PARTICIPATORY ACTION RESEARCH WITH PEOPLE WITH DISABILITIES: EXPLORING EXPERIENCES OF PARTICIPATION

Harriet L Radermacher

Thesis submitted as a partial requirement
for the Doctor of Applied Psychology

February 2006

School of Psychology
Faculty of Arts, Education and Human Development
Victoria University

If you come here to help me, you're wasting your time. If you come because your liberation is bound up with mine, then let us work together.

Lilla Watson,
Australian Aborigine Organiser

When we realize our shared oppression is our common ground, we suddenly become something much bigger. Same struggle, different difference.

Dan Wilkins,
The Nth Degree

ABSTRACT

The social model of disability requires that research about disability should be controlled and managed by people with disabilities themselves. Traditional research has tended to marginalise people with disabilities, and the outcomes have been meaningless and irrelevant to them. Three years ago I approached a small disability advocacy organisation, and through six months of collaboration with Disability Justice Advocacy (DJA), the need for a strategic plan was identified.

Developing a strategic plan for DJA became a vehicle for exploring the primary aim of my research, which was to conduct participatory action research with people with disabilities, and to examine its value as an empowering research practice. The literature indicates that while participation, and participatory action research in particular, has the potential to empower people with disabilities, it can also serve to disempower them. This study draws on the experiences of participation in this process, both from the perspective of the participants (six board and six staff members) and myself, as the researcher.

Thematic analysis of the interview data identified barriers to participation at different levels of intervention. At an intrapersonal level, competence of people with disabilities emerged as a critical issue for DJA. This issue resonated with my own experience of the process and, through ongoing critical reflexivity, revealed that underlying ableist attitudes (i.e. attitudes based on non-disabled standards) reinforce the ongoing victimisation and oppression experienced by people with disabilities. This study builds on current knowledge regarding the role and tensions of a community psychologist working with a social justice agenda with people with disabilities.

STUDENT DECLARATION

I, Harriet Radermacher, declare that the Doctorate of Applied Psychology (Community and Health) thesis entitled *Participatory action research with people with disabilities: Exploring experiences of participation* is no more than 40,000 words in length, exclusive of tables, figures, appendices, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.

Signature: _____ Date: _____

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ACKNOWLEDGEMENTS

I feel both overwhelmed and privileged when I think about all the people that have shaped and supported me to this point.

First of all, I'd like to thank everyone at Disability Justice Advocacy for your ongoing support, generosity and engagement. It has been a while since I first arrived at DJA, and many of you have come and gone since. I feel honoured to have had the opportunity to work with and get to know you. In particular, I'd like to thank Gillian Meldrum, Sue Whiting, Niki Sheldon, Kerry Potter, Tom Moore, Delwyn Riordan, Helen Chilcott, Peter Gibilisco, Margaret Stevens, Lachlan Jones, Glenn Lott, and Robert Brown.

This research has not only been a journey involving participants, but many others have served to influence its course. This includes people that I have come into contact with through various placements and employment, and also peers and lecturers at Victoria University. In particular, I would like to thank:

Chris Sonn, my supervisor. It has been a long and bumpy road. Thank you for your guidance and prodding, patience and time. You will always be an inspiration.

Millie Olcay, my study buddy and soul mate. Thank you for your support and vision not only throughout the course, but for many years prior. If it had not been for you, I may never have ventured into the disability field and community psychology in the first place. So, I have you to thank, and curse!

Paul Duckett, my friend and mentor. Thank you for your ongoing energy, encouragement and faith in me. You have been with me throughout this journey, despite being on the other side of the world. Thanks too for always keeping my coral full of positive thoughts!

Emma Sampson, my friend and colleague. I have always valued your insight and friendship ever since we met at the community psychology conference in Perth in 2002. Thanks for actually volunteering to read a draft!

Delwyn Goodrick, my fellow cat lover and research consultant. Thank you for your support and clarity at a time when things were far from clear.

And finally, Rebecca Hickmott, my partner. Thank you for being a star. You were supportive in the best way possible, always remaining calm and undemanding.

PREAMBLE: A JOURNEY

I sat in Fitzroy Library early in 2003, scanning the disability section in the local service directory. The directory provides a listing of all the disability services across Melbourne, their contact details, and a brief summary of their main activities. I hadn't yet started my Masters in Applied Psychology (which I later converted to a Doctorate), but in anticipation of the requirement to carry out my own research, I had decided to do some preliminary investigations. Disability Justice Advocacy (DJA) caught my eye like a neon sign. For as well as being local and disability-focused most importantly, it also claimed to be 'consumer-led'. DJA appeared to imbue practices and values inherent in a social model approach to disability, and hence, in my view, hope for a better life for people with disabilities. I wrote an email to DJA explaining that I was interested in the work of their organisation and that I had an opportunity to do some research. This thesis tells my story of the journey from that very first email through to the completion of this thesis, three years later.

A NOTE ABOUT TERMINOLOGY

For the purpose of this thesis, when I refer to ‘disability’, I am talking about the ways in which the social world does not accommodate for people with impairments, and hence, the environment disables them. It is also appropriate to clarify my use of the term ‘people with disabilities’. The reason given for using the term ‘people with disabilities’, particularly in Australia and the United States is that it places the person first, before the disability. However, advocates of the social model of disability in the United Kingdom, for example, prefer to differentiate and separate the terms disability and impairment. The term ‘disabled people’ is used due to the belief that the disabling experience of living with an impairment is very much a part of an individual’s identity and it cannot be removed from the experience of that person.

A closer look at the semantics offers further insight. The term ‘people with disabilities’ presents disability as a noun, suggesting that it is tangible, while the term ‘disabled people’ presents it as a verb, emphasising that it is a process that occurs. While I agree with the justification for using the term ‘disabled people’, I have chosen to conform to convention in Australia. This is despite the personal tensions, arising from the nature of semantics, which I experienced in doing so.

CHAPTER 1
INTRODUCTION

In 1998, it was estimated that 19.3% of Australians had some form of impairment (Wen & Fortune, 1999). While the exact definition of disability is a contentious issue, what is not in dispute is that the experience of disability affects millions of people worldwide.

It is often assumed that "the impairment itself presents the greatest obstacle or source of distress. However, people with disabilities typically identify social barriers and negative attitudes as the greatest impediment to wellbeing" (Prilleltensky, 2005, p.423). Growing awareness of the social and attitudinal barriers that people with disabilities face has paved the way for the disability movement to emerge as the fourth civil rights movement (Shakespeare, 2005). It is clear that people with disabilities do not have their human rights acknowledged (Rioux, 2002), and as a result people with disabilities form one of the largest, and most diverse, minority groups across the world (White, 2005).

With the commitment of community psychology to explore the impact of wider social, economic and cultural factors on individual wellbeing, it is perhaps surprising that disability does not have a place higher on the agenda. Community psychology in practice is embedded in a broad set of principles, such as social justice, equity, diversity, social change, empowerment and participation (Dalton, Elias, & Wandersman, 2001; Nelson & Prilleltensky, 2005). While these concepts are often overused in the field, and are in danger of losing any substantive meaning (Ife, 1995), what is clear is that they can offer community psychologists a foundation from which to address the ongoing oppression that people with disabilities face. The challenge for community psychologists lies in translating these values and principles into practice.

Traditionally, disability research has served to marginalise people with disabilities (Abberley, 1987). A participatory approach offers researchers ways to conduct research in anti-oppressive ways. Described as a tool for empowerment and an empowering research practice (Duckett & Fryer, 1998), participatory action research attempts to engage and involve participants in meaningful ways, create opportunities for participation, and share control over decision-making between the

researcher and the researched. Hence, the primary aim of this study is to conduct participatory action research with people with disabilities and to explore its value as an empowering research tool.

It is on this basis that I made contact with Disability Justice Advocacy (DJA), a small disability advocacy organisation in Melbourne, with the intention of doing some research. Through six months of collaboration, DJA and I decided to embark upon a strategic planning process (for a definition of strategic planning see chapter 3). Such a process was expected to reveal the key priorities for DJA and document the associated tasks in a strategic action plan.

The strategic planning process, while it was an intervention with an organisation, also became the vehicle for enacting participatory action research. My role in the process was not only as a researcher, but it was also as co-facilitator of the strategic planning process, which I undertook in the capacity as a student on placement. Following the cessation of my student placement and the strategic planning activities, I also gained part-time employment, as a project worker for DJA. Negotiating these roles formed part of my broader agenda for social justice and equity.

This thesis is a study of the experiences of participation and, in particular, the challenges and barriers to participation that emerged during the research process both from my perspective, as the researcher, and from the perspective of the participants. Through seeking to understand the experiences of participation in this research, this study aims to contribute towards knowledge of participation in research and societal relations more broadly.

Having opportunities to be involved in community life is not only a human right, but it also has economic, social and cultural benefits for the individual, community, and society at large. The Victorian State Disability Plan 2002-2012 has been developed to strategically address the inequality and discrimination experienced by people with disabilities. It outlines a vision of creating a supportive environment of community inclusion whereby people with disabilities can pursue individual lifestyles (Victorian State Government Department of Human Services, 2002). While the presence of the State Disability Plan illustrates that there is acknowledgement and support for greater participation of people with disabilities in society, it appears to be

much easier to say rather than do. This study has emerged from my desire to address the challenges of translating rhetoric into reality.

Structure of Thesis

The next chapter of this thesis presents some of the relevant literature in the field. Different conceptualisations of disability are explored, along with the implications that this has on research, participation and empowerment. The chapter highlights the need for anti-oppressive research and practice to be underpinned by the social model of disability. This sets the focus for the study. The third chapter, in presenting my epistemological perspective, emphasises the importance of the role and values of a community psychologist within research and practice. It explores how critical reflexivity enables a community psychologist to build on existing knowledge in the field. On this basis, the preliminary methods used to identify the potential participants and outline their involvement in the study are presented. The fourth chapter describes the seven phases of the research process, the two discrete stages of data collection, and the method of analysis. The fifth chapter presents an analysis of the experiences of participation, particularly from the perspective of the participants. It focuses on the barriers to participation, and Ife's (1995) conditions of participation are used as a framework for analysis. The sixth chapter addresses my own experiences of the research process, and my multiple roles within the organisation, and draws on the literature to examine how participatory action research served as an empowering research tool with DJA. The seventh and final chapter presents a summary and conclusion.

CHAPTER 2
LITERATURE REVIEW

The concept of ableism provides the context for this chapter. Acknowledging that people with disabilities have been discriminated against in society forms the basis for understanding why disability is an important field for community psychologists to work within. This chapter reviews how disability has been conceptualised and the implications this has had for the ongoing experience of oppression for people with disabilities. The literature indicates that by adopting a social model of disability approach to research and practice, it has the potential to address some of the inequities in power experienced by people with disabilities. Participatory action research provides a way for researchers to conduct research in anti-oppressive ways. Despite participatory action research being regarded as an empowering research practice, this chapter highlights how it can also serve to disempower. In addition to a review of the concepts of participation and empowerment, the primary aim of the study is presented.

Ableism

People with disabilities have a long history of being excluded, discriminated against, and marginalised (Mullaly, 2002; White, 2005). People with disabilities are still discriminated against in the same way as people that are discriminated against according to race, gender, age, and sexuality (racism, sexism, ageism, heterosexism respectively). The difference is that while racism and sexism, for example, are now widely recognised, ‘ableism’ (also referred to as ‘disablism’), is not. This is reflected in the small, but growing, body of literature about ableism (White, 2005).

There is a lack of clarity in the literature about the use of the terms ableism and disablism. The terms either appear to be used interchangeably dependent on the author’s personal preference, or they have different foci of interest. White (2005) defines ableism as “a non-factual negative judgement about the attributes and capabilities of an individual with a disabling condition” (p.406). In this way it seems to imply that discrimination is linked to an intrapersonal behaviour i.e. the behaviour as a manifestation of a negative stereotype. Thompson (2001), on the other hand,

describes disablism as the “systematic discrimination and prejudice against people with disabilities which produces a milieu of oppression and degradation” (p.111). In this way, Thompson seems to regard disablism as discrimination linked to behaviour at the interpersonal and social system level.

Of more significance than entering a debate about terminology, is the impact of such discrimination. For, there is no denying that, regardless of which term is used, such social practices prevent people with disabilities from fully participating in their communities and in society (White, 2005). The extent and experience of discrimination is significantly influenced by the way in which disability is understood and conceptualised. By exploring the different perspectives in detail in the next section, it is argued that it is only through regarding disability as a social phenomenon that we can begin to tackle oppression and discrimination.

The Medical Model of Disability and Dominant Paradigms

In summary, a positivist paradigm has its roots in rationalist and empiricist philosophy, and subscribes to the dualistic notion that researcher and participant are independent (Nelson & Prilleltensky, 2005). While I describe this paradigm further in chapter 3, suffice to say now that a positivist asserts that there is one external reality, and therefore to understand the phenomenon of interest, research must be objective and value-free. The positivist paradigm has been and continues to be the dominant paradigm of inquiry in the social sciences and psychology (Nelson & Prilleltensky, 2005), and in doing so has considerably influenced our understanding of concepts and the meanings that we attribute to words. For example, social phenomena may be interpreted as something more biological in nature, due to the tendency for positivist paradigm to measure that which is real.

In the case of people with disabilities, a positivist paradigm has served to contribute to the ongoing experience of oppression and marginalisation. Historically, and still largely influential today is the idea that, disability has been regarded as a state arising from an impairment (Barnes, Mercer, & Shakespeare, 1999). Disability understood in this way is regarded as something that is located within an individual, an objective and measurable state. Thus a person with a disability, for example, is a

person who has paraplegia and, as a result, cannot walk. This is also known as the medical model of disability, due to the tendency to medicalise disability (Barnes et al., 1999; Oliver, 1996). In this way, the medical model has strong connections with a positivist paradigm.

Disability is often associated with negative connotations. This originates from the belief that individuals with disabilities are somehow incomplete, and that they deviate and are inferior to the norm. They are regarded often in terms of what they cannot do, due to their physical, sensory or mental impairments, relative to a non-disabled person. Statistics that provide a picture of the extent of disability (e.g. see beginning of chapter 1) are defined by medical standards. Often services are provided on the basis of a specific impairment, and to access disability benefits, for example, people with disabilities are assessed according to certain individually-located criteria. All these factors serve to reinforce the idea that people with disabilities are defined by their impairments, which perpetuates ongoing negative stereotypes and oppression.

The medical model of disability, by reinforcing the notion that disability is located within the individual, has led to the tendency to 'blame the victim' (Ryan, 1971), and has also encouraged feelings of pity and compassion. This has ultimately led to interventions that care for and 'help' those in need, and the emergence of charities to respond to such 'tragic' circumstances (Shakespeare, 2000). Caplan and Nelson (1973) also alluded to the problems of framing social problems at an individual level perspective.

People with disabilities have found their lived experiences colonised and devalued by mainstream professional practice (Ife, 2001). In practice this means that "the practitioner is coming from a position of superiority, whereby the world-view of the practitioner is thereby imposed on others, and where practice serves to promote the interests and needs of the practitioner rather than those with whom the practitioner is working" (Ife, 2001, p.155). The non-disabled majority has therefore defined what it means to be disabled, as well as the needs of people with disabilities. Consequently, many services designed to respond to the needs of people with disabilities based on these perspectives have not only been ineffective, but have also served to perpetuate oppression.

The Social Model of Disability and Human Rights

Both the medical model, and society's preoccupation with individual differences as opposed to their similarities (Ryan, 1994) has led to a lack of acknowledgment for the rights of people with disabilities (Rioux, 2002; White, 2005). Traditionally, services have been provided for the non-disabled majority and have not taken account of the rights of people with disabilities (Thompson, 2001). This social injustice, and denial of human rights, is the catalyst driving the disability movement, which emerged in the 1960s. The movement is based on the principle that it is not people with disabilities who are the problem, but society's inability to accommodate for, and include, them. This forms the basis of the social model of disability (Barnes et al., 1999) which challenges traditional medical model understandings of disability, rehabilitation, and the privileging of professional expertise (DeJong, 1979; White, 2005).

Practice that adopts, or is based on, a medical model of disability continues to perpetuate oppression and discrimination of people with disabilities. By promoting the social model of disability (and placing emphasis on changing society rather than the individual) disability advocates and activists have been able to use it as a launching pad to demand equal opportunities and rights, and fight discrimination, oppression and marginalisation. Indeed, a human rights perspective demands that practitioners work consciously to counter the effects of colonialism, and not to practice from a colonialist position (Ife, 2001). This has otherwise been challenging with the adoption of a medical model perspective.

Regarding disability as something that is imposed upon people with impairments due to the structure of their environment has implications for how we react to people with disabilities and intervene in their lives. In practice it means that interventions may have a focus on removing barriers in society (attitudinal, economic and political as well as physical) to facilitate access for people with disabilities to their communities.

A further compelling argument for such structural intervention is that it not only promotes access for people with disabilities but it has the potential to improve conditions for everyone, promoting a socially inclusive society. For example, low floor buses are not only of benefit to people with physical disabilities but also assist parents with prams. Making services accessible to all has the potential to change attitudes. For example, people with disabilities, who have opportunities to participate, raise awareness amongst the broader community that they can indeed be active contributors in their communities as opposed to passive recipients of welfare services. Accessible services also have the potential to reduce the demand for disability-specific services, lessening the tendency to differentiate between those with and without disabilities, and hence perpetuating exclusion.

Thus, it is clear that the way in which disability is conceptualised is extremely significant, and has enormous implications for the manner in which people with disabilities are, or are not, accepted, included and permitted to participate in society. By advocating for the social model of disability, it offers great potential for tackling ongoing oppression and discrimination faced by people with disabilities.

The Link Between Disability Studies and Community Psychology

The overarching goal of the disability movement to end discrimination, and the core principles underlying it (e.g. those of empowerment, self-help, consumer control, and self-determination), reflects values at the heart of community psychology. Bringing about real social change for marginalised groups is a goal these two disciplines share. In the disability field, without ongoing reflection and change, disablement is merely recycled (Moore, Beazley, & Maelzer, 1998). Likewise, two prominent community psychologists have advocated that transformative change challenges current systems that reinforce the ongoing oppression and marginalisation of certain groups (Nelson & Prilleltensky, 2005). In sharing a vision for social change, equity, social justice, celebration and promotion of human diversity, the potential for these two disciplines to inform and learn from one another is vast (Balcazar, 1990; White, 2005). Yet, the links between community psychology and disability studies have not yet been widely acknowledged or pursued. This is despite sharing many

common values and being established within the same time frame (Dowrick & Keys, 2001).

Embracing a social model approach to disability offers community psychologists a way in which to effect transformative change, which is one of their key roles (Nelson & Prilleltensky, 2005; White, 2005). People with disabilities are the most disenfranchised and disempowered groups in society (White, 2005) and for this reason alone disability falls within the domain of interest of community psychology. Community psychologists also have an obligation to counter traditional psychological practices that, through their emphasis on individual differences, has led to marginalisation and exclusion in the first place (Ryan, 1994). Framing problems at the individual level can, not only, lead to fragmented services, but also diverts the focus away from collective and social change (Caplan & Nelson, 1973; Nelson & Prilleltensky, 2005). As Ryan (1994) puts it "we bear a heavy burden of responsibility for our enthusiastic pursuit of individual differences" (p.7).

Speaking as a person with experience of disability, Ora Prilleltensky (2005) has welcomed community psychologists to join the struggle to end oppression, and work within disability research, as she believes they are well equipped to understand the tensions between researchers and participants. However, the wider perception by people with disabilities of psychologists, and psychology itself, is one of skepticism and resistance. This may in large part be due to psychology's historical roots in a medical perspective, and as a result community psychologists must work even harder to explain how our perspectives differ from a more traditional viewpoints, that we are sincere, and that we can be of assistance. The following section, with its focus on research, further demonstrates the values and principles that community psychology and disability studies share.

Disability Research

Traditionally, disability research has often been done 'on' or 'to' people with disabilities, by non-disabled researchers. It has been described as parasitic, alienating, unrepresentative and exploitative (Olcay, 2001). At best it has "marginalized and at worst exacerbated the experience of disabled people" (Abberley, 1987, p.5).

A growing body of advocates for people with disabilities objected to research being done in this way, stating that not only was the research not meaningful or useful to people with disabilities, it simply served to reinforce their oppression. For as Oliver (1992) describes:

> Disabled people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than as part of the solution…Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life. (p.105)

The common adage ‘nothing about us without us’ (which was noted by James Charlton to be first referred to in a conference in South Africa in 1993) emerged in response to people with disabilities not having had a say in their own lives. This reinforced the notion that people with disabilities should have some form of shared ownership of the research, either as researchers themselves or as participants engaged with researchers. Involving people with disabilities in research can make it more meaningful and useful (Kerruish, 1995). It also recognises their right to be part of activity that impacts on their lives. The following account by Moore et al. (1998) describes what such rights might look like in practice:

> There are various rights that we feel disabled people are entitled to in relation to disability research. A preliminary list includes rights of access to the process of research (planning, carrying out, dissemination), entitlement to set agendas, to describe one’s own experiences and to have personal experience valued. Rights to confidentiality, ownership of data, to ask for account to be taken of one’s views in implementation of policy and practical changes arising from research, the right to understand the nature of research and to challenge and reject research are all important. (p.16)

The role of non-disabled researchers conducting disability research has been disputed. One of the reasons against their involvement was due to the likelihood that oppressive relationships might be perpetuated. One way in which to avoid the occurrence of ongoing oppressive relationships is for non-disabled researchers to engage in research in a way that places their skills "at the disposal of disabled people" (Barnes, 1992, p.122) and "for them [people with disabilities] to use in whatever ways they choose" (Oliver, 1992, p.111). In so doing, a place emerges for non-disabled people to undertake research in partnership with people with disabilities.

Thus, it is only in committing to the social model of disability, and hence recognising disability as social oppression and discrimination, that a non-disabled researcher is provided with an opportunity to work in the field of disability studies (Barnes & Mercer, 1997; Corker & French, 1999; Oliver, 1996). Furthermore, that there is no choice but to conceptualise disability in this way, if community psychologists are serious about doing research with people with disabilities.

Engaging in a participatory action research approach can provide a practical way in which to embrace a social model of disability. This is due to the ability of participatory action research to facilitate "the self-empowerment of disabled people" (Stone & Priestley, 1996, p.703). This 'ability' for participatory action research to 'empower' its participants is addressed shortly. Firstly, however, it is pertinent to briefly describe the concept that lies at its foundation – participation.

Participation

Participation has been defined in numerous ways, and it is not within the scope of this thesis to review them here. Suffice to say that these definitions tend to be narrow and limited on account of being defined by the dominant group (i.e. white, male, non-disabled, heterosexual, westerners). In this way, deeper issues of equity and justice are not addressed (Nelson & Prilleltensky, 2005).

The World Health Organisation (WHO, 2002) has defined participation as:

> A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about

> factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change. (p.10)

This definition conveys participation as a process of being involved in making decisions about our own lives. It also implies that support is needed for people to become actively involved in making those decisions. Stohl (1995) noted that, in the workplace, participation typically refers to participation in decision-making. Furthermore, when there is participation in decision-making it leads to higher satisfaction among workers (Locke & Schweiger, 1990). However, rarely does it mean that management shares 'power' to make strategic and long-range decisions. On the contrary, such decisions are considered to be the 'management's prerogative' (Stohl, 1995). Despite this Stohl (1995) asserted that:

> Participation decentralizes, interconnects, and establishes new networks, often breaking down hierarchical boundaries. Traditional perspectives focus upon three basic outcomes from participation in the workplace – better decisions, enhanced productivity/quality, and increased job satisfaction. (p.160)

Likewise, Heller (1991) noted five objectives for participation. These were to improve the quality of decisions and communication, to increase satisfaction, to train 'subordinates', and to facilitate change. In this way, participation is essential to the functioning of both individuals and organisations and "by choosing to participate, we can empower ourselves, making our organizations more consistent with democratic values and ideals" (Stohl, 1995, p.160).

Since the late 1960s it has been popular to conceptualise participation as a ladder that reflects a hierarchy of involvement. Arnstein (1969) developed the concept of a ladder to describe the nature of participation and the ways citizens can be part of decision-making processes. Figure 1 indicates that in this model there are eight levels of participation, from the powerless lower rungs of manipulation and therapy to the powerful heights of delegated power and citizen control. Using the ladder as a metaphor, however, can be problematic and needs to be applied with caution. Ladders

tend to narrow thinking about participation, particularly towards a hierarchical model, and can lead to the assumption that the bottom rung is the beginning, that we want to get to the top, and that the higher we get the better it is. What is problematic is that not everyone wants to get to the top and be in total control.

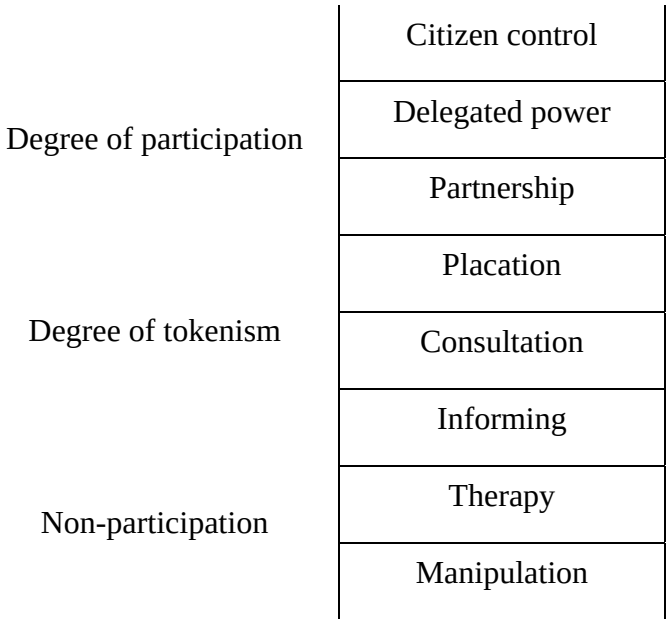


Figure 1. Ladder of participation (adapted from Arnstein, 1969)

In response to Arnstein's (1969) model, Fajerman and Treseder (2000) developed a non-hierarchical, circular, six-degree model of user involvement. This was first employed in the context of children's participation, particularly because it was recognised that it is not always possible for children to have complete control, particularly in schools and local government decision-making (Treseder, 1997). Figure 2 displays this model, adapted to represent six different levels of participant involvement in research.

Thinking of participation as non-hierarchical avoids the common assumption that there is an 'ideal' form of participation - that of having and being in total control. As a non-hierarchical model each form of participation can be regarded in its own right, with its own unique set of characteristics, with the type of participation that a person is engaged with being dependent upon the context. What becomes important,

therefore, is that people have access to and are provided with opportunities to participate in whatever way they desire, and that they have a choice to participate in the first place. Indeed, in the case of children, there is a growing body of evidence to suggest that where opportunities to participate are provided, children acquire greater levels of competence, which in turn enhances the quality of participation (Lansdown, 2004).

