrate the potential for further stigmatisation of clients by making judgements on their capacity to contribute, fearing what might happen if clients are given an opportunity to participate and failing to listen and act on their feedback if they do participate. The feelings of uselessness and isolation that some clients experience, simply because they are in receipt of social services, have been noted in earlier chapters. The type of treatment from professionals described here participates in that stigmatisation, and continues to damage clients and their self-esteem.

7.9.5 Content, Structure and Use of the Rubric

With this theme, I sought participants’ initial reaction to the discussion rubric, which, at the time the focus groups were conducted, was referred to as a ‘tool’. I was particularly interested in obtaining comments on participants’ practice with clients, with the intention of learning whether participants thought there was anything missing from the rubric that was critical to their practice. I proceeded with questions about the rubric’s structure and content, and I also asked how participants might administer or utilise the rubric.

In each focus group, more than one participant’s initial reaction to the tool was both enthusiastic and positive, with agreement from the rest of the group. My assessment of why this occurred was that, first, organisations appreciated the value of the rubric as a method to stimulate discussion on the process of client participation and, second, participants valued being able to refer to concrete definitions and
practical examples of what was necessary for them to have in place when reflecting on their practice with clients. Representative feedback includes comments such as the following:

*I think it’s a good document, I think it really makes you think about where you’re at by looking at this document.*

*I think it’s a really good guide. I keep going between 3 and 4 (on ranking scale) and my mind is thinking about what would you do and how you would implement this but it really gets you thinking, it’s a good start for how to build client participation and how to embed it in the organisation.*

*It was quite overwhelming when first looking at it but I thought oh yeah, that’s a tool. It is very easy to read and it’s clear. I found it, just by reading it for a while, it didn’t take me long to work out how to use it.*

The quotes below illustrate that participants viewed the rubric as having the potential to be a useful resource to guide their work: first, by reflecting on the elements of their practice that enabled client participation; then by providing a mapping of what features of their practice required improvement or were missing; and, once in place, as a reference to keep them on track.

*My instant thought when I first looked at it is gee we really have a hell of a lot of work to do.*

*I think we’d transcend this pretty quickly. It is worthwhile as a reference and I would see us moving well into the very good area in all these fronts. I would be happy to see it used at a day-to-day level.*

### 7.10 Rubric Indicators

Participants were asked to consider each of the indicators used on the rubric, which are *Values, Relationships, Processes, Management* and *Leadership*. As the indicators were based on the enablers of participation investigated in the stage one study, I was interested in participants’ views on, and knowledge of, any of the five enablers and their applicability to their practice with clients. I discuss responses to each indicator in turn below.

#### 7.10.1 Values
The importance of cultural and personal values, and their contribution as the basis to good practice with clients, is exemplified by the quotes provided below. The first quote points out the difficulty in trying to assess individual values, but all three quotations highlight the need for practices within organisations to ensure the appropriate values are learned and displayed by workers in their behaviour towards their clients and one another.

You can never measure individual values and attitudes of staff but you can measure (the) parallels between what an organisation values and how the development occurs for that person.

If the values of the organisation are strong and clear and people are clear about them, the same values apply in relationships with consumers/service users as do with a departmental head. We tend to think that values are applicable to certain domains where they are and where they are not and where they underpin all our kind of practice. I think we have really good relationships with our consumers because we make sure they hold the same dignity we give a departmental head. It (organisational values) should be easier than what I hear organisations say to me because they’ve got their framework in their values; it is not a different set of values.

Are the values apparent all the time as the organisation conducts its business? Does the board regularly refer back to the values?

The academic literature on participation, noted in previous chapters, has emphasised the importance of personal and professional values in shaping an organisation’s culture. Values were clearly seen as an enabler of participation, particularly the importance of shared values across an organisation, consistent with the results of the stage one study. Nevertheless, Agbényiga (2011, p. 1768) notes the findings of Hofstede et al. (1990) that shared perceptions of daily practices, rather than shared values, were seen as the core of an organisation’s culture.

The second quote above possibly reflects a feature of some social services that place values in their organisational framework, but seem to fail at “practicing what they preach” (Greenwood, 1993, p. 1183). Respect for clients has become more of an aspiration than a reality in their practice.

7.10.2 Relationships
The quotes below demonstrate that relationships need to be genuine and based on mutual respect in order to be a significant component of any service provider’s practice with clients. The first quote clearly defines how clients expect to be treated and, although the quote is not directly from the client, the perspective implied in the reported comment - of “not wanting to be a tick-box for quality control” - suggests that the practitioner regards the sentiment as expressive of the views of an experienced client with much to offer the service provider. The second quote highlights the need for organisations to look beyond their front door and consider the environment and relationships their clients will return to. The perception of relationships holding people, as articulated by one participant, frames the importance of client-worker relationships precisely. The nature of these relationships determines the success and/or failure of the service.

Consumers would say when you build relationships with us; part of the dignity you give me is saying no sometimes because that is a normal response in the world. We don’t want consumers to think we’re giving out show bags. When you’re building relationships with us don’t tell us we’re going to have more impact than we will. They say: ‘Don’t give us padded up show bags, we don’t want to waste our time and we don’t want to be a tick box for your quality control’.

What about service users relations with the community or how service users interact with the community? A lot of people we see are very isolated.

We use the term of managing relationships. What that did was do away of all things (sic) like rules and what we have now are more guidelines about communication. In the past we’d have to deal with a young person who had broken a rule but now there is no rule. It is now we all need to sit down and have a discussion and it is psychotherapeutic in it’s intent. That’s the basis of our particular program. The development of relationships is the key to participation and holding people.

The notion of “normative violence”, noted earlier by Ward et al (2016, p.3), relates to the experience of clients not having their voices heard or not experiencing what they have to say as being treated respectfully. Such disrespect excludes them from participatory processes and creates feelings of what Francis et al (2006, p. 45) refer to as “self-stigma”. It is through relationships with staff that clients may reduce feelings of self-stigma and thereby achieve more successful outcomes for themselves.

The participants’ quotes presented above reinforce the notion that participation requires a relationship that allows the voices of clients to be heard. When Ward et al
(2016) speak of normative violence they are describing the “routine activities” that occur in services that prevent the voices of clients from being heard because they are not considered “legitimate” (p. 3). As I have noted above, this is particularly true for marginalised clients, such as people with cognitive impairment. Ward et al suggest challenging what they consider the “dominant view” (p. 4) of who can speak for marginalised clients. The term managing relationships, in the quote above, suggests that this organisation is challenging the dominant view by developing relationships that empower clients to have a voice.

7.10.3 Management and Leadership

The first two quotes listed below emphasise the essential requirement for the leadership of the organisation to support a client participation approach to service delivery, and also highlight the positive impact that a change to leadership with a less punitive approach may have on clients and workers. Participants acknowledged how changes in management brought about an emphasis on creating a new collaborative and less restrictive environment, which resulted in a more reasonable approach to risk taking. The remaining quotations reflect on management’s capacity to take risks, which stimulated much discussion among participants. The essence of the discussion in one group centred particularly on the view that service providers are operating in a risk controlled, litigious environment where client participation becomes a paradigm shift that in the minds managers increases risk.

It’s true about the rules, there’s a lot more flexibility and we tend to be more flexible. In that we are more flexible about the residents and send that back to management so they can then provide a discussion rather than being punitive. It is far more effective, punitive responses don’t work.

I was here when there was a change and our new manager came in and the change in our service was a dramatic shift. The service ran very punitively. It was us versus the environment.

Management needs to understand and be honest about risk. It really does play a role because if you’re engaging with consumers who are technically in a more fragile space at that particular time than are the providers of the service there is a risk element that needs to be considered.

The ability to do that (take risks in the treatment of clients) and to know you’re being supported gives you the comfort to make those decisions. Because there
are times when you question yourself but I believe as long as I can justify the reasons I did those things I’ll always be supported.

The first two quotes are examples of how a change in leadership can impact on the organisational life of both staff and clients. They also resonate with Schön’s (2013) concept of the ‘learning system’ of an organisation, as noted in chapter 3, which Schön describes as an organisation’s ‘behavioural world’ of knowledge, principles and practice. According to Schön, the learning system can inhibit, as well as enhance, a manager’s capacity to work through conflicting views and adapt to unfamiliar circumstances. In the examples described above, the learning system of the organisations may have severely limited the previous manager’s capacity to manage uncertainty in the form of their perception of risk and strict adherence to established practice. However, Schön does point out that organisational structures are also adaptable to new findings and tasks (p.242), which the new leadership demonstrates.

To be fair to management, the quotes from participants regarding management noted above may not reflect the organisation-wide contexts in which they may have occurred, or the attitudes and experiences of the people involved. Alternatively, the previous management may have simply been inept. Kruger and Dunning (1999) hypothesise that people that are incompetent suffer from a ‘dual burden’ of not being competent enough even to recognize their degree of incompetence. In a management role, this could play out in the dual form of not only being an incompetent manager, but also being sufficiently incompetent as to be incapable of realizing it (p. 1121).

The final quote is reflective of the work of Spence Laschinger et al (2009, p. 303) and their assertion that an organisation must first empower their workforce, in order to be successful in empowering their clients.

7.10.4 Rubric Descriptors

My main objectives in relation to this concept were: first, to check the discussion rubric’s descriptors for clarity and appropriateness as examples of practice; second, to encourage participants to offer their own examples of practice; and third, to seek comment from participants on the use of a ranking scale of 1 to 5 for each descriptor.

A consistent view across all focus groups, when asked to reflect on the content and structure of the rubric, was the importance of being more specific in describing each of the five measurable indicators used and to include simple examples of each descriptor. The first quote below is indicative of participants’ views. The second quote
referred more to a discussion rubric for use in a conversation with clients. An untested revised rubric for clients, developed in response to such feedback, can be found at Appendix H.

*I think on the back of your tool you could have a two page with some practical examples of what you mean when you talk about what they measure, just to make it a bit more helpful.*

*One thing I thought about is the ranking scale, is the time it takes staff to collect the information, assist in the reporting, educate clients as to what we’re talking about and getting that information back to the clients so they know that information is worthwhile.*

While not amounting to a significant reconstruction of the rubric, these changes, in the views of participants, were seen as improving its usefulness. The modified rubric for practitioners is presented in Appendix J.

### 7.11 Data Analysis – Overarching Research Questions

The focus group results presented in this section offer insights into why the social services that participated in the study appear to have difficulty embedding client participation in their practice. There was also agreement among participants regarding the components of practice, what I call the *enablers of participation*, as important contributors to good practice in their day-to-day work with clients. In particular, their comments highlighted *values* and *relationships*, which have been consistently noted in the academic literature, and appeared in the results of the stage one study, as the critical enablers of participation. In addition, there was consensus amongst participants regarding the rubric as having the potential to be a useful document to generate discussion, and be a ‘back of the envelope’ self-assessment of, their practice of client participation. In the following sections, I pan back from the thematic analysis of specific enablers, considered in isolation, and concentrate on applying the results of the focus groups data in answering each of the second stage study’s research questions.
7.11.1 How is client participation defined in the context of service delivery in participating social services?

Previous chapters have discussed the difficulty the academic literature describes in defining participation. For the social service organisations that participated in the stage two study, this question is further complicated by a number of factors and influences, highlighted in the participant responses detailed above. What became clear in participants’ responses to this question is that the practice of client participation in social services continues to be perceived as something inherently complex, unconnected to good practice, difficult to do well and often too hard to try. To repeat Stoecklin’s (2012) words, participation remains a “concept in need of an explicit theory of action” (p. 13).

Participants were consistent in their view of client participation as engaging clients in a collaborative relationship aimed at improving the quality of a clients’ life in some way, and as a process that involved, in part, obtaining evidence from clients regarding the effectiveness of the services they received, and then feeding that information back through the management structure to the board of management. Participants did not offer specific detail on issues like: how this flow of client-specific evidence would be obtained; what processes would be required to encourage it; what training and support clients would require to accomplish this; and what actions, if any, would be taken. The following quotes are typical of responses when participants were asked to describe client participation in their practice:

how you develop and feed back information provided by consumers through the client group to leadership, to the board, it’s that organisational cycle which changes an organisation from having a limited capacity to a very good consumer participation process.

we’re thinking of including clients in exit interviews or residents’ overviews but it’s been a bit haphazard and that’s been identified by our whole service not just this program.

The above comments demonstrate a significant aspect of the discussion - that none of the participating service providers had a tangible method of ensuring client participation in their practice.

The quote below highlights the need for client participation to be part of the everyday practice of the organisation - a practice, which stems from an organisational
culture built on values and beliefs that promote, support and encourage clients to participate:

It needs to be in the policy and procedures, constitution, board make ups and reflected in so many areas of an organisation that it needs to becomes an embedding of a philosophy rather than an attachment of tools. Tools that become pains in the ass for everybody and people forget what they are there for if they don’t make sense schematically for people.

Hernandez et al (2010), as discussed in Chapter 3, refer to what this participant described as a “whole-systems approach”, in which all aspects of an organisation work together to imbed client participation into everyday practice (p. 716). Hernandez et al emphasise that a whole-system approach requires exactly what this participant has described, which begins with the beliefs and values that build an ethos of participation which becomes the soul of the organisation (p.721). A whole-systems approach demands that participation is not ‘added-on’ but is conceived on an equal footing with all other organisational activities. Hernandez et al believe that, in order for participatory processes to work, they be merged with the four main aspects of an organisation, namely: culture; structure; practice; and review.

Nevertheless, as I have noted above, each participating organisation had yet to establish a practice model for participation, and each were at different stages of developing their particular model of client participation. I suggest that the absence of such a model indicates that these services have not made clear their understanding of what client participation means in the context of their service delivery and cohort of clients. Wright et al (2006) advise that, in operationalising participation, services ensure that clients and staff understand the reasons why participation should be an integral component of their practice. Wright et al (2006) insist that services first articulate the benefits of participation for clients and staff, and then commit to a shared definition or understanding of participation (p. 6).