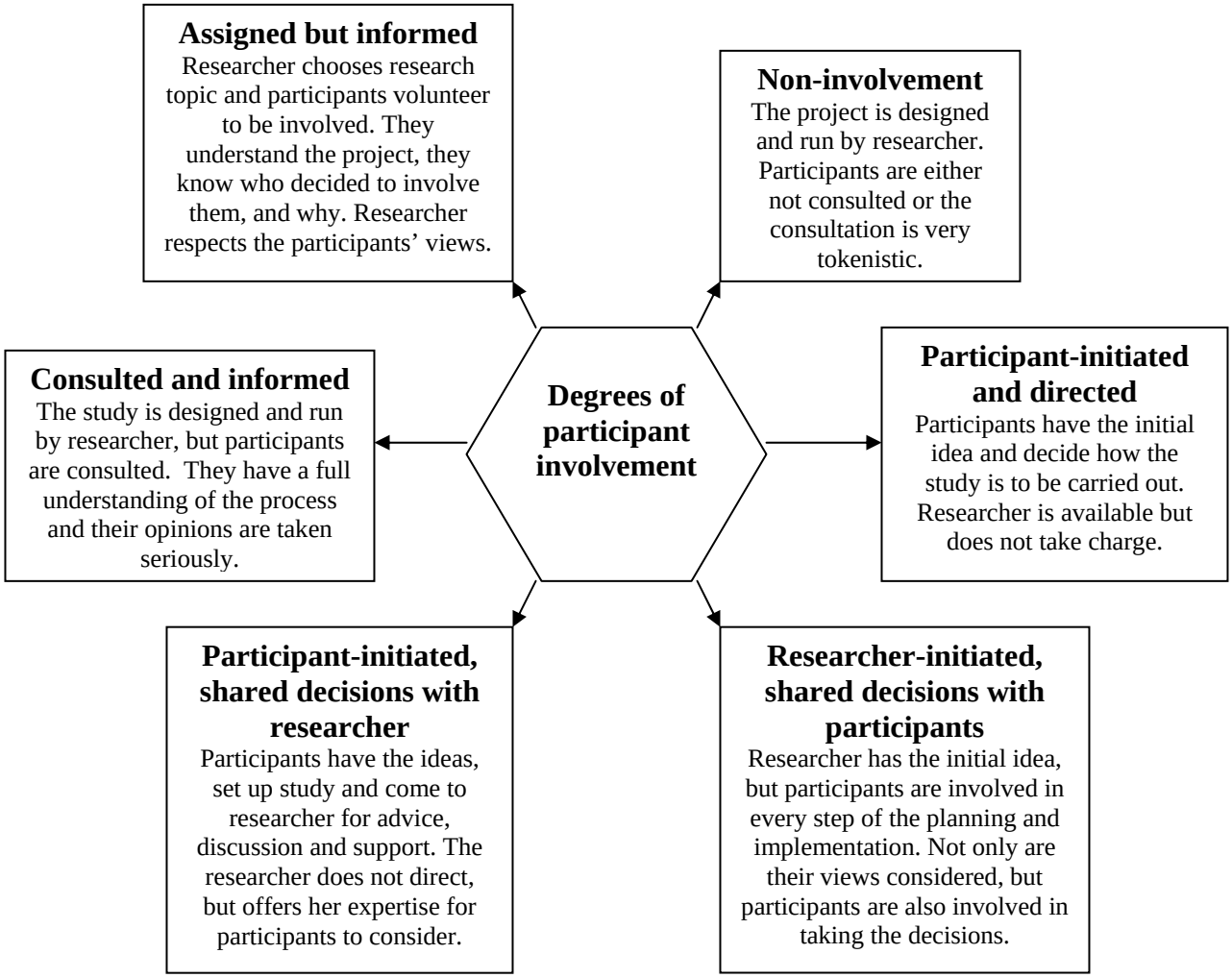


Figure 2. Degrees of participant involvement (adapted from Fajerman & Treseder, 2000)

In reality, however, creating opportunities to participate are fraught with obstacles. There are barriers to participation for everyone, but for people with

disabilities these barriers can be more apparent. Such barriers can be social, attitudinal, physical and environmental, economic, or political in nature (White, 2005). More specifically, lack of resources and geographical distance can act as barriers (Bostock & Freeman, 2003). There are further difficulties associated with fostering meaningful participation in service delivery, and these relate to practical issues such as making meetings more accessible and provision of support (Whittell & Ramcharan, 1998).

Ife (1995) described some 'problems of participation' which included the concept of participation itself (which challenges our socialisation into passive consumer roles), tokenism (in that participants may be informed or consulted about a decision but rarely have the power to affect it), and co-option (where participants find themselves becoming part of the power structures that they were originally trying to oppose) (Ife, 1995). Too much participation can also generate limitless problems and aspirations (Menzies, 1996).

Ife (1995) listed some 'conditions' to encourage 'genuine' participation. These were that:

1) People will participate if they feel the issue or activity is important;
2) People must feel that their action will make a difference;
3) Different forms of participation must be acknowledged and valued;
4) People must be enabled to participate, and supported in their participation; and
5) Structures and processes must not be alienating.

Heller (1991) also noted that competence was a condition of participation, "in so far as the absence of skill and experience in those who are asked to participate reduces activity to an empty gesture" (p.278). Drawing upon these conditions, in the context of participatory action research, presents an opportunity to overcome some of the previously highlighted barriers to participation. The next section begins to explore the process of participatory action research in more depth, and describes how it is rooted in an explicit value-base.

Participatory Action Research and its Underpinning Values

Four key values of participatory action research have been described as empowerment, support and relationships, learning and social change (Bostock & Freeman, 2003; Nelson, Ochocka, Griffin, & Lord, 1998; Whyte, 1991). These correspond closely to the ten values guiding community research and action that were identified by Fawcett (1991).These include the importance of building collaborative and anti-colonial relationships with participants, and Fawcett's (1991) assertion that research should contribute to change and that participants should be supported throughout the process. In having such a strong value base, it is perhaps not surprising that community psychologists have been attracted by participatory approaches to community research (Bostock & Freeman, 2003; Duckett & Fryer, 1998). Doing participatory research encourages participants to share the research process, and presents a way to overcome and address the exclusion that people with disabilities have faced in the past. As Dockery (2000) described:

> Participatory research has the potential to strengthen social bonds and thus contribute directly to a decrease in health inequality and an overall improvement in health status. A participatory approach where the process is owned and shared by all participants, generates much more than just data; it brings about positive changes amongst individual and groups as a whole. (p.109)

A participatory action research philosophy can also help researchers and practitioners solve problems using local resources and participants (White, 2005), and it offers the flexibility necessary to adapt to particular situations and the different people involved (French, 1994). Furthermore, as well as the knowledge gained in the form of outcomes and findings, there are additional benefits gained from the process of the research, such as the relationships formed. These may be over and above what is learned from the research itself (Archer & Whitaker, 1994). In discussing their hopes for the research, Archer and Whitaker (1994) illustrated how these benefits may emerge:

> We hoped that what we would achieve would be a way of conducting research that mattered to the agency, to the on-the-ground practitioners (and increasingly to their clients) in ways that included all levels of the organization in the research. We planned that all participants would be kept in touch with both the processes and the findings from the work as it went along. We expected that the different perspectives of the staff and the managers on the issue would become visible not just to the researchers but to each group and that this would have an impact on service provision as well as the research. We hoped for a sense of ownership to be developed. (p.164)

Similarly, Speer, Jackson and Peterson (2001), noted how "a focus on participation within organisational and community contexts allows not only for opportunities to enhance empowerment but to support a sense of community or the connections between individuals so that a collective sense of trust, investment, and action can be developed" (p.279).

Beyond the role of participatory action research in fostering learning and creating change is its ability to empower participants through building relationships and supportive structures. The appeal of participatory action research is that in claiming to 'empower' it has the potential to address the profound inequalities in power between the participants and the researcher. White (2005) noted how participatory action research changes the traditional research dynamics whereby the researcher becomes the learner, and the participants are experts due to their experience. Power, and empowerment, are core concepts of community psychology (Serrano-Garcia, 1994) and the challenges that they pose in practice are innumerable. Reason (1994) wrote:

> As soon as we touch upon the question of participation we have to entertain and work with issues of power, of oppression, of gender; we are confronted with the limitations of our skill, with the rigidities of our own and others' behaviour patterns, with the other pressing demands on our limited time, with the hostility or indifference of our organizational contexts. We live out our

> contradictions, struggling to bridge the gap between our dreams and reality, to realize the values we espouse…. 'How do you actually do it?' It is as if many people feel intuitively that a participatory approach is right for their work and are hungry for stories and accounts that will provide models and exemplars. (p.2)

In this account, Reason (1994) manages to convey the appeal of a participatory process as well as highlighting the many challenges to actually making it a reality. Participatory action research and the notion of participation carry strong positive connotations for many people, and yet while it is very easy to espouse participation, it can be incredibly difficult to practice 'genuinely.' However, "while it may be difficult, it is certainly not *too* difficult" (Reason, 1994, p.3) and the challenge lies in doing it well. There is a need to be courageous enough to openly acknowledge the limitations and dangers of our research practices (Lennie, Hatcher, & Morgan, 2003) And by noting and addressing barriers along the way, in collaboration with participants, temporary obstacles can become vehicles to create new learning and strengthening partnerships (Reason, 1994). "I would argue that the participatory process by itself is important but insufficient to enhance quality. A thorough analysis of the dynamics of oppression and attention to the issues raised here are key to that process if one is to 'somehow get it right'" (Whitmore, 1994, p.98). Thus, it is to the concept of 'empowerment' that I now turn.

Empowerment and the Problem of Conceptualisation

The concept of empowerment first entered the field of community psychology when Rappaport (1981) argued for an approach whereby people, organisations, and communities could gain mastery over their lives. As well as being conceptualised at multiple levels of analysis (Rappaport, 1981), the term has been used to such an extent that it has almost lost any substantive meaning (Ife, 1995). "Empowerment is not a stable or global state of affairs. Some people feel empowered in some settings but not in others, whereas some people work to empower one group while oppressing others along the way" (Nelson & Prilleltensky, 2005, p.98). This relates to Riger's (1993)

discussion about ‘what’s wrong with empowerment’, where she suggests that with psychology’s traditional focus on the individual, empowerment has often been regarded in terms of personal control. Having such an individual agenda may therefore compromise and conflict with more community orientated goals, such as collaboration and connections with others (Riger, 1993).

Empowerment has been described as aiming to increase the power of the disadvantaged (Ife, 1995). This resembles the claim that empowerment is both a goal and a process for overcoming oppression (Mullaly, 2002). Participation is integral to the process. However, Riger (1993) has noted the problem of equating empowerment with participation “as if changing procedures will automatically lead to changes in the context or in the distribution of resources” (p.282). Riger emphasises that a sense of empowerment at an individual level may have little effect on the actual distribution of power, particularly within organisational and political contexts.

Ife (1995) asserted that any discussion of empowerment typically embodies issues of power. In trying to understand the nature of power in modern societies, Ife identified four broad categories of power: pluralist; elite; structural; and post-structural. He noted that the goal of empowerment varies depending on which perspective is adopted. Thus, a pluralist perspective emphasises the competitive nature of power, and in this way, the goal of empowerment is to teach individuals how to compete within the rules. An elite perspective regards power to be exercised and controlled by elite groups, and a key to empowerment is to join or form alliances with such groups. A structural perspective suggests that power is exercised by dominant groups through structures of oppression, and consequently people may be empowered through structural change and challenging oppressive structures. A post-structural perspective in regarding power as being exercised at a more subjective level, acknowledges how empowerment can occur through changes in discourse and re-constructions of knowledge. This final perspective resonates with Foucault’s (1980) conceptualisation of power. When power is conceptualised in these four different ways, it becomes easier to appreciate the great diversity of its meaning, and provides justification for the need to specify personal understandings and interpretations of the term. Having briefly discussed the concept of empowerment, it suggests that community psychologists may need to apply caution when using the concept and, in

particular, be wary of how its conceptualisation may also be disempowering and destructive.

Participatory Action Research, Empowerment and the Role of the Researcher

This section explores how participatory action research can break down the power of professionalism, which helps to explain why some researchers feel that it is 'intuitively' right for their work (see Reason, 1994). A fundamental aspect of participatory action research is its potential for empowering participants (e.g. Stone & Priestley, 1996). It is a tool for empowerment, and an empowering research practice (Duckett & Fryer, 1998). Participatory action research promotes group empowerment and self-reliance among people with disabilities and shifts the balance of power and control over resources and decision-making (Stewart & Bhagwanjee, 1999).

The aim of such a collaborative research practice is to demystify the research process to participants (Kerruish, 1995; Stewart & Bhagwanjee, 1999) and break down barriers created by expertise and professionalism. Whitmore (1994) recognised how her self-disclosure helped break down the barriers between herself and her participants. The underlying goal of this was to make the relationship between researcher and participants more equal and non-hierarchical (Reinhartz, 1992; cited in Lennie et al., 2003). This reflects a post-structural view of power (Ife, 1995).

Despite these seemingly positive outcomes, however, involving community members in research, in particular people with disabilities, poses many challenges for community psychologists. Our values and issues around power remain critical factors to be continually aware of and reflect upon (Bostock & Freeman, 2003). Most importantly, it appears that using a participatory framework to alleviate historically entrenched power differentials caused by our professional status may not be working quite as we desired (Tomlinson & Swartz, 2002). As practitioners we need to recognise that our so-called 'empowering' practices may be somewhat paradoxical. For in attempting to be empowering to clients/participants, it might only serve to empower ourselves. The ways in which empowering practices may also be disempowering are explored in the next section.

Empowerment or Disempowerment

In undertaking participatory action research, the researcher can assume that participants want or need to be empowered, and that the process is empowering (LeCompte, 1995; cited in Lennie et al., 2003). One of the reasons cited for developing relationships with participants (prior to and during research) is for its ability to empower them. However, developing relationships may have unintended negative consequences (Lennie et al., 2003). For example, it might make participants feel obligated to take part (Duckett & Fryer, 1998; Kerruish, 1995). Furthermore, initial negotiations with community leaders, or managers of organisations, may mean that participation by individuals becomes obligatory rather than voluntary (Tomlinson & Swartz, 2002). This can occur, for example, when a manager of an organisation thinks that the participation of her employees is so important that she makes it compulsory. Thus, in attempting to be empowering to participants, it may have the opposite effect.

Lennie et al. (2003) argued that empowerment and disempowerment can be viewed as intersecting discourses, which means that with empowering research it may also inevitably be disempowering. This multiplicity of discourses may relate to what Rappaport (1981) noted as the paradoxical nature of empowerment. It has been suggested that the relationship between researcher and participant may never be equal (Archer & Whitaker, 1994; Lennie et al., 2003) and that the drive to make the process participatory, equal and empowering is fraught with obstacles and contradictions (Lennie et al., 2003). To examine these contradictions in more detail, Lennie et al. (2003) looked at the different discourses used by researchers and the participants.[1] These included the 'egalitarian', the 'academic expert' and the 'care and connection' discourses. They noted that while each discourse had both empowering and disempowering impacts, that certain empowering aspects of some discourses served to conflict with the empowering aspects of others. For example, an 'egalitarian' discourse was one where inclusive language and strategies were used to position

[1] This relates to what Ife (1995) referred to as a post-structural account, that identified power as something that was exercised through the control of discourse. In this way, empowerment can be developed through changing the discourse, and developing new subjective understandings (Ife, 1995).

researchers as non-experts and as ‘equals’ in the research relationship. This clearly conflicted with the ‘academic expert’ discourse that was used, for example, during the introductions and to describe the nature of the project. While the expert discourse was noted to have some disempowering effects (such that it emphasised the differences in power, knowledge and expertise between the researchers and the researched), it was also seen to be empowering in the way that it gave the project greater credibility and validity. The ‘care and connection’ discourse was illustrated by the desire to foster friendships, trust, mutual care and support, and this clearly became problematic when researchers had to assert their authority as facilitators.

Community psychologists, with their principles embedded in the notion of empowerment, have been keen to emphasise the role of communities themselves in determining their own future (Webster, 1986; cited in Tomlinson & Swartz, 2002). Being somewhat preoccupied by a desire to right past wrongs and address oppression, community psychologists have employed a number of strategies to attempt to shift the balance in power. One such strategy was to ‘give psychology away’ (Miller, 1969) by disowning their expert status (Tomlinson & Swartz, 2002) and essentially belittling their own knowledge and skills. Claims to ‘know nothing’ and enter a community with a ‘blank slate’ can lead to confusion for clients and the community, and create the illusion that they have no agenda (Tomlinson & Swartz, 2002). However, in reality community psychologists enter with a lot of assumptions, and while they try not to impose their own ideas on the communities within which they work, to some extent it is unavoidable. A researcher has a locus of expertise that they bring with them, and even if they contest to having no agenda, it is still an agenda.

There are numerous instances where authors have referred to the unavoidable inequities in power between workers, or ‘professionals’, and their clients (Fook, Ryan, & Hawkins, 2000; Healy, 2000; Rees, 1991). Hart, Jones and Bains (1997) provide an example of attempts to promote positive social change in a particularly disadvantaged community by way of a community consultation process. They noted the ‘paradox’ whereby service providers appeared to employ methods of empowerment that actually disempowered their consumers, resulting in paying ‘lip service to the notion of empowerment’. Thus, “organisations are effectively creating a myth of empowerment by ignoring consumer demands; making closed decisions; not providing alternative

choices; breaking promises; withholding information; not providing adequate support" (Hart et al., 1997, p.197). Therefore, despite the desire of service providers to have local participation, the community's interest and belief in the process waned as they failed to see that their contribution was acknowledged or valued.

This discussion highlights that in pursuing the goal of equity it has become somewhat problematic, and may actually, unintentionally or otherwise, lead to disempowerment as opposed to empowerment. Emphasising the skills of the community and making assumptions that their knowledge is useful, for example, may put undue pressure on the community to perform and to solve their own problems (Tomlinson & Swartz, 2002). It seems that community psychologists may be "insufficiently aware of the responsibility that professional knowledge brings with it" (Tomlinson & Swartz, 2002, p.100), and in relinquishing themselves of any responsibility, the community then has no avenue to criticise researcher involvement, rendering them more powerless. In this context, therefore, power is being equated with responsibility. In developing joint ownership of the research process, it can have the effect of reducing professional responsibilities of the researcher if it were to fail.

Through attempting to fix what seems, on the surface, to be quite explicit and transparent imbalances in power, community psychologists may have failed to ignore the subtle and complex dynamics at work. This may have served to conceal the power dynamics, making them even harder to address. Assumptions have been made that there is power in knowledge and that community psychologists have it to give away. In assuming there is power in knowledge certain strategies have been used to attempt to 'rearrange' knowledge, such as facilitation and raising awareness that a community's own knowledge can be powerful (Tomlinson & Swartz, 2002). Foucault (1997) argued, on the contrary, that power is dynamic and relational. Moreover, that it cannot be localised or held in one place, but rather that it is constantly being negotiated, and exists between people and between groups. Hence, such strategies to 'rearrange' knowledge may prove to be redundant. This has many implications for community psychologists who seek to work with a transformative agenda.

The body of literature to which I have referred draws upon some very important issues for community psychologists to consider in their work with communities, particularly relating to the complexities of power. These may have many

implications for the ways in which community psychologists negotiate entry and develop relationships with a community.

Evaluation of Literature and Focus of Current Study

The literature highlights the pervasive experience of discrimination that people with disabilities face and the ways in which conceptualisations of disability have served to perpetuate oppression. It also highlights how, by looking at disability as the result of oppressive social structures, it can open up new avenues towards addressing discrimination and acknowledging human rights.

Through conducting participatory action research it is possible to promote a social model of disability in practice. However, it remains very easy to espouse in theory and incredibly difficult to translate in practice. One reason for this is that efforts to work in anti-oppressive ways can still be experienced as disempowering to those that we seek to empower.

Literature in the fields of disability research and participatory action research has offered insights into working with people with disabilities in more equitable ways. It is on these grounds that the focus of this study emerged. Hence, the primary aim of this study was to conduct participatory action research with people with disabilities, and to examine its value as an empowering research tool. This was done through investigating the experiences of participation in the research process, in particular the barriers to participation, both from my perspective, as the researcher, and also from the perspective of the participants.

CHAPTER 3
RESEARCH METHODOLOGY AND PRELIMINARY METHODS

This chapter outlines the critical and postmodern epistemological perspective that underpins my research, and in this way provides the context for the methodology, and choice of methods employed in this study. Integral to a postmodern perspective are the expression of values, and I explore this in relation to how the role of a community psychologist has been conceptualised in the literature. The nature and purpose of critical reflexivity is then presented, along with an exploration into its potential as a methodological tool in this study. After situating myself as the researcher, and identifying my own social identities, I then introduce the organisation with whom I embarked upon a participatory action research process. The preliminary methods used to engage participants are described as well as the process towards identifying strategic planning as the vehicle to explore the primary aim of the research.

Approach to Inquiry

Epistemology has been described as "the study of the nature of knowledge and the methods of obtaining it" (Burr, 1995, p.185). It is about 'what' and 'how' we know the things that we know (Willig, 2001). Potter (1996) argued that it is imperative that researchers acknowledge their epistemological perspective in reporting research, otherwise "the reader is not given adequate basis for evaluating the study or knowing where to stand (conceptually to judge the study)" (p.283). Declaring my epistemological perspective, therefore, assists the reader in understanding the lens that is orienting my approach to the research and the criteria by which judgements of the quality of the research can be made. It also accounts for my choice of methods and the way I have reported the findings of the research, because they are influenced by my beliefs about what counts as knowledge and how I can best attain that knowledge. In this way, our epistemological perspectives tend to be intimately linked with the methodologies that we choose to employ (Duckett, , 1998a).

Training, experience and personal values tend to lead researchers to favour one epistemological perspective over others (Blaikie, 1993). While I may have grounded

myself, in the past, in positivist epistemological frameworks, this was mainly due to them being readily available, traditional, and dominant in the field of psychology. In this way, I naturally gravitated toward a positivist perspective. As I have undergone further study and training, I have come to appreciate how a postmodern perspective can offer me a more appropriate platform from which to explore disability issues. By not challenging the status quo, methodologies developed under a positivist research paradigm fail to provide disability researchers with tools to study disability issues in a way that is commensurate with a social model of disability (Duckett, 1998a). Furthermore, postmodernism can provide a panacea for disability research as it opens the possibility of multiple realities and multiple "truths" and can break the hegemony of the researcher's expertise and reposition disabled research participants as expert on their own experiences (Duckett, 1998a). Therefore, it is probably of no surprise that I tentatively began to reject a positivist paradigm. For, in assuming there to be one overarching truth, a positivist paradigm has the tendency to marginalise those that are 'different', and unfairly privilege that which is considered 'normal' or 'mainstream'. I believe it does so because the 'truth' that is sought is usually based on and constructed by those who hold privileged positions in society. Thus, in its place, I have welcomed postmodern and social constructionist ways of thinking, for they allow me the opportunity to explore disability in ways that are anti-oppressive and resonate with my own values.

A postmodern view asserts that there is no universal truth and that the world and our knowledge of it are socially constructed, and therefore they do not exist in isolation from ourselves (Dahlberg, Moss, & Pence, 1999). For these reasons "knowledge and its construction is always context-specific and value-laden, challenging the modernist belief in universal truths and scientific neutrality" (Dahlberg et al., 1999, p.23). The way that postmodernism embraces the essence and expression of values, and acknowledges how values vary historically (Serrano-Garcia, 1994), has created a space in which to respect and explore a diversity of views and, in particular, investigate the influence and role of the researcher. A postmodern platform therefore complements the field of community psychology, where the role and significance of values are foremost and widely acknowledged.

However, while a postmodern perspective has provided the space to break away from more traditional forms of research, it is actually only upon embracing a critical perspective that I believe a community psychologist can truly flourish. For integral to a critical paradigm are the drive, desire, and commitment to social justice, social change, and participation (Nelson & Prilleltensky, 2005). Critical theory "attributes social problems to social structures that favour certain groups in society and oppress others along lines of class, race, gender, and so on…The solution is to transform society to one where social equality replaces the present system of dominant-subordinate relationships" (Mullaly, 2002, p.5). In this way a critical paradigm offers a safe space from which I can explore the implications of a social model of disability, as it too points to societal structures as integral to the experience of disability. Thus, adopting a critical paradigm provides me with tools from which to set forth on a journey to discover and address the nature of oppression.

The next section describes my perception of the role of a community psychologist and how values, while providing a guide for practice, also present many challenges and tensions. This description leads into a discussion about how a community psychologist can best manage and learn from these experiences to contribute to knowledge. In this way, it sets the scene for the study and provides a basis from which I selected the methods to be employed.

Role and Values of the Community Psychologist and the Emerging Challenges

I concur with Ryan (1994) when he stated that psychologists "can help to develop a world that is more just and equitable" (p.7). Nelson and Prilletensky (2005) have explicated this by stating that "our challenge as community psychologists is to promote the growth-enhancing aspects of community and power and to diminish their negative potential. We want to use community and power to promote social justice and not to stifle creativity or perpetuate the status quo." (p.92-93) Furthermore, Riger (1993) asserts that the focus for community psychologists ought to be on understanding how the conditions that facilitate both efficacy and personal control (i.e. individual sense of empowerment) can also serve to facilitate a sense of empowerment at the community level.

These perspectives, that outline the role for psychologists in working towards equity and social justice, emphasise the importance for community psychologists to question how they can be most effective and of assistance in the communities within which they work. They need to reflect on how they sit, as psychologists, researchers, and practitioners, within the community or organisation. Whether they are perceived as insiders or outsiders can impact on their effectiveness (Dockery, 2000), particularly with regard to whether they are seen as equals (Lennie et al., 2003), or as superiors or inferiors.

Community psychologists are often explicit about their values, and this has an impact on their work. There may be a preoccupation with ensuring that their interventions are useful, sustainable (White, 2004), pragmatic and meaningful to participants, and that they contribute to change (Carrick, Mitchell, & Lloyd, 2001). And yet as well as trying to maximize community interests and control, there is also the challenge of preserving sufficient benefits for researchers (Fawcett et al., 1994) and allowing them to meet the requirements of external agencies, such as funding bodies or research institutes (Lennie et al., 2003). “In choosing to implement empowering interventions with marginalized populations, community psychologists often have to merge research and action” (Balcazar, Garate-Serafini, & Keys, 2004, p.243).

Community psychologists have multiple roles in research, as mediators, instigators of change, and advocates, and often these roles are in addition to the task of getting research done and constitute additional actions (Balcazar et al., 2004). Managing these multiple roles can be challenging and community psychologists require skills of negotiation. For as well as being propelled by the principles of social justice and change, community psychologists must also be sensitive and respectful of their relationships with others, and must work to sustain relationships with ‘key’ individuals (Balcazar et al., 2004).