7.11.2 What are the barriers to including client participation in service delivery and how can these be addressed?

Focus group results suggested four main barriers to client participation, which included fear as the main barrier for some, and client capacity, knowhow and resources as the remaining three. Although both fear and client capacity have been given detailed treatment in the previous section, my purpose in revisiting these
concepts here is to reiterate that both appear to be a product of values and beliefs that, instead of creating an ‘organisational ethos’ that encourages and supports participation, actually shape a culture that hinders it (Hernandez et al, 2010, p. 721). By doing so, the lost opportunities for clients to participate impact on clients’ self-worth, and put an organisation at risk of causing greater harm to their clients.

A consistent view was that overcoming barriers to participation starts with being honest with clients about what the organisation can offer, and with explanations about the how and why decisions are made. The quote below provides a practical example:

_Sometimes the Department (DHHS) will stipulate something we have to do. We treat the consumers with respect by coming to them and actually say, in a nice way, you don’t really have a choice in this being implemented and explain why. That’s when they think you are actually trying to treat them as a human, not as a client as such. Generally, when we’ve done that approach it has worked really well. As soon as you try to implement something and don’t say anything to them and just do it, they will react._

The power imbalance between staff and clients never disappears, but it can be balanced through the actions of honesty and explanation, as the above quote suggests, which will assist in building trust. The following quote provides an example of the effort it takes on the part of workers to build trust with their clients:

_We have thirty people a month come through and the experience of most of that thirty is distrust for us. All day, every day all we’re doing is building trust. We have this stream of people at the other end saying, “you guys are amazing”. It’s like Groundhog day._

In one group, a concern emerged during a discussion of being honest with clients, when a participant raised the matter of ‘manipulating choice’ and the rationale behind it:

_It’s about a strategy based on what we know about them (clients) or what people tell us about them._

_We know that if you said, ‘here’s six things’, you mightn’t get any decision and you might get some behaviour from it as well but if we said, ‘we know this person likes this, this and this, we are going to say these are the choices and what amongst those are you going to choose’?_
But there is also a flip side of manipulation of choice, which might also be for our (staff) benefit. So, we don’t get behaviour or we get something done in a timely manor due to organisational pressures.

This is one of the conversations (manipulation of choice) I’d like to explore amongst the team. For instance, why do we do certain things? What thought do we give it before we actually do, do that?

The importance of building collaborative, trusting relationships between staff and clients has been highlighted throughout this thesis. The first three quotes presented here illustrate the fine line staff sometimes needs to follow to maintain and sustain these relationships. The final quote offers a model of a potential use for the rubric to assist in discussing the professional practice of this participant’s service. The purpose of the conversation might be to answer the question of “why do we do certain things”? In this context, the rubric would be used to structure the conversation on the practice examples contained in the rubric to elicit discussion and debate on participants’ professional practice, which could be directed toward an examination of why they do the things they do with clients. This is an example of the type of dialogue among staff, and between management and staff, that the rubric could provoke. Robson et al (2003) support the notion that “firm statements” about client participation are valuable for initiating debate, and offer a starting point to monitor progress or measure the lack of it (p. 7).

The barrier of knowhow seems to surface when the apparent goodwill and motivation in social services to improve participative processes, appears to be overwhelmed by not knowing where to start. This makes operationalising client participation appear unachievable to such an extent that it becomes much easier not to do it. Goodwill may also dissipate if there is a lack of understanding of what participation means in practice. The quote below seems to describe an example of a funding body, attempting to write guidelines for participation, with little understanding or direct experience of the practice of social services:

One of the quality accreditations that work in community services had a couple of goes at this (guidelines for client participation) and they didn’t understand they had real goodwill to capture and support it in the organisation. They didn’t have an understanding of what the indicators might be and what evidence to look for so it’s (client participation) in the organisation in a sustainable way.

The following quote is a practice example of a theme from my earlier review of the participation literature, which warned that what is described as participation by
service providers often varies greatly in practice (Arnstein, 1969; Padilla et al, 2007; Cornwall 2008). The different meanings and terms given to participation often cause confusion about the practice of participation, as do models of participation that offer opposing goals for participatory processes, such as Arnstein’s goal of the transfer of power or Hart’s (1992) interest in allowing clients to participate at the level they choose.

The organisation that I used to work for, participation was a big part of our role. Making sure we were getting the right amount of clients in a group for example but just because they attended a group doesn’t mean they got a lot out of it. It was always a concern for me, client participation. It was just like... they were a number but what did participation really entail for them?

In the above example, the service’s focus appears to be on recording the number of participants, which would be a condition of their contractual arrangement with their funding body, and points toward the barrier of resources. In this case, it seems that the content and purpose of the group discussion is of no significance to the funding body. This quote also introduces the need for organisations to develop effective review systems, as noted by Wright et al (2006, p. 6).

The barrier of resources presented itself in various forms, but each appears to relate to either risk-averse management practices, or limitations imposed by funding bodies:

I was in a housing support role, if you support them (clients) for an hour then for recording purposes that is one support period. That’s great for the organisation but what does that one hour mean for them?

The department has guidelines for support periods and as a program here we try to maintain a degree of flexibility around that but there are; well, those timelines don’t at all match what a client wants - like a four-week transitional support timeline. Clients... actually want someone to work beyond that. We have a degree of flexibility here that is a bit more than other services perhaps but... the client doesn’t have a full say in that at all.

There is always going to be a power imbalance. Even though our service is voluntary, if you want housing, food vouchers or something else, you have to engage in the program that we have which is defined to some extent by the government.
The above quotes underscore what I consider to be the non-negotiable requirements of funding bodies, which are designed solely as a mechanism to account for public monies. The challenge for service providers in the first instance is to make certain their contact with clients is as meaningful and effective as possible. Then, they must also manage their existing resources more efficiently and/or gather evidence of a shortfall in funding to build a case for more resources.

7.11.3 Are the building blocks necessary for client participation included in the rubric?

The findings of the stage one study, presented in Chapter Six, highlighted the importance of values, both personal and organisational, as essential contributors to good practice with clients. The results of the stage two focus group interviews placed organisational values at the top of the list of the necessary enablers of participation. The consensus of opinion among focus group participants was their understanding that individual attitudes and values underpin the development of shared values across an organisation. The values are shared and reflected from the Board of Management and be operationalised in management practices, reflected in decision making processes in the application of the rules of the organisation, and professional practice with clients. Are the values regularly discussed, are they in the organisation’s constitution and part of induction and the development of staff? A difficulty with values is that they can be seen as a form of words without substance unless the organisation has a clear sense of purpose that translates values into actions. The quote below is from a participant who works in an organisation that appears to live the concept of shared values:

Every decision made in this place, especially after hours is that every person who works here cares deeply about the lives of the young people we have here so, you don’t make a mistake when you’re working from that space.

The emphasis in this quote is on taking the needs of clients seriously through basing all decisions on what is in the best interests of the client.

The next indicator to prove significant was relationships. Comments from participants suggested that establishing and maintaining relationships with clients is not as complex as some people seem to portray it. Participants based their views on the values of the organisation, and on whether or not the organisational values were clear and people understood that the same values applied to anyone who came in
contact with the organisation. In other words, everyone, no matter their status within or external to the organisation, was accorded the same level of respect and dignity.

For some participants, their clients, particularly young people, have had few if any meaningful relationships with adults, as the quote below highlights:

*I think the fact that we are in formative relationships for some of these young people. They don’t have other positive relationships in their world and we have a real opportunity here to tap into that and I think that’s amazing.*

At times, maintaining relationships with clients not only tests a worker’s strength and level of tolerance but also depends on the worker’s experience and understanding of their client group, as the next quote exemplifies:

*In the early days, we use this notion of positive regard and active tolerance. We expect a lot of shit from these young people and we just take as much as you can, to take on a young person’s anger and it dissipates over time.*

Participants in one group questioned whether relationships as an indicator should be included as part of the processes indicator, but further discussion made it clear that it should stand on its own. This particular group also asked about relationships with the community, which has been included in the results section above. Another participant supported this notion and their comment is included below:

*Being part of the community is a huge protective factor and being part of the community. I am sort of with (participant N) does it need the same sort of space.*

It is, of course, important for clients and services to develop relationships and supports in the community where clients live. The revised rubric (Appendix J) includes relationships external to the service in the description of the relationships indicator.

The final comment about relationships that requires mention here, seems to sum up a critical difference that separates effective social services from others:

*If you don’t have good relationships between staff, you’re not going to have good relationships with your clients.*

The indicator of management and leadership also received considerable attention from the groups. Participants’ comments related mainly to being honest and clear about managing risks. For management, participants suggested that managing risks begins with the power imbalance between workers and clients. At the beginning of their involvement with the organisation, clients are generally in a fragile space. Care should be taken by service providers at that particular time. This is significant because
of the risk to do great harm to clients. One participant pointed out the importance of providing an explanation or rational for decisions. As the participant put it: “feed back what the outcome is with an explanation”.

In the final version of the rubric (Appendix J), the difference between the indicators of management and leadership includes a more specific distinction between the two.

Although the indicators were never meant to be an exhaustive list of the enablers of participation, there was consistent agreement across all focus groups that the current indicators formed enough of a foundation to begin a worthwhile discussion on client participation. Nevertheless, it was suggested that each indicator be revised to include a practice-based definition in future versions. In considering this suggestion, I decided to include a brief description for each indicator, and leave the specific practice-based examples to the participants from the services utilising the rubric, so that these dimensions of the rubric could be localized and situated to reflect true examples of their practice.

7.11.4 Do the descriptors for each indicator provide clear examples of limited, adequate and good practice in community sector services?

Groups pointed to the possibility of including, possibly on the back of the rubric so that it remained a single page, concise practice examples of each level of the ranking scale, for each descriptor. One group suggested including practice examples for each indicator in order to ensure all staff were clear on what was meant by each indicator. This suggestion was initiated by some participants who were confused by the language used in the rubric, such as the differences between management and leadership:

Underneath the indicators would you consider putting questions that would clarify what they mean, what they’re asking?

Groups were positive and supportive of including the ranking scale in the final version of the rubric. I have noted earlier in this chapter the initial reactions of participants to the rubric, which was followed by participants undertaking a self-assessment of where they believed their service ranked on the rubric’s scale. The immediacy of this self-assessment suggested that the ranking scale needed to remain as part of the rubric, but with the numbering from one to five removed. This, I believe,
would allow the rubric to be viewed as more of a guide than as a measurement tool. A few examples are presented below:

*Say in the leadership one, I’d say we’re in a good section but how do we get ourselves into a very good section. The clients we work with are virtually all in crisis and we have a very limited time to work with them.*

*Some of it is a little bit subjective in terms of their reading, the four and fives in particular. Do you want it to be a document that you measure yourself on or is it designed to be a good guiding principle?*

The discussion on the rubric also highlighted the fact that services are attempting to work through improving their participative processes, as the comment below demonstrates:

*When we looked at Hart’s (1992) document 18 months ago we weren’t very far from tokenism in everything.*

Other participants had also proposed developing a version of the rubric for client use, asking, for example, for:

*A tool for service users as well, we could use this tool so clients are aware of what client participation means.*

Initially, I dismissed the idea but, on reflection, I decided a client version could be used, as the above quote suggests, for having a conversation with clients about what participation means for them and what their rights and responsibilities are as a client, such as participating at the level they choose, in the services they receive. Moreover, the draft version presented in Appendix H provides an untested example of what a discussion rubric to be used with clients might contain.

In the following section, I present a summary of the significant points this chapter has contributed to the goals of this thesis.

### 7.12 Summary – Chapter Seven

In summarising this chapter, I take a step back and first review my initial aims for the second stage study, and I present this review in combination with my analysis of the data obtained in the focus groups. I begin with my primary goal of the second stage, which was to investigate and find answers to the questions left unanswered by the first stage study. The most significant objective was to resolve the question of why social services seem to have difficulty incorporating participation into their everyday
practice with clients. In addition, I was determined to gain service providers’ perspectives on the current state of play in social services in Victoria, through focused discussions of their understandings of client participation and the barriers and enablers they face in applying participatory practices in their services.

In examining how client participation is defined in the current context of practice in social services, the findings indicate that practitioners in the second study are capable of describing their approach to client participation in their hands-on practice with clients. Their descriptions of the practice of participation in the social services sector, however, implied that participation is something that happens in addition to their normal work with clients. As I have noted earlier, the academic literature on participation continues to offer a variety of descriptions, models and goals of participation, after decades of research. Nevertheless, Wright et al (2006), while acknowledging the plethora of definitions of participation, propose at least two causes for the difficulty social services have in implementing participation in their practice. The first, which I have noted previously, relates to the failure of services to establish an agreed understanding of what participation means at the organisational level, so that it can be understood, shared, marketed and embedded in practices across the organisation. The second, in their view, is that participation may have become “the latest ‘buzzword’ for policy and practice - it becomes simply a ‘tick box’ exercise” - a requirement that leaves organisations with little time to fully understand how to properly operationalise it (Wright et al, 2006, p. 6). The focus group discussions of participation with professional practitioners identified the need for them to combine their knowledge of good practice in the context in which they work, with a deeper understanding of what the often-academic theoretical models on participation have to offer.

Something analogous is also reflected in focus group discussions regarding personal values and attitudes. In this case, practitioners put their personal values into action in their relationships with, and treatment of, clients and each other. Conversely, in the professional experiences of participants, these values are not always seen as part of the organisational culture of some social services. Both of these examples resonate with Wright et al (2006) and Hernandez et al’s (2010) observations on the need for social services to develop an integrated, whole-systems approach to implementing participatory practices.