There are also a number of ethical dilemmas for community psychologists in their work with marginalised groups. They must ask if the community really wants to change and if it is in their best interests to change. There is a dilemma about whether it is a community psychologist’s job to reveal the oppression of marginalised groups, and to encourage change. Balcazar et al. (2004) asserted that community psychologists

have a professional responsibility to work towards social change, despite not being able to ensure that change will happen and that it will be for the better. Nelson and Prilleltensky (2005) observed that the process of 'liberation' is "analogous to Freire's concept of conscientization, according to which marginalized populations begin to gain awareness of oppressive forces in their lives and of their own ability to overcome domination" (Freire, 1972, cited in Nelson & Prilleltensky, 2005, p.108). Nelson and Prilleltensky (2005) continue:

> Research on the process of empowerment shows that individuals rarely engage in emancipatory actions until they have gained considerable awareness of their own oppression and have enjoyed support from other community members…The preferred way to contribute to the liberation of oppressed people is through partnerships and solidarity. This means that we work with them and learn from them at the same time as we contribute to their cause. (p.108)

Montenegro (2002), however, highlights a tension inherent in Freire's concept of 'conscientization', such that it appeals to a universal truth. It asserts that a community needs to uncover the 'truth' about their oppressive situation, and that an external agent has access to this 'truth' and can facilitate the process. In this way it establishes and perpetuates a set of asymmetric relations, and simultaneously contradicts and inhibits a postmodern perspective that values diversity through seeking other opinions and viewpoints. For this reason, Montenegro (2002), argues for a concept of 'habitus' (a transmission mechanism by which social structures are incarnated in daily social activity) that avoids the need to assume that the oppressed are oblivious and in need of enlightenment.

This contradiction reflects one of many found in community psychology research and practice. One of the reasons for this, as alluded to in chapter 2, is that the dominant positivist paradigm has served to influence the way words, and discourse, are interpreted. Another reason for the contradictions that emerge is that while values may serve to guide the work of community psychologists, they also present several tensions. This is partly due to the multiple ways in which they can be interpreted

(Allan, 2003). Another reason is that in attempting to engage and embrace a multitude of values, they do not always align and complement each other. For example, Allan (2003) claimed that “there is an inevitable tension between the attempt to hold to a universal value such as social justice while valuing diversity and giving voice to the oppressed and marginalised populations with whom [they] engage” (p.53). In the same way, Nelson and Prilleltensky (2005) noted the tension between pursuing and promoting the values of liberty as well as equality. For in promoting liberty, and individual freedom, it may impose on someone else’s freedom and simultaneously impact on equality.

Methodological Framework

The challenge that remains for practitioners in the human services is to work with and negotiate the contradictions and tensions that arise (Allan, 2003). One way in which to facilitate this is through ongoing and open critical engagement and reflexivity. Nelson and Prilleltensky (2005) listed reflexivity as a core principle of critical research and declared that “researchers should write about personal experiences and their perspectives in research reports” (p.279). Parker (2005) emphasised the need to use our subjectivities as a resource, and indicated that reflexive engagement was one way in which to do this. Moreover, Elias (1994) stated that “it is an implicit view of community psychology that ongoing critical self-awareness is a necessary precursor to lasting change; it also appears to be necessary for effective, enduring collaboration” (Elias, 1994, p.294). From these perspectives, it is clear that there is support for engaging with our subjectivities and being reflexive. This is the focus of the following section.

Reflecting on ones own practice is central to the role of a community psychologist and through this action of critical reflexivity community psychologists may be able to achieve their wider goals of social justice, equity, social change and empowerment. Indeed, Smith (1983) argued that it is only through our capacity to self-reflect and learn how we frame our experiences, as ‘participant conceptualizers’, that we can understand our role as co-participants in human systems. Elias (1994) proposed an ‘expanded’ role for community psychologists, that of ‘participant

conceptualizer and praxis explicator'. The additional role involved "not only of working within settings to understand and help conceptualize change processes but also of reflecting on action processes that are a part of the setting of reflection on theory, and of generating products that share relevant learnings" (Elias, 1994, p.294). Thus, Elias claimed that the role for community psychologists was to identify elements of their 'best' work, while being guided by the principles and values of community psychology, and to share it with other practitioners with a view to building knowledge and contributing to the development of the community psychology field. This is in accordance with Freire (1970), who regarded the process of liberation as one that could be achieved through praxis, which is the equal use of action and understanding.

Primavera and Brodsky (2004) emphasised the need for more research that looks at the tensions in the research process, to explicate the difficulties, and to be true to the research. Through revealing the difficulties "attention to these complex and sometimes messy process variables enriches rather than limits what we have to say and what we have to offer" (Primavera & Brodsky, 2004, p.179). Reflecting on such tensions, with their emphasis on the research process and their desire to articulate the challenges of community psychology praxis, resemble that of a 'confessional tale' (Sparkes, 2002). Sanders (1995) described confessional tales as 'postmodern ethnography-like exercises'. Confessional tales "explicitly problematize and demystify fieldwork or participant observation by revealing what actually happened in the research process from start to finish" (Sparkes, 2002, p.58). In essence, therefore, the research process comes alive and the flaws and struggles that researchers desperately try to ignore are brought to the surface and addressed head-on. Thus, we can learn directly from exploring the struggles we face in trying to do research in particular ways, and try to make it better – rather than keeping our learnings private. In doing so, Sparkes (2002) advocated for the great pedagogical potential of confessional tales.

While I agree with the theoretical underpinnings of confessional tale telling, my only discomfort is with its name. By calling them 'confessional' tales it conveys an admission of guilt, as if the research should have been done in a different, and better, way. In contrast to this, I believe that such 'tales' are constructive additions to the research story, providing additional insight. Underpinning these insights is not a

sense of guilt, but a desire to be open, honest and transparent from the start. In this way they are proud declarations, and allow researchers to embrace their subjectivities.

"All too often, the political, personal, ethical, and messy realities of qualitative research are not formally documented" (Sparkes, 2002, p.70). Likewise, Primavera and Brodsky (2004) noted that "working in the real world is messy, yet when we read our journals everything seems so easy, so uncomplicated, and so predictable" (Primavera & Brodsky, 2004). If we are to practise what we preach and not try to convey that one size fits all (Primavera & Brodsky, 2004), we may be much better prepared for such realities in our own research endeavours (Sparkes, 2002).

Parker (2005) expressed caution that "reflexivity should not be a self-indulgent and reductive exercise that psychologizes phenomena and psychologizes your own part in producing them" (p.35). This resonated with the criticism of confessional tales cited by Sparkes (2002), specifically that such tales were self-indulgent, narcissistic, paranoid, and self-pitying. Sparkes (2002) stated that often those who misunderstand the nature of the genre and its purposes have made these attacks.

In the context of this study, there is a clear role for critical reflexivity and confessional tale telling (although not labeled as such), provided the cautions and criticisms are addressed accordingly. In the spirit of confessional tale telling, I decided to use 'reflection boxes' (see Reflection Box 1) as a way to communicate my initial reflections of the research process as it occurred. In this way, the reflections provide a dialogue that can be told in parallel to the research story, without serving to eclipse or belittle the voices of the participants.

In carrying out this research, therefore, it is clear how a critical postmodern perspective allows for an exploration into areas that might have remained unexplored, were I to have adopted a positivist approach. It provides a space to reveal and explore the more murky challenges and the tensions of the research process. And, as Primavera and Brodsky (2004) asserted, it is the exploration of process variables that pave the way towards establishing standards of best practice. Critical reflectivity, grounded in a postmodern epistemological perspective, can offer a way to explore the power relations in this study, where otherwise they might have been ignored (Parker, 2005). Critical reflexivity also provides an opportunity to conceptualise my own role

in this particular setting with a view to learning how I can be of most use as a researcher, and how I can influence social change.

> Reflections appear interspersed throughout this thesis. The reflections that are directly quoted from my journal are presented as thought bubbles. Other more detailed reflections are presented as 'reflection' boxes such as this one. In this way it more closely resembles what actually happened in practice and, by conveying some of the tensions as they occurred, aims to bring the research process alive. The use of reflection boxes facilitates, and forms part of, the reflexive process that is employed as a methodological tool in this study. The reflections are explored in greater depth in chapters 5 and 6.

Reflection Box 1. Explanation of reflection boxes

Situating the Researcher

Parker (2005) emphasised that through attending to the position of the researcher (i.e. the researcher's structurally-constituted research subjectivity), critical reflexivity can reveal important information about how some things may have been highlighted, and others left out. This section provides an initial exploration of my own social positioning in relation to this study and research field, as a way of beginning my engagement with a critical reflexivity.

I identify not only as a non-disabled researcher, but also as a white, female, middle-class, 30-year-old lesbian. All of these social identities have, and still, impact on my life and my work, and go some way towards explaining why I am working in the disability field. I think, most importantly, my experiences of belonging to 'other', both marginalised and dominant, groups provides an interesting platform from which to reflect on activities in the disability field. For, by making connections between our own oppression and the oppression of others it can offer us ways to be effective in the work that we do (Duckett, 24 September 2005).

It is at this point that I want to elaborate on my position as a non-disabled researcher. In participatory research in particular, there has been an issue raised as to whether there is a role for non-disabled researchers in the disability field (Branfield, 1999; Duckett, 1998b; Mertens, 1998). Branfield (1999) explained that in allowing non-disabled people to join as allies in the disability movement, it can lead to people with disabilities being side-lined, and hence perpetuate their ongoing oppression. Duckett (Duckett, 1998b) insisted that "disabled people do not come in a neat, clear-cut package, there are as many differences within the disabled population as there are similarities, and disability status is much more fluid than is often described…The voices of non disabled allies should be heard, as voices that add to the vociferous activities surrounding the disability movement" (p.628). Likewise, T. Shakespeare (1993) stated that "it's too simplistic to suggest that disability alone unites us and distinguishes us from non-disabled people. We identify in various ways, and therefore form various alliances" (p.31).

Thus, the argument for non-disabled people to work in the disability field is that due to the diversity of experience of disability, it does not make sense to exclude those that are non-disabled on the grounds that they have not experienced disability. For a person with a visual impairment, for example, is no more likely to understand what it is like to experience a mental illness than a person without an impairment.

In light of this, I believe that I do not need a disability to be able to make a positive contribution to the disability field. My engagement with the disability field is based on my commitment and belief that everyone should have their human rights respected, and that discrimination and oppression is a breach of those rights. I agree that it is easy to perpetuate the ongoing oppressive experience of people with disabilities, but this can be done by anyone, whether they have or have not experienced disability. The key to liberation lies in raising awareness of the structures and nature of oppression, and the collective action that is taken as a result (Freire, 1970). Thus, it is not my intention to 'help' people with disabilities, but to join forces, for we are part of the same struggle in the fight against oppression (in accordance with the quote at the beginning of this thesis).

The aim of this study was to conduct participatory action research to explore its value as an empowering research tool. Being a non-disabled person with a

background in psychology, carrying out research with people with disabilities has the potential to be extremely problematic. However, with a commitment to critical reflexivity, it provided the potential to address some of these tensions and contribute to knowledge in the field. The following section provides an introduction to the organisation with whom I chose to embark on this research journey.

Introducing Disability Justice Advocacy (DJA)

Conducting participatory action research with people with disabilities formed the primary aim of this study. Fundamental to a participatory approach is for the participants themselves to identify the research topic (Moore et al., 1998). This section describes the part of the journey towards discovering the focus of my involvement, and the more specific aims of the study. To set the scene, I present the local context of DJA.

Disability Justice Advocacy (DJA) is a consumer-led organisation that provides individual advocacy to people with high support needs associated with a physical disability. High support needs are such that a person requires a wheelchair to move around, and may require additional assistance with eating, drinking, toileting, communicating, reading and so forth. Founded in 1989, DJA formed as a result of collective action by a group of people with physical disabilities, who were then part of another widely established organisation (a not-for-profit organisation providing disability services throughout Melbourne and Victoria). As one board member recalled "*they felt trapped in the [previous organisation's] system, and didn't have an opportunity to speak up about the service they depended on*" *(board member, personal communication)*.

In 2005, DJA had a membership of about 200 people. While DJA is located in Victoria, it is accountable to its funding body, Family and Community Services (FaCS), which is a federal government department. This funding arrangement is based on the condition that DJA provides 70% individual advocacy and 30% systemic advocacy. The difference between the two forms of advocacy can be illustrated by equating individual advocacy with a 'treatment' approach to an issue, while systemic advocacy is more of a preventative strategy. Thus, while individual advocacy attends

to needs at an individual level (such as having nowhere to live, not being able to get out and about), systemic advocacy attends to needs at a broader, societal level (such as lobbying government to provide more accessible accommodation for people with disabilities). In the words of one staff member, DJA "*is about providing advocacy to people with high support needs on an individual level, and then taking through those issues to the systemic level*" *(staff member, initial interview)*

Members of a board, all of whom have physical disabilities, govern the activities of the organisation. Such activities include the employment of three advocates and an executive officer. Figure 3 displays the organisational structure of DJA, and who is 'accountable' to whom. DJA is a unique organisation, in that it is the only one of its kind that provides advocacy to people with high support needs. Being consumer-led, it suggests that people with disabilities take part in decision-making processes. Hence people with disabilities are fundamental to the development and structure of the organisation.

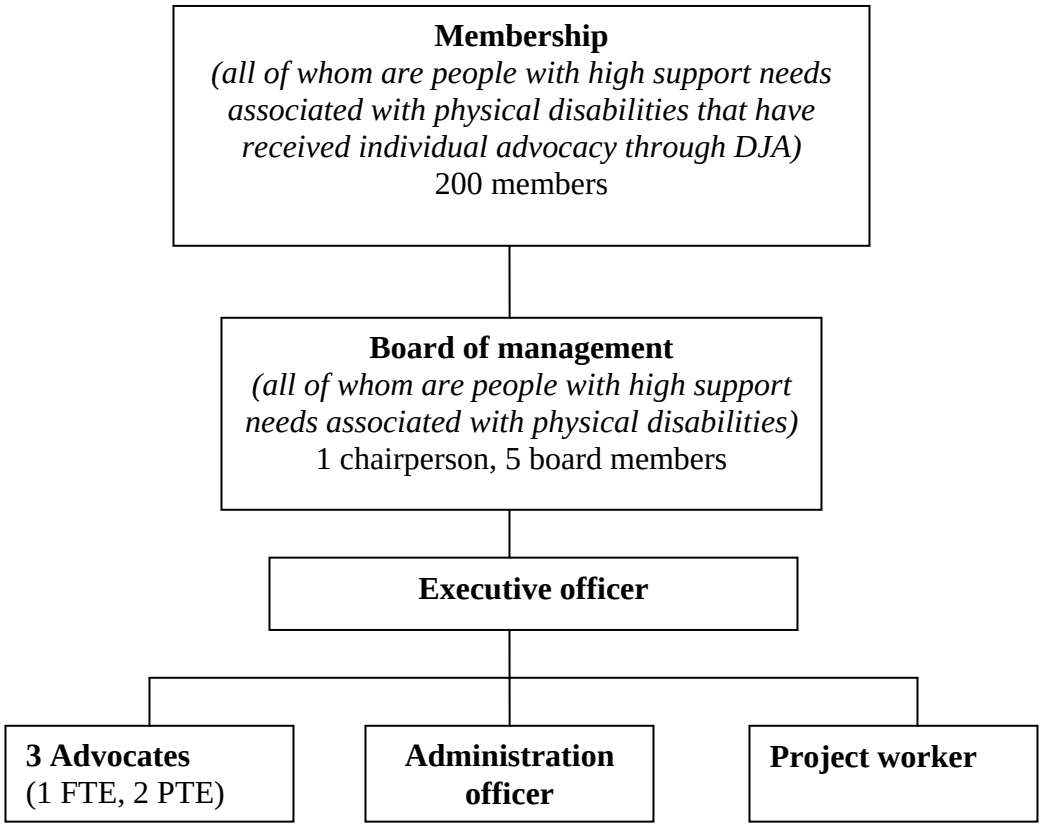


Figure 3. DJA organisational chart

DJA works towards justice and inclusion for people with a disability, focusing on their fundamental needs, rights and interests. The most common reasons for referral for individual advocacy include issues with accommodation, transport, sex and relationships and employment. These issues are addressed as part of the systemic work of the organisation. For example, DJA initiated the development of the Safe Transport Action Group (STAG). The work of STAG, particularly through its campaigns, was seen to be particularly integral to the identity of DJA, especially from the perspective of the board members. As one board member said "*if I jump up and down about how I can't get on a tram I am only one person but if a group does it, it has a bigger impact*" (board member, 23-09-03).

Engaging with DJA and Developing a Research Topic

I sent an email to the organisation outlining my proposal *(see Appendix A)* and the executive officer responded immediately with a warm welcome and encouraged me to get involved. This contact was made two years prior to the expected due date of the final research report. This was in anticipation that it would take several months alone to build up a relationship with the organisation and develop a research topic.

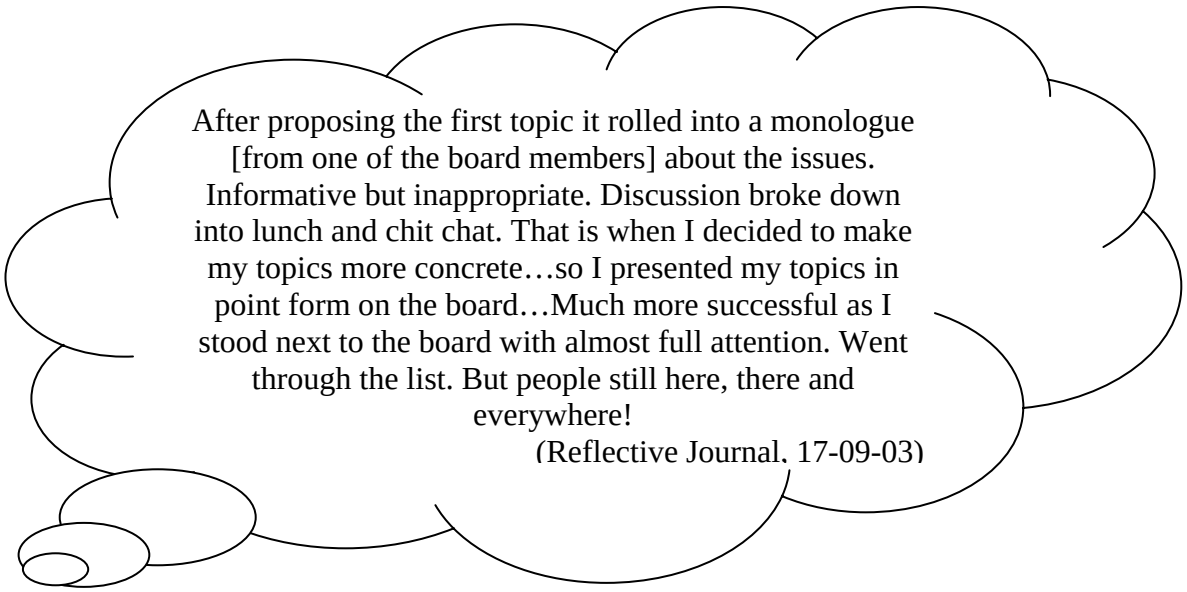
To learn more about the organisation and discuss the logistics of working together, I initially met with the executive officer. Having established that it was my intention that people with disabilities themselves direct the research, I was invited to the next board meeting. The board of DJA, the executive officer, and the administrative assistant all attended this meeting. A space in the agenda was set-aside for me to introduce myself, explain why I had contacted the organisation, and to gauge their interest in becoming involved.

The general consensus was that I was welcome, and that they were interested in getting involved. From this point forward, I became a regular fixture on the monthly board meeting agendas. There were two aims of this regular contact: 1) to establish and build a relationship and make myself known around the organisation; and 2) to inform them about the research process, where I was coming from, and to develop a research topic. In addition to monthly board meetings, I met with a few of the board

and staff members individually to discuss topics, ideas and areas of interest. Both members and I initiated this contact.

Based on my ongoing discussions with DJA, I developed a list of options for the research topics. This list was based on my own understanding of what some feasible research topics might look like. I presented these to the board at a board meeting six months after my initial contact.

Strategic planning was one of the six options for the research topic. Through my discussion with staff and board members, it was clear that they thought DJA required more focus, and that there was a desire for change. Members described that DJA, in trying to address every relevant issue, was in danger of "*spreading itself too thin" (board and staff member, personal communication).* Given DJA's financial position, where funding was non-recurrent and subject to an annual review, it was seen to be imperative that DJA makes the most effective use of its limited and conditional resources. One way in which to achieve this was through conducting a strategic review.



However, due to the lack of consensus about which topic to choose, and due to my own timelines and university requirements to submit an ethics application, I made the final decision to make strategic planning the focus of the research. While I gave myself plenty of time to get to know members of the organisation prior to the start of the research, university procedures demanded that an ethics application be submitted

prior to data collection. Ethics applications outline the proposed research, with particular attention to the processes that involve participants. The proposals are reviewed by an elected board of representatives with the purpose of ensuring that the research poses minimal risk (e.g. emotional, physical, psychological etc.) to potential participants. The research proposal is then accepted or declined on this basis. However, this procedure is problematic since ethics forms are often predicated on positivist research assumptions that the researcher knows what should be researched and how it should be researched before meeting potential participants, and this is the level of detail that is required on such forms. In this way, the forms do not create much opportunity for the research method and topic to evolve throughout the research process. Rather the forms demand proscription from the start. Hence, the requirement to submit such an ethics application at this early stage of this study, may have served to compromise my intention to follow a participatory research process.

Knowing that both the chair of the board and the executive officer were keen to pursue a strategic planning process was instrumental in my choice of research topic. I felt that by choosing this option, there was a greater likelihood that participants would invest time and energy into the process, and develop ownership. For it has been observed that when participants play a key role in formulating and implementing a project, ownership develops (Figueroa, Kincaid, Rani, & Lewis, 2002). This interest or influence over the research process increases ownership which in turn has the ability to bring about positive change (Dockery, 2000). Factors such as these accorded with the values underpinning my study.

- This was an extremely exciting part of the research process. I was spending a lot of time getting to know people in the organisation, attending board meetings, and learning about a whole range of complex issues in the disability field. Not only was this from the perspective of advocates working in the field, but also from people who had direct experience of disability.
- However, this period of contact was also one imbued with uncertainty and frustration. Prior to each board meeting I would have great expectations that we would all come to some mutual agreement about the focus of the research, and while we had some interesting discussions these often ended in

a free-for-all, which left me feeling no closer to my goal and a little disheartened. I was very conscious of not wanting to dominate and steer the discussion, but in not doing so, it may have compromised having a focus.

- Not being able to reach a consensus about a focus for my involvement was my first realisation that this was going to be harder than I had anticipated. I was very uncomfortable about having to make the final decision about the focus of the research. However, the pressure of having to submit an ethics application made it a necessary decision to make.

Reflection Box 2. Excitement, discovery, uncertainty, and discomfort

Strategic Planning

Hence, through six months of collaboration, DJA and I decided to embark upon a process of strategic planning. Strategic planning is "a disciplined effort to produce fundamental decisions and actions that shape and guide what an organization is, what it does, and why it does it, with a focus on the future" (Alliance for Nonprofit Management, 2003, p.1). It involves strategy because it must consider the objectives of the organisation, in relation to its resources and the dynamic state of the environment in which it sits. The benefits of strategic planning include ensuring the most effective use of an organisation's resources by focusing on key priorities, bringing together individual efforts to build a consensus about direction, increasing productivity, providing a clearer focus for the organisation, building bridges between groups and individuals, and fostering greater satisfaction among planners around a common vision (McNamara, 2003). Change can be managed through the creation of a vision (Waddell, Cummings, & Worley, 2000).

Strategic planning is a universal tool that can be applied in many contexts. It has been approached in many different ways dependent on such contexts, and comprises of various phases. These include: outlining the purpose of the plan; doing an environmental scan; analysing the situation which might involve the SWOT technique (i.e. identifying the strengths, weaknesses, opportunities for and threats to an organisation); establishing goals; constructing strategies to achieve those goals;

allocating tasks and responsibilities within time lines; documenting both the outcome and the process; and finally congratulating and rewarding efforts (McNamara, 2003). Involving the right people in the plan is crucial, as is communicating the process and outcome of the plan across the organisation. In summary, strategic planning is the collaboration by a group of people to produce an agenda for change.[2]

It is on this basis that DJA and I embarked together upon a journey, and strategic planning became the vehicle for enacting and exploring the participatory action research approach. The next chapter describes how the strategic planning process was carried out as part of the wider research process.

[2] Whilst the activities that constituted 'strategic planning' in this research (i.e. a six-hour process, in two sessions, over a two-week period) may not be similarly characterised as 'strategic planning' in the literature – particularly due to its brevity in duration and range in the current study – I, nevertheless, decided that as this was the term used by participants to describe our activities then it was appropriate to continue to refer to the process we embarked upon as a 'strategic plan'.

CHAPTER 4
METHODS

This chapter presents the details of the methods employed in this study. It begins with an introduction to these methods, and then systematically describes the research process according to seven discrete phases. While the method of analysis is presented at the end, reflection boxes, that comprise the initial stages of analysis, are located throughout the chapter.

Introduction to Methods

This study employed a qualitative research design, which consisted of two discrete stages of data collection. These stages comprised an individual semi-structured interview prior to, and following, the strategic planning days. For the purpose of promoting clarity in this chapter, the two stages of data collection are incorporated into the description of the seven research phases. Table 1 indicates at what point the stages of data collection occurred within the research phases.

In addition, I kept a journal to document my experiences throughout the research process. These included observational notes, design and sampling decisions, comments made by participants, and personal reflections and recommendations about how things might have been done differently. The use of a reflective journal by researchers has been identified as a criterion to verify rigour in qualitative inquiry (Lincoln & Guba, 1985).

The procedure and the methodological decisions made throughout the process, hold specific significance in this study, particularly because the focus of the research is on the process itself. For this reason, the detail of the procedure is thorough and comprehensive. It is suited to a temporal description i.e. detailing activities in the order that they occurred. The methods are therefore documented in phases, serving to structure the proceedings and clarify when particular actions took place, and identify when corresponding decisions that were made.

Analysis occurred concurrently with the data collection, as well as part of a more discrete phase following the data collection. For this reason, analysis is not

recorded as an additional ‘phase’ of the research process. Rather, the method of analysis is reported as a separate section at the end of this chapter. The text in the ‘reflection boxes’, that appears throughout this chapter, constitute part of this analysis. They include descriptions about what actually happened in the research process, and the tensions that arose. In more traditional studies, this would constitute the ‘limitations’ of the study. However, in this particular study, where the nature of the research process was also the focus of the research, these boxes form a significant part of the analysis itself and are incorporated as such.

Table 1

Mapping Seven Phases of the Research Process against Two Stages of Data Collection

PHASES OF RESEARCH PROCESS		STAGES OF DATA COLLECTION	
Research proposal and participants	1		
Organising strategic planning days	2		
Initial interviews	3	1	Initial individual semi-structured interviews
Strategic planning days and developing the strategic action plan	4		
Follow-up interviews	5	2	Follow-up individual semi-structured interviews
Follow-up workshop	6		
Ongoing dissemination of research findings	7		

Phase 1: Research Proposal and Participants

Having identified the topic, I developed the research proposal in collaboration with my research supervisor. This was developed in accordance with university criteria, and was submitted to the university ethics board. A review of the ethical considerations specific to people with disabilities was included. To support my

application, DJA wrote a letter of invitation, which was also submitted with the application (*see Appendix B*).

To involve potential participants in developing the research design, I initially emailed some preliminary ideas and a timeline for the strategic planning process to the chair of the board, and asked for some feedback. The chairperson sent it on to the executive officer, and this was then circulated to all the staff. This proved to be a constructive exercise. For example, the preliminary ideas proposed that the executive officer would facilitate the planning days. However, feedback from one of the staff members highlighted that there was a need to investigate the feasibility of having an external facilitator, primarily to enable the executive officer to contribute in the same way as other participants.

As well as searching the archives to build up a deeper understanding of the organisation, I reviewed the literature and searched the Internet for information about strategic planning. This was specifically to look at how strategic plans have been developed, what has worked, what tools have been used, and how it has been done in participatory ways.

To identify the participants, I employed a purposive sampling technique (Patton, 2002). Identifying participants in this way ensured that the individuals most critical for addressing the research question were included in the study. These particular individuals, or 'key informants', were those with intimate and valuable knowledge and experience of working within and for DJA. Thus, the number of individuals actively involved in DJA determined the sample size.

Having gained ethics approval, I asked 12 participants (five male and seven female) to participate in the research. Six of the participants were active board members all with physical disabilities associated with high support needs. The remaining six were current staff working full and part-time at DJA (one executive officer, three advocates, one project worker, and one administrator). Two staff members identified themselves as experiencing disability, although not associated with high support needs. Participants all had current contact with DJA and were recruited through the organisation. Their ages ranged between about 24 –50 years.

- Initially, the project worker was excluded on the grounds that he was not directly involved in providing advocacy, and would not have knowledge of the bigger picture of the organisation. However, his exclusion became a point of discussion between the executive officer and I, and he was later invited to become involved.
- Ensuring that there were effective lines of communication between the participants and myself was a high priority for me. This was not only so as to keep participants informed about the process, but also to seek feedback regarding the design and structure of the strategic planning process. By encouraging their participation in this way, I hoped that participants would take more interest and ownership over the process.
- However, ensuring that participants had equal access to this information, and opportunities to feedback presented some tensions. Those participants who were email users had access to regular updates and information. Furthermore, staff members, who were based at the organisation headquarters, had access to hard copies of updates and information. I was aware that two members of the board that were not email users had fewer opportunities to access these lines of communication. While I would present regular verbal and written updates at board meetings, if these board members were absent for any reason, they might miss out.

Reflection Box 3. Inclusion and inclusive lines of communication

Phase 2: Organising the Strategic Planning Days

I established a project guidance group in anticipation of the large number of decisions required to determine the structure of the strategic planning process. The group needed to: (1) be small enough to ensure efficient decision-making; (2) be representative; and (3) involve people committed to the task. The group therefore

comprised of the chairperson, the executive officer and I, representing the board, staff and university respectively.

In the first project guidance group meeting we discussed the purpose of the group, the strategic planning process, the timeline and the allocation of tasks *(see Appendix C for minutes).* A revised timeline was drawn up. While this was the only official group meeting, ongoing contact and decisions were made between group members face-to-face and via email as appropriate. Facilitating the management of the strategic planning process was the primary task of my student placement at DJA[3]. Being on placement two days a week for a period of five months during the planning process was strategically arranged so as for me to be onsite and available as required. This also enabled me to have plenty of regular and informal communication with the participants.

I drew up and distributed an information sheet (based on discussions with the project guidance group members) for all participants outlining how the strategic plan would be developed (*see Appendix D*). I also went through it with the board at the following board meeting. Also at this meeting, the executive officer proposed to the board, that DJA consider funding an external facilitator. They accepted the proposal, agreeing that it was an appropriate use of funds. However, I also agreed to investigate alternative funding sources (e.g. via a grant) that might be prepared to financially support such a project and thus cover any expenses incurred. In the following days the executive officer identified a suitably qualified facilitator through her networks, and in the process set some provisional dates for the planning days that ensured the facilitator and all participants could attend.

I met with the facilitator to make arrangements and discuss the logistics of the planning days. Decisions were guided by the facilitator's knowledge of strategic planning, and my own knowledge of the organisation and the participants. We decided that there were potential benefits of having two smaller sub-groups at occasional points during the day. "Breaking discussion down into groups of six or eight gives those who are unaccustomed to or afraid of speaking in public the chance to express

[3]The placement was a separate component of my course requirements, however, I decided that by undertaking a placement at DJA in addition to the research, it would have multiple benefits. These include being on site to make preparations and organise strategic planning, continue to build relationships, further increase my understanding of the organisation, and hopefully be of benefit to DJA too.

their own thoughts and feelings. By doing so, they develop a sense of being a part of the organization. They feel they are valued for who they are and that their views are also important" (Kahn, 1994, p.44-45). For this reason, we decided that I would act as a co-facilitator. The presence of two facilitators was also expected to enhance the fluidity and management of the discussion.

- Rather than send the draft timeline directly to the executive officer, I decided to send it initially to the chair of the board. I was concerned that my previous negotiations had generally been with the executive officer, and that this contact might serve to disempower or exclude the board. After all, it was my aim at the outset that people with disabilities should own and control the process. However, the chair sent the draft timeline directly to the executive officer, and in this way it reassured me that involving the executive officer in the initial decision-making was what the board wanted.
- Decision-making was integral to the process, and in many ways, in setting out to do this research I had envisaged that everybody would and should be involved in every decision that was to be made. I soon discovered that this was not going to be feasible, and it highlighted the significance of examining how and why decisions were being made, and who was making them.
- In my eagerness for people to be involved in the process, I was glad when the executive officer proceeded to set dates for the planning. However, she did it without consulting myself or any other members of DJA. She made the decision based according to both board and staff availability. She also decided that it would take place over two days, for three hours each day, which was due to her experience that this would accommodate for varying levels of participants' concentration, and also their ability to get to the venue. This action made me realise that while I wanted people to make suggestions and provide input, I did not want them to take over the process. While her contribution was welcome because it indicated that she felt a sense of ownership over the process, it may have served to compromise a sense of collective ownership among other participants in the research.

Reflection Box 4. Who makes the decisions?

Phase 3: Initial Interviews

The purpose of the initial interviews was to develop rapport with participants and to develop an understanding of their perceptions of DJA and their role within the organisation. I sent every participant an official letter of invitation and introduction to the research, which outlined the process involved (*see Appendix E*). I chose interviews as a way in which to gather data particularly in an attempt to "understand people's experiences, to uncover their lived world prior to scientific explanations" (Kvale, 1996, p.1). Interviews also provided the kind of detailed information necessary to meet the aims of this particular study. By using this approach, I was able to gather data which reflected individual emotions, experiences and feelings, possibly of a sensitive and deeply personal nature (Denscombe, 1998). This was privileged information and was treated as such. A further aim of interviewing was to engage each participant individually, build up a relationship, increase lines of communication, give participants a voice, and to encourage them to start thinking about strategic planning. It also provided participants with an avenue to ask questions.

The structure of the initial interview schedule was informed by discussions I had with the facilitator at our previous meeting. We discussed what information was required to shape the strategic planning agenda, and in this way it guided what questions to ask in the interview. For example, the focus of strategic planning can vary greatly depending on what is required or deemed useful by the organisation. Therefore by asking the participants what they hoped to achieve at the end of the strategic planning days their comments were able to shape the agenda, as well as maximise the likelihood of their visions being achieved. Finding out what participants understood about strategic planning, their expectations of it and how it fit with the future of DJA formed the first half of the interview schedule. The second half focused on eliciting information pertinent to the research aims. Reflections and feedback from a practice interview session with a colleague was used to refine the draft interview schedule (*see Appendix F for revised interview schedule*). As interview sessions got underway, occasionally some wording was adjusted to facilitate understanding and, in some cases, participants required further clarification.

I contacted all participants individually to arrange initial interview times according to both our own availabilities and also the availability of a suitable venue. Interviews were conducted at a site that was convenient for both interviewer and interviewee. For staff members this was at the DJA meeting room during office hours. For board members this was at a range of different locations (DJA, at participants' home or work, or at TADAS[4]). For myself, as the researcher, only one location (at a participant's home) was not particularly convenient to get to, however I believe that the advantages gained from meeting this participant in her own home outweighed the extra effort involved in getting there.

I conducted all 11 interviews with participants.[5] Interviews took between 12 and 61 minutes (at an average of 32 minutes each). Prior to the initial interviews, I provided participants with an information sheet (S*ee Appendix G*). This outlined the purpose of the research and the nature of the topics to be discussed. The form also presented information about the research requirements, including what participants were expected to do and how long it was to take. Consent forms were also supplied to each participant and they were asked to sign it prior to the first interview (*see Appendix H*). Some participants were unable to sign the form themselves (due to their physical impairments), and either gave their verbal consent or allowed me to sign on their behalf. Those agreeing to participate in the interview were also provided with contact details of the 'principal researcher' (i.e. my research supervisor), and the Secretary of the University's Human Research Ethics Committee, to discuss any problems or issues that might arise from the conduct of the research. This is standard procedure for all research undertaken by students at Victoria University.

Interviews were semi-structured, using open-ended questioning, which allowed participants to explore points that were personally meaningful to them. I used specific tactics during the interview process, such as prompts, probes and checks to maximise the chances of eliciting the most pertinent data (Denscombe, 1998). In addition to the interview questions, there was a standard introduction. In this I emphasised the dynamic nature of the research process in the hope of encouraging people to provide

[4] Travellers Aid and Disabilty Advisory Service, Swanston St, Melbourne.
[5] One participant was not interviewed at this initial stage due to issues previously discussed in Reflection Box 3. However, I did have an informal (i.e. non tape-recorded) 1-hour discussion with this participant.

ongoing feedback, and discuss the process outside of interview sessions. However, this rarely happened with those other than the chair of the board and the executive officer.

I transcribed all the interviews. The length of the transcripts for the intial interviews ranged between 5 and 21 pages, at an average of 11 pages each (for details of transcription format, see p.66). Where possible, this was done immediately after the actual sessions. However, all the initial interviews were conducted within two weeks of each other to be completed before the first strategic planning day, and due to their close proximity over a small period of time, immediate transcription was not always possible.

- The interview process not only presented a way to collect data for the research, but also served to provide information to structure the strategic planning process in ways that were responsive to the needs of participants. In addition, it allowed me to relate with each participant individually, gauge what people understood about the process, what their agendas were and why they were involved with DJA. I encouraged participants to ask questions, in the hope that I would be better able to address any individual concerns. True to the principles of community development, it was also a way to generate interest and enthusiasm in the process, and engage participants.
- Most participants used the interview time to ask questions about the process. While this was encouraging, it meant that in one interview for example, it was almost exclusively directed towards informing the participant about strategic planning and addressing his concerns.

Reflection Box 5. The multiple uses of interviews

Phase 4: Strategic Planning Days and Developing the Strategic Action Plan

In a second meeting with the facilitator, I presented the data from the initial interviews. With this data we created the agenda for Day One (*see Appendix I*), including a list of issues to be used to structure discussion on the day. I compiled the data and sent copies to all participants in advance of the first planning day (*see Appendix J*).

The strategic planning took place in the DJA meeting room, as this was familiar and convenient for the majority of participants. It was also the present location for board meetings and could accommodate the support needs of the participants. Each strategic planning day consisted of three hours including lunch. Data was captured on audio-tape as well as by a 'note based' format (Krueger & Casey, 2000). Notes were made on butcher's paper, and recorded by different participants at different points in the proceedings. The reason for the dual data collection was to increase its trustworthiness and to provide a back-up should any communication by the participants' not be understood by relying upon one method alone. Trustworthiness is equivalent to the notion of validity in positivist research, and is important in qualitative inquiry as a means of achieving methodological rigour (Lincoln & Guba, 1985).

A third meeting with the facilitator was used to compile data from strategic planning Day One, reflect and review the process, generate feedback for the participants, and also construct an agenda for the strategic planning Day Two. The facilitator and I constructed a framework based on the data from Day One. This provided a context for the action statements that had been highlighted. I wrote this up and ensured all participants got a copy before Day Two *(see Appendix K).* The facilitator revised the agenda for Day Two (*see Appendix L*) and it was handed out to participants on arrival. Three participants did not attend the second planning day: one participant had prior arrangements; another participant had to attend to an urgent appointment; and the other participant forgot. Day Two proceeded in a similar way to Day One but had a focus on developing the action statements and associated tasks.

I consulted with the facilitator over the phone about how to present the data from Day Two. The facilitator then took no further part in the proceedings as it was

beyond the conditions of her employment. Using the facilitator's advice, the notes made on butcher's paper, and the existing framework for the action statements, I drafted a strategic action plan. I constructed several drafts, which only differed in format and presentation. I sent a letter with a copy of the strategic action plan enclosed to all staff, and invited them to make comments (*see Appendix M*). I presented these comments to the board at their next meeting, and the board then discussed and reviewed the draft plan on this basis. Following this procedure, I amended the draft plan based on what had transpired, and sent copies of this revised strategic action plan to all participants (*see Appendix N*). I chose to refer to the plan as a 'draft', even in its most final form, to reflect its ongoing dynamic nature.

The executive officer invited me to talk to the staff about the strategic plan at the next staff meeting. This provided staff with a similar opportunity to re-group, look over and discuss the plan (the project worker was not present at this meeting). We revised some of the items, clarified some statements, and identified some solid commitments regarding the future of the plan *(see Appendix O)*. In all my communication with the staff and the board, I emphasised that, for the plan to have an impact, it was their collective responsibility to use it, revisit it, and review it.

After the initial work with the strategic planning was over, I followed up a potential funding source and wrote a funding application to cover the cost of having an external facilitator *(see Appendix P)*. The application for funding was accepted by Interact Foundation a few weeks later.

- Originally I anticipated that the administrative assistant of DJA would be the primary note-taker, as she was both experienced and familiar with that role. However, in the same way that it was inappropriate for the executive officer to facilitate (due to being a participant herself), DJA and I decided that participants should share the role. Ideally this would have been done by someone external to the process, as writing notes at the same time as contributing to discussion can be problematic. The note-taker also has to translate what has been said verbally into written form, and because it requires their own methods of interpretation, it resulted in a variety of notes

with varying levels of detail.

- Creating the first draft of the strategic action plan lay in my hands. There was an incredible amount of work to be done in translating the notes on the butcher's paper into a strategic action plan. I felt uncomfortable with having this responsibility, not because I felt like I couldn't do it, but because I did not feel that it was my role to be interpreting what these statements meant for DJA. However, while I felt unqualified to do the job, I also felt a responsibility as the coordinator of the process, to produce a document.
- An ad hoc suggestion was made by the executive officer to review the draft strategic action plan with staff. How to get feedback from participants about the plan was something that I had not yet addressed, and I was glad that the executive officer made the suggestion. It reassured me that there was still interest and concern in the research process.

Reflection Box 6. Assumptions about roles and responsibilities

Phase 5: Follow-up Interviews

I constructed a follow-up interview schedule in collaboration with my supervisor. Several drafts were created, and further adjustments were made as the interviews progressed. The aim of the interview was to elicit participants' views and experiences of the strategic planning process. We decided that it would comprise of three distinct areas of questioning: (1) the research process; (2) the strategic planning days; and (3) the strategic plan itself (*see Appendix Q*). To facilitate recall, participants were also given a sheet outlining ten distinct stages of the research process (*see Appendix R*). [6]

I conducted 12 interviews, between 20 and 80 minutes in length (average length was 42 minutes), within three months of the second strategic planning day. I transcribed the interviews as soon as time permitted after they had taken place. All

[6] It was only when it came to writing up the research that I decided that the process would be better conveyed as seven distinct phases.

transcripts were formatted in the same way, single-spaced, with each line numbered, and the initials of the participant, date of interview, session number, and location of interview all recorded at the top of the page. The length of the transcripts ranged between 5 and 21 pages (at an average of 13 pages each). Participants received copies of their respective transcripts, and were invited to read them and make comments and revisions as necessary. Despite making several attempts, I failed to provide two of the participants with a copy of their transcripts. This was due to my lack of time, and the limited means of communication i.e. that these participants did not use email.

- Some participants were interviewed nearly three months after the strategic planning days, and this meant that a lot of the detail of the days had been forgotten. Their reflections on participation were therefore sometimes more generally about DJA and their overall experience of board meetings.
- As I asked participants what they thought about the process, and whether they felt involved, it led me to query the usefulness of the question. For those that said they thought it was good, I couldn't help feeling that they were just telling me what they thought I wanted to hear. For those that said that there were some issues for them, I felt it was a more realistic appraisal. I wondered why it took me less than positive feedback to accept what someone said.

Reflection Box 7. Issues concerning the follow-up interviews

Phase 6: Follow-up Workshop

Due to my conversion from a Masters to a Doctorate during the course of this study, it had several implications for this research. In addition to a change in the requirements for a Doctorate thesis (primarily in length and depth of the report) it also meant that I was able to extend data collection. I was keen to continue with a participatory approach to the follow-up phase, encompassing what I had learnt from my previous experiences in working with DJA. On this basis, I made contact with the

executive officer to explain my circumstances and to propose some further involvement (*see Appendix S*). We agreed that I should come to the next board meeting and present a summary of my findings from the first part of the study (*see Appendix T*) and to discuss the next stage.

Since the strategic planning days (that had occurred a year before), one board member and the administrative assistant had left and been replaced. One of the existing part-time advocates had also since become full-time, replacing the other part-time advocate who left. Following my presentation to the board, my proposal to continue the research in some capacity was accepted. We discussed some ideas for how I could be involved, and there was a consensus to focus on an aspect of the strategic plan. This related to action statement seven: 'identifying the priorities for systemic advocacy' *(see Appendix O for a list of the action statements)*. As a group, we decided to allocate two hours at the beginning of the next board meeting to discuss these ideas in a workshop. I agreed to draft an agenda for the workshop based on our discussions.

In the meantime, I contacted the executive officer to review our initial discussions and my ideas for the draft agenda and, as a result, further topics for discussion emerged. After a discussion with a research colleague from another university, I decided to shift the focus of the workshop to 'training for the board'. The 'training' that this referred to included developing an understanding of the purpose of the organisation, the board, and the mission statement, in addition to skills associated with being a board member. I decided that 'training for the board' was a priority over the initial topic (of 'identifying priorities for systemic advocacy'), in the belief that once members received training they would be better equipped to go on to address other issues, such as the initial topic proposal. I further justified this decision by noting that: (1) 'training for the board' was an action statement in the strategic plan; (2) it was raised in the initial discussions; and (3) the chair and another board member were currently working on a funding proposal and it would assist them in the process.

In light of this, I drafted an agenda, which incorporated some participation strategies with a view to making it more engaging, and hence productive. These strategies are outlined in a Save the Children publication (Save the Children, 2002). I emailed the chair of the board, the board member involved with the funding proposal

and the executive officer to get their feedback about this new focus for the workshop. With their feedback, I revised the follow-up session agenda (*see Appendix U).*

The day before the workshop was due an issue arose about who should attend the workshop. The advocates had been asked to come to the workshop and yet a session to review 'training for the board' was regarded by the board as not a good use of their time. Therefore it was agreed that the workshop time would be split between the original topic (priorities for systemic advocacy) and training for the board. With such late changes to the agenda, the session plan was compromised and replaced with a more ad hoc arrangement. I co-facilitated the session with the executive officer, and made notes of the proceedings, which I later emailed to DJA *(See Appendix V).*

- The substantially reduced contact with DJA in the last few months had meant that when I returned to address participants at a board meeting to raise the possibility of doing something further, I was both excited and re-energised. It presented the opportunity to provide feedback to the group about my preliminary findings, and to use this information to inform the process and content of our next activity. In my desire to learn from the last process, one of my key aims was to keep the task very focused, and keep people's thoughts and discussions on track within our pragmatic limitations (e.g. amount of time and resources). I was prepared for the difficulty in gaining consensus, and prepared that I might have to make some executive decisions against my better judgement. However, while I had arrived with a renewed sense of vigour, I left with old feelings of disillusionment. There were the familiar looks of confusion, intermingled with some inkling of interest. It made me question and examine what it is that seems to be preventing progress here. Again, participants were faced with the prospect of having an opportunity to get involved in some way. My services were free. While obviously their resistance could be a factor of not wanting to be engaged in another process coordinated by myself, instead I sensed that there were some other underlying factors that were at play.
- The issue of 'training for the board' is an interesting one especially in light

of my commitment to respecting and recognising the expertise of people with disabilities. It is an excellent example of how ableism plays out in practice and goes unnoticed.

Reflection Box 8. Patterns repeating themselves in the follow-up workshop

Phase 7: Ongoing Dissemination of Research Findings

A primary purpose for doing this research was for it to be meaningful and of use to people with disabilities, and the participants involved. Therefore, the process does not finish with the submission of this thesis. Rather, after submitting my thesis, it is my intention to formally feed back the findings of this research to DJA. A copy of my thesis will also be available for participants to read.

I plan to contact the chair of the board and the executive officer to discuss how I can most effectively communicate some of the findings, and what information might be of most use. I imagine that this will include a list of recommendations to inform future activities with regard to strategic planning in particular, DJA, and people with disabilities in general. It will be written in plain English, and restricted to two pages, in order for it to be accessible and useful to all participants. I will also suggest that some of the report be put up on the organisation website for wider dissemination, and offer to orally present some of the findings at the next board meeting, or Annual General Meeting.

- While wanting to honour my original intention of ensuring that participants receive feedback about the study, only four out of twelve participants are still currently involved with the organisation. This reveals one of the challenges of undertaking research in a community organisation. Intentions must be adapted to fit the dynamic circumstances. I feel that those participants that have left may be left wondering what happened with the research. In this way, the experience might simply have perpetuated the ongoing perception

that research is exploitative and disrespectful to research participants. However, while I may not be able to contact every participant, it may be possible to tailor my feedback to make it relevant to new board and staff members, who were not participants in the study. In this way, it might serve to inspire current board and staff members to either revisit the current strategic action plan, or even contemplate developing another.

Reflection Box 9. Seeing it through: plans for dissemination

Data Analysis

"Data analysis consists of examining, categorizing, tabulating, or otherwise recombining the evidence, to address the initial propositions of a study" (Yin, 1984, p.99). The purpose of analysis is driven by the original aims of the research (Krueger and Casey, 2000). Thus, in accordance with the aims of the research, the purpose of the analysis was to conceptualise the experiences of participation in the research process. Analysis occurred throughout the research process, and was not solely confined to the latter stages, which is often reported to be the case in positivist research. In the following section, I describe the method of analysis in two inter-related parts: firstly, that which focuses primarily on the interview data; and secondly, through regarding myself, the researcher, as an instrument of analysis.

Analysis of the Interview Data

Analysis of the interview data started as the interviewing commenced. As soon as I started to engage in conversation with participants, I was engaged in critical reflection and interpretation. These influenced the course of the interview and the subsequent questions chosen. This began a journey of subjective sense-making. Together with a more traditional form of analysis (e.g. content analysis of transcripts) this served to build upon these initial reflections.

To familiarise myself with the content and to check the accuracy of the transcripts, I listened to all the tapes several times. The text of each transcript was then content-analysed. I considered this to be appropriate as the interviews were ‘fairly straight forward’, ‘obvious’ and ‘simple’ in subject matter, and this is when content analysis is at its best (Denscombe, 1998). The procedure was logical and ordered, consisting of a breakdown of the text into smaller components or units of analysis (e.g. sentences), which were then grouped into relevant categories, issues or themes. As previously alluded to, these issues and themes were not simply constructed from the transcript data, but were grounded in my experiences of the research process, and my previous interaction with participants.

As I read through the first transcript, I highlighted sections of the text and wrote short descriptive headings (e.g. lack of resources as barrier to participation) in the right-hand margin. I wrote out these headings on a separate sheet of paper and in this way it was possible to group the headings together to identify some themes. As I read through the second transcript, I followed the same process, and when descriptive headings did not fit into the existing themes, I identified new themes. Employing the same process for the rest of the transcripts, I ended up with a substantial list of themes. I grouped the themes together according to what level of variable they corresponded to e.g. intrapersonal, interpersonal, organisational. While this ordering of themes into levels allowed for greater clarity whilst interpreting the data, it was artificially imposed and not something that emerged from the data. Unfortunately, there was insufficient time and resources to verify the consistency of the coding, for example, by having another person independently code the transcripts.

Using the descriptive headings, I constructed a thematic matrix. I used a Microsoft Excel spreadsheet because of its ability to accommodate for large amounts of text. I inserted the themes into the left hand column and positioned the initials of each participant into the top row, which were grouped according to whether they were staff or board members. Then, by referring to the marked transcripts with highlighted text, I copied and pasted the sections of highlighted text from the corresponding electronic copies into the appropriate cell in the Excel spreadsheet. After each copy and paste action, I also inserted the corresponding line number. I did this to facilitate

finding the statement's location in the transcript, should it be necessary to check the context of the statement at a later date.

I printed out the entire contents of the Excel spreadsheet on to about sixty individual pieces of A4 paper and then stuck them together in the appropriate order. Having this thematic matrix as three poster-sized displays facilitated the identification of common themes that were raised amongst participants, and also highlighted any gaps. It was also possible to quickly note any distinctions between the themes raised by the board members themselves and that of the staff. While the size of the thematic matrix was large, I felt that it was necessary to keep the text as it appeared in the interview transcript. This would allow less room for error made in the process of paraphrasing, and facilitate the identification of appropriate extracts to use in the report-writing phase.

Having thematically analysed the transcripts, I used Ife's (1995) conditions of participation (see chapter 2) as a further framework to analyse the themes relating to barriers to participation. It was my intention to invite participants to verify the coding of the transcripts and to reflect upon Ife's conditions of participation. However, there was insufficient time and resources for this to occur.

As I was reading through the transcripts, I also made comments in the left-hand margin. Rather than identifying themes, however, these comments were generally about the methodological process of the research itself. Often as I read through the transcripts it triggered a memory about the interview, or the participant, or I would notice an issue about a certain question that I had asked. These comments are dealt with in my description of the second part of the analysis in the following section.