The interview data identified four barriers to participation, which included fear, client capacity, know-how and resources. Combining these four barriers would
produce an environment that: perceives client participation as a complicated addition to the day to day work with clients (Hernandez et al, 2010); fails to take into account the vulnerability and feelings of stigmatisation clients experience (Gupta & Blewett, 2008; Hickey & Kipping, 1998); lacks an understanding of the importance of culture in developing a commitment to participation (Wright et al, 2006; Happell & Roper, 2009); and contains a professional ethos that resists change for fear of losing power and control (Bennetts, et al, 2011). An environment in which these barriers are in place would cause clients significant harm.

Examining the adequacy of the rubric was useful in that it revealed a great deal about the participants’ experience of good and bad practices of participation. As experienced social services professionals, the participants described the things that they value most in their practice with clients. Personal values aside, they were concerned with treating clients with respect, listening to what their clients have to say and ensuring they responded in a timely manner to meet the needs of their clients within the confines of conflicting organisational demands. All of these issues came up readily in the context of discussing the content presented in the discussion rubric.

As a practitioner in social services in Australia and overseas and, now, as a doctoral researcher conducting an exploratory qualitative study, I am naturally cautious of confusing the practice I value, with the practice values of participants. Mauthner and Doucet (2003, p. 414), in their reflections on their early experiences of qualitative analysis, caution about this risk. Nevertheless, I have become confident enough in my approach to qualitative analysis, to state that the practitioners who participated in the seven focus groups appeared to freely and spontaneously discuss their own professional practice in ways that suggest that the positions articulated were already matters of professional concern and reflection, for which the rubric provided structure and focus.

The results of the second stage study, if posited as the attributes of an imaginary social service, would give birth to an organisation that contained a core group of committed professional staff that believed in and understood the necessity of building a culture of participation. Their tasks would be to: first, engage with clients to ensure they gain an understanding of what participation means for them; second, educate management on participation to establish an organisation-wide understanding of participation; third, assist management and some professionals to overcome their fear of losing power and control; fourth, define participation in the context of their service as inclusive of everyday practice with clients, not as an additional activity; fifth, work
with all segments of the organisation to develop processes that enable and sustain the active participation of clients; and, sixth, utilise a discussion rubric to review progress.

In the concluding chapter, I return to my goals, aims and intentions for this research and recall the history and evolution of participation in the State of Victoria. I revisit this historical discussion to connect the progression of participation from its beginnings in social movements and academia, to the present time.

I present the themes that have emerged in this thesis and describe how they combine, in stage one and stage two studies, to make a contribution to the international discussion of participation by increasing the knowledge and understandings of the practice of participation and the necessity of client participation for social services and their clients.
Chapter Eight: Conclusion

8.1 Introduction

The political structures that individualise social problems and create barriers that stigmatise people with disabilities and prevent them from participating in society as equal citizens, also exclude, in similar ways, all people who are in receipt of social services. All professional social service organisations maintain some form of commitment to service user participation - and yet the goal of maximising service user participation remains elusive. For vulnerable clients – sharing a history of oppressive dimensions of practice, theories, and models of service delivery, whose common characteristic is their failure to give them a say in their treatment - progress has been even more difficult. This Australian case study has explored the reasons why the international discussion on service user participation has hit a roadblock over how to implement these ideals in professional practice. The results offer some potentials for achieving higher and more meaningful levels of service user participation in the social services sector in Victoria, Australia, with potential implications beyond the Victorian case.

In seeking answers for the apparently limited success in implementing participatory processes in social services in Australia and overseas, this study has investigated the current representation of the problem of participation from three distinct theoretical categories. These categories relate to: the perceptions and attitudes of the wider society toward people 'on welfare'; the social constructs that cause the marginalisation of these people; and the recurring examples of professional practice that often diminish, rather than enhance, the self-esteem of service users. By focusing on these three perspectives, the study confronted the questions of: why participation is important; why social services require it; what participation constitutes in the practice of social services; and why it is difficult to achieve. Through a thorough examination of the international academic literature on participation, by conducting interviews with the clients and providers of social services, and then focus groups with professional practitioners in social services, I was able to better understand the effects of the barriers and enablers of participation, both as noted in the international literature, and as they manifest in the practice of social services.

This chapter presents a summary of this research. I discuss the contribution of this research to the practice of participation in social services and its implications for clients and providers of social services in Victoria, Australia. Given my study of the international literature on participation, I suspect my findings may prove useful for
practitioners in the United Kingdom and North America. I also note the limitations of this research and propose future lines of research.

8.2 Research Summary

In the 1960s, Goffman (1986, p. 5) discussed how "we normals" create an ideology to explain why people considered inferior to us are "not quite human" and describes stigma as a mark of social disgrace. The academic literature provides insight into the numerous contexts of stigma in our society and the role social policies play in continuing the construction of the institutions that create stigmatised contexts, rather than addressing the social conditions, professional attitudes, values and beliefs that build institutions that "mark" clients.

Goffman’s (1986, p. 3) conception of stigma as a product of the interaction of an individual and their society, is what fashions the social identity of both people with disability and the lived experiences of the clients of social services. Social policies sometimes perpetuate the marginalisation of individuals in need of social services. Applying Bacchi’s (2009) analysis of the ways in which problem representations can create social relationships within discourses that create inequality, assists us in determining what Foucault refers to as the "dividing practices" that underlie the experience of service users, turning them into "subjects of a particular kind" in the eyes of their community (Bacchi, p. 16).

Schön (2013) provides insight into the practice of some professionals through his discussion of the positivist epistemology of technical rationality, and through his insight that professional practice has both a high ground where decisions are made using technical solutions, and a complex and confusing swampy lowland, where the problem of service user participation is found. Sennett’s (2003) work on respect illuminates the importance of personal and professional values as a critical building block of the type of client/staff relationships that form the underpinnings for achieving the full participation of clients in the services they receive.

This research applies these theoretical categories to confront Stoecklin’s (2012) statement that participation is a “concept in need of an explicit theory of action” (p.13). Over the past fifty years, the academic literature has offered a diverse range of approaches to, and perceptions of, participation that, in the eyes of professional practitioners, appear as fragments of practice. This is not, in any way, due to a failure of scholars to address the complexities of implementing participation in the practice.
of social services. I argue, instead, that this problem is born from, and sustained by, the internal beliefs and values of individuals and of organisational leadership and management, which set and maintain the culture of the organisation. An organisational culture in some services can inhibit professionals from being more inclusive in their work with clients. This problem is also maintained by the lack of respect for clients exhibited by some professionals, which is expressed in their fear that client involvement will lessen their professional status, their lack of interest in the knowledge and life experience that clients hold, and their limited understanding of what this experience has to offer them as professionals.

### 8.3 Contribution to existing knowledge

This research offers significant insights into why the participating social services have difficulty embedding client participation in their practice. It names the critical dimensions of the **barriers** and **enablers** of participation in the international academic literature and in the practice of social services in Victoria. The findings of this research attempt to address Stoecklin's (2012) concern by offering a model for contextualising the insights of the academic literature on participation into a coherent, practical body of knowledge that assists social service practitioners in advancing their practice of participation. The main contributions of this Australian case study to the international discussion of participation are:

- The research provided evidence that social services experience difficulty in embedding participatory practice into organisational culture due to factors such as: a failure to establish an agreed understanding of what participation means in practice; fear of losing control of their service; and a predisposition to think of participation as something special and different from their day to day practice with clients, which causes them to disregard existing examples of good practice of client participation in their service.
- The study established the contribution to the practice of participation in social services of five **enablers** of participation, which I have named: *values; relationships; processes; management; and leadership*.  
- The study highlighted the key significance of the influence of *values* in shaping client/staff relationships, organisational processes, management approaches and leadership styles in ways that may enhance or inhibit the participatory nature of social services.
• The research identified four main barriers to participation, which I refer to as: fear; client capacity; know-how; and resources.

• The study demonstrates how the barriers of fear and client capacity are both products of a particular form of personal and professional values and beliefs that, rather than working to encourage and support participation, actually shape a culture that hinders it.

• The barrier of know-how was demonstrated to arise when the goodwill and motivation to improve practice is overwhelmed by the apparent complexity of not knowing where to start.

• The barrier of resources was revealed as relating to either risk adverse management practices, which actually translate into the fear of losing power and control of the service, and/or to limitations imposed by funding bodies.

• The research determined the content, structure and the potential usefulness of a discussion rubric, which would be used to prompt a professional conversation that reflects on the participatory practice in a given social service.

These findings contribute to our understanding of the perceptions of service user participation in a selection of Victorian social services. The section to follow discusses how this research illuminates the international discourse on participation in relation to the vulnerable clients of these types of services, and illustrates its value to the clients and staff of social services.

The many models, applications, definitions and further developments of participation since Arnstein’s (1969) work, have portrayed participation, in the minds of service providers, as a complex, abstract concept that ignores context and confuses purpose. This research offers service providers a more pragmatic conception of participation by focusing on the lived experiences of participation by service users and practitioners, and by providing practice-based examples of the factors that enable participation and those that present barriers to it.

The findings highlight the clear expectations of service users to be treated respectfully and fairly, and for staff to gain their trust and build relationships through their actions and be responsive to their particular needs, as important contributors to good practice. The findings also note the significance of shared values across the whole of an organisation, as a contributor to a positive work environment and the development and maintenance of relationships between all actors in a social service.
The quality of these relationships was shown to be a significant facilitator of participation. The barrier of *fear*, highlighted above, requires social services to take note of and manage the professional attitudes and culture of their organisations.

In order to improve their practice of participation, this research suggests that social services first acknowledge that barriers to participation may exist within their culture, structure and practice. Utilising a *discussion rubric* may be a useful prompt for services to begin a professional conversation on their practice of participation. The *discussion rubric* developed in this research attempted to provide a summary of the academic literature on participation and offered varying practice examples of the five enablers of participation. The practice examples were provided as a resource that practitioners could recognise in their own practice with clients, helping to translate between more abstract concepts and the context of professional practice. These practice examples were further developed through feedback from professional practitioners.

Second, the research suggests that service providers undertake an appraisal of all staff relationships with, and attitudes toward, clients, with a particular focus on how they balance the ‘double-bind relationship’ of authority over, and care for, their clients. Third, the research suggests that organisations reflect on whether staff value their “professional status” over their relationships with clients (Stoecklin, 2012, p. 9).

### 8.4 Research Limitations

The eight social service organisations that participated in this research were located in the State of Victoria. One was located in a rural region and the rest were part of the greater Melbourne metropolitan area, which may present as a limiting factor in this study. Nevertheless, participants represented a broad range of human services programs, which have been outlined earlier in this thesis. Twenty-nine individuals participated in the stage one study, of whom 16 were service users, while 35 practitioners participated in seven focus groups in the stage two study. No service users were excluded from participating because of physical or cognitive impairment.

The research was also limited by its aim to contribute to the understanding and knowledge of the practice of participation in social services. In doing this, I traced the evolution of participation from a positivist perspective to a more collaborative approach based on individual human rights, which mapped onto the historical changes to service delivery in the State of Victoria. Changes that were influenced by
transformations in service delivery for vulnerable clients in the United Kingdom and the USA. I offered my professional experience in Victorian social services to add insights into these historical shifts.

My professional experience, closeness to the research aims, and the qualitative nature of the study, may be viewed as adding an element of bias to the study – or, by contrast, may be viewed as shaping my ability to serve as an effective research instrument for this kind of project. My values and beliefs, made clear in the Preface to this thesis, are at the forefront of this research. As discussed in the methodological sections in previous chapters, I have taken steps to limit any personal bias in my interpretation of the data, by applying an autoethnographic method which drew on my professional experience to facilitate the development of rapport and to interpret the results arising from both interviews and focus groups.

I do not underestimate the importance of these limitations or their potential to undermine the veracity of this research; the findings present a provisional beginning which necessarily requires further research to develop a comprehensive theory of action for client participation.

### 8.5 Directions for Future Research

This research raises a number of questions about the nature of personal and professional values, the existence of prejudice in our communities toward people in receipt of social services and the manner in which our identities are shaped and maintained by the circumstances we experience. Having witnessed, through my years of professional practice, the progression of generations of families through both social services and the criminal justice system, I have remained concerned that this phenomenon has not waned. Yet, the findings of this research have highlighted the importance of what practitioners value in their work with clients and what, in turn, clients value in the services they receive. What people value, defines how they form and maintain their relationships with others and, therefore, the quality of the consequences of these relationships. This points to the potential for research into what a more comprehensive range of social services value - the implications for outcomes for clients, staff training and selection, funding mechanisms, policy development, and what the community values in the provision of its social services. A further direction to take in this regard is to explore the notion of an organisation’s cultural identity. Although this research has discussed the influence of an organisation’s culture in forming and maintaining its approach to clients, the details of how and why this
occurs, for better or worse, remains an area that can be further explored. This form of inquiry could also examine the differences in values between varying types of social services programs and the impact of these values on the benefits for clients.

These findings highlight the barriers to, and enablers of, participation, which also suggests the potential for further research relating to issues such as: the recognition of the role leadership plays in enabling the participation of clients in social services by confronting the causes of the constraints that prevent it; empowering clients and staff to recognise the barriers to participation in the individuals, culture and processes of an organisation and to take action to address them; and how to develop and maintain a culture of shared values across the whole of an organisation.

An important question to pursue in future research is the development of techniques or strategies for social services to sustain a continuous process of regular reflection on their practice with clients. The purpose of these strategies would be to provide opportunities for practitioners to discuss, debate and question why things are done in certain ways and to present ideas for improvements in their practice with clients. The findings indicate that the rubric used in this study has the potential to be a useful document to generate a back of envelope self-assessment of an organisation’s practice of client participation. The value of the rubric, as indicated in the findings of this study, is that it includes clear statements about an organisation’s practice of client participation, which offers a starting point to compare current practice with suggestions for improvement.