The Researcher as an Instrument of Analysis

As emphasised previously, the analysis began as the research process itself began, and ceased as the process ended. This is because the entire research process itself was a form of data to be analysed. My reflections and observations of the process, recorded as journal entries (and comments in the left-hand margin of the transcripts), while constituting 'data', they also marked the initial stages of data analysis. The analysis was ongoing, occurring concurrently with data collection.

Being an instrument of the research meant that my ongoing reflexivity often influenced the direction of the research process. This occurred both within and between each stage of the process (e.g. reflections about an interview with one participant influenced the shape of questions both in that particular interview and in subsequent interviews). Data collection was a cyclical process: data were collected (e.g. as personal observations), they were reflected upon, more data were collected and, as a result, data collection procedures were often adapted to better fit the research aims.

The written analysis that is presented in the following chapters is the result of a long and complex procedure. It is based on the thematic analysis that derived from the interview data, and is combined and supported by data in the form of my reflective journal and personal observations. It also incorporates a further stage, described by Wolcott (1994) as 'interpretation'. It relies on reflecting on how the literature relates to what was discovered, and looks beyond the scope of the study to examine the implications of the research.

- My concerns about the analysis were primarily that the participants were not involved. While participants had been given the opportunity to feed back regarding their transcripts, they were not involved in generating the themes of the research and making sense of the findings.
- I have experienced an incredible tension the entire way through regarding the lack of participant involvement in some of the decision-making processes involved in the wider research, beyond merely the strategic planning activities. While I made several ongoing attempts to engage participants in the wider research activities, the fact that it did not happen made me feel like I had a hidden agenda, that I was being deceptive in some way.

Reflection Box 10. The lack of participant involvement outside of strategic planning

This chapter has provided a detailed account of the methods employed in this study. I presented some of my reflections at specific points in the process in order to create a richer account of what happened. This constituted the initial stages of an ongoing period of analysis. The next chapters proceed to analyse the data further, guided by the aims of the research, and draws on the literature to discuss the findings.

CHAPTER 5
ANALYSIS AND DISCUSSION

The purpose of this study was to conduct participatory action research with people with disabilities, and to explore its value as an empowering research tool. Through six months of collaboration with Disability Justice Advocacy (DJA), DJA and I decided that we would embark upon a strategic planning process. Developing a strategic plan became a vehicle for enacting participatory action research. Investigating the experiences of participation in this research process, in particular the barriers to participation, both from my perspective, as the researcher, and also from the perspective of the participants provided a way to explore the primary aim of the research.

The primary methods used to collect data regarding the experiences of participation were: (1) through semi-structured interviews with participants both before and after the strategic planning days; and (2) reflective journaling throughout the research process. The analysis and discussion of the findings comprise two parts:

1) The first part (chapter 5) focuses on the experiences of participation in the strategic planning process, in particular the participants' perceptions of the barriers to participation.

2) The second part (chapter 6) focuses on the experiences of participation in the research process more generally, with an emphasis on my perspective as the researcher.

This chapter encompasses what is traditionally known as the 'results' section of a research report. However, such a label is nonsensical in the context of this study, where the notion of 'results' implies that there was a single truth to be found. Rather, my postmodern and critical epistemological perspective guides me to look for and accept multiple interpretations of realities. Therefore, this chapter presents a discussion of my findings and learnings, based on the many different experiences of those involved.

The first part of this chapter focuses on the experiences of participation in the strategic planning process and DJA more broadly, in particular the participants' perceptions of the barriers to participation. While the participants remain anonymous to protect their identities, their voices are differentiated according to whether they are a board or staff member. As far as possible, only those quotes that do not reveal the identity of a participant are used. This is in accordance with the ethical requirements of the study and the ethical agreements reached during discussion with participants.

The barriers to participation are then thematically grouped, and I analyse these themes in relation to Ife's (1995) five conditions of participation. I examine the usefulness of thinking about 'conditions' for participation, as a way to understand the barriers to participation, especially for people with disabilities. First of all, to provide a context for the ensuing discussion, I clarify how the strategic planning process relates to the wider research process.

Strategic Planning as Part of the Research Process

As Figure 4 indicates, the strategic planning process formed part of the wider research process. While my involvement with DJA constituted a research process, it was also an intervention with an organisation. One of my primary concerns upon embarking on the research was for it to be of some use to DJA. Developing a strategic plan addressed this concern. However, developing a strategic plan with DJA did not meet the criteria for a postgraduate research study, as specified by my discipline and my institution. It therefore required some careful consideration and negotiation with the organisation as to how the two activities could be married.

DJA allowed me to organise the strategic planning process in a way so that it would simultaneously serve to meet my own research needs as well as the interests of DJA. For example, the interviews arranged prior to and following the strategic planning days, while they were not essential to the strategic planning process, provided two opportunities for data collection as part of the research. The amalgamation of the research and strategic planning activities posed few pragmatic problems at the time. However, in attempting to analyse and report the experiences of participation both from my perspective, and from the perspective of participants, some

complex issues emerged. In particular, these issues related to the difficulty of differentiating between the experiences of participation as part of the strategic plan, DJA more generally, or as part of the overall research process.

It was also difficult to separate the interwoven experiences of the participants from myself as the researcher. Despite this, I have chosen to focus predominantly on the perspective of the participants in this current chapter, and mostly on my own perspective in the following chapter. I decided that it was a useful and necessary distinction to make for the purpose of writing this thesis and to enhance the clarity of the following discussion.

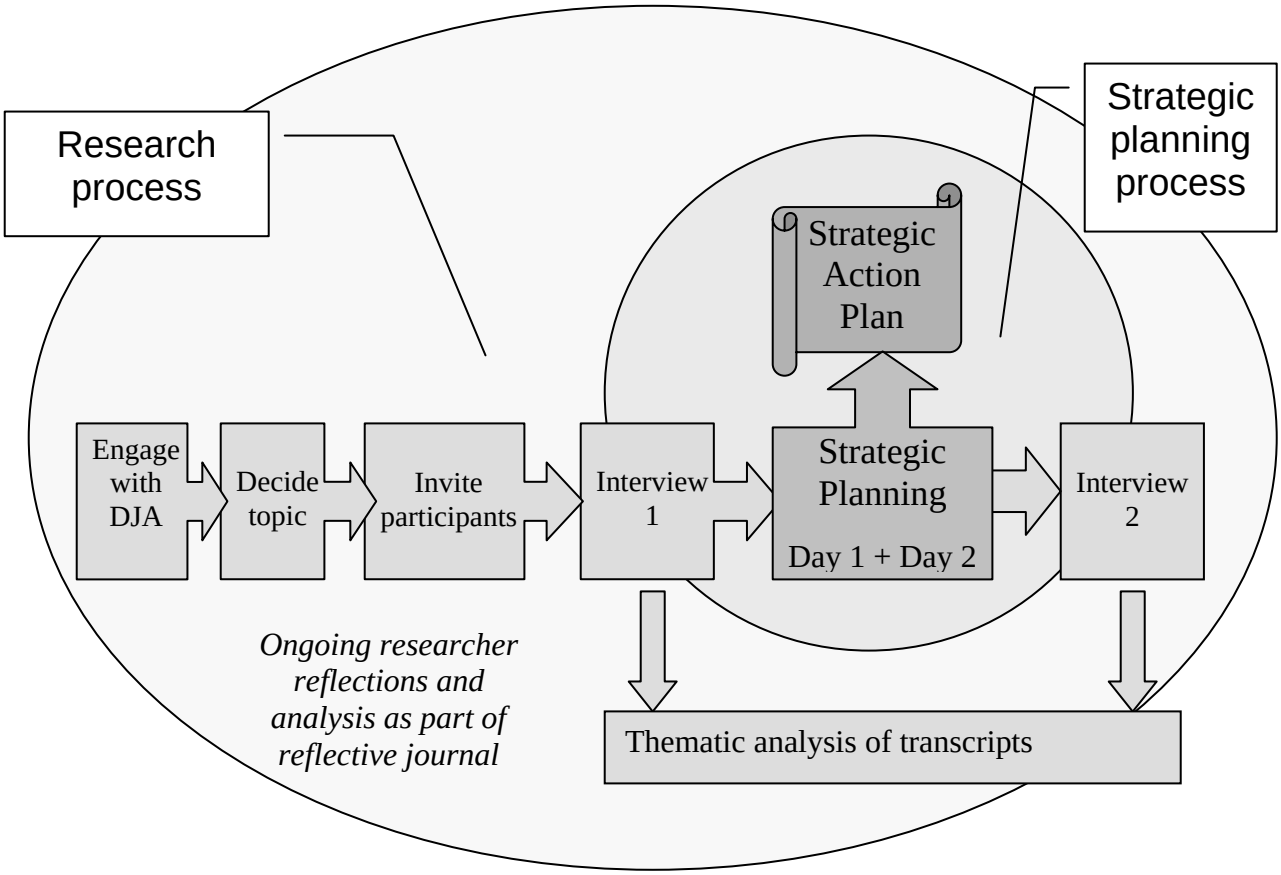


Figure 4. Strategic planning as part of the wider research process

Participant Perspective of Strategic Planning

Two strategic planning days were held in March 2004, and I developed a draft of the strategic plan shortly afterwards *(see Appendix N).* While, it is beyond the scope of this thesis to explore and explain the content (objectives and actions) of the strategic plan in detail, I raise many of the issues and concerns in the following discussion. This is because factors relating to participation were integral to the organisation and consequently featured in the plan.

The following sections serve as a descriptive account of the proceedings, while later sections are much more analytic in nature. To set the scene, and prior to an exploration of the barriers to participation, the next section describes participants' perceptions of the purpose of strategic planning. An overview of their experiences of being involved in the process is then presented. This provides insight into what participants perceive participation to be.

The Purpose of Strategic Planning

Most participants were clear about what strategic planning meant for DJA. In the words of one board member: *"you can't have a vision without action, and you have got to take action to get to your vision" (board member, initial interview).*

Generally, the process was seen to involve establishing a 'direction' for the organisation, over a specified period of time, with the production of "*a written document*" *(staff member, follow-up interview). "It's a process that ends up with what we would imagine is an agreed set of statements that give a sense of meaning and identity to why an organisation exists" (staff member, follow-up interview).* The plan was noted to set out *"a clear picture of our goals" (staff member, initial interview)* and the "*procedural method" (board member, initial interview)* for how to go about it, and also provided a way for DJA to do its "*own auditing" (staff member, initial interview).*

It was stated by one board member that strategic planning also gave staff *"a basis for feeling comfortable in their job" (board member, initial interview),* which

was confirmed by the following comment: *"This is great. This is the core of the organisation, this stuff. This is what it should all be about. So I could come in here everyday and know exactly where we are going" (staff member, initial interview).*

Most participants explicitly expressed the need for DJA to have more of a sense of direction and focus. There was general consensus that in tackling 'everything', DJA was *"spreading itself too thin" (board and staff member, personal communication)* and what was being done was in danger of not being done very well. As described by one staff member, *"there's so many things that we could do, you know, so many projects we could get involved in, so many things that are going on in disability advocacy, but we are just not big enough to do all of them" (staff member, initial interview).* All participants raised the issue of funding. In particular, that in the light of such a 'tiny' budget there was a need to look at *"how we can use our money better" (staff member, initial interview).* Thus, developing a strategic plan was not only perceived to be a way in which to highlight some priorities for DJA but also to assist the organisation in providing a more efficient and effective community service.

Overall Experience of the Strategic Planning Process

Most participants appeared to be happy at the prospect of developing a strategic plan and said that they were happy with the process. This was illustrated by comments such as: *"Terrific, it's the only way it could have been done" (board member, follow-up interview)* and *"I was extremely happy that we were going to do a strategic plan. I think it was organised really well" (staff member, follow-up interview)* and *"it was very good. It brought into focus a lot of issues that DJA is facing" (board member, follow-up interview).* There were also some references made to the largely unsuccessful previous attempts at strategic planning early in 2003, as described by the following participant: *"I felt a lot more positive about the attempt at strategic planning this year than last year" (staff member, follow-up interview).*

One participant proceeded to explain why she thought the process was a good one:

> *I think it was quite thorough in terms of getting everyone's viewpoints, trying to bring them together, trying to discuss that in a way that made them all open and discussable, and didn't set up divisions or competing groups in that way. Like it tried to discuss things as they were presented and I think that worked really well. So my feelings were generally very positive about it.*
>
> (staff member, follow-up interview)

However, amidst the positive feedback there were some voices expressing dissatisfaction, indicated by both staff and board members alike. For example: "*I guess it would be untruthful to say that I didn't have some frustrations during the process" (staff member, follow-up interview)* and "*the process for me, obviously, there has been a significant element of exclusion" (staff member, follow-up interview)* and finally, *"it was good…but it was a bit hard to be involved" (board member, follow-up interview).* One board member elaborated: *"If they put down basics, instead of chopping and changing ideas – one thing at a time, then they wouldn't be all over the place" (board member, follow-up interview).*

So, while there was an overall sense that it was a satisfactory process, there were some indications that it could have been a better experience.

Participant Understanding of Participation

> *I thought the whole thing involved everybody really well…As a participant I feel like I was given every opportunity to give input, and that my input was listened to, and I thought that was very valuable for everybody…But I don't think when I had the opportunity to give input, I don't think that input was degraded or looked down on. It was taken on board and written down and incorporated in the plan and I thought that was quite good. So, my personal involvement I was happy with, being listened to, being given the opportunity to provide input, and that was nice.*
>
> (staff member, follow-up interview)

These comments revealed how this participant regarded being listened to, having an opportunity to speak, and having her contributions valued and incorporated into the plan were important. She continued to say:

> *I think for the organisation the participation of every person who was in the meeting was really good. I think some could have said more and some could have said less but it all balances itself out…So I wouldn't want to change anything about my level of participation. When I put my hand up I was allowed to speak, and I think that's really all you can expect. I think that was, you know, I've got no complaints about how I was allowed to participate.*
>
> (staff member, follow-up interview)

This participant further indicated that participation involved a verbal contribution to discussion, and she emphasised the importance of having the opportunity to contribute. However, by using the word 'allowed' it implied that she sensed there was some form of authority that dictated how she could participate. This was echoed by the observation of another staff member who noted that there were too many gaps in her own knowledge about how decisions were made throughout the process. Thus, participation for her, ideally, would have been to be involved every step of the way, and to have had more solid and transparent processes and procedures.

Another staff participant noted that *"I guess the real experiences of participation I had was that conversation that we [participant and I] both had where I began to talk about what I considered to be the important dynamics that drove how decisions were made within this organisation" (staff member, follow-up interview).* Again, this perspective indicated that participation was considered to be a form of communication, and it also suggested that it was about being part of a process. These perspectives resonated with the literature that regarded participation in the workplace to be specifically about decision-making processes, and these comments supported the notion that non-management employees have limited access to these processes (Stohl, 1995). In this way, these experiences of participation appeared to relate most strongly to what Arnstein (1969), and Fajerman and Treseder (2000), referred to as a level of participation, whereby participants are 'informed' or 'consulted'. However, while

Fajerman and Treseder (2000) presented this as one of six non-hierarchical levels of user involvement, Arnstein (1969) interpreted this level as a degree of 'tokenism' whereby participants don't have complete control. In this way, Arnstein encouraged different levels of participation to be valued differently i.e. as one level 'better' than another. In the context of this study, because it appeared that there was a mixed opinion as to whether being 'informed' and 'consulted' constituted participation, it was difficult to interpret whether participants perceived there to be different and 'better' forms of participation. It was also beyond the scope of the study to ask them directly.

Other participants had a very individually oriented understanding of participation. They viewed participation as a choice, and that it was very much dependent on personal attributes or personality. For example, the following comment described how a staff member perceived communication to be a personal choice as opposed to something that may be limited by organisational variables: *"I know the avenues of communication here* [DJA] *are very open, it's just whether, as individuals, we choose to use that or not…So communication is limited by personality types more than lines of communication in the organisation itself" (staff member, initial interview).* Furthermore, participation was noted to be influenced by individual attributes, such as commitment and motivation. For example, one participant noted how no previous strategic action plan had held any currency, and proffered that "*people weren't committed to following it through*" *(staff participant, follow-up interview).* Another participant noted how "*everybody's different, everybody has different opinions, everybody works for different motivation" (staff participant, initial interview).*

In summary, it was evident that participants thought about participation in different ways. Their comments revealed that participants talked not only about the 'conditions' for their participation (e.g. individual attributes), but also about participation as a process (e.g. making verbal contributions and decisions). Furthermore, participant comments revealed that participation was experienced and understood as something influenced by factors at the individual, micro, level, as well as factors at the wider, macro, level. It appeared that depending on the context, the nature of participation can be interpreted at many intersecting levels. The next section

moves into an analysis of the barriers to participation, and in this way it offers further insight into this complex phenomenon.

Participant Perspective of the Barriers to Participation in Strategic Planning and DJA More Broadly

Throughout the interviews, participants identified many barriers to participation, not only within the strategic planning process itself, but also it was common for participants to talk more generally about their experiences at DJA. Strategic planning therefore provided a space in which issues about DJA became visible. This section provides an overview of their insights, with a view to exploring the nature of the barriers to participation, and the implications of these for the organisation.

The barriers that participants identified took a number of different forms. Through the process of observing, and listening to what participants said, I was also able to infer and identify additional forms of barriers. Table 2 displays these barriers to participation as a group of themes, and this provides the basis for the ensuing discussion. The left-hand column represents the level of analysis. The three levels of analysis are: intrapersonal; interpersonal; and organisational. These levels, and what they encompass, are described at appropriate points in the text to follow. Within this framework of analysis, the barriers have been grouped into themes, displayed in the middle column. Illustrated examples, described by participants, are listed in the corresponding right-hand column. It must be acknowledged that while I have identified these themes as a way to organise the data, the themes are often inter-related and many features overlap. Furthermore, due to the large amount of rich data, I was not able to address all the issues that were raised by participants.

Table 2

Barriers to Participation in Strategic Planning and DJA: A Summary of the Themes

LEVEL OF ANALYSIS	THEMES	EXAMPLES OF SPECIFIC ISSUES ARISING
Intrapersonal	Self-censorship and emotionality	Feeling unsafe or inhibited to speak, throwing tantrums and getting easily hurt
	Individual agendas	Too many different ideas and reasons for being involved, individual needs superseding those of the organisation
	Skills and competence	Feeling confused and not being able to keep up with the ideas being discussed, illiteracy and innumeracy
Interpersonal	Team dynamics	Conflict and tension impacts on communication and teamwork
Organisational	Decision-making processes	Limited access to decision-making, who is included/excluded, ad hoc decision-making, hierarchy
	Historical practices	Out-dated and ineffective organisational practices, low expectations of change
	Resources	Lack of time, lack of funding, lack of support for board, lack of privacy
	Strategic planning structure	Splitting into groups, dates of planning days, facilitation

Intrapersonal Level

Barriers categorised within the intrapersonal level were those perceived to reside within the individual. Comments that related to psychological factors (such as self-censorship and emotionality), individual agendas, and skills and competence comprised the data that informed the discussion below.

Self-censorship and emotionality

There was a sense that the overly 'sensitive' and 'emotional' nature of some participants' negatively impacted on participation because it meant that others could not be open and honest, and say what was on their minds. One participant described how "*often I bite my tongue, and I don't say anything, and then it all piles in and then I get upset, and then once every few months I burst into tears" (staff member, initial interview).* While this description referred to a participant's general experience at DJA, it provided the context for the following observations that targeted 'sensitive' individuals as a hindrance to progress in the strategic planning process more specifically. For example, one participant noted, while reflecting on her participation in one of the smaller discussion groups: "*Because they're emotional, their emotions kind of get in the road, which is a pity because so many people have things to say" (board member, follow-up interview).* Another participant described it as *"that tension about not necessarily saying things that you want to say because you're concerned about how it will impact on somebody" (staff member, follow-up interview).*

Self-censorship and emotionality presented significant barriers to participation within DJA more generally, especially amongst the staff. In the words of one participant: *"we've got a lot of very needy people here" (staff member, follow-up interview).* The negative impact that individual's and their reactions had upon the workplace environment was highlighted:

> *I do get tired of the tantrums that come with some of the questions that I ask, or I get tired of listening to people that throw tantrums, so that they can get the things that they want here. And I think that that's a real problem here, and I*

> *don't throw tantrums and I don't want my co-workers to throw tantrums, or to ignore things, or to pretend it's not there or to avoid it or whatever. And it's just about wanting to have a nice, harmonious workplace, you know?*
>
> (staff member, initial interview)

This participant went on to note how easily people got hurt, describing DJA as a *"very tetchy workplace"* where she felt uncomfortable with saying what was on her mind. Predominantly these comments regarding self-censorship and emotionality were aired in the context of interactions between the staff members, not the board. This way led me to interpret that this barrier to participation was not necessarily influenced by broader discourses to do with disability and impairment.

Individual agendas

Individual agendas were defined in this context as the personal motivations and interests of individual participants. Accommodating for the vast array of individual agendas and ideas were noted to present a barrier to participation. This was illustrated by the following comment:

> *I think in any kind of process like that there is going to be bits that are difficult for different people at different times for different reasons. I think that's unavoidable when you are dealing with a large, or even a small group of people, who have different interests in the organisation. So, different people come to a strategic planning process with a different history with the organisation, and a different agenda for its future.*
>
> (staff member, follow-up interview)

The same participant also expressed her frustrations at points in the process, particularly about the slow pace of change and the different priorities people have for change. Another staff participant echoed this sentiment, noting that: *"I think it's really hard when we're mixed in with members of the board - and staff are mixed in and we've got different agendas for different reasons" (staff member, follow-up interview).*

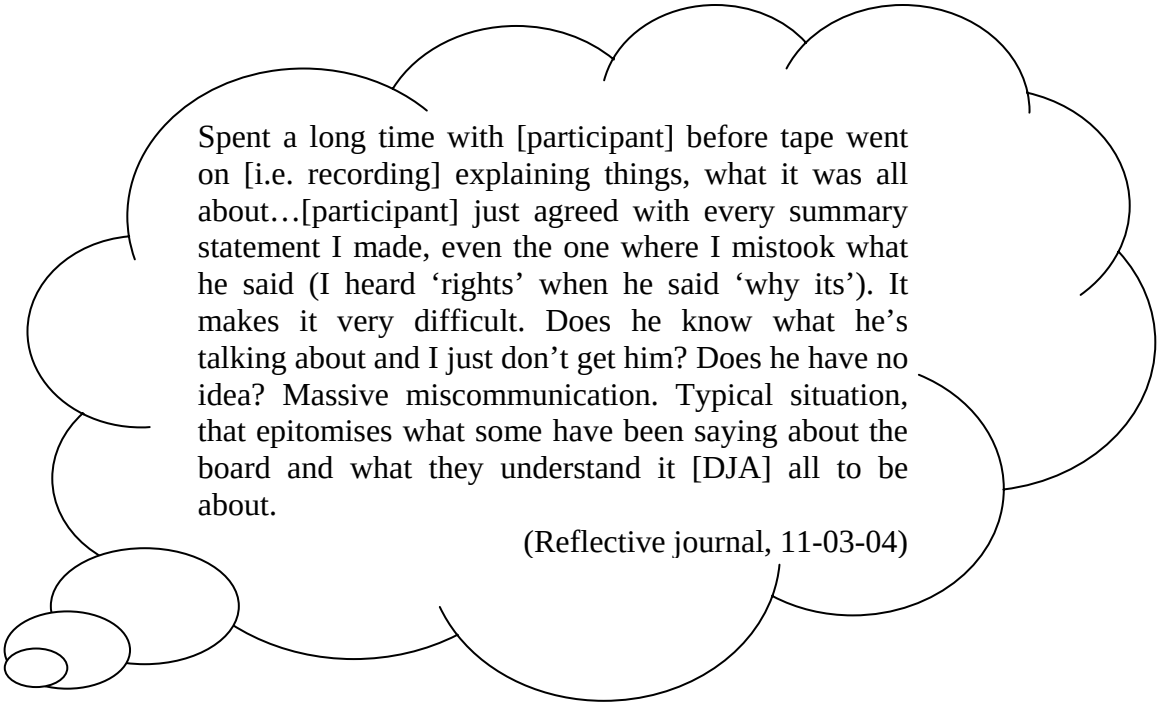
When an individual's own needs and interests superseded those of the organisation, it was considered to be a barrier to participation. As one participant described, there are people at DJA who are "*very destructive, and they're out for their own aims and their own gains and that can be really quite challenging" (staff member, follow-up interview).* Another participant noted that "e*ach person in a team is an individual, with a personal agenda, and I find differences with personality types to be very prohibitive" (staff member, initial interview).* As well as having questionable agendas that are not conducive to team work, another participant mentioned the challenge of accommodating for so many different reasons for being at DJA, especially amongst the board members (e.g. that being a board member is a way to meet people), and how this negatively impacted on participation.

In addition to having what was perceived to be quite an intentional and alternative agenda, there were also perceptions that indicated that board members were unable to think beyond their own difficulties, barriers and experiences. In other words, some board members were seen to have a personal agenda simply because they did not have the capacity to appreciate other people's perspectives. In contrast to the previous theme (self-censorship and emotionality), therefore, it appeared that some participant comments may have been specifically shaped around broader discourses of disability i.e. that comments were based upon deeply entrenched attitudes towards people with disabilities. It was also of interest that while staff members appeared to recognise the problematic nature of the subjective agendas of others, they did not necessarily reflect on how their own agendas might also have been problematic. This issue relates closely to individual skills and competence, which is the next theme to be explored.

Skills and competence

Poor skills and low competence of the board were cited as significant barriers to the participation process, particularly by staff members. One staff member noted how, in not wanting *"to patronise people or put people down by bringing up things that they are not going to get anyway"(staff member, follow-up interview)* she felt she had to censor what she said. Three board members said that they often found discussions confusing, and found it hard to keep up. This was both in the context of

the strategic planning, and also at board meetings. One staff member noted that the competence of the board "*definitely impacts on planning when you are spending more of the day explaining to people about how things fit together, than actually moving forward" (staff member, follow-up interview).* This comment resonated with my experience during the interviews with these board members, where I found myself spending a lot of the interview explaining what I perceived a strategic plan to be, and answering various other queries. My reflective journal illustrated this further:



As part of the interview process, I encouraged participants to ask questions. One of the reasons for doing so was to engage participants and increase their interest in the process. While most participants asked questions, the types of questions that they asked varied immensely, and illustrated the huge range of skills and competencies of the participants. Many participants, predominantly staff members, noted the necessity of 'training for the board', and the implications that a lack of competence had for the organisation.

While the competence of the board appeared to present significant barriers to participation within the strategic planning process, most staff members also referred to competence of the board as an issue pertaining to wider organisational activities. It

appeared to strike at the operational heart of the organisation. The board had a responsibility to oversee the management of the organisation. However, many participants described some board members as not being sufficiently aware and competent to carry out this role and this was noted to have huge implications for the organisational management.

An explanation given for this perceived lack of competence of the board was that:

> *It's because they haven't had life experience and they haven't worked a lot, and they don't understand. And I think we need input from people who work, and have life experience, who understand the complexities and the issues that go on. And I find it really frustrating, in the past, our past boards have said about previous EO's [executive officers] 'oh, they're too bossy, they do all the talking, they do everything'. And I can see where that comes from, because they have to take a lead and they have to do the talking because the board don't have the ability to do that. So even though we have quite a good board now, there are still a lot of weaknesses there, and there is still that lack of experience of running an organisation, and I'd like to get a better balance.*
>
> (staff member, initial interview)

One staff participant noted that by claiming that the board lacked skills she was "*not belittling anyone on it. They are all valuable people. They just don't have the level of skills they need" (staff member, follow-up interview).* While the issue of competence was one mainly raised by the staff, it was not exclusively so. One board member, for example, stated:

> *Without putting myself on a pedestal, I get frustrated because other people on the board are not quite as knowledgeable as me…Sometimes you have to keep on repeating over and over again. And that slows it down. And by the time you get home, you're exhausted…I really don't think they understand what it involves…I think there are only two and a half people [on the board] who really put in, or make an input.*

(board member, initial interview)

The impact of this perceived lack of competence for the organisation was a situation whereby the executive officer, while at the same time as being accountable to the board, was also providing support and training. One staff participant described it in this way:

> *I struggle with the board because – it's fantastic that we have people with disability represented on the board, I just actually believe that, still, that some of that stuff – some of the people on the board are gaining skills – and I agree with that too – but at the detriment of the management of the organisation. Because what we are doing is two roles. One, we've got a board that is supposed to actually oversee an organisation, and in the next breath, we are teaching people how to do that. And I just find that really, really messy. And I think it should be separate, or different, or something, you know? I just don't think it works, and I don't think it's right.*
>
> (staff member, initial interview)

Thus, it led one staff member to conclude that "*I don't believe the present structure compliments the organisation…if we are to grow we need a more able board" (staff member, follow-up interview).* This final comment encapsulated how ableism had manifest in this organisation and within the research process itself. Lack of competence presented a significant challenge for the organisation. Underlying the tension was the belief that some board members lacked the competence to fulfill their 'role' within the organisation. However, it was clear that these beliefs were based on non-disabled standards about how things were supposed to be done and what kinds of skills were required to do them. My own reflections (as illustrated by my journal entry) conveyed how I also aligned with ableist assumptions. For example, rather than questioning the accessibility of the process to all participants, I instead chose to locate the source of the tension as an attribute of people with disabilities themselves. In this way, I failed to realise how the notion of 'training for the board' conflicted with my commitment to respect and value the voices and experiences of people with

disabilities. This is a fundamental issue of the study, and is further explored in relation to one of Ife's (1995) conditions of participation towards the end of the chapter.

Interpersonal Level

Barriers categorised within the interpersonal level were those perceived to reside between individuals. Comments relating to team dynamics presented the major barrier to participation at an interpersonal level.

Team dynamics

While tensions between some of the staff and board members during the strategic planning days were evident, they were not discussed on the strategic planning days themselves, but were reflected upon during the interviews. One staff member expressed concern over whether *"the board might be aware of or pick up on the underlying tension within the staff team" (staff member, follow-up interview).* An incident occurred during the first strategic planning day whereby one participant requested that another participant leave the room to attend to some other business. The participant that was asked to leave regarded the request as completely inappropriate considering that a group discussion was taking place at the time, and it resulted in a few heated exchanges. The participant who was asked to leave explained: *"well, it was just after the groups had come together, and I was listening quite intently to what they had been saying. I had to explain that 'no, I couldn't do that because I was still quite busy', and I was asked again…and was then told 'well, don't come to me asking for support again if you can't do this'" (staff member, follow-up interview).* The participant that had requested another participant to leave said of the day that *"there were a few interruptions and I had to get up and leave the meeting but the organisation rolls on regardless of meetings and things like that, so you've got to do that" (staff member, follow-up interview).*

Clearly, individual's ideas about what was and was not appropriate conduct during the planning days conflicted, and this resulted in some tension. Another staff participant reflected: *"I was really distressed over that incident, that sort of really*

ruined a lot of my concentration for the day, and it made me really angry as well" (staff member, follow-up interview). A board member also mentioned that "*it was interesting watching the staff. They don't agree with each other!...That's probably why I didn't contribute as much, as I was too busy watching everybody's interactions" (board member, follow-up interview).* These comments suggested, therefore, that the relationships between members contributed to levels of participation.

Participants observed barriers in the wider context of DJA in the form of people who don't '*give*' as a team, and the consequences that "*it tends to make team players hold back a bit and it is very destructive for the team" (staff member, follow-up interview).* Another staff participant noted how *"the internal dynamics between the staff members of DJA, impact on the decisions that get made at DJA" (staff member, follow-up interview)* and not in a positive way. Desires for the team to be a lot 'tighter' with improved "*lines of communication*" *(staff member, initial interview)* reflected this. One participant also described feeling unsafe, particularly within staff meetings "*because of the inability of the organisation to be able to effectively address how personal and group dynamics inflicted and impinged on, I guess, on organisational policies and directions" (staff member, follow-up interview).* Thus, the perception of safety significantly impacted on this participants' sense of involvement, and consequential willingness to be involved, as part of a team.

Interpersonal factors, in the form of team dynamics, therefore appeared to present quite substantial tensions for DJA, particularly relating to the relationships between staff members and the day-to-day management and decision-making. However, while team dynamics posed a significant challenge for DJA, this theme appeared not to have an underlying basis in the wider context and discourse around disability. In this way, team dynamics drew parallels with the theme 'self-censorship and emotionality' in that the theme did not seem to be disability-related.

Organisational Level

Barriers categorised within the organisational level were those relating specifically to DJA as an organisation. Comments that related to decision-making

processes, historical practices, resources, and the structure of the strategic planning process itself comprised the data that informed the discussion below.

Decision-making processes

References to the role of decision-making processes in creating barriers to participation littered the data. Participants highlighted how decisions made during the process had negative impacts. One obvious example of this related to who was asked, or not asked, to participate in the research process. One staff member noted how not consulting the membership was problematic because it meant that they had not been given the opportunity to participate. She explained how the entire membership should have been consulted, especially since DJA was supposed to be a 'consumer-led' organisation. Thus, at some stage in the research process, a decision had been made not to involve the membership and this posed a barrier to participation.

There was also another instance where as a result of decision-making between the project guidance group (the executive officer, the chairperson and I), one participant was almost excluded from the strategic planning process. The reason for the doubt about his inclusion was due to his position as a project worker in the organisation. Specifically, that it would not be appropriate to include him due to him having insufficient knowledge about DJA's wider activities and purpose as a whole. It was also thought that the focus of his project work would lead to his interests becoming unfairly represented in the course of the strategic planning activities, whereas it was felt that all issues should have a fair hearing. Despite the doubt surrounding his participation, on the morning of the planning days, he was invited to attend. As far as I was aware, this decision was made on the basis that everyone else in the office was attending the planning day, and it was unfair and inappropriate to exclude him. This issue is also an example of the problematic nature of ad hoc decision-making within the organisation, and is explored later in this section.

One participant who expressed considerable concern about certain 'gaps' in the process, where she was unaware of how decisions had been made, illustrated another issue that related to decision-making. This was specifically regarding the stage

between having notes written down on butcher's paper, as part of the planning days, and the production of the strategic action plan. Of this process, she commented:

> *All of the questions – when this happened, when that happened – how did it get on to here? What things were left off? And that's the most – you know, if you're going to say this is the document, I'd be interested to say 'well, what happened to all our other stuff?' and 'where is it?' and 'where's the recording of it?'*
>
> (staff member, follow-up interview)

This participant referred to this stage (of the paper notes being transformed into a strategic plan) as the most 'crucial part'. To which I replied "*Yeah, and ideally I would not have wanted to do that! [laughs] I didn't enjoy it at all. I didn't feel like it was my place to do it, because I don't understand all of the issues" (follow-up interview with staff member).* I remember how I had felt that no-one had wanted, or had had the time, to be involved in this part of the process. I felt extremely uncomfortable doing it, and I felt like it was assumed that I would do this job, in my role as coordinator and facilitator of the process.

These comments all highlighted that not everybody had access to decision-making, and that the decision-making processes were not clear or transparent. Furthermore, that while I attested to wanting less decision-making responsibility, other participants would have liked more. The project guidance group clearly had much more decision-making power, and this illustrates what Ife (1995) named as the 'elite' perspective of power, whereby certain groups exercise disproportionate influence over decision-making. While the purpose of setting up the guidance group was to facilitate the coordination of the strategic planning process, it may have served as a barrier to participation for those that were not a part of the group and perpetuated the inequities of power and control amongst participants. The impact of the project guidance group in relation to decision-making processes is explored further in the next chapter.

Decision-making, as discussed in the context of the day-to-day life of the organisation more broadly, also presented barriers to participation in many shapes and forms. One staff member noted the "*different levels of decision-makers in this*

organisation" (staff member, initial interview). She proceeded to describe workers as having a huge power of decision-making, along with the executive officer, and the board, and while she wasn't questioning them, she stated that "i*t's not properly acknowledged"*.

Most of the staff participants mentioned the problematic nature of having poorly defined policies and procedures. Most significantly it meant that operational decisions were made on an ad hoc basis, with little rhyme or reason. This elicited feelings of uncertainty, vulnerability, and lack of clarity in staff roles and activities. In the words of one staff member:

> *I think that sometimes a lack of clarity and structure around meetings can act as a barrier to people being able to express their thoughts on the organisation, or just to generally participate in things…sometimes participation can come down to who's here the most – various different things…I guess I would say that we are probably not great at the structures that ensure that people have equal participation.*
>
> (staff member, initial interview)

With regards to the presence of a hierarchy within the organisation, there were mixed opinions. One staff participant noted that:

> *There are very few layers of management here and well, we've only got 2 layers. We've got the board, then the EO [executive officer] and then the workers. But there's no perceptible hierarchy as such we're all just slogging in, and we're all doing the same thing, and we've all got the same resources. So the levels of authority here are there, but they're not perceptible, and they're not practiced to be perceptible.*
>
> (staff member, initial interview)

However, in contrast another participant noted that there were distinct layers of management, and that she had *"trouble with having, you know, a person who oversees a very tiny organisation"* and declared *"cut down the hierarchy and get on with the*

job" (staff member, follow-up interview). In summary, therefore it appeared that hierarchy (defined as people having disproportionate decision-making responsibilities), presented a significant barrier to participation for some participants. Interestingly, participants' comments about hierarchy did not refer to the board of DJA, which might appear strange in an organisation where the staff team, including the executive officer, is accountable to the board (see Figure 3 in chapter 2 for organisational chart). In this way it appeared that this theme, in not being raised by, or relevant to, the board, may have revealed something about the way in which it is grounded in ableist practice.

Historical practices

Historical practices and procedures within the organisation were regarded as barriers to participation in all planning processes. As one staff member highlighted:

> *We haven't had a history of planning in the organisation. We've worked in a very ad hoc way ever since I've been here, and they did prior to that, and so this hasn't been a culture in the organisation…there's a lot of history, and there's a lot of personal intent on maintaining and hanging on to old stuff, or individuals decide what they think they should do rather than it being a group decision.*
>
> (staff member, initial interview)

Many staff members associated how organisational practice based on historical factors, had created a 'culture' in the organisation, and this had served as a force or 'resistance' to prevent progress and change. *"People take such ownership of the history and aren't prepared to change when new people come in, or it's very slow to change" (staff member, initial interview).* There was much frustration expressed regarding the slow pace of change: *"I guess my frustrations weren't around the process as such. It's just about organisational stuff, and that organisational change is slow" (staff member, follow-up interview).* Thus, while individuals certainly talked

about a desire for change, they implied that they were powerless in the face of such an entrenched culture and history.

While historical practices within the organisation were identified as barriers to participation this was not an issue raised by any of the board members. This is possibly due to historical practices, in this context, being related to operational procedures within the day-to-day running of the organisation. The barriers to participation due to historical practices did not appear to be impacted by wider disability discourses, however, historical practices may well provide a mechanism for promoting ongoing ableist attitudes and processes.

Resources

Lack of time for discussion and decision-making presented a major barrier to participation in the strategic planning process. This was especially evident in that it was the reason one board member had given for not being able to attend the second planning day i.e. he had had another commitment. Participants stated that they felt 'rushed' and that the "*planning days were very quick. I always find that really serious, long-term, decisions which is what I think we were trying to do, are being taken too quickly" (staff member, follow-up interview).* Time was also the reason stated for strategic planning not happening more often. Indeed, one participant stated that *"I don't think it would have happened as well, or as soon, or as clearly if it had been a staff member's responsibility to do it. Because, you know, it is just so hard to juggle all the work we have to do already, without then having another task" (staff member, follow-up interview).* So, while it was regarded as a good thing that there was the time and opportunity to conduct a strategic planning process, it appeared that there had not been sufficient time to do it thoroughly.

Whereby, time posed the significant barrier for participation within the planning process itself, many more resource-related barriers emerged as participants discussed their wider experiences of DJA. These were all underpinned by minimal and lack of ongoing funding. DJA's *"tiny budget, with no security" (staff member, initial interview)* presented significant barriers to participation, primarily because DJA was unable to get involved with all the projects that it wanted to. A small budget also

created widespread anxiety particularly about job security. Participants noted how DJA is "*stretched to its limit" (board member, initial interview)* and *"we've got no guaranteed future…I could say we'd be forever funded, but we don't know that. So, in practical terms, that makes it always difficult to plan" (staff member, initial interview).*

Many participants noted how "*burnt out"* the staff were, and the subsequent lack of support for the staff. Limited funds also meant that staff had to put up with inadequate working conditions: *"I'm living in a corridor for god's sake. Everyone hears every conversation I ever have. How is that? You know, how do I cope with someone hearing every single conversation I have? It must be so boring for them!"(staff member, initial interview).* The lack of privacy for advocates was even more significant considering the nature of their work, where often issues are highly confidential and deeply personal. Lack of funding also had implications for the amount of time available to spend on certain activities. While delivering individual advocacy got priority this was to the detriment of organisational planning and teamwork.

Lack of tangible support for the board, in terms of basic assistance for board members during board meetings (e.g. assistance with toileting, eating and drinking, turning pages of documents etc.) was also regarded as a barrier. For example, a staff member alluded to the difficulty that board members with visual impairments have in participating in board meetings due to being unable to read documents as part of the proceedings. Ideally, in such situations, the board member should have an assistant available to read the document.

Resources, therefore, appeared to present significant barriers to participation at an organisational level. The resource-related issues that emerged in the context of wider discourses of disability (e.g. attitudes towards the additional resource requirements of people with disabilities) are explored later in the chapter.

Strategic planning structure

Participants raised several issues pertaining to the structure of the strategic planning process itself and how they served as barriers to participation. Facilitation

was one of them. Prior to the strategic planning days several participants noted the need for an independent facilitator. Having sought feedback from potential participants regarding the preliminary ideas for the strategic planning process, one staff member suggested that there should be an external facilitator (initially it was assumed that the executive officer would take on this role). After the planning days, this same participant emphasised the benefits of having an external facilitator because it allowed participants to participate in more equal ways, because they did not have to take on their usual roles and responsibilities within the organisation (e.g. administration officer as minute-taker). She also implied that in having someone external to the organisation, that this person was able to act as a form of arbiter. One participant stated: *"we'll need strong facilitation, and I can't emphasise that enough, because there are people with communication impairments and there are people that don't, and everyone should have their say and some people will just take over" (staff member, initial interview).* On reflection, however, participants appeared to be divided over the role of facilitation in the process. One staff participant stated that it was *"just great to have someone who is external from all of that who can kind of moderate the whole meeting" (staff member, follow-up interview),* while a board member said it *"needed better facilitation, as it is very important, to keep people on track and not ramble"(board member, follow-up interview).*

Several participants thought that the strategic planning would have been more effective had it have been held in a different venue. It was held at the organisation headquarters, in the same room where board meetings were held. Participants' inferred that had the planning days been located off the organisation's premises, attitudes would have been different as *"it generates different ideas" (board member, follow-up interview).* Furthermore, with regard to the arrangement of planning days, one board member stated that: *"the way it worked out, one day one week, and one day the following week, it was a bit too big a gap…I personally think we should have done it two days in the same week" (board member, follow-up interview).*

On dividing the larger group into two smaller sub-groups for discussion on both days, the participants had mixed responses. One participant noted the benefit of splitting up into smaller groups, however, the majority said that they would have preferred to remain as one whole group. One staff member stated that it was *"a little*

bit disappointing that some of the issues didn't get to be aired by everybody in the group because there was splitting up into groups, but I understand that there were reasons why that process was chosen" (staff member, follow-up interview). Another participant noted that due to splitting up "*there wasn't really time for the two groups to get back together" (board member, follow-up interview)* and she felt like the groups had "*doubled-up*". Two further participants implied that in splitting up, it meant that they were excluded from the other group discussion and decision-making, and that actually *"everyone needed to hear what was going on" (staff member, follow-up interview).*

The structure of strategic planning, therefore, appeared to present general barriers to participation for a range of participants, without being specifically associated to wider issues around disability and impairment. Having explored some of the major themes, the next section attempts to understand these barriers in the context of ableism.

Ableism as a Context to Understand the Barriers

Ableism, defined as false beliefs and attitudes about people with disabilities (White, 2005), was not explicitly stated by any participant as presenting a barrier to participation. Nor was there any other comment implicating a barrier of a socio-cultural nature i.e. residing externally of the individual and the organisation, representing structures in the wider social and cultural environment. This did not surprise me, as ableism is not a concept that is widely used or referred to. Rather, it is an ideological concept used primarily within academia. While it could be seen to be problematic that I, as the researcher, have deduced and named ableism for the reader to be aware of, I believe that such a deduction and naming are helpful and may raise awareness about the omnipresence of ableism. I believe that ableism presented many barriers to participation in this study. The fact that people do not talk about or acknowledge ableism compounds its impact, and perpetuates the ongoing barriers to participation for people with disabilities. For this reason, ableism provides a useful platform from which to explore the barriers to participation that participants did identify.

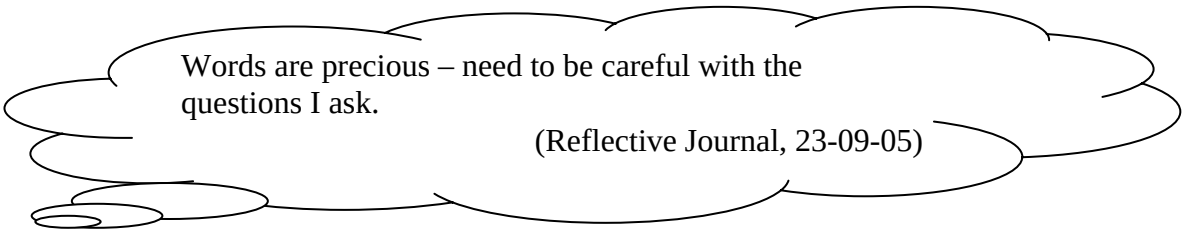
In this study, ableism was expressed in a number of ways. While participants did not refer to ableism directly two particular comments illustrated typically ableist attitudes. One participant noted with regard to her experience at DJA, that *"its opened my eyes to what people with a profound disability are capable of doing when they sit at a board meeting" (staff member, initial interview).* This comment implies that the participant's expectations of the capabilities of people with disabilities were low. Likewise, another participant, in discussing his experiences of receiving advocacy from a person with a visual impairment said that "*it's like the Blind – I'm partly blind – it's like the Blind leading the Blind, if you know what I mean!" (board member, initial interview).* In saying this, this participant appeared to be degrading the ability and worth of people with visual impairments. Attitudes such as these certainly led me to question to what extent they posed additional barriers to participation.

Ableism was manifest in some of the experiences described by participants. In particular, it appeared that ableism underpinned the perception that competence of the board presented a barrier to participation. To a lesser extent ableist attitudes may have shaped the comments made by participants regarding the role of different agendas of board members and resources. This was due to these comments being grounded in non-disabled standards of what it is to be competent, assumptions about what an agenda should look like, and the types of resources and support that are required to participate.

Ableism did not only present barriers to participation with regard to participants, but I too became aware of my own ableist attitudes, and how they served to impact on the process and my interpretation of it. I can illustrate this point through discussing how I had expected participants' impairments to have more impact on the process. I observed in the interviews that participants with disabilities rarely talked about their own impairments as being significant barriers to participation. Indeed, of the eight participants that did identify as experiencing a disability, only one participant indicated that his speech impairment might present a barrier. This was evidenced by a comment that his communication 'might' make it difficult for people to understand him.

While I agree with Ora Prilleltensky's (2005) statement that there is often an unquestioned assumption that it is the impairment itself that presents the greatest

obstacle, and am disappointed by the common assumptions that are made regarding people's impairments, I was still expecting something to be said about the impact that impairments posed for participation. For example, that using a communication device as a result of a speech impairment would decrease the amount contributed verbally to a discussion, and in this way impact upon active participation. As the researcher in the process, I certainly noted how speech impairments had a variety of impacts on the participation process. In particular, it made the rate of discussion slower, it disrupted the flow of discussion, and it made it less likely for me to pursue a line of questioning (i.e. as it required more effort). It also meant that there were less verbal data overall, shorter transcripts, it demanded closed questioning in interviews, and made it harder to decipher the interview tapes for transcription. Due to the longer time it took to discuss ideas with one board member in particular, I felt I needed to adjust the way I conducted the interview. The following extract from my journal illustrates my reflections at the time:



This reflection indicated how I imposed double standards: one for a participant with a speech impairment, and another for those who did not. Through examining my observations about how a speech impairment had an impact on the process, it was clear how I had been drawn into problematising the impairment and the effect it had had on the outcome of the process, instead of looking at how the process itself might be problematic. I identified a speech impairment as a barrier to participation, while actually, on closer examination, my underlying ableist assumptions led me to regard it as a barrier.

In his 'conditions' of participation, Ife (1995) stated that all different forms of participation should be valued. He was talking about different forms of participation in terms of participating on a board, or reading a newsletter. However, the same principle may be applicable in this context. For example, if I were to have placed less emphasis

and value on the amount and speed of communication, would I have perceived it to be less of a barrier?

In this section, I have illustrated how through exploring the notion of ableism it can begin to provide opportunities to discover how to create non-ableist spaces to work within. Whilst, in this current study, it was me, as the researcher, who named ableism as a barrier, it would have been interesting to engage and reflect on this notion with participants. These reflections highlight the need for future research to articulate what non-ableist spaces might look like and how they might be constructed, and how we might engage others in this work.

This chapter proceeds to explore how Ife's (1995) conditions of participation may be used as a framework to analyse the barriers to participation that were observed in this study. Firstly, however, an overview of the barriers to participation in the follow-up workshop is presented.

Barriers to Participation in the Follow-up Workshop

With the conversion of my Masters degree to a Doctorate in December 2004 (which occurred after all the strategic planning activities and interviews had taken place), it gave me the opportunity to extend my involvement with DJA. I was keen to build upon my experience of the process so far (as well as encourage members of DJA to do the same) in order to maximise the opportunities and likelihood of a positive outcome for our ongoing involvement. Therefore, I returned to DJA and presented some of the findings of the research so far *(see Appendix T).* I emphasised that for our continued involvement to be a meaningful and useful process a clear focus would be required.

DJA and I decided that we would allocate two hours of the following board meeting to run a workshop to address a specific action statement of the strategic plan, and to explore in further detail how it fit with DJA's overall objectives and activities. However, between this initial meeting and the workshop, the focus for the workshop had shifted, and by the morning of the workshop DJA and I were faced again with an agenda that far exceeded what was possible within the space of two hours.

For me, the process simply served to replicate the tensions and challenges that were evident in the strategic planning process, and in this way I felt that DJA and I had failed to implement any changes or improvements based on our previous experience. I observed the same barriers to participation, including too many different agendas, conflict within the team, different layers of decision-making processes, and a lack of resources.

It was a disappointing process for me. I had returned to DJA with expectations that we could learn from previous challenges and focus, as a group, to achieve a specific goal. In this way, it may have served to emphasise the role of social and organisational barriers to participation. There appeared to be something about the culture of the organisation that posed a significant barrier to change. It was an experience that at times led me to conclude that it was just all too hard.

Having provided an overview of the barriers to participation in this study, the next section uses Ife's (1995) conditions of participation as a framework for further analysis, and to develop understanding about their nature of the barriers.

Analysing the Barriers in Relation to Ife's Conditions for Participation

As reported in the literature review, Ife (1995) identified the following five conditions for participation:

1) People will participate if they feel the issue or activity is important;
2) People must feel that their action will make a difference;
3) Different forms of participation must be acknowledged and valued;
4) People must be enabled to participate, and supported in their participation; and
5) Structures and processes must not be alienating.

The following section addresses how the barriers to participation, that were experienced in the research process and at DJA more generally, relate to these conditions. In this way, I examine if the barriers to participation in this particular study can be usefully explained in terms of a lack of these 'conditions', or whether there might be an additional condition or dynamic in operation. I also examine whether

these conditions adequately account for, and are relevant to, the experiences of people with disabilities in this study.

Table 3 shows how Ife's conditions of participation relate to the thematic barriers that I identified in the previous section. For example, I identified 'resources' as a barrier to participation, and it also constitutes part of the wider condition of 'enabling participation and support'. Therefore, in Table 3, I placed 'resources' in the corresponding column to this condition. It should be noted that not all of the themes that were identified directly correspond to one of Ife's conditions. I reflect upon the implications of this at the end of the chapter.

Table 3

Ife's (1995) Conditions of Participation and the Corresponding Thematic Barriers

CONDITION OF PARTICIPATION	THEMATIC BARRIER
Degree of importance and level of interest	Individual agendas
Expectation of change i.e. that their participation will make a difference	Historical practices
Valuing different forms of participation	Skills and competence
Enabling participation and support	Resources
Participatory structures and processes	Decision-making processes Historical practices Strategic planning structure

Degree of Importance and Level of Interest

Ife (1995) believed that people will participate if they feel the activity is important or interesting. By initially providing the opportunity for participants to develop their own topic of research, it was my intention that the research would be directly relevant and interesting to them. However, while all participants took part in

these discussions, the idea to conduct a strategic plan was initially conceived by the executive officer and the chair of the board. Ultimately, the decision to choose strategic planning was one made by those in positions of greater decision-making responsibility and power. This could have meant that other participants did not feel that it was so important and hence had less desire to be involved and participate.

Another issue of concern to me at the initial stages of the research was the voluntary nature of participants' involvement. After all, it was important to me that participants perceived that they had a choice to participate, as I felt it would have a direct impact on their level of interest in the process. Tomlinson and Swartz (2002) cautioned that by having initial negotiations with community leaders, as opposed to community members themselves, it may lead to participation that is more obligatory than voluntary in nature. Community members may feel coerced into taking part because their 'leader' has agreed to participate and, therefore, so must they. Thus, instead of being a potentially empowering experience, whereby a participant has decided to take part for a range of reasons, it could also serve to be disempowering if it was a decision made under a form of duress. For this reason, I was especially alert to the nature of people's participation in the context of this study.