This research, though based on a small sample of Victorian social services, offers important contributions to the existing knowledge and the international discussion of client participation by adopting a perspective based on the views of the clients and practitioners of social services. This perspective was chosen in order to address the current representations of the problem of participation for service users and providers. In the first instance, this research has determined that participation is important simply because it demands that people be treated with dignity and respect as valued individuals. Eliminating barriers gives people opportunities to choose in what way and to what extent they participate.

Finally, the thesis has characterised the problem with participation as two-fold: first, it exists in the swampy lowland of confusing situations, making it devoid of technical solutions and ensuring it remains of great concern to clients and practitioners in social services. Second, it is an area of practice in social services that has yet to develop a theory of action. In failing to address these two significant features of
participation, we are putting our service providers at risk of doing great harm to their clients. This research has tried to contribute to the theory of action dimension of the problem of participation – but much more work remains to be done. This study can be regarded as a proof of concept of the professional value of structured discussions of practice examples of participation. Future work should explore how this concept can be extended to a wider range of organisations here in Australia and overseas, and how the impact of such structured discussions translates into sustained transformations in organisational culture and practice.
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Appendix A

Stage One Study

Service User Interview Schedule

Overview

• Purpose – Why am I here?
• You can leave whenever you like/you don’t have to answer my questions
• Privacy
• Recording/note taking

Background

What program(s) do you attend here? How long have you been in the program? How old are you?

Attitudes/values

Do you like coming here? Do you feel safe here?
What is it like for you living/attending here?

Relationships

Is the staff here OK?
How do you get on with them?
Do the staff ask you what you think/want? Who do you talk to if you have a problem? Do the staff speak to your family much?
Do you have many friends here?
Do you get a chance to visit your friends?
 Processes

How do you find out about programs here? Do you choose what programs you attend? Do you have a support plan?

Did you help write your plan?

Is what you want in your plan?

 Management/leadership

Who is the boss here?

Does he/she ever come and have a chat with you?

Do they ask you what you think about living/attending here? Is there anything about this place you’d like to change?

Is there anything else you’d like to talk about?
Appendix B

Stage One Study

Staff and Board Member Plain Language Statement

Project Title:

An Exploration of User Participation in Service Development

Investigator:

Mr Lou Iaquinto (PhD student) BA, Grad Dip, MSc
Dr Karen Nankervis (Senior Supervisor, Adjunct Professor, Disability Studies, RMIT University and Director, Centre of Excellence for Behaviour Support, University of Queensland,

Who is involved in this research project? Why is it being conducted?

My name is Lou Iaquinto and I am the investigator conducting this research project. I am a PhD student in the School of Health Sciences at RMIT University and this research project is part of my degree. The aim of this project is to identify community service organisations that utilise participative processes to inform their service development.

The RMIT University Human Research Ethics Committee has approved this study. If you have any reservation or complaint about the ethical conduct of this research, and wish to talk with an independent person, you may contact RMIT University’s Research Ethics Office on 03 9925 2251 or email to human.ethics@rmit.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

You may also contact my Senior Supervisor, Dr. Karen Nankervis, Adjunct Professor, RMIT University and Director, Centre of Excellence for Behavior
Why have you been approached?

Your organisation has been chosen at random from a list of community service organisations.

What is the project about? What are the questions being addressed?

The aim of this research project is to identify community service organisations that utilise participative processes to inform their service development. This study will define the elements of user participation processes and use this data to describe a model of user participation that achieves meaningful participation for service users.

In many states in Australia, new legislation reflects a change in the community’s attitude toward what should be expected of CSOs in regard to user participation. There is now an emphasis on individuality and the rights of service users to make decisions and choices about their life. This study will investigate CSOs to seek answers to the following research questions:

- What are the models of user participation currently in use by community service organisations?
- What do CSOs need to have in place for effective participation?
- What changes have occurred within the organisation as a result of user participation?
- What are the needs of users in relation to participation?
- What are the impacts of user participation processes on outcomes for service users?

If I agree to participate, what will I be required to do?

The project will involve conducting an individual semi-structured interview with two managers or team leaders, two service users and the Chair of the Board of Management or their nominee of each participating community service organisation. The individual semi-structured interviews will be of approximately one-hour duration for each participant. The interviews will take place at the organisation’s premises so as to minimise any disruption or inconvenience to staff, users and participants. With permission, I plan on making a recording of interviews but this is not a requirement for participation.

I will also seek advice from staff regarding a service user’s capacity to participate fully in the interview process and to give informed consent.
Service users that are unable to give informed consent will be excluded from participation in the study.

**What are the risks or disadvantages associated with participation?**

There should not be any risks to participants outside their normal day-to-day activities. Interviews will be conducted in a professional, sensitive and non-threatening manner. Should a participant decide during the interview that they do not wish to participate, the interview will be concluded immediately.

Some participants may require support from staff. In this case, a request will be made to have a staff member in reasonable proximity to where the interview is being conducted in order to provide assistance should the participant become uncomfortable during the interview.

**What are the benefits associated with participation?**

The main outcome of this research will be to describe a meaningful model of user participation for community service organisations, based on current practice. Although your organisation and all participants will not be identifiable in my thesis or any subsequent publications, there is a potential benefit of increased knowledge of participative processes for all community service organisations that participate in this study.

**What will happen to the information I provide?**

All organisations and participants will remain anonymous. The investigator will address the participants by their first name during the interview only. Then, a pseudonym will be recorded for each participant and organisation. No personal information will be stored for any participants. With the permission of participants, interviews will be recorded digitally and transcribed but the participant will not be identifiable. Recording of interviews is not required and hand written notes will be taken if the participant does not wish to be recorded. The transcribed interviews will be stored in a locked cabinet at RMIT and digital recordings of interviews will be stored on a secure non-networked computer at RMIT University. The research data will be kept on these systems for five years and then destroyed in accordance with RMIT University procedures, which comply with the Australian Code for the Responsible Conduct of Research.

**What are my rights as a participant?**

Each individual participant and community service organisation that participates in this study will remain anonymous. Each participant has the right to withdraw from participation without prejudice at any time and to have any questions answered promptly.
Whom should I contact if I have any questions?

In the first instance I would prefer for you to contact the investigator, Lou Iaquinto on [phone number] or email to [email address].

If you prefer, you may contact my Senior Supervisor, Dr Karen Nankervis on [phone number] or email to.

What other issues should I be aware of before deciding whether to participate?

There are no further issues for you to consider but please contact Dr Nankervis or me if you have any questions.

Yours sincerely,

Lou Iaquinto

BA, Grad Dip, MSc

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT GPO Box 2476V, Melbourne, 3001.

Details of the complaints procedures are available at: [http://www.rmit.edu.au/rd/hrec.complaints]
Appendix C

School of Health Sciences,
PO Box 71
Bundoora VIC 3083
Australia

I utilised a variety of approaches to obtaining consent from service user participants. The approaches used are discussed on pages 92 and 95 in Chapter 5.

Stage One Study

Service User Plain Language Statement

Project Title:
An Exploration of User Participation in Service Development

Investigator:
Lou Iaquinto

Who is involved in this research project? Why is it being conducted?

My name is Lou Iaquinto
I am conducting this research project as part of my study in the School of Health Sciences at RMIT University.
I am studying how organisations like <name of organisation> make their services better.

Why have you been asked to participate?

<name of organisation> agreed to advertise my project. I need to talk to people who come to this service.
What is the project about?

I am studying how organisations like <name of organisation> make better programs for the people that go there.

If I participate, what will I have to do?

I will ask you some questions about your programs at <name of organisation>. You can take your time answering the questions. It should take about an hour. If it’s OK with you I’d like to make a recording of you answering my questions. It’s OK if you don’t want me to make a recording. I’ll just take notes.

Will answering your questions make me uncomfortable?

The questions are about your programs at <name of organisation>. If at anytime you don’t like how answering my questions makes you feel you do not have to talk to me anymore.

Why should I answer your questions?

I am interested in what you think. I hope your answers will help places like <name of organisation> offer people even better programs.

What will happen to my answers?

Your answers will remain private.

What are my rights as a participant?

If you decide that you don’t want to talk to me anymore we will stop.

Whom should I contact if I have any questions?

I will answer any questions you have. A staff member will be nearby to help us if we need it.

What other issues should I be aware of before deciding to whether to participate.

I think that’s all for now. Yours sincerely,
Lou Iaquinto

BA, Grad Dip, MSc

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT GPO Box 2476V, Melbourne, 3001.

Details of the complaints procedures are available at: http://www.rmit.edu.au/rd/hrec.complaints
Appendix D

Stage One Study

Service User Consent Form

Prescribed Consent Form For Persons Participating In Research Projects Involving Interviews, Questionnaires or Disclosure of Personal Information

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<thead>
<tr>
<th>Portfolio Disability Studies</th>
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<tr>
<td>School of Health Sciences</td>
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<td>Name of participant:</td>
<td></td>
</tr>
<tr>
<td>Project Title:</td>
<td>An Exploration of User Involvement In Service Development</td>
</tr>
<tr>
<td>Name of investigator</td>
<td>Lou Iaquinto</td>
</tr>
<tr>
<td>Office Phone:</td>
<td>992 7376</td>
</tr>
</tbody>
</table>

1. I have received a statement explaining the interview/questionnaire involved in this project.
2. I consent to participate in the above project, the particulars of which including details of the interviews or questionnaires - have been explained to me.

3. I authorise the investigator or his or her assistant to interview me or administer a questionnaire.

4. I acknowledge that:

o. Having read Plain Language Statement, I agree to the general purpose, methods and demands of the study.

p. I have been informed that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied.

q. The project is for the purpose of research and/or teaching. It may not be of direct benefit to me.

r. The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.

s. The security of the research data is assured during and after completion of the study. The data collected during the study may be published, and a report of the project outcomes will be provided to ______________ (researcher to specify). Any information, which will identify me, will not be used.

t. I consent/do not consent to having my interview recorded electronically.

Participant’s Consent

Participant: ................................................

(Signature) ................................................

Witness: ................................................

(Signature) ................................................
Appendix E

Stage One Study

Staff and Board Member Interview Schedule

Study Overview

- Purpose
- Use of interview data
- Definition of a service user
- Anonymity/Confidentiality
- Recording/notes

Background

1. What’s your job title?
2. How old are you?
3. How long have you been with the organisation?
4. How would you describe your role in this organisation?
5. What information do you receive to help you judge the quality of your work?
6. Do you get much feedback from service users?

Attitudes/values

7. What would you say are the personal values you bring to your work?
8. What would you say are the values of this organisation?
9. Do you feel there is a good match between your values and those of the organisation?
10. What is it like for you working within this organisation?
11. Could you give me examples of how the people that use this service make choices?
Relationships

12. How would you describe your relationship with service users?
13. How do these relationships form?

Processes

14. What does the organisation have to say about relationships with service users?
15. Can you tell me about the training you have received here?
16. How do you find out what your service users want/need?
17. In a normal day, what decisions would a service user make?
18. Give me an example of what the organisation does about getting service users to participate.
19. From your personal experience, what are your views on service user participation?

Management

20. How frequently do board members engage with service users?
21. When do you meet with your service users?
22. Do management structures facilitate participation?
23. What things would you like to see improved?

Leadership

24. How would you describe leadership in this organisation?
25. How does the leadership respond to the needs of service users?
26. What do you feel is the vision of this organisation?
27. Is there anything else you’d like to talk about?
### Appendix F

#### Transcript Example

<table>
<thead>
<tr>
<th>Questions</th>
<th>Content (pseudonyms are used)</th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Background</td>
<td>Josh has been a resident of the house for 25 years. His family knew another residents' parents quite well. I was 32 at the time, living at home and my parents said it was time for me to move out. I was in the hospital at the time and a couple days later my parents said they had a house for me to look at. I am 57.</td>
<td></td>
</tr>
<tr>
<td>2 What is it like for you living /attending here?</td>
<td>I get on well with the staff, like every household you have little rumbles ever now and then but that's what a family is and is part of life.</td>
<td>Attitudes/Values</td>
</tr>
<tr>
<td>3 Is the staff here OK?</td>
<td>I talk to the residents or the staff and talk it out with them. I have quite a bit of contact with my brother and my sisters. I lost both my parents in the space of 5 weeks but they were in their 90s so they had a good life. I have friends at where I do singing lessons. I've been doing that for seven years. I want to make a CD next year. I have a huge family and I keep up with them. Lots of nieces and nephews.</td>
<td>Relationships</td>
</tr>
<tr>
<td>4 Do you have a support plan?</td>
<td>No support plan. I am pretty busy during the week. There aren't too many days I am not out.</td>
<td>Processes</td>
</tr>
<tr>
<td>5 Who is the boss here?</td>
<td>The boss is Ellen; she's the team leader. I talk to her and she's been a good support to me especially last year when I lost my parents. I like to change (improve) the communication between residents and staff. Whether it's a cultural thing or a lack of understanding of client needs. They try to do their best.</td>
<td>Management/Leadership</td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>Response</td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>6</td>
<td>What sort of things do they have difficulty communicating?</td>
<td>If there are particular areas of our house that need attention there are different opinions from CSO's perspective.</td>
</tr>
<tr>
<td>7</td>
<td>Any questions for me?</td>
<td>No, not really.</td>
</tr>
<tr>
<td>8</td>
<td>Had issues with hospital costs. Wrote to finance person at agency.</td>
<td>Josh’s complaint to agency</td>
</tr>
</tbody>
</table>
Appendix G

Stage Two Focus Group Running Sheet

Welcome:
Thanks for agreeing to participate in this focus group. I appreciate your willingness to assist me with my research project.

Introduction:
My name is Lou Iaquinto and I am a PhD student at RMIT University. You all would have received a participant information sheet? Is there anyone here that hasn’t? Any questions regarding the information I’ve sent?

As you are aware, the reason I am conducting this focus group is because I am interested in getting your views and opinions on the opportunities your service users have to participate in the programs you offer and in particular, the tool I’ve designed to measure service user participation in organisations like yours.

Ground rules:
I am interested in everyone’s opinions and experiences and want each of you to participate.

I want to capture everything you have to say so I will be recording our conversation.

You or your organisation will not be named or identified in any way in a report, article, book or thesis. You will remain anonymous.

Initial question:
1. What does service user participation mean to you?
2. How would you define participation in the context of your service delivery?
3. Could you give me examples of client participation in your practice?

Rubric:
Copies of discussion rubric (attached below) circulated to all participants.
You all now have a copy of the tool; please take the time to read it carefully.

The rows of indicators on the left are what I believe to be the components necessary for effective participation to occur. The columns to the right are the descriptions of those components in the practice of organisations which are ranked from 1, little or no significance; to 5, very good or effective.

Let’s take each indicator one by one and consider the following:

4. Consider each indicator as a contributor to participation?
5. Are the descriptors clearly written?
6. Are the descriptors realistic practice examples?
7. Is the ranking of each descriptor appropriate?
8. Are there descriptors for each indicator you would add?

Now let’s consider the indicators:

9. Do you consider this to be a complete list of what needs to be in place in the practice of community service organisations for effective participation?
10. Is there anything you consider significant missing from this list of indicators?

Administering the tool:

11. How would you administer this tool?

Close:

Thank you all for your participation and input today. Your organisation will receive a summary report of my findings when it is completed.
## Appendix H

### Client Discussion Rubric

<table>
<thead>
<tr>
<th>Relationship Management</th>
<th>Values</th>
<th>Attitudes and Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do you get people to listen to what you have to say?</td>
<td>How do staff behave toward clients?</td>
<td>&quot;I have no choice in what I do here.&quot;</td>
</tr>
<tr>
<td>People tell me about programs I wanted to do here.</td>
<td>It's take it or leave it.</td>
<td>&quot;I have no choice in what I do here.&quot;</td>
</tr>
<tr>
<td>People asked me if I wanted to speak to me about the programs here.</td>
<td>Some staff help me answer my questions.</td>
<td>&quot;Most people here are going down the road.&quot;</td>
</tr>
<tr>
<td>People here ask me how I am going.</td>
<td>Some staff tell me what to do and how to do it.</td>
<td>&quot;People just tell me how to go about the work.&quot;</td>
</tr>
<tr>
<td>Sometimes, they respect me. I like it or not. I am doing here.</td>
<td>I am always helped here. The people here respect me.</td>
<td>&quot;I never help me with the work.&quot;</td>
</tr>
<tr>
<td>People here are doing here.</td>
<td>If I need help.</td>
<td>&quot;I always help me with the work.&quot;</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Start here!</th>
<th>How do you get people to listen to what you have to say?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relational</td>
<td>Relationship Management</td>
</tr>
<tr>
<td>How do staff behave toward clients?</td>
<td>People tell me about programs I wanted to do here.</td>
</tr>
<tr>
<td>People asked me if I wanted to speak to me about the programs here.</td>
<td>Some staff help me answer my questions.</td>
</tr>
<tr>
<td>People here ask me how I am going.</td>
<td>Some staff tell me what to do and how to do it.</td>
</tr>
<tr>
<td>Sometimes, they respect me. I like it or not. I am doing here.</td>
<td>I am always helped here. The people here respect me.</td>
</tr>
<tr>
<td>People here are doing here.</td>
<td>If I need help.</td>
</tr>
</tbody>
</table>
Appendix I

School of Global, Urban and Social Studies,
GPO Box 2476
Melbourne VIC 3001
Australia

Stage Two
Participant Information Sheet

Project Title:
Who Knew? Examining the experiences of participation for vulnerable clients

Investigators:
Mr. Lou Iaquinto (PhD student) BA, Grad Dip, MSc
Dr. Nicole Pepperell, Program Manager, Social Science Psychology, School of Global, Urban and Social Studies, RMIT University, nicole.pepperell.

Who is involved in this research project? Why is it being conducted?
My name is Lou Iaquinto and I am the investigator conducting this research project. I am a PhD student in the School of Urban, Global and Social Studies at RMIT University and this research project is part of my degree. The aim of this project is to obtain feedback on a tool I developed to measure service user participation in the services they receive at community service organisations.

The RMIT University Human Research Ethics Committee has approved this study. If you have any reservation or complaint about the ethical conduct of this research, and wish to talk with an independent person, you may contact RMIT University’s Research Ethics Office on 03 9925 2251 or email to human.ethics@rmit.edu.au. Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
You may also contact my Senior Supervisor, Dr. Nicole Pepperell at nicole.pepperell@rmit.edu.au or on 03 9925 8248.

**Why have you been approached?**

Your organisation has been chosen from a list of community service organisations and consumer groups.

**What is the project about? What are the questions being addressed?**

This research project is the continuation of an initial study, which resulted in the development of a tool to measure service user participation. In this stage of the project, I will be seeking advice from human service professionals on this tool and answers to research questions that include:

- Do service providers have a way to measure the extent of service user participation in the services they offer?
- Is service user participation embedded in the practice of community service organisations?
- Is service user participation an indicator of quality service delivery?
- Would participants utilise a tool to measure service user participation if one was available?
- Are there indicators of participation that should be included in or omitted from the tool?

From six to twelve focus groups with up to ten participants in each will be conducted to complete the study.

**If I agree to participate, what will I be required to do?**

The project will involve conducting a focus group of up to ten participants for approximately ninety minutes. The focus groups will take place at your organisation’s premises so as to minimise any disruption or inconvenience to participants. With permission, I plan on making a recording of the focus groups.

**What are the risks or disadvantages associated with participation?**

There should not be any risks to participants outside their normal day-to-day activities. Focus groups will be conducted in a professional, sensitive and non-threatening manner. Should a participant decide during the focus group that they do not wish to participate they may leave immediately.
What are the benefits associated with participation?

The main purpose of this research is to develop a meaningful tool for measuring service user participation in community service organisations. Although your organisation and all participants will not be identifiable in my thesis or any subsequent publications, there is a potential benefit of increased knowledge of participative processes for all community service organisations that participate in this study.

What will happen to the information I provide?

All organisations and participants will remain anonymous. I will address the participants by their first name during the focus group only. Then, a pseudonym will be recorded for each participant and organisation. No personal information will be stored for any participants. With the permission of participants, focus groups will be recorded digitally and transcribed by the researcher. Participants will not be identifiable. All electronic data will be encrypted and password protected. Hard copy documents will be stored in a locked filing cabinet at RMIT University.

Only my senior supervisor and myself will have access to the data. Data will be kept for five years and then destroyed in accordance with RMIT University procedures, which comply with the Australian Code for the Responsible Conduct of Research.

What are my rights as a participant?

Each individual participant and organisations will remain anonymous. Each participant has the right to withdraw from participation without prejudice at any time and to have any questions answered promptly.

Whom should I contact if I have any questions?

In the first instance I would prefer for you to contact myself, on or email to. If you prefer, you may contact my Senior Supervisor, Dr. Nicole Pepperell on or email to

What other issues should I be aware of before deciding whether to participate?

There are no further issues for you to consider but please contact Dr Pepperell or me if you have any questions.

Yours sincerely, Lou Iaquinto

BA, Grad Dip, MSc
Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT GPO Box 2476V, Melbourne, 3001.

Details of the complaints procedures are available at: http://www.rmit.edu.au/rd/hrec.complaints
| Value | Indicator | Important | Improvement | Change | Position | Management Change | Some Participation | Some Participation | Some Participation | Support Client | Problem-Solving | Problem-Solving | Process | Relationship | Relationship | Relationship |
|-------|-----------|-----------|-------------|--------|----------|------------------|-------------------|-------------------|-------------------|----------------|---------------|---------------|---------------|---------|------------|------------|------------|
| Values | External | External | External | External | External | External | External | External | External | External | External | External | External | Value |
Appendix K

Detailed Thematic Analysis

Service User Participant A

Natalie is in her early twenties, has two young children and a partner. She utilises family services and, at the time of her interview, had been a client of the CSO for eighteen months. Natalie was referred to the CSO by her local hospital after being admitted for self-harming injuries. Natalie does not drive and has the occasional anxiety attack.

At the interview, Natalie described the differences between her first caseworker and the one she has now had for six months. Both caseworkers were from the same CSO. Here is a sample of the discussion:

She’s (new caseworker) really good in the sense that she likes to have both of us in the room and sit down with us and talk one to one, not with just one of us. My other caseworker it didn’t seem to matter whether I was in and out of the room or whether my partner was there or up in the bedroom. My new caseworker helps more in the sense of getting things done kind of thing; it’s not all up to me. For example, if I was to say to (new caseworker) I need to get in touch with my child’s doctor, she would say, ‘here’s the phone ring them now’, where (previous caseworker) would say, ‘you need to get that done’. Things like that help a lot more to get things done. I don’t want to sound selfish but with my illness (anxiety) I really need to be kind of pushed, I can’t be expected to say here, go and do this. I really need to have someone there to say, ‘I can take you to your appointment and be with you and help you write things down’ because I am really bad at things like that.

Natalie provides a description of what, for her, is the right “help” she needed to “get things done”. Her initial caseworker was well meaning in attempting to have Natalie take responsibility and do things for herself. This approach is understandable and appropriate for some, but not for Natalie.

Natalie’s references also demonstrate the importance of the quality of the relationship the individual worker establishes with a service user. In Natalie’s case, the new caseworker realised that Natalie needed to be “kind of pushed” to reach her goals. The new caseworker also seemed to be more respectful of Natalie as a person, by the simple act of ensuring that both her and her partner were present at meetings, which took place in their home rather than the office.

Service User Participant B

Fiona is in her fifties, has hearing and vision impairments which made it necessary for an interpreter to be present during the interview, is now receiving case management and community access services from her CSO and has been a client of this service provider for more than twenty years. Fiona lives in her own apartment and receives an individual support package (ISP) that she has had for about ten years. She also receives some additional help from the local council. Fiona feels she has no control over how her support package is spent:
I feel out of control of what’s going on with the ISP. I say I’d like to do this and they (CSO) say, ‘that can’t happen’. I can’t get the support on that day. There are always lots of ‘can’ts’. They are very much in control of how the ISP works for me. I think last year they started this new thing where I can control some of the money and that’s a really good start. I suppose it’s going to take a little while before I am in control of more of the money.

When I asked her how she got on with the staff, she responded by saying: “do you want both the positives and negatives?” Fiona went on to say that she enjoyed the services at (CSO) but:

Sometimes things go wrong. The board makes decisions that we (clients with similar impairments) don’t think are right for us. I think recently they’ve changed some of the policies and have become quite strict and firm about things. The rules have gotten a lot tighter so sometimes it makes it more difficult to get exactly what you want all the time, so that’s happening in more recent times I suppose.

When asked if she had many friends at the CSO, Fiona replied:

That’s a really interesting question. I have friends from when I was young that were deaf but when I lost my sight as well I lost a lot of my friends as I became deaf and blind. I don’t have anywhere as many friends now. They weren’t willing to support me as I became deaf and blind as well.

Fiona’s comments highlight the difficulty service users and organisations have in determining how individual support packages are monitored and controlled. At present, these funds are allocated to a person to assist them to meet their disability support needs. CSOs are faced with the problem of balancing their financial accountability with service user need and choice.

Fiona’s reflections on losing her place in the “deaf community” because of the loss of her sight, and her displeasure at the CSOs’ inclusion of people with different impairments from her own emphasise the fact that people with disabilities often face prejudice and discrimination from others with disabilities, as well as the community in general.

**Staff Participant A**

Mike is in his fifties and is the team leader of a service for people with intellectual disabilities who require communication support. He has been at the CSO for more than five years and has previously worked in residential services for people with disabilities. When I asked him how he would describe his role in the CSO, he responded in this way:

I think it’s a fairly important role I do here. I take it seriously. I think the client base I work with are the most marginalised people in our society. They haven’t got a voice. I really take that seriously in how and what we can give them. Of course, the fact that most of them have complex communication needs, we have to take the time to make an effort to respond and work with them. A lot of the time we might just achieve little things but working with these guys; some people might walk away at the end of the day but if we can make a slight difference when they come here; I sum it up at the end of the day, what did we do here today? Well, such and such had a good day. I think we take it step-by-step, day-by-day as to what we can give
them; a bit of quality. I think it is the most important thing with my job is what I can do for these guys.

Mike describes the effort many professionals make in trying to give a voice to people with profound communication needs and limited decision-making capacity. Through his experience of working with this group of service users, he has learned that everyone has a way of communicating. This is achieved by taking the time to get to know the person and become familiar with how they communicate in order to give them opportunities to make choices.

**Staff Participant B**

Colleen is a manager in a family services CSO, is in her forties and has been at the CSO for three years. I asked Colleen what sort of information she receives to judge the quality of her work. She described the following process:

The clearest one is, at the end of every family intervention I do a telephone survey with the client. I explain the conversation is a focus on how we provide the service. Not so much about the individual worker. I have a range of questions (copy received). I ask them what best suits their experience. I make three attempts to contact the family. I don’t want to be abusive. We don’t send out questionnaires because past experience is they don’t get read or sent back. Sometimes we arrange for some of the families to come in because it may be easier to do it face to face. Another client was deaf so she needed an interpreter. We try to best support the client to provide the information. That’s our main source of formal feedback. But throughout the life of all of the team’s interventions because it’s about relationships and the encouragement for staff to be checking in along the way, and if there seems to be a blockage for example around relationships if they’re not getting somewhere to be having those conversations with the family. The relationship is fundamental to being able to get anywhere with the intervention you want to put in place.