Due to having had initial contact with the executive officer, I was concerned that participants' may have felt 'coerced' or obligated to be involved. Obviously participation in the 'research' was voluntary and consent was obtained. However, as strategic planning was also an organisational activity, it was also in a sense required and assumed by the executive officer that everyone would be involved. Since the research and the strategic planning processes were intimately linked, there may have been a sense of obligation to participate in the planning process, despite there being no obligation to participate in the research.

Fortunately, however, most participants appeared keen to be involved in the strategic planning process as part of a wider research study, and any feelings of 'obligation' to participate were not apparent. All staff members directly expressed how happy and excited they were about participating and that it was taking place at all. The majority of the board members were less explicit about their emotions. Rather board members appeared to take it in their stride, as part of their role, and regard the process as just another board meeting. In this way, it appeared that the sense of

coercion alluded to in the literature did not occur in this context, or at least, it was not revealed to the researcher. Furthermore, because the majority of participants had been involved in the initial negotiations, it may have lessened the degree to which participants felt that they did not have a choice.

In this study, no participants specifically indicated that a lack of interest presented a barrier to their participation. However, participants did describe how different individual agendas (i.e. the vast range of ideas, interests, and motivation amongst participants) were experienced as a barrier to participation, and this theme appears to relate to Ife's first condition. For example, having different agendas may have impacted on the degree to which participants found the research process important. This condition of participation, therefore, appeared to play a role in explaining some of the barriers to participation in this study. For people with disabilities, this condition of participation may be particularly significant, due to traditional practices that have often served the interests of the non-disabled majority.

Expectation of Change

Ife (1995) asserted that if participants believe that their participation will lead to change and make a difference then they will be more likely to participate. In this study, many participants referred to their frustrations about the slow pace of change and had doubts about whether the strategic plan was really going to make any difference or have a positive impact on the organisation. Participants felt resigned to the fact that despite what they said or did, organisational culture and historical practices prevented change, and in this way, individuals appeared to feel powerless in their efforts to facilitate change. This seemed to be a factor experienced by the staff in particular.

This condition of participation, therefore, may have served to influence the extent of participation in this study, particularly for staff who viewed historical practices within the organisation as hindering the process of change. For people with disabilities, in this study, expectation of change did not appear to significantly influence their level of participation.

Valuing Different Forms of Participation

According to Ife (1995), people will participate if different forms of participation are valued. He described this condition from a community perspective, and thus, explained the need to value for example, child minding and cooking, as well as involvement in committees. In the context of this study, it appeared that this condition was useful to explain some of the barriers to participation, particularly regarding competence of the board. There was a general opinion, predominantly held by staff members, that the board had insufficient skill and competence to carry out their role and duties. Having identified lack of skills and competence of the board as a barrier to participation, it indicated that these participants did not value the different and diverse ways in which people with disabilities participated.

In this study, therefore, this condition appeared to underlie some of the most substantial barriers to participation. For people with disabilities, valuing different forms of participation appears to be especially significant, and relates closely to socio-cultural issues such as ableism.

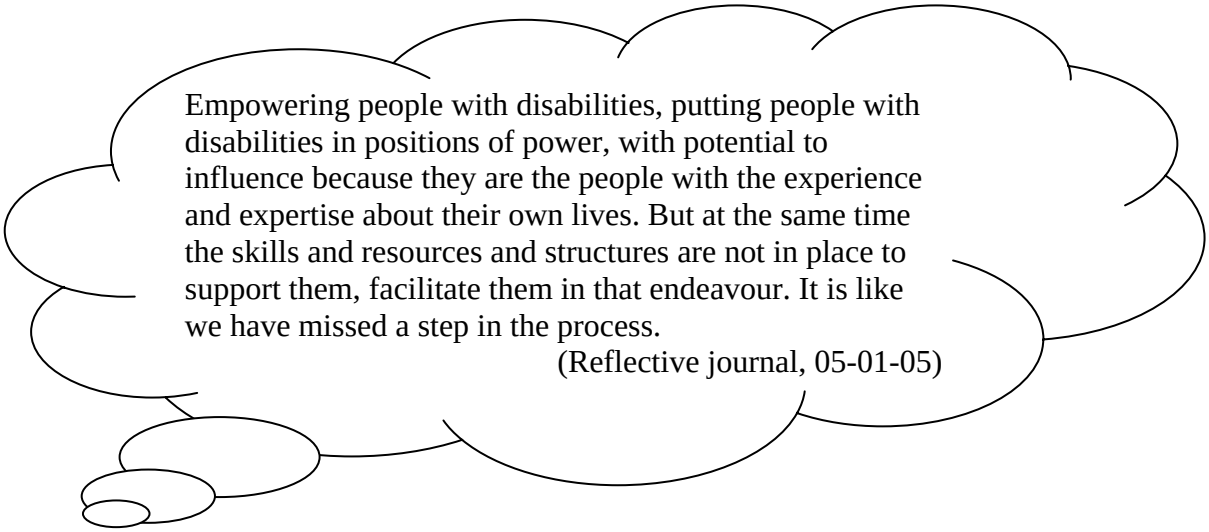
Enabling Participation and Support

Ife (1995) asserted that for participation to occur people need to be enabled and supported in their participation. In the context of this study, this related to the resources that were required for people to participate. A lack of resources (such as funding, time, support, and physical location) was clearly experienced as a barrier to participation by participants. This reflected what Hart et al., (1997) described in their experience of conducting a community consultation that a lack of adequate support negatively impacted on participation. In this way, participants' comments clearly emphasised the importance of this condition in this study

Being so tangible, resources are relatively easy to identify and address as barriers For example, it is clear that in the absence of funding members of DJA would not be able to participate in the activities of the organisation. However, for people with disabilities, additional resources are required to enable participation in an equitable way, and these can be overlooked or taken for granted in wider society. These include

resources such as an accessible venue, personal assistants, subsidised transport, and documents in accessible formats. In this study, additional resources such as these were not highlighted as significant barriers to participation. I suspect that this was due to DJA's awareness and consequent attempts to address the additional support needs of people with disabilities. This suspicion was based on the significant time I had already spent at DJA, and my conversations with both board and staff members.

Participatory Structures and Processes



Ife's final condition for participation illustrated the importance of participatory structures and processes, and emphasised how they should not be alienating. Participants made ongoing references to the barriers to participation, relating to structures and processes and, in this way, indicated that the conditions for their participation were not optimal. In particular, participants referred to decision-making processes, the historical practices of DJA, and the structure of the strategic planning process itself that presented barriers to participation.

This condition also encompasses the notion of ableism. For, if participation is to be facilitated for people with disabilities, it requires social structures that do not discriminate against people with disabilities. In the context of this study, both the strategic planning process, and wider processes within DJA, appeared to be exclusionary to people with disabilities.

At DJA, many of the board members were regarded by participants to have only a limited understanding of what their role in the organisation entailed, and that they lacked skills and competence. For this reason it was concluded by several participants that ‘training for the board’ was required to address this issue. This perception was based on an expectation that board members require a certain level of skill and competence, and that it was not ‘right’ to have an ‘illiterate’ person on the board. These perceptions illustrated how processes and structures within DJA have served to exclude people with disabilities. Participants have chosen to identify people with disabilities themselves as the problem, rather than the processes and structures that led people to make these conclusions.

The organisation, in trying to honour and respect people with disabilities by providing opportunities for them to sit as members on the board of management, is therefore serving to undermine its own agenda due to its own institutional and bureaucratic structures, and also the ableist attitudes of its members. As the extract from my reflective journal indicates, people with disabilities have been put into positions of responsibility at DJA, but they have not been adequately supported in their roles. DJA is responding to a set of social rules in relation to what constitutes a board, and the organisation seems to be attempting to align with external expectations as to how to conduct their affairs rather than generate their own social and organisational rules and roles.

Summarising the Applicability of Ife’s Conditions in this Study

In summary, most of the barriers to participation experienced by participants in this study were accounted for in relation to a lack of optimal conditions for participation, as defined by Ife (1995). Using Ife’s conditions as a framework to further analyse the barriers to participation in this study have indicated that for people with disabilities, the conditions that are of most significance are those relating to ‘valuing different forms of participation’, and ‘participatory structures and processes’. This suggests that when conducting participatory action research with people with disabilities particular attention needs to be paid to ensure that different forms of participation are valued and that structures and processes are not alienating.

Ife's conditions did not appear to account for the impact of more individually-located psychological variables, such as self-censorship, emotionality and the relationships between individuals, that were also identified as barriers to participation by participants. This omission may be explained by Ife's professional background that is in the field of social work and community development, rather than psychology. For this reason, Ife does not necessarily deal with the social psychological dimensions of participation (such as the role of the individual, of individual personalities, the relationships between individuals, and the nature of teamwork). Table 4 illustrates how Ife's model may be elaborated in light of the findings from this study. The additional row placed at the bottom of the table emphasises the importance of psychological factors in the context of participation. However, in the context of this study, the themes relating to self-censorship, emotionality and team dynamics did not appear to be specifically relevant to participants with disabilities alone. Rather they were regarded as barriers that appeared to impact upon all participants.

Table 4

Proposed amendment to Ife's (1995) Conditions of Participation and the Corresponding Thematic Barriers

CONDITION OF PARTICIPATION	THEMATIC BARRIER
Degree of importance and level of interest	Individual agendas
Expectation of change i.e. that their participation will make a difference	Historical practices
Valuing different forms of participation	Skills and competence
Enabling participation and support	Resources
Participatory structures and processes	Decision-making processes Historical practices Strategic planning structure
Trust of others and safety	Team dynamics Self-censorship and emotionality

Moving Beyond Barriers

I acknowledge that having primarily considered the barriers to participation in this study, as opposed to the facilitators for example, I am in danger of providing a one-sided, weaknesses-based, perspective that contradicts the values of community psychology. Despite the many challenges to participation highlighted in this study, and for the purposes of revealing a more balanced overview, it is pertinent to briefly outline some of this study's many strengths and contributions.

This study essentially provided participants (both staff and board members) with an opportunity to take part in an organisational planning activity, which resulted in the development of an action plan. Such an activity appeared to surpass previous attempts by the organisation. Moreover, I am unaware of any literature that has used a planning activity, with a small disability advocacy organisation, as a basis for research. Participatory action research has rarely been used in community settings with people with disabilities (Balcazar, Keys, & Suarez-Balcazar, 2001). This is despite the potentially substantial contributions of this form of research for understanding fundamental issues faced by people with disabilities (Balcazar, Keys & Kaplan, In Press). Thus, while the focus of this study may have seemingly gravitated towards a preoccupation with the barriers, some significant lessons and findings have been unearthed in the process.

In this chapter, I have presented an overview of the experiences of participation in the strategic planning process, and at DJA more generally. Both board and staff members experienced several barriers to participation, and these were explored at different levels of analysis. The next chapter examines the experiences of the participation in the context of the wider research process. In so doing, it enables me to reflect upon, and develop, the meanings and barriers to participation that have emerged in the initial discussion presented in this chapter.

CHAPTER 6
FURTHER ANALYSIS AND DISCUSSION

The purpose of this study was to conduct participatory action research with people with disabilities and to examine its value as an empowering research tool. Underpinning this aim was my desire to be commensurate with a particular set of values, and doing participatory action research provided an opportunity to attempt to enact these values in practice. The previous chapter presented an analysis and discussion of the experiences of participation, principally based on the perspective of participants, in the strategic planning process and DJA more broadly. This chapter focuses on the experience of the research process more broadly, particularly from my perspective as the researcher and as a community psychologist.

First of all, I review the purpose of the reflection boxes (interspersed predominantly throughout chapter 4) which present my reflections at particular points in the research process. The reflection boxes constitute part of the initial analysis and focus on methodological issues as they arise. These reflections form the basis of the following issues that are addressed in this chapter:

1) Keeping participants informed;
2) Managing participant feedback;
3) Preliminary discussions with management and gaining legitimacy;
4) Responding to the influence of external requirements;
5) Marrying research with an intervention;
6) Forming a project guidance group;
7) Sharing responsibility for decision-making;
8) Managing my different identities;
9) Developing a research relationship; and
10) Recognising ableism and oppressive structures.

These issues encapsulate some of the challenges that emerged for me, as a community psychologist, whilst conducting participatory action research with people with disabilities. After examining these challenges, with a focus on both the

empowering and disempowering aspects of the research process, I reflect on how to maximise the likelihood that participatory action research will be an empowering research experience for participants.

Reflection Boxes as a Tool for Initial Analysis

My reflections on the research process constituted an ongoing mode of analysis in this study. Due in part to their potential for developing understanding, I decided to present some of these reflections on the research process as 'reflection boxes' interspersed predominantly throughout chapter 4. The boxes included descriptions about what actually happened in the research process, and the tensions that arose for me. In more traditional studies, this may have constituted some of the 'limitations' of the study. However, in this particular study, where the nature of the research process was also the focus of the research, these reflections formed a significant part of the analysis itself and were incorporated as such. Furthermore, rather than just presenting them as unfortunate occurrences at the end of the study, they were transformed into opportunities for learning.

By incorporating the reflection boxes within the body of this thesis, it was my aim to provide a rich and additional perspective to the research story. I also hoped that it would afford the reader an opportunity to gain insight into ongoing decision-making, my observations, topical issues and challenges, and my struggles during the process. They conveyed both a sense of my positive and negative experiences in the process. For example, they indicated at times how I would revel in having such a great opportunity, with a flexible, open-ended agenda, and a chance to work with DJA; and how I was excited about having discussions with people and having the opportunity to share ideas, backgrounds and interests. However, they also revealed that lurking beneath this excitement, warmth, and belief that it was the best way to conduct research, were conflicting feelings of despair, of being out of my depth, and of lacking the skills to do the research justice.

Driving this research was my desire to maximise meaningful opportunities for people with disabilities to engage in community psychology research. There was limited literature available regarding participatory action research with people with

disabilities, and even less literature that divulged the tensions that occurred 'behind the scenes' in such research (Primavera & Brodsky, 2004; Sparkes, 2002). In agreement with Sparkes (2002), I felt that there was great pedagogical potential in revealing my experiences and reflections of these challenges. Being explicit in this way enabled the research process to come alive for the reader, as it conveyed the tensions as they occurred. This was intended to facilitate not only my own understanding and conceptualisation of the experience, but also to convey to the reader the tensions inherent in attempts to be participatory. Thus, as well as potentially offering insight to the reader, for the purposes of taking the work forward (Parker, 2005), it forced me to articulate my own observations and feelings and in this way brought them out into the open. Being part of the report-writing process, it kept the process alive for me too, as the researcher, and minimised the possibility of allowing me to look back on my own experience with rose-tinted glasses.

Reporting on my reflections in this way, therefore, provided a useful tool for the initial analysis, and one that very much complemented the research process. Being underpinned by a postmodern and critical perspective allowed me to embrace this reflective practice as positive and useful, rather than wayward and self-indulgent (as it might have been regarded from a positivist perspective). While the reflection boxes highlighted methodological issues as they arose, in a chronological order, this chapter attempts to consolidate these issues. The ensuing discussion draws on the literature to review and consider the challenges that doing participatory action research with people with disabilities poses for a community psychologist. In this way, it can also offer insight regarding the value of participatory action research as an empowering research tool. In some instances, I use extracts from my reflective journal to illustrate the issues. These are presented as thought bubbles in the text.

Challenges for a Community Psychologist Doing Participatory Action Research with People with Disabilities

The literature indicates that that there is a role for community psychologists as participant conceptualizers and praxis explicators (Elias, 1994). That is, through our capacity to self-reflect and learn how we frame our experiences, we can understand

our role as co-participants in human systems (Smith, 1983). The following chapter explores my role in this research, and illustrates how reflexivity and subjectivity can reveal the tensions and challenges that accompany this way of doing research. In this way, it serves to build understanding towards achieving community psychology's wider goals of social justice and equity. All the challenges that are raised in the following sections impact on the ways in which research can be experienced as both empowering and disempowering, and this is what drives the discussion.

Keeping Participants Informed

Keeping participants informed throughout the process was important for a number of reasons. As well as my believing that it was respectful to participants, it was also meant to reveal that there were no hidden agendas. I felt that it would also serve to generate their interest, commitment, and engagement in the process. This related to Ife's (1995) first condition of participation, where he stated that 'genuine' participation was more likely to occur when people perceive their participation to be of importance and that it is of interest to them. For this reason, I employed several strategies to keep participants informed. For example, by conducting interviews prior to the planning days, it provided the opportunity for the participants and I to discuss the key role of participants in the process, to talk about strategic planning and how it relates to them, and to talk about my intentions for the research. In this way, the interviews also demonstrated to participants that I was interested in them, that their contribution was important, that they had a voice, and that I was keen not to work in colonising ways i.e. not impose my own understanding and assumptions upon theirs. The following comment from one of the staff participants conveys a sense that this was what occurred: *"I guess the whole process has been pretty clear about how people could be involved and what the expectations were" (staff member, follow-up interview).*

However, keeping participants informed was not always straightforward. While the interviews provided the perfect opportunity to relate to participants, on a one-to-one basis, and directly address their concerns, outside of this space it proved to be more challenging. Throughout the process, I distributed information 'updates' to

participants. Early on, this information consisted of preliminary ideas about the strategic planning structure, and planning dates. Towards the middle and end, this information was about the content of the strategic planning discussions, the strategic plan itself, and general information about the research process. However, I found that the delivery and format of the information that they received depended on each participant's role in DJA, and their preferred methods of communication. For example, staff members usually received hard copies on their desks at work, while board members with email accounts received information electronically. I felt that board members without access to email could not participate and be kept informed in the same way. While I made an effort to fax one board member, and made specific arrangements to meet with another, I felt that in particular, these two participants were the least engaged with the process. Whether this was due to these alternative arrangements of communication, I was not able to find out. While, it was my intention at the beginning of the research to be flexible, and use forms of communication that were familiar and preferable to each participant, it did make me question whether this impacted on their level of participation, interest and commitment i.e. that in using different forms of communication, it might have led to different forms of interpersonal engagement between participants and myself, as the researcher.

Thus, in striving to keep participants informed, my efforts may have been perceived as both empowering and disempowering, depending on what information participants received and how it was delivered. It was also possible that the information received was too much and served to overwhelm participants. By having established at the outset what information participants would like to receive and would find useful it may have served to maximise the likelihood that the experience of the process was an empowering one.

Managing Participant Feedback

Keeping participants informed provided a basis from which participants could reflect on the information given to them (e.g. proposal for strategic planning structure, draft strategic action plan etc.) and then feed back into the process. By providing participants with opportunities to feed into and shape the process, it was my intention

to encourage ownership over the process, which would in turn increase levels of interest and involvement. Furthermore, by taking participant comments on board, I not only aimed to demonstrate that their contributions were important and that they were a part of the process, but I also aimed to increase the likelihood that the process was responsive and relevant to participants' needs.

For example, I used the initial interview data to shape the content and nature of the strategic planning days themselves. In my presentation to participants the morning of the first planning day, I fed back a summary of the interview data using their own (anonymous) words (e.g. about what they wanted to achieve from a strategic planning day), and hence the reasoning why the day was structured as it was. On another occasion, in an initial interview, I emphasised to the person that suggested that there should be an external facilitator that it was due to her suggestion that there came to be a facilitator. Whether these strategies achieved a greater sense of involvement and ownership, however, was difficult to assess within the current focus of the study.

Likewise, it was difficult to assess the reason for the minimal response to my ongoing requests for feedback and comments. It could have meant any number of things. For example, that participants were generally happy with the process so far, and that they had no significant contributions to make. It also could have meant that participants were not familiar with this kind of process, and that having the opportunity to really have an impact on a process was quite alien to them. Alternatively, participants could have perceived that it was not safe to say what was on their minds or that their contributions would not be listened to or taken on board. The possibilities were endless. While I think it was important to give participants the opportunity to feed back, it made me question whether simply providing a vehicle through which they could provide feedback was sufficient. This 'vehicle' was something that I had created. Possibly it was not adequate to meet their needs, and not something that they could relate to.

Another perspective on this issue, too, is that my expectations for their level of interest and involvement may have been too high. I asked participants if they would like to edit or make comments about the transcripts of their interviews. Three out of the twelve participants did make comments and expressed some interest at being given the opportunity to read it. To have had three responses under these circumstances, a

few months after the strategic planning process, may reflect an average response rate (if I were to base judgement on the accepted notion that a 30% response rate for postal questionnaires was seen as normal). However, given my previous and extensive contact with participants, I remained a little disappointed.

Low rates of feedback may also be accounted for in terms of one of Ife's (1995) conditions of participation, namely that people must believe that their participation will make an impact, and that it will make a difference. Participants appeared to be quite excited at the outset, and talked about how a strategic plan was exactly what DJA needed. However, in the latter stages when some participants perceived that the strategic plan was not necessarily going to lead to the changes that they had anticipated, it may have negatively impacted on their level of participation.

In retrospect of these experiences, it made me ponder alternative ways in which I could have addressed this issue of feeding back to participants from the beginning. I wondered about how it might have been useful to establish a set of group strategies; to have been explicit from the start, and asked how participants would have liked to feed back their comments. A process whereby it was established and known to all participants how people's comments would be delivered, managed, and acted upon. However, such a process also conflicted with my desires of not wanting to overly influence or control the process. While it would have been good to establish some 'ground rules' and a commitment from individuals to ensure that they would be involved in particular ways, I also did not want to impose any structures that might serve to disempower them.

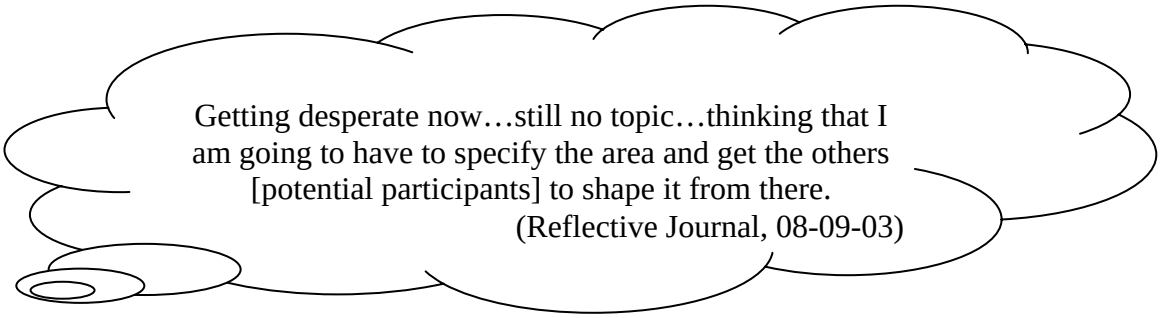
Preliminary Discussions with Management and Gaining Legitimacy

According to Archer and Whitaker (1994), prior to any research partnership taking place, an agreement has to be reached between the university-based researchers and the upper management in the service-providing organisation that a piece of research will be carried out. They discuss what issues are currently pressing, and together negotiate a suitable general topic for research. The reasoning behind such a process is that for the work to be successfully accomplished, legitimisation must come from the top of the organisation (Archer & Whitaker, 1994).

In this study, I made initial contact with the non-disabled executive officer of DJA, followed by the board of management of DJA. The fact that the board was comprised of people with disabilities meant that this negotiation process was commensurate with my original aims for carrying out such research. Specifically, that it should be controlled and managed by people with disabilities. Over a period of six months DJA and I discussed current issues, and generated a list of six topics between us. In this way, on the surface it appeared that 'legitimisation' did indeed come from the 'top' and, due to all participants being involved in these preliminary discussions, that those who participated also legitimised it.

However, the organisational structure of DJA affords different individuals within the organisation more decision-making power, on account of their positions within the organisation. For example, the executive officer has a lot more decision-making responsibility. In this way, I questioned whether I was indeed being commensurate with my original aims. For, while I was indeed attempting to conduct participatory action research, and while people with disabilities were present in the process, in reality most of the decision-making was actually done by non-disabled people (the executive officer and I). And it is the executive officer and I who appeared to have disproportionate decision-making responsibility afforded to us by account of our positions within the organisation and the research process, and also possibly due to our non-disabled status. So the board, while they may appear to be at the top of the organisational hierarchy do not appear to have the associated decision-making responsibility that goes with it. In this way, I could not help but wonder whether the study actually constituted participatory action research with 'DJA', as opposed to research with 'people with disabilities'. In so doing, it highlights some of the tensions and debates around doing research in the disability field, because it tends to get overrun by non-disabled people (Branfield, 1999).

Responding to the Influence of External Requirements



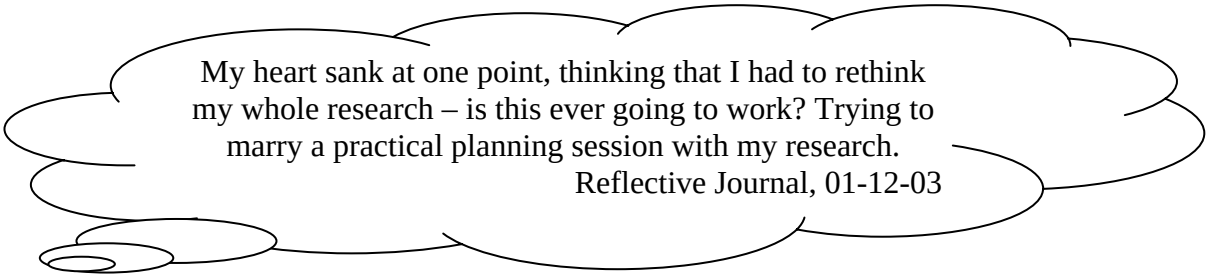
While I could claim that the final topic was one that was identified through a lengthy participatory process that involved people with disabilities, I could not say the same for the final decision. I presented a list of possible topics to the board, with a view to making a final decision with them, and yet still no consensus was reached. Six months had passed and the reality of my timelines in which I was required to collect data, analyse it and write it up, was becoming ever more apparent. I had to submit an ethics application, and for this reason, I also made the final decision about the topic. This experience highlighted the tensions between having to adhere to the restraints of conducting a university-based piece of research, and also of wanting to remain true to my initial desire of doing research that was accountable and meaningful to people with disabilities. This was the first point at which I realised that some of my hopes for the research were going to be compromised.

It was also at this stage that I began to understand what Fawcett et al. (1994) had described as the challenge of preserving sufficient benefits for researchers. I certainly had my own favourite in the list of six possible topics, and was aware that since I was about to invest a substantial amount of time involved in this research, ideally it should be something that was also of interest to me too. In this way, I felt that the final choice was in some way a compromise, in that while it would not have been my own personal choice, it certainly was still of some interest to me.