When Colleen was asked what were the personal values she brought to her work, she said in part:

To be working with people is to continue to have a sense of hope, if you don’t have it you shouldn’t be doing this work. A sense of curiosity just stands out for me. Unless you have a sense of curiosity about a person and a person’s situation you often aren’t going to understand what is going on.

In her responses, Colleen provides three significant examples of what is required for effective service user participation. Colleen’s first example is her approach to obtaining feedback from service users regarding the service they received. In describing her process, Colleen highlights the sensitive approach she uses in contacting service users and how she ensures service users are supported to respond to her questions. Her second example is her practice of focusing on the quality of the relationship between the service user and the staff. Critical to this is her emphasis on checking with staff to see if the relationship is working, and providing guidance and support if necessary. Colleen’s final example is her personal values, which were reflected in her comments about having a “sense of hope” and a “curiosity” about service users and their situation.
Board Member Participant

Brendan has been a board member for five years, is in his fifties and has no background in social services. When asked to describe the information he receives to judge the quality of the work of the CSO, Brendan responded in this way:

As a board, we don’t have a way of measuring the quality of our service. The only way we get a measure of that is through a range of audits that we have. In part through winning a range of contracts, which says, we are doing reasonably. The fact that we get invited to put tenders in for new contracts is a vote of confidence from the departments. We have no real mechanism to gather and see client-based feedback. So as a board we don’t see anything.

Brendan is on the Board of the same CSO where Colleen is employed. It is curious that, while Colleen can describe what appears to be an effective method of obtaining service user feedback, the Board seems unaware of her efforts.

Revision of Codes

The initial schedule of fifty codes included some duplication of codes and some required their descriptors to be edited in an attempt to achieve an improvement in the level of clarity for each code. Other codes, which emerged in early interviews, were deleted because of a lack of any further comments or merged with other codes.

Table 9 below provides a record of the changes I made to the themes and coding schedules over an eighteen-month period. The descriptor for each code, and all deleted and merged codes, are included. Identical codes were used for staff and board member participants.
Table 9: Development of Codes for Stage One Study

**Participants**: Service Users (SU)

<table>
<thead>
<tr>
<th>Theme/Final Sub-categories</th>
<th>Values</th>
<th>Deleted (d) and Merged Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Respect</strong>: SU articulates the feeling of being respected or not by staff.</td>
<td><strong>Advocacy</strong>: Service User (SU) describes an event, process or action (or lack of) taken by an individual in support of a service user (d).</td>
</tr>
<tr>
<td></td>
<td><strong>Beliefs</strong>: SU expresses their likes or dislikes of the services they receive.</td>
<td><strong>Attitudes</strong>: SU expresses their likes/dislikes towards individuals, programs, processes or the service delivery in general (d).</td>
</tr>
<tr>
<td></td>
<td><strong>Processes</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Complaints</strong>: SU describes their experience of making a complaint; knowing or not knowing who to speak to about a complaint.</td>
<td><strong>Disability</strong>: SU impairment impacts on their capacity to participate. Codes moved to Access.</td>
</tr>
<tr>
<td></td>
<td><strong>Training</strong>: SU describes their opportunities to make choices; to learn new skills.</td>
<td><strong>Management</strong>: SU expresses an understanding of the management structure (d).</td>
</tr>
<tr>
<td></td>
<td><strong>Communication</strong>: Processes-SU refers to the timeliness and appropriateness of communication methods.</td>
<td><strong>Privacy</strong>: SU describes action/event that relates to their right to privacy (d).</td>
</tr>
<tr>
<td></td>
<td><strong>Control</strong>: SU describes their experience of being able to decide how they spend their time and resources.</td>
<td><strong>Environment</strong>: SU describes whether the organisation’s environment supports or inhibits participation (d)</td>
</tr>
<tr>
<td></td>
<td><strong>Process Experience</strong>: An event, conversation or discussion that describes an organisational process that facilitates or inhibits participation.</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Management</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Access</strong>: Opportunities or lack of for SU to engage in community-based activities.</td>
<td><strong>Resources for Choice</strong>: SU comments on the organisation’s capacity to support and provide</td>
</tr>
</tbody>
</table>
resources for Su(s) to have opportunities to make choices (d).

**Relationships**

**Family:** SU capacity, including assistance by organisation, to maintain their relationship with family.

**Flexibility:** SU suggests organisation takes flexible or inflexible approach to meeting SU needs.

**Trust:** Participant expresses a view, describes an event that relates to establishing or destroying trust between service users and staff.

**Communication:** SU refers to method of communication used by organisation (d).

**Dependence:** SU articulates their experience of being dependent on others (d). Information moved to Capacity for Choice.

**Forming Relationships:** SU describes how their relationships with staff and/or other Sus have developed or what inhibits relationships from developing (d). Considered redundant, included in Relationships.

**Relationships:** SU describes their relationships with staff and other SUs; how relationships are formed or what inhibits development of relationships.

**Safety:** SU expresses feeling of personal safe attending programs or residing at organisation.

**Leadership**

**Service Delivery Style:** SU presents a view on how the organisation’s culture/style impact on SU participation.

**Participants:** Staff and Board Members (S/BM)

<table>
<thead>
<tr>
<th>Theme/Final Sub-categories</th>
<th>Deleted (d) and Merged Sub-categories</th>
</tr>
</thead>
</table>

**Values**

**Beliefs:** S/BM express their own or describe another’s views/opinions in regard to; individuals; programs;

**Attitudes:** This code was changed to Beliefs.
processes; service delivery; that reflects an approach to or perception of service user participation.

**Reflection:** S/BM provide reflections on their past and present work with service users; personal experiences and values; service delivery with other agencies and/or reflect on the differences with their current organisation, in regard to service user choice and decision-making.

**Respect:** S/BM comment on the importance of and provide examples of treating service users with respect; may also emphasise the importance of service users treating each other respectfully and staff respecting the views of others, particularly the views of service users.

**Rights:** S/BM expresses a view on the basic human rights of service users and how these rights are respected and acknowledged.

**Processes**

**Board Member Training:** S/BM describes board member training accessed; required; available.

**Staff Training:** S/BM describes staff training available; accessed; required.

**Processes:** S/BM describes an organisational process that directly impacts on service user opportunities for decision-making and choice.

**Role Clarity:** S/BM expresses an understanding of their role in the organisation in regard to service users and/or other staff and board members that assists or inhibits service user participation (d). All information was moved to **Purpose**.

**Vision:** S/BM describes the CSO’s priorities now and into the future. Participants understand and were able to explain their role but this did not appear to have an impact on service user participation and was deleted,

**Facilitating Choice:** S/BM describes an event; conversation; process; that assists opportunities for choice. Integrated with the code **Choice**.
Capacity for Choice: S/BM articulates a view; experience; event; regarding a service user’s capacity to make his or her own decisions and choices.

Choice: S/BM describes the choices available to service users; how staff facilitates choices; and service users’ capacity to influence or negotiate choices.

Options for Choice: S/BM describes the choices available to service users. Integrated into the code Choice.

Influence Choice: S/BM describes choices available where the service user has the capacity to influence or negotiate choice. Integrated into the code Choice.

Management

Board Member Training: S/BM describes board member training accessed; required; available.

Staff Training: S/BM describes staff training available; accessed; required.

Board Contact: S/BM describes; expresses a view of; board of management engagement with service users (d). Appeared to have no significance impact on participation.

Relationships

Family: SU capacity, including assistance by organisation, to maintain their relationship with family.

Flexibility: SU suggests organisation takes flexible or inflexible approach to meeting SU needs.

Trust: Participant expresses a view, describes an event that relates to establishing or destroying trust between service users and staff.

Relationships: SU describes their relationships with staff and other SUs; how relationships are formed or what inhibits development of relationships.

Safety: SU expresses feeling of personal safe attending programs or residing at organisation.
**Leadership**

**Service Delivery Style:** S/BM describes how specific aspects of the organisational approach to service delivery impact on service user choice and decision-making.

**Leadership:** S/BM describe the impact of leadership style on staff attitudes; organisational culture; processes, service user participation and board members.

**Staff/Service User Interaction:** S/BM describes their approach towards interactions with service users. Interview data coded under this code was moved to Relationships code.

**Service User Education:** S/BM describes a process; structure; action; that provides service users with opportunities.

**Accountability:** S/BM describes reporting arrangements.

**Organisational Structure Theme (DELETED)**

The structure of the organisation impacts on how it responds to the needs of service users and should reflect a clear understanding of these needs. This is achieved through; the creation of specific position descriptions; how these positions relate to one another; their accountability and reporting requirements; reflect the goals and purpose of service delivery.

There were no references to this theme by any participants.
Appendix K: Analysis of Interview Data

Values Theme

For service user participants, there were two sub-categories for the Values theme. Respect, where a service user articulates the feeling of being respected or not by staff, and Beliefs, which captures when a service user expresses their view of individual, programs, process or the service delivery in general. Of the service user participants interviewed, only one made any reference to the theme of Values. This one reference was by a service user who was an adolescent in a residential program who said, “staff treat us with respect”, when asked what it was like to live at the service. In other words, this service user was stating their satisfaction with the relationship they have with staff at this service. Also, this service user has family intervention orders against his family, which in the State of Victoria protects this service user from a member of their family who has been violent towards them. This suggests the service provider is meeting the service user’s need to have a safe place to live, but this did not seem to have any relevance to the Values theme or to a service user’s level of involvement in the service. Nevertheless, it may imply something about how the personal and professional values of staff influence their approach to service delivery and their interactions with service users. The values of staff most likely influenced how service users were treated, which impacted on whether or not the needs of service users were being met. Staff and board member quotations to the Values theme outlined in the following section, support this conclusion.

Beliefs

Responses coded here related to staff participant’s opinions and experiences that could be interpreted as representing their intrinsic motivators for working in social services. My inference is that an individual’s intrinsic motivators are inclusive of their personal values. When asked if they thought there was a good match between their personal values and the values of the organisation, typical responses from staff participants were:

*I think if there was a big mismatch I wouldn’t stay; that’s why I left (CSO)*

*I really love working here, it comes through so much that everyone believes in it and sees value in every person that walks through that door*

*Yes, absolutely because I couldn’t work for an organisation that didn’t. That’s why I left (CSO) and why I won’t go back. It’s ‘an incongruence’. You can have organisational values but how do people in the organisation actually live them?*

These quotations support the notion that shared values within an organisation contribute to a positive work environment that may benefit service users by supporting their right to participate. They also highlight that shared values do have some significance for staff.

This board member is at the same CSO as the staff member quoted above. The quotation represents commonly held values at this CSO, which support an organisational culture that puts the needs of its service users first:
Having gone through the exercise of putting together our mission and our values which some people see as just one of those corporate things but the pride everybody took coming to our mission really was just a clarification that staff and board members, everybody, have that same set of values, it’s really interesting putting the clients first.

The Reflection sub-category that follows includes quotations supporting my argument that participation for service users begins with personal values that underpin the appropriate organisational values that are shared by all. In practice, this contributes to a purposeful environment for staff and a supportive but challenging environment for service users.

Reflection

My personal values, as how I was raised; everyone is equal and deserves an opportunity in life. I am very easy going as far as I am always willing to listen and give them (service users) the opportunity to try things out and I am very patient which I think is a good thing to have in this occupation.

(Laughs) People would describe me as ‘an old fashion lefty’. I have a social justice streak; I do this because I believe in social justice. It’s my life and it’s my work. I’ve raised my children to believe in social justice in the world.

This manager expressed the significance of shared values from their perspective of recruiting people with shared values:

We realised when trying to decipher which are the important key areas to put into a position description. We said well, that’s a value, are we recruiting to values? I think we should recruit to values. How do they become our values, my values, unless I am recruited to them?

The Reflection sub-category also incorporated participants’ reflections on their approach to their work and what gives meaning to their work. Statements such as: “My drive is to give them (service users) a chance to speak for themselves. I think it comes from my values as well as that’s the job” and “to be working with people is to continue to have a sense of hope; if you don’t have it you shouldn’t be doing this work” are examples of the care some staff take in their interactions with service users and the importance they place on these relationships.

When asked about their personal values, board member participants from one CSO responded in a manner that suggested they did not appreciate the difference between personal values and experience:

For me it’s the 36 years of experience of working with people with disabilities. The empathy I have for people with disabilities. I didn’t have a clue about people with disabilities. I was an engineer by trade. I jumped at the chance to be on the board here.

A second board member from the same CSO made a similar comment: “I suppose my greatest attributes are my years of experience, knowledge and participation”, and then went on to say:
No family makes a choice to have a child with a disability. So these clients that we work with have never been the great joy and celebration in life that our children have been.

This disturbing comment captured a sense of moral superiority over service users, rather than a concern for their dignity and human rights. Further reflections from these board members contributed to this assumption. In particular, when asked to describe their relationship with service users, the response was, “we have a very high respect for them” and a comment from another board member regarding their motivation to be on the board because they “have a genuine commitment to people that are less fortunate”. Another mentioned receiving financial support: “It was only last year after all the years we’ve been on the board that we’d get some financial compensation for being on the board”. The implication here is that their behaviour needs to be applauded and rewarded, while the life experiences of service users are not as important. The board member participants from this CSO seemed to hold values and beliefs that differed greatly from the staff participants from the same CSO.

My inference is that being positive about their work and caring about the people they work with will make for meaningful relationships with service users, which will contribute to service user participation. The results from these two sub-categories demonstrate that personal values, if they are appropriate to the needs of service users, will become the shared values of the organisation. This provides the foundation necessary to develop an organisational culture that: (1) is focused on building a quality service; (2) is responsive to the needs of both service users and staff; and (3) creates the potential for establishing an environment where service user choice and decision-making can occur. Without the values and culture to underpin this potential there would appear to be little chance of service users having opportunities for choice and decision-making.

As described in the beginning of this section on the Values theme, there was only one comment by service users applied to the Values theme. Although not specifically articulated by service users in the stage one study, there is an assumption that staff will treat them fairly and with dignity and respect. If this is not the case, service users will respond appropriately. For staff and board members, the Respect sub-category refers primarily to respecting the views and life experiences of service users.

The comments below are examples of responses when participants were asked to describe what the organisation had to say about relationships between staff and service users. The responses reflected different perspectives on respect. The following comment emphasises respect as an organisational value that contributes to service user choice:

The values are treating service users with respect. Providing them with information they need to make choice and assisting them with resources. Validating what you believe in and what the young person is telling you.

The comments by board members were more concerned with respect as a necessary component of establishing relationships with service users:

It certainly has the view that relationships are important and the staff should be working to establish relationships that are respectful and have dignity with service users.
It depends on the quality of the relationship you establish with the (service user), but you also need to have a degree of respect.

These comments may represent an organisational culture that first empowers their workforce, which in turn facilitates building positive relationships with service users (Spence Laschinger, et al, 2009, p. 303).

Rights

The human right of the individual service user to be involved in all aspects of the services they receive is now recognised in state and federal legislation in Australia. In discussing the purpose of this research with staff and board member participants, all acknowledged their respect and support for the fundamental human rights of services users and the requirement to involve them fully in services. One staff participant said, “I have a social justice streak. I do this because I really believe in social justice, it’s my life and it’s my work”. A board member said, “It is the right of the individual to make decisions about their own life”. However, no staff or board member participant articulated specific examples of how they would ensure the rights of service users were addressed in the day-to-day practice of their organisations.

The significant points in the preceding analysis of the Values theme are summarised in the section to follow. In this section, I also begin to discuss my rationale for further investigation of the findings of the stage one study, in what I refer to as my stage two study.

Processes Theme

Complaints

Service users were asked if they knew who the boss was at their service, and to whom they would speak if they had a problem. Each service user participant responded with the name of their case manager or direct staff member as their first point of contact. It is the strength of this relationship that contributes to successful outcomes for service users. For the service user participants in the stage one study, senior management and board members are generally of no significance to service users. As an example, “We talk to the Manager, I think sometimes if you go higher up people don’t really listen”. In another example, the service user’s complaint appears to have not been taken seriously, but the details of the complaint or how it was expressed is unknown:

I tried to make complaints. I got told off by the team leader, ‘we don’t want to know any of that we just want you to get better’.

In another reference from this service user, the same team leader “has been a good support to me, especially last year when I lost my parents.”

Although the statements from this service user are contradictory, the fact remains that at least one person in the organisation had a meaningful relationship with a service user, and that person is generally the one that has the most regular contact and has made the effort to establish a relationship with them.
However, a service user participant with hearing and vision impairment said, “agency staff don’t sign” and then proceeded to name all the regular staff that work with this service user who can and cannot sign or fingerspell and continued with their complaint:

_ I can’t hear, I can’t hear. It’s hard if people don’t sign. I don’t know who works here with me. It’s better if they sign. It’s hopeless when they do this little signing._

The fact that only a small number of staff that work with this service user are able to communicate with her, confines her to her own world, where choice and decision-making are severely restricted.

The response from one staff member regarding complaints, displayed feelings of frustration and a sense of helplessness in trying to provide a better experience for service users:

_In disability it is always happy, there is no language for complaining. Everyone is so worked up about behaviour and his or her lives (service users) are so impoverished and everybody is so desperate for it all to be good, there is no option to complain._

**Trust**

Trust is explored as a key factor in establishing or destroying relationships between service users and staff.

Although not articulated by service user participants, there is an expectation their confidentiality will be maintained. The statement included below is an example of how a breach of trust can impact on the well being of the service user and their continued involvement in the service:

_I’d spoken to other counsellors about a year ago but it didn’t work out. They gave me up to my parents when I told them something I didn’t want my parents to know about. They (counsellors) always told me I was doing something wrong. So I gave up on counsellors._

The need for trust in order to establish relationships with service users was highlighted by the majority of staff and board member participants. The importance of maintaining a professional relationship with service users is raised in a comment from a staff member participant: “if there is a risk, you still treat the young person with respect while you’re watching out for your own safety”. This reflection is a reminder of the complexity for staff in building trusting, supportive and helpful relationships with service users while maintaining appropriate boundaries to avoid unnecessary risks to themselves and others.

Board members offered similar views to staff of the importance of staff and service user relationships and the need for trust in developing these relationships. The following reference is typical of responses when a board member participant was asked to describe how they thought staff formed relationships with service users:

_Are they (clients) going to somebody for support and if they are who do they trust? Once that’s happened, there will be choices about their life situation._
The key significance of this statement is the participant’s view that choices evolve from relationships that are built on trust.

**Purpose**

Participants were asked to articulate their perceptions of what the organisation is trying to achieve with service users. All staff and board member participants presented as being very clear about what the organisation was trying to achieve with service users. What was significant to staff participants was whether or not this aligned with their belief of how this should be achieved. This seemed to be more of a reflection of their personal and professional values: “I suppose I see myself as an advocate for young people” and “being a voice for a child”. The following quote supports the feelings of staff that their personal values are what matters. The corporate values from mission statements and strategic plans seem to only become significant to staff when they are not evident in service delivery or conflict with their own values and attitudes as a professional:

*I hate all that stuff (organisational values). I know it’s there and I know it’s all-good but I wouldn’t be here if it wasn’t. I don’t pay any attention to the formal language of it.*

Responses from board member participants were similar in their description of what they believed the organisation was trying to achieve with service users. One board member responded by saying, “in an ideal world, we’d be putting ourselves out of a job”. Another board member described it in this way:

*Certain events are happening in one person’s life that could steer them down one particular course unless some helpful intervention might put them back on a more desirable course and one more of their choosing is how I like to see it.*

This comment includes the offer of opportunities for change and guidance in assisting the service user to choose the appropriate option for them. More importantly, the implication here is the service user has choices and decision-making opportunities, which the organisation’s processes allow.

**Supervision**

Both staff and board members cited staff supervision as critical to maintaining quality in service delivery, but neglected to provide a description of how this was achieved. A staff participant stated, “I am proud of our supervision record, regular staff supervision, case conferences but staff can approach me at any time”. One staff participant and a board member from the same CSO held opposite views of the organisation’s approach to measuring the quality of their work:

*At the end of every family intervention I do a telephone survey with the client... I make three attempts to contact the family. I don’t want to be abusive. Sometimes we arrange for the family to come in because it is easier to do it face to face. Another client was deaf so we arranged an interpreter. We try to best support the client to provide the information. But throughout the life of all of the team’s interventions because it’s about relationships and the encouragement for*
staff to be checking in along the way, and if there seems to be a blockage for example around relationships if they’re not getting somewhere to be having those conversations with the family. The relationship is fundamental to being able to get anywhere with the intervention you want to put in place.

A board member participant from the same CSO made the following comment:

_No, there is no mechanism (for client feedback) that I am aware of other than there’s a suggestion box that sits in the foyer of the building._

It would seem that the work of the staff member quoted above is not reaching the board of management of this CSO. However, a board member from another CSO noted a similar approach of combining staff supervision with service user feedback that depends upon the relationship staff have with the service user: “I think we primarily rely on the relationships between our staff and clients to get that feedback”. The following reference is from a board member who refers to a process used to judge the quality of the work of the Board. This was the only reference from six board member participants in the stage one study that related to a board of management assessing their own performance:

_We do an annual group self-assessment. We set out how the Board is intended to perform and what it should be doing and achieving. Even down to things like; is meeting attendance satisfactory? It is a fairly rigorous process and it goes into the annual report._

Of the board member participants from the three CSOs in the stage one study, participants from one CSO stood apart from the others in the views and attitudes they expressed. In regard to receiving information useful in judging the quality of their services one board member responded with, "We get very comprehensive reports” and a second board member from this CSO responded with:

_I always find the reports well defined. They report on the aims that have been agreed through the strategic plan. Those reports are progressive reports; down to the details of what’s happening in our residential units, the employment of staff, the welfare of staff and any specific details about difficulties with clients and we have (a service user advisory committee), where we actually meet with clients. I chair that meeting and we spend two and a half hours and then we have an afternoon tea together. These clients can actually report on what’s happening in their world, whether they are actually getting what we think they should be getting. That is actually very valuable. It is grassroots reporting from the clients that comes straight back to the board. We usually meet about once every six months (had not met for 12 months at date of interview) It is not an easy meeting to organise because we need so many different interpreters to meet the needs of the clients._

This quote is problematic in that it suggests that detailed information is being presented to the board of management regarding operational issues such as the “welfare of staff” and “grassroots reporting from the clients” that would be the responsibility of the CEO and senior management. Another concern is the description of the advisory committee, particularly the time- spent meeting and the frequency of meetings. Also, a service user participant from this CSO was a member of this committee and offered the following reflection:
I was involved with a group that was supposed to enable you to bring forward issues but in practice I didn’t find it all very good. I found it wasn’t a very good environment. It takes you a couple of meetings before you get anywhere near understanding what people are saying.

Management Theme

My approach here was in finding the ways in which the management approach of a service provider facilitated the participation of its service users. The data discussed below reveals aspects of the client’s experience of the service with a particular emphasis on the matter of choice for clients. As Smyth and Bell (2006, p. 227) point out, choice impacts on a clients’ potential for success in achieving their program goals and contributes to a person’s quality of life. Choice for clients is achieved by providing opportunities and experiences for them to make choices. Without choices, clients may feel that they have no control over what happens in their life, which may lead to feelings of powerlessness. My reading of Ife (1997, p. 16), discussed later in this chapter, infers that it is the responsibility of management to establish structures in which choice, access, control and processes that support client participation can occur.

The data collected in regard to this theme implies limited choices and decision-making opportunities for service users at all three organisations participating in the stage one study.

What was evident is the lack of choice among service users with physical and cognitive impairment. The more severe a service user’s impairment, the fewer choices they have. The quote below is an example of one staff participant’s frustration with the reality of choice for service users with communication support needs:

What I find is that so often there is no concept of choice actually, so it is a foreign concept.

Access

Service users with disabilities were more likely to experience difficulties in accessing the usual activities outside the home, which persons without disabilities can often take for granted. For example, one service user who resides in supported accommodation and uses a wheelchair kept looking at his watch during our interview because he had arranged to meet his friends at the local shopping centre. Although this service user is able to access these activities independently, service user choice regarding community access is generally influenced by the availability of support staff and, in at least one instance described below, the preferences of staff:

I’ve had a few issues with my health this year... the staff said, ‘once you get it all sorted out we can get back to the gym.’ It’s not for me. I was quite happy to do those eight months ago but I am not interested now. The staff says, ‘you’ve got to get fit.’ I am doing that in other ways, I’ve got feelings and I am doing other things. At least that’s my perspective anyway.
A female service user with hearing impairment commented, through an interpreter, on her supported access to the community: "Mondays, Wednesdays and Fridays I come here. Today I go walking to the shops for coffee and cake. Wednesdays I go to city by train". Later, the person in charge of her program provided this insight into this service user’s life:

**The program that she did really like and she did choose was going for coffee and cake and going into the city. Every person here needs one to one but no person here has one to one funding. She can go out as often as she can but not every day because she doesn’t have the funding for it. Every time she is here she might do other things, reading, art but I always make sure she goes out for coffee and cake because she is totally isolated in her life.**

The statement above is an example of how some staff make a genuine attempt to facilitate community access and improve the quality of life for service users, in spite of limited resources. It also highlights the plight of service users with sensory impairment and their risk of isolation with little choice, as the following quote from a staff participant suggests:

**We’re (staff) the main social contact they have, we’re the only social contact they have, people with communication difficulties can’t really become friends with the other clients since they don’t sign, it’s staff or nothing, but that’s what the program is all about, offering social opportunities. Where else? They’re not going to get it at the cafe.**

**Control**

Service users discussed their experience of being able to control resources that may be allocated specifically to assist them with their disability support needs.

The intention of Individual Support Package (ISPs) was to give service users a choice of service providers and control over how their package is spent. This comment describes one service user’s experience of the program:

**I am a little bit fed up I suppose. I feel out of control of what’s going on with my ISP (Individual Support Package) I say; "I’d like to do this” and they say; "oh, that can’t happen”. There are always lots of can’ts; they (CSO) are very much in control of how the ISP works for me.**

This service user later commented on the possibility that she may eventually gain more control over how the ISP is spent. This loosening of control by the CSO appears to be an example of organisations attempting to give more choice and decision making to service users with ISPs.

**Process Experience**

In regard to formal processes, service users seemed to rely more on the relationships they have with key staff members to respond to requests, answer questions and meet their needs. As noted in one of the quotes below, formal processes seemed to be acknowledged when attempting to justify saying no to a request, which in some instances would probably be appropriate. Another factor that influences the
opportunities for choice is that programs often operate within a long-established structure, and sometimes only in a particular geographic location. These factors all contribute to little or no choice for service users.

The first two quotes presented here describe an informal approach by an individual staff member that may be better placed in the Relationships theme. The emphasis here is that both staff members at two different CSOs tailored the delivery of the service in collaboration with the service user in order to respond to the service user’s specific needs. The first reference is from a service user who was reluctant to speak to a counselor because of their prior experience of having their confidentiality breached:

*When I first came here I told them I just wanted someone to talk to. I'd spoken to other counsellors about a year ago but it didn’t work out. They gave me up to my parents when I told them something I didn’t want my parents to know about. They always told me I was doing something wrong. So I gave up on counsellors. The counselor here called me after my Mom told him I was hesitant about coming in to see him. I thought he was a real cool bloke. I am happy about it and they’ve done a great job. Mom says she’s seen a lot of improvement in my attitude. I am not as unhappy anymore. I’ve got a lot of connections to people I can talk to.*

This service user highlights the impact that a simple difference in a staff member’s approach can have on their success in achieving their goals:

*Yes, we didn’t do a completely new plan, which just broke it down a bit better. The things that I want to get done and we just make our way through them. It’s not really a schedule it’s just what we do, appointments, routines, we’re pretty much flying through these things where with the other case manager it took quite a while.*

The next quote from a service user with sensory impairments appears to indicate a policy change toward a more restrictive practice. The purpose of this change is unknown, but organisational processes and management’s interpretation of them and staff impact on service user choice and involvement, will be considered in the research to follow.

*I think they’ve changed some of the policies and have become quite strict about things. It makes it difficult to get what you want all the time.*

No staff or board member participant described a process in place at any of the three CSOs in the stage one study that provides service users with opportunities to make choices. The comments below from a board member and staff at the same CSO describe the situation in regard to service user choice:

*Some young people will come in; they have made a choice in what they want to do. They’ll come and say, “I want to get a place to live, my mates and me.” I’ll say, this is how it is and they go away and I know they’ll come back because it isn’t going to work; these are some of the things you can do, here are your options. Sometimes I ask myself, what am I doing here because there aren’t any choices.*

*To some extent service users don’t have many choices; if you want to do a certain program and you live in a particular place, you do it with us.*
Capacity for Choice

Participants were asked what decisions a service user would make in the course of a normal day, how staff find out what a service user wants and what the organisation does about getting service users to participate. The initial three quotes below are common examples for staff working with people with disabilities. The service providers that participated in the stage one study were genuinely concerned with providing their service users with real choices but struggled with how they would implement this approach. A common question to me was, “how do we do this?”

The following quotes describe how a staff member often decides on behalf of the service user. As one staff member participant stated, “The move to Person Centred Planning has made us think a bit more but I have people with severe sensory disabilities and for them we’re still assuming”. Another staff participant said, “they tell us through their parents”. This, again, is someone else speaking for the service user.

The quotes below provide examples of where a staff member makes an effort to improve the opportunities for service users with limited capacity to make choices.

We do have A at the moment (service user) is high care. She does 150 signs but I’ve started speaking to her without signing and after a year she’s responding, setting the table with placemats. I think she didn’t use it for so long she just became withdrawn. She’s very much communicating.

With my client group it’s really about getting to know them. When a staff first comes here they (Service users) aren’t physically talking to you with language, the staff actually have to get to know them and that happens by getting to know them individually, just by spending time with them. It’s a long process.

These are examples of the importance for staff to take the time to get to know and establish a relationship with service users.

Board member and staff participants from one CSO offered conflicting views regarding service user choice and decision-making. The staff participants quoted above commented on their attempts to support users with limited decision-making capacity to have and make choices. Board member responses reflected a paternalistic attitude toward service users making choices:

The changes to the legislation... giving people their individual packages. My concern is that some clients don’t have the level of insight as to how to judge which service has more to offer.

One board member participant from a different CSO, when asked what choices service users would make in a normal day, provided a complex response that highlighted the critical importance of decision making for a group of adolescent service users:

I think the role that some of our staff take on; the role of a mentor in helping young people make decisions about their life, will I go to school, will I go to work, will I get some counselling, will I get help with my substance abuse problem? So a lot of options being presented to them by staff in a supporting role. These are the decisions you could make to help you move forward. It is such an underrated area, because they are not two year olds that could be beaten to death by an adult, they are not seen as vulnerable but in my opinion it is the crossroads of
their life and it is the most under funded area and the most significant point in their lives.

Summary of Management Theme Results

The results in regard to this theme suggest service providers have difficulty in responding to the specific needs of service users. Although this result was not unexpected, service users with disabilities are clearly disadvantaged. The individual effort some staff participants described in attempting to provide their clients with genuine choices demonstrated the importance of staff knowledge of clients in providing opportunities for choice and decision-making. Failing to provide these opportunities simply because of a person’s limited capacity to do so is unacceptable.

Although the analysis of this data implies a significant lack of choice for service users in the types of services they may receive, the fact is that all the service user participants in stage one study were in receipt of a service. The data from service user interviews did not include any comments stating they desired a different service. What they required, aside from being treated fairly and with respect, was enough flexibility in the delivery of the service to meet their needs.

The results suggest that a measure of a CSO’s effectiveness is whether choices exist and are able to be implemented, as well as their capacity to use their processes in flexible ways that meet the needs of service users. The aspects of choice to be examined further are: what are the examples of choice in service provision; how are service users supported to make these choices; are there structural factors in the design of services that inhibit choice; and what are the expectations of service users regarding choice?

Relationships Theme

Relationships focus on building and maintaining relationships between service users and staff in the first instance and should also reflect what I have referred to earlier in this thesis as an evenness of relationships. The interactions between all players within and external to some organisations are conducted with a level of dignity and respect that remains constant.

Communication Processes

Only one service user participant made reference to the communication method used by the CSO, which seems inappropriate for a service user with sensory impairments. It is included here, as a reminder of how the basic needs of service users can sometimes be overlooked.

I am a member of (CSO) but I feel I am left out of the loop. They send me a printed letter of information (newsletter), it’s not a braille copy or anything so I can’t read it.
**Flexibility**

Although similar to Service Delivery Style, this code is concerned more with an individual staff member tailoring their approach to suit the needs of their client. The statement below is included as an example of similar comments that describe the respect staff demonstrate to their clients by considering the client’s circumstances and needs in how they deliver the services required which can enhance the client’s chances of success:

*I don’t actually come to the office. I have my caseworker come to me, which is really convenient. She comes to my home. I have a tendency to miss appointments so I prefer her coming to my home and I have two young children.*

**Planning**

Most service users expressed a dislike for formal planning processes by deciding not to participate. This was particularly true of services users involved with disability support services, preferring to pursue activities of their own choosing when it suited them and forgoing participating in any formal planning process. The first quote is an example of a service user making the decision not to participate:

*No one can plan his or her life because you don’t know what might happen tomorrow and no one can plan my life for me.*

For some, planning is part of the process of relationship building between service user and staff: “It’s nice to have help working out what you can do” and for others, it is a “to do” list that provides the structure and support they require.

**Relationships**

Responses from service user participants were universally positive about their relationships with most staff, but emphasised their direct worker or team leader as the person they would approach first if they had a question or problem. Some service users were aware of the hierarchal structure of the CSO, such as who was the person in charge, but none seemed to be concerned with the senior staff or members of the board of management. It is common for service users to speak to the person they have the most regular contact with, such as a case manager or direct worker. These two quotes are typical examples:

*The boss is A; she’s the team leader. I talk to her and she’s been a good support to me, especially last year when I lost my parents.*

There were more than a dozen quotes relating to Relationships from staff and board members. These comments all supported the notion that the quality of the relationship between the staff member and the service user has a direct impact on the effectiveness of the services being provided. The first reference is another example of the importance of staff taking the time to get to know their clients. This is highly significant for staff working with service users with communication support requirements. Without this effort, the relationship will be one sided and of no value to a service user. The quotes that follow describe the need for staff to maintain limits in
their professional relationships and another that reinforces the relationship as the first step in achieving a successful result with a service user:

*I think I have a great relationship with most of my clients. I take the time out to spend time with them. I’d say I am not an office bound manager. I know paperwork has to be done and that’s my responsibility and I have to keep that turning over. My responsibility to my staff and my clients here is to really get to know them. I have a good knowledge of all my clients because I spend time with them.*

You are supposed to keep or not supposed to be that close to them. You’re supposed to keep your distance but you’ve been around people for so long, they make you happy.

*The relationship is fundamental to being able to get anywhere with the intervention you want to put in place.*

The next quote is an example of Collaboration in practice. The approach describes the establishment of a relationship that is based on appreciating the service user as an individual.

*I go with their pace; every client is different. As time goes by I figure out their personalities as well, you just know them and know how to act with them or how to respond to them.*

This quote displays a board member’s understanding of the key importance of the relationship between service user and staff as the basis for a successful outcome for service users.

*What’s more important is each individual worker dealing with each family and how the exchange between our workers and families works.*

**Safety**

Service users were each asked if they felt safe attending or living at their service. The environment service providers establish to support their service user also needs to be safe for them and staff. This sub-category emerged when, at one of the initial interviews, a female service user participant in her fifties related her experience of being molested by a staff member at her previous accommodation service. The only other reference in this sub-category is from a service user requiring protection from members of their family:

*No one is allowed to know this address, which is something I really like about living here.*

**Relationships Theme Summary of Results**

The above discussion on this theme indicates that a sound relationship between a service user and a least one staff member enhances a service user’s chance of success and empowers service users to make choices. As discussed previously, service users’ social status and sense of themselves may inhibit their willingness to ask
questions, and some might find making decisions and choices difficult because of their lack of experience. This can be overcome through their relationships with staff, where the service user is supported and encouraged to ask questions and given appropriate choices. Simple considerations of a service user’s practical needs such as preferring visits at home rather than travelling to the office give service users the sense that staff value and care about them first as a person and their success in reaching their goals.

A significant contribution to the results of this theme was the service user’s point of view that a relationship between a service user and at least one individual staff was the one that mattered. As many authors have noted, participation is a form of a relationship, and participation does not occur without a relationship (Padilla et al, 2007; Checkoway, 1998; Shier, 2001).

The practical outcomes of Relationships, combined with the appropriate Values for some service providers are: the belief that service users come first; a shared value of “doing the right thing”; value and respect for all within the organisation; a predilection for service improvement; and an awareness of the importance of simply asking service users what they think and respecting their response.

**Leadership Theme**

The role of Leadership is to provide the vision and model the behaviour, attitudes and values that contribute to the development of the organisation’s culture. Leadership is required to bring about improvement and change.

**Service Delivery Style**

The particular style of service delivery for each CSO seemed to have a significant impact on the service users’ view of the organisation and their success in achieving their goals. However, it is often the approach of the individual worker that made the difference for some service users. One male adolescent service user made the comment that his counsellor did not have to say much, “it’s just the fact there’s someone there that actually cares, you start feeling a lot better”. When asked what the counsellor did to let them know they actually cared, the service user responded in this way:

> They’re always supportive, he says, “if you need me, call me, these are the days I work, if you need someone to talk to just come in and talk to me.” They are taking time out of their day to talk to me, to talk about things that don’t really have anything to do with what they’re doing. If you’ve got someone to talk to, it’s a great help.

The following quote is an example of how a more action oriented approach by a caseworker can assist a service user rather than telling them what they need to do:

> My other caseworker used to say; “you need to make this appointment.” Now the new caseworker says; “you need to make this appointment, here’s the phone, call them now”.

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These statements mainly describe an approach to service delivery that, in the first instance, increases a service user’s chance of success. My inference is that this will also increase their opportunities to participate more fully.

The staff participant quote included next is significant for a number of reasons: (1) people seeking help are treated with respect; (2) people are heard; and (3) people leave knowing what to do next. The final point - that people “never leave with uncertainty” - demonstrates the care this individual takes in providing assistance to people in need of information. This is a reflection of not only this individual’s professional values, but also the culture of the organisation:

*We get a lot of people walking in the door and most of them are fairly desperate since most of our work is outreach. I make sure they are heard. I am very careful and clear they have a hearing. They never leave with uncertainty, they’ve got the next step; a phone number or we’ve often made the appointment while they’re still here.*

**Leadership**

All participants provided both positive and negative experiences of leadership. The following quote is an example of how leadership style has affected the culture and work environment of one organisation in the stage one study:

*I’ve seen it under another CEO; the leadership of our current CEO has made a huge change in all this positively. It didn’t feel the same. Individual leadership has an amazing impact. I don’t know how much of that is related to the board; to me it seems like the individual CEO and his style.*

A further example is this quote from a staff member when asked how the management of the organisation supports the needs of service users:

*If there are enough of us saying we’re having this issue with our clients, I know it will be acted upon (by management). Something will change to make it work better.*

**Leadership Theme Summary of Results**

Both staff and board member participants provided little evidence of how leadership contributes directly to service user participation. My expectation was that, with effective leadership, comes an improvement in services to clients, but this remains unclear from the data collected. What the data did provide was evidence of how a change in leadership influenced a change in the style of service delivery. This change, at least in one of the participating organisations, led to a shift toward a more client-focused approach. The responsiveness of management to the needs of clients, noted by staff participants, also appeared to reflect the leadership’s role in building a culture that puts the needs of clients first.
Appendix L

Study Two Consent Form

Consent Form

School of Global, Urban and Social Studies,
GPO Box 2476
Melbourne VIC 3001
Australia

1. I have had the project explained to me, and I have read the information sheet

2. I agree to participate in the research project as described

3. I agree:
   To participate in a focus group to be held at your workplace
   That my voice will be digitally recorded

4. I acknowledge that:
   (a) I understand that my participation is voluntary and that I am free to withdraw from the project at any time and to withdraw any unprocessed data previously supplied (unless follow-up is needed for safety).
   (b) The project is for the purpose of research. It may not be of direct benefit to me.
   (c) The privacy of the personal information I provide will be safeguarded and only disclosed where I have consented to the disclosure or as required by law.
   (d) The security of the research data will be protected during and after completion of the study for five years. The data collected during the study may be published, and a report of the project outcomes will be
provided to your organisation. Any information, which will identify me, will not be used.

Participants' Consent

Participant: ........................................ Date: ......................
(Signature) ........................................

Any complaints about your participation in this project may be directed to the Executive Officer, RMIT Human Research Ethics Committee, Research & Innovation, RMIT GPO Box 2476V, Melbourne, 3001.

Details of the complaints procedures are available at: http://www.rmit.edu.au/rd/hrec.complaints