Preferably, I would have liked to examine the effectiveness of the organisation's structure, and to investigate DJA's claim to be consumer-led and that it was 'managed' by people with disabilities. For it was due to my expectation that people with disabilities were in 'control' that I chose to approach DJA in the first place. Ongoing comments made by many staff members about the organisation's

structure only served to fuel my interest in this topic, and it intrigued me that only the staff members emphasised the need to review the organisation's structure, not the board itself.

Marrying Research with an Intervention



Archer and Whitaker (1994) noted that for any general topic that was suggested by an organisation, it had to also be perceived as potentially researchable by the researcher. However, without prior experience of conducting participatory action research, I was not fully aware of how 'researchable' the topic of strategic planning was. It was only later that I realised that in choosing to go with strategic planning it did not fit with my initial conception of what participatory action research entailed. This is because my understanding at the time was that participatory action research involved participants in all stages of the process from developing the research aims through to analysing the data and disseminating the results. In the context of this study, while participants were involved in identifying the research topic, and the actual planning process itself, they had only limited involvement in the research activities outside of the strategic planning. Figure 4 (in chapter 5) depicts how the strategic planning process was enveloped by, and an integral part of, the research process. In this way, it illustrates which activities occurred outside of the strategic planning process (i.e. that were unique to the research process itself) and which activities participants had only limited involvement in, such as analysing the data.

This highlighted one of my earliest tensions with the research. I wanted to be involved with DJA in a way that was meaningful and useful to them. I believed that this would be possible through conducting a strategic planning process. However, whilst embarking on this 'strategic planning' process with DJA, I felt that I was

simultaneously embarking on the ‘research’ process alone. My discomfort resided in my realisation that in being unable to engage DJA in all the research-related activities of the process, this study could be criticised by some as just another piece of research about people with disabilities conducted by a non-disabled researcher.

As the research process proceeded, I began to realise how participatory action research can take on many forms, with participants having different degrees of involvement. So, whilst participants might not be involved in all aspects of the research, and have full control over decision-making, it did not necessarily deny the worth of the process or their participation. There is a tendency when talking about participation to assume that there is an ‘ideal’ form, and a hierarchy whereby some forms are better than others, and this is reinforced by models such as Arnstein’s (1969) ladder of participation. However, in accepting all forms of participation, and acknowledging the diverse ways in which participation can manifest, it may offer more scope for developing empowering research practices. Fajerman and Treseder’s (2000) model of user involvement, which moves away from a hierarchical design, supports this notion.

Forming a Project Guidance Group

In anticipation of the large number of day-to-day decisions that would need to be made for the strategic planning to go ahead, I decided to set up a ‘project guidance group’. I had assumed that it was impractical for everyone to be consulted on every decision that was made, and that they would not want to be. I had further assumed that in setting up such a group, and taking minutes, the decisions that were made would be held more accountable than if I were to have made them alone. At the time, I had felt that the obvious choice for membership of this group was the executive officer and the chair of the board, particularly because they were the most influential people in the organisation, and were most likely to be able to ensure that things actually got done. They were also the people that originally had the idea for conducting a strategic plan.

In retrospect, I think that membership in this group should have been put to the vote, if it was to have been a meaningful, empowering, and equitable process. Some participants noted in their interviews, that these layers of management created barriers

for active participation of other member in the organisation. In particular, this related to how it allowed people to justify certain actions and decision-making. Furthermore, by assuming that the executive officer and the chair of the board would be involved, I was conforming to working within already established power differentials. In this way, I was condoning and perpetuating a decision-making process that was not necessarily democratic, and those people who were already in positions of authority arguably controlled the process. In this way, I engaged in what Ife (1995) called the elite power of the organisation. Thus, while the project guidance group may have reduced the time allocated to decision-making, it also served to maintain hierarchical structures and disproportionate influence of decision-making to certain individuals

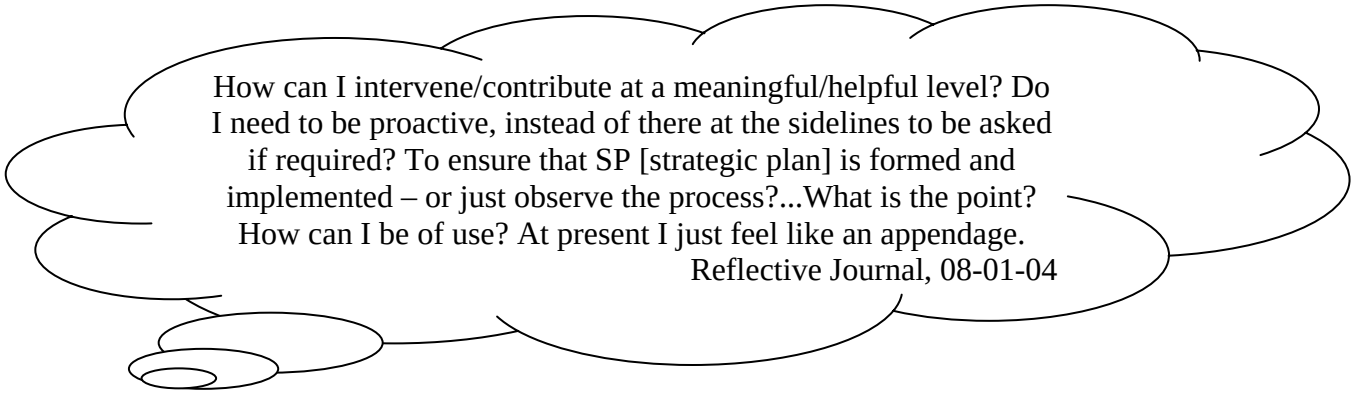
Sharing Responsibility for Decision-Making

I embarked upon the research with a desire to take on a 'facilitating' role. By this I meant that while I would co-ordinate the process, and act as a mediator (Balcazar et al., 2004), I was expecting that all the decisions about the process and how it would be structured would be made by participants. Perhaps this was a little idealistic and unrealistic. For, on later reflection, I realised that participatory action research is not about handing over responsibility for decision-making to participants. Rather, it's more about equalising power relations, working 'in collaboration with', sharing decision-making, and making agendas as explicit as possible.

Hart et al. (1997) noted that in their research they saw a 'reconsolidation' of professional power, specifically that individuals were making decisions on behalf of the organisation in order for decision-making to be seen to be done. Similarly, I felt that there were times that I was making decisions on behalf of participants in the strategic planning process that I didn't necessarily want or feel I should be making (e.g. what and how items should be recorded on the draft strategic action plan). I also felt, as also described by Hart et al. (1997), that this was primarily due to an administrative necessity to get the job done in the limited time available. Hence, the necessity to accomplish my own aims, as set out by the external constraints of a particular set of university requirements, had begun to take priority over my desire for participants to be involved in decision-making. In retrospect, if I were to have asked

participants from the outset if they were happy for me to make certain decisions (e.g. regarding the structure of process, writing up etc.) it may have served to increase the likelihood of it being an empowering experience.

Managing my Different Identities



As well as being a co-facilitator and coordinator in the planning process, I was also a researcher, a student on placement, and later, an employee of DJA[7]. I believe that these different roles and identities I assumed during the course of the process significantly influenced the research process and level of participation amongst participants. For example, perceiving me to be a student may have encouraged participants to speak up and take more control, as they may not have regarded me as such an 'expert' in the field and therefore felt less intimidated than if I had of been a fully qualified academic or practitioner. As a student, I may also have been pitied, for being unpaid. Alternatively, in perceiving me to be a student, participants may not have taken me so seriously and doubted my capabilities and therefore the importance of the process. In contrast, participants may have perceived me to be a member of an elite group and institution, and therefore as a privileged person.

In some ways, I had felt that I could use my student hat as a way to absolve myself of any responsibility for the research process, and to encourage others to take more control. Lessening my burden of responsibility may simultaneously have burdened participants' and served to disempower them, as suggested by Tomlinson

[7] This was in the form of part-time employment that commenced in April 2004, almost immediately after the strategic planning days.

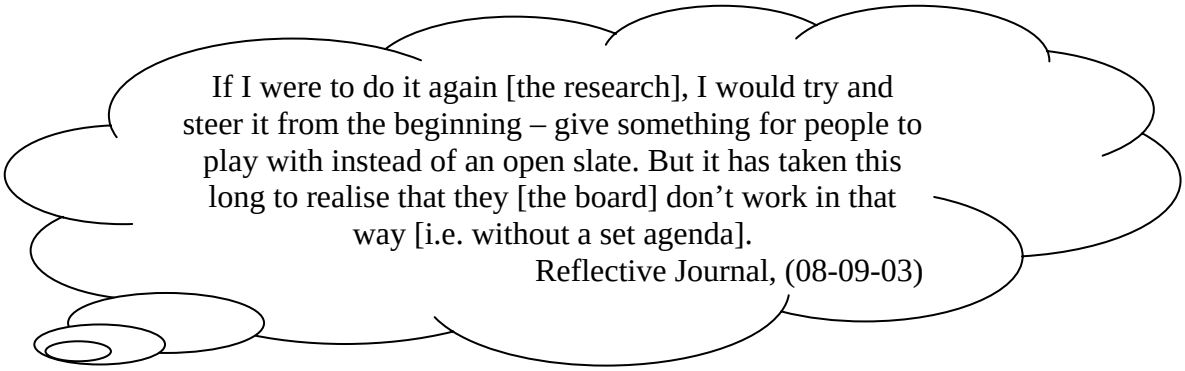
and Swartz (2002). However, there were also times when I used my student status to make decisions without consulting participants.

The overall response from staff participating in the strategic planning process was overwhelmingly positive. There was a lot of interest and eagerness for the strategic planning to begin. Participants appeared to be very excited and had all sorts of expectations, in light of previous poor experiences where it hadn't been done well. I welcomed this reaction because I was aware that a positive attitude was more likely to foster active engagement and commitment, and therefore lead to a successful outcome. However, it simultaneously left me with a sense of pressure to perform. This was related to a fear that it would fail like the other planning processes before it, and that I, being the researcher, would be responsible. This appeared to contradict my previous sense that as a student, I was absolved of some sense of responsibility for the course and content of the planning.

It was interesting to hear from one participant that my status as an employee had impacted on how people responded to me. He noted that as an employee, I was now considered more of an insider, and with that, I was now perceived to be at the 'mercy' of the organisation's hierarchical forces. Specifically, this meant that my integrity and loyalty to other participants might have been compromised due to becoming answerable to the executive officer as were all the other staff participants.

As Lennie et al. (2003) discussed in their research I feel that, due to these many roles and identities, I was taking part in many different discourses throughout the process which often contradicted each other. I was trying to be all things to all people. For example, in one instance, in my researcher as 'expert' role, I would address the group in a relatively formal way and present a summary of the findings from the interviews. In another instance, I would be receiving supervision from the executive officer, in my role as a student on placement, who was also a participant in the planning process. I think that these conflicting identities were partly the reason for why I appeared to be caught in a dilemma about how to act in the process (as indicated by my reflection in the bubble) and that at times I felt like an 'appendage'.

Developing a Research Relationship



In nearly all my initial addresses to the board, I reminded them about what my aims were for the research, and what I wanted my role to be. I emphasised that in having a flexible agenda, my aim was for them to identify what was of interest to them. I explained that in this way the research might be more meaningful than if I was to have come in and dictated what I wanted to research.

This encouraged some people to raise their own topics of interest. These topics included strategic planning, an evaluation, the impact of new legislation on the functioning of DJA, and the link between systemic and individual advocacy. Everyone present expressed at least one thing that they were interested in, or at least supported someone else's contribution. In some ways I felt that this was a very positive process. It allowed everyone to speak and to be heard. It allowed us to develop a working relationship. However, it also made me question to what extent I might be raising false hopes.

My reflection, in the bubble, illustrates two important points. The first relates to participants' expectations as to my role, and their level of knowledge, comfort and familiarity with the way in which I proposed to work. The second is that I believe that there was a certain culture within the organisation that determined how decisions were made, and this actually presented a barrier towards working in the way that I had envisaged. These two points are inter-related.

This first point relates to what Tomlinson and Swartz (2002) described as psychologists needing to be aware of the responsibility that their professional knowledge brings, and the problematic nature of claiming to have no agenda. On entering DJA, and attempting to work from a 'blank' slate, I was also assuming that

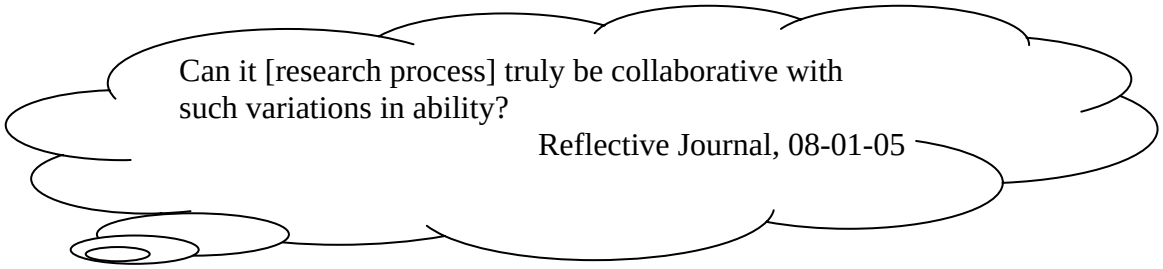
participants had a level of knowledge, comfort and familiarity about working in this particular way. However, I felt that participants were not prepared for, or given enough support to, work in such a way. This approach might well have served to overwhelm and disempower them, as Tomlinson and Swartz (2002) cautioned. Furthermore, I don't think that I was sufficiently skilled in facilitating and managing their responses. For example, when participants did proffer ideas and topics of interest, I felt that if I were better able to encapsulate those ideas and feed them back in a way in which everyone present could understand and work with, it might have been a more productive and empowering process for all of us. Participatory action research assumes a certain level of skill in facilitation and coordination, and for this reason I believe that facilitation emerged as one of the most critical aspects for promoting meaningful and equitable participation.

This issue relates to the second point, that of organisational culture. Due to historical reasons, practices and procedures are done in certain ways at DJA, and as an outsider it can be very difficult to introduce new ways of working and doing things. As was discussed in the previous chapter, participants identified historical organisational practices as presenting barriers to participation, and my own experience at DJA concurred with this view. However, despite acknowledging that there may be inefficient procedures in effect (e.g. lack of clarity about procedures, ad hoc decision-making etc.), they remain extremely difficult to change. Furthermore, in some cases, it is not clear in whose interests it is that they should change. For instance, at many points in my attempts to address the board and make a decision about which topic to choose, people got up to make coffee or leave the room for a cigarette. While I respected that this was the way things were done at DJA, it did not make achieving my own goals very easy, whereby I regarded it as important that everybody was aware of the whole content of discussion. However, I felt that it was inappropriate to enforce a situation whereby people had to remain in the room at all times.

The tension that arose between wanting to respect the ways of the organisation (because they were probably there for good reason) and yet also recognising the inefficiency of certain procedures emerged continuously throughout the process. I think this emerged as a key issue of note for researchers who are working towards social change, and yet who also value building partnerships. It highlighted critical

learning for me in undertaking this research, that of allowing myself permission to apply and acknowledge my own skills and knowledge. Just as I regard each participant to have their own valuable set of skills and knowledge. I think that I do have a certain amount of responsibility, which varies according to which role I am playing out. When I am able to accept and work with these differences, it may become easier for me to be involved and part of a more effective and empowering research process.

Recognising Ableism and Oppressive Structures



Being new to the organisation, and a little idealistic, I was probably expecting people to respond to me, and the opportunity that had been presented to them, in a certain way. I assumed that people would be interested and keen to be actively involved, that they would shout out their ideas and rise to the challenge. In this way we would identify many potential areas for research, and happily come to a consensus about which option to pursue. In contrast to my own expectations, I often found there to be a general ambience of disinterest, lack of engagement and motivation particularly amongst the board members. It was very disconcerting, and often led me to question what the point of it all was.

Perhaps my perception of the board's apathy was due largely to my own high expectations of the level of energy and enthusiasm that people would bring. Having attended many board meetings since, the energy levels and interactions have always been similar. I found a comment from one of the participant's insightful and, at the time, it encouraged me to keep going. She emphasised that while progress within board meetings was excruciatingly slow, and that there were often many blank expressions, occasionally there might be a hint of understanding, or a sparkle of

interest. This participant noted that when she was a witness to such moments, it was enough to keep her going.

While at the time I found this comment to be reassuring, I realised that underlying the comment, and my connection with it, were ableist attitudes. This participant and I had resorted to making assumptions about how board members should act and behave. This is illustrative of victim blaming i.e. blaming people themselves for problems as opposed to the social structures in which they reside (Ryan, 1971). In the context of this study, this participant and I were directing our frustrations onto, and 'blaming', people with disabilities for their disinterest, rather than 'blaming' the inappropriateness, or lack of relevance of the activity itself.

There have been many points throughout the research process where I have felt that it would have been much more easy and efficient if I had not chosen to do participatory action research. In this way, I agreed with Menzies (1996) when he stated that the most overwhelming challenge inherent in attempts to encourage participation is that other people's involvement, while it generates limitless aspirations, can also generate limitless problems (Menzies, 1996). Indeed, the effort that it required to maximise opportunities for involvement certainly made me consider the positive aspects of hierarchy, especially the efficiency in terms of time saved. However, what I failed to realise was how a hierarchy may actually create the conditions that make it difficult for group decision-making in the first place. By seeing how I led myself to consider the benefits of hierarchy, it becomes easier to fathom how the ongoing cycle of oppression continues.

I feel almost ashamed of thinking some of the thoughts that I have (for an example see the reflection bubble). For, it is disappointing to learn how unknowingly ableist and discriminatory I was being by having such a thought. On the positive side, however, at least I can now identify and acknowledge that that is what they are. It has allowed me to understand how deeply entrenched ableist attitudes are, and has provided insight into the mechanisms that maintain power and oppression. I suppose that it is not until we can get to this point that we can ever truly hope to work in empowering ways.

There was certainly a tension that emerged for me; that in being so concerned about the presence and perpetuation of ableism, and the need to be politically correct,

it may have served to immobilise me and prevent me from achieving certain research goals. This experience may have implications for others working in the disability field and, in particular, those people who advocate for a social model of disability. There is a danger that reinforcing the notion of ableism may unintentionally serve to hinder progress, or worse still, deter others from working in the field. Political correctness has emerged as a strategy to address discrimination, particularly with issues of race. However, in the context of race, political correctness has often only served to hinder attempts to address discrimination by concealing what is really going on. Exceptional care may need to be taken to ensure that the notion of ableism can be discussed freely and openly. Specifically, that people do not feel afraid about causing offence, are open about not necessarily understanding all the issues, and willing to learn how to think and behave in non-ableist ways. It is clear that maintaining ongoing critical reflection, and awareness of our own subjectivities (Parker, 2005), provides one way to reduce the likelihood that ableism will prevail.

Overview of the Challenges

Decision-making processes were clearly an integral and challenging part of this participatory action research study. This is probably not surprising in the light of Arnstein's (1969) ladder of participation, where she asserted that participation is about the degree to which people are involved in, and exert control over, decision-making. However, Arnstein also emphasised that the more control people have over decision-making then the more participatory it is. At the outset of this study, I challenged this view because I believed that a process can be participatory even if participants are not making all the decisions. Of course, participants must initially be given the opportunity to choose in which way they want to participate and how much decision-making power and responsibility they take on. If they have these opportunities then this is when it has the potential to be empowering.

Providing opportunities for people to participate in this study raised many challenges for me, and certainly, I feel that there were several ways in which I could have maximised the possibility for more empowering outcomes. For example, it was evident how by establishing some guidelines with DJA at the beginning of the process

it would have served to build a framework for the research process. These guidelines would have addressed items such as what kind of information would be useful for participants to receive, how they would like to receive it and have their feedback managed, and what types of decisions need to be made and by whom.

If possible, it would also have been preferable for participants to be involved and engaged in a process of critical reflection themselves. In particular, to explore how our experiences are intricately related to the roles and positions that we assume; and to explore that what, how, and why we do the things that we do are shaped by the social, cultural, ideological spheres that we occupy. This is particularly in relation to our roles and positions within the organisation and the research process. For example, for myself as a researcher in this study, it provided me with many opportunities to make decisions about the shape of the research. Likewise, the executive officer, by account of her position was also afforded certain opportunities, as well as constraints. In reflecting upon the disproportionate influence that certain people had over decision-making, it may have enabled us to minimise the experience of exclusion and disempowerment. This provides a clear justification for further research in this area, in particular, using participatory action research to enable participants to delve in, and broaden their own knowledge and awareness in the process.

Thus, while it was not possible to eliminate the disempowering aspects of this participatory action research study, and ensure that it was an entirely empowering experience, there were certainly ways to maximise the likelihood. Ultimately, of course, it is not for researchers and practitioners to say whether the process is empowering. Rather, that is a role for the participants. And even then, given the multi-faceted and complex nature of the phenomenon of ‘empowerment’, we might find that there are many different and contradictory experiences.

CHAPTER 7
SUMMARY AND CONCLUSION

'Nothing about us without us' is a common mantra within the disability field. It was from this premise that I sought to embrace a participatory action approach to conducting research with people with disabilities. For in doing so, it not only attempted to address the rights of people with disabilities to be involved in directing and shaping their own research but, at the same time, it hoped to increase the likelihood that it would be relevant, effective and empowering.

This study drew on the model of the community psychologist as a participant conceptualiser and praxis explicator (Elias, 1994), and used it as a methodological framework. This framework provided an anchor from which to conduct the principles of participatory action research. By simultaneously engaging in critical reflexive practice, it enabled me not just to 'do' community psychology, but also to investigate how community psychology is done. Hence, critical reflexivity was employed as a way to enact the participant conceptualiser and praxis explicator role, and allowed me to theorise and make visible the institutional structures and processes that support inequities in power. Through embracing critical reflexivity as a resource (Parker, 2005) it has provided an opportunity to develop a deeper understanding of how to more effectively pursue a social justice agenda.

This study highlights the multi-faceted nature of transformative research and builds upon current literature to suggest that in attempts to do research and engage people with disabilities in empowering ways it can also serve to disempower. There are many challenges for community psychologists in trying to address these often contradictory outcomes.

The findings from this study indicate that the key to addressing the challenges of maximising empowering outcomes in research with people with disabilities lies in the ability, of participants and researchers alike, to recognise and confront ableism and other oppressive structures and practices. In particular, there is a need to identify our own assumptions and attitudes, and acknowledge how they impact on our practice. Ongoing critical reflexivity, in this study, enabled me to identify and explore some of the challenges as they emerged. It also developed my understanding of how deeply

entrenched ableist attitudes serve to reinforce the tendency to victimise people with disabilities, hindering our attempts to do research in empowering ways. Until we recognise this, community psychology research and practice may fail to be meaningful and empowering for people with disabilities.

Our quest to do participatory action research in the 'right' way (Reason, 1994), and the preoccupation with searching for the elusive 'ideal' form of participation, is often based on non-disabled assumptions about the best ways to participate. This can lead to exclusionary processes. It also diverts attention away from, what I would consider, the more important aspect of participation, that is, of having a choice to participate. We need to work towards valuing and acknowledging the many different faces of participation and accept that while there may be a 'right' way, that this 'right' way must not be based on non-disabled standards. We can do this by lessening the emphasis on enabling participants to maximise their 'level' of participation, and emphasising the need for them to be informed and have opportunities to choose.

Participatory action research is a 'messy' activity (Primavera & Brodsky, 2004). For as well as trying to conduct research, we also try to learn from it and adapt the research process as it is going forward. In this study, this messiness was compounded by the fact that the primary aim of the research was to investigate the process of the research itself. Through embracing this messiness, and sharing our experiences of it, it can offer valuable insight for other community psychologists towards establishing standards of best practice.

While we, as community psychologists, cannot ensure that our research practices will be empowering, through critical reflection and less of an emphasis on how to do things in ways based on non-disabled assumptions, we may be more likely to succeed. And, as Balcazar et al. (2004) stated, while we cannot ensure that our practices will promote social change, and that change will be for the better, we still have a responsibility to try.

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APPENDIX A

INITIAL EMAIL CORRESPONDENCE WITH DJA

----- Original Message -----
From: Harriet Radermacher
To: info@justadvocacy.com
Sent: Saturday, March 22, 2003 6:49 PM
Subject: introducing myself...

To Whom It May Concern

I am writing to you for a number of reasons. Firstly to introduce myself, secondly to find out some more information about your organisation and the services you provide, and thirdly to find out if you might be interested in doing some research together.

I am currently doing my masters in community psychology at Victoria University. Community psychology is a relatively new discipline, and it is often associated with the more traditional views of psychological practice. However, there are many differences. To sum up briefly, community psychology is based on a set of values promoting diversity, equality and justice. Some of the roles of a community psychologist include liaising and networking with agencies, program evaluation, case management, counselling, and facilitating support groups. Community psychologists aim to apply their skills for the well-being of the community not just the individual. Furthermore they recognise the wealth and value of personal knowledge and experience within a community and focus on strengths not weaknesses. I hope this gives you some idea of the way in which we work.

I found out about your organisation through the Community Referral Directory. It particularly caught my attention because you are a consumer-managed group, an area that I have been interested in for some time. The kind of research I would be interested in doing would be very much dependent on what your members considered to be of importance, and thus would thus involve a certain amount of individual and group discussion.

If you would like any further information about myself or any of the above please feel free to ask. I look forward to hearing from you and hope to meet in the future.

Kind regards
Harriet Radermacher

From: "Gillian Meldrum"
To: "Harriet Radermacher"
Subject: Re: introducing myself...
Date: Mon, 24 Mar 2003 09:09:12 +1100

Dear Harriet,
Myself and the staff and committee at DJA would be interested in talking to you further about doing some research with us. we are a small community based organisation who works with people with high support needs. There are many areas of research that we would like to explore, but don't have the money or time.
I am also interested in the course.
Call me on 9416 3488
Regards
Gillian Meldrum
Executive Officer

APPENDIX B
LETTER OF INVITATION FROM DJA TO ACCOMPANY ETHICS APPLICATION

FAO: Victoria University of Technology
Human Research Ethics Committee

To Whom It May Concern

Re: Invitation to conduct research

Disability Justice Advocacy (DJA) is a consumer-led organisation that provides advocacy to people with physical disabilities. It was formed 12 years ago as a result of a collective realisation that people with high support needs did not have an opportunity to speak up about the services that they depended on. DJA is funded by the Federal Government and currently consists of up to 200 members. DJA is governed by a board, which employs 3 people to provide individual advocacy and manage the organisation on a day-to-day basis.

Harriet Radermacher has been informally visiting DJA since April 2003. During this time she has attended board meetings and met with both members and advocates, gaining an understanding about DJA as an organisation and what it does.

We formally invite her to conduct some research based here at DJA. I understand that this may involve exploring the archives, carrying out interviews, and running focus groups on the premises. The exact location of which will be dependent on what is most convenient for the participants and the researcher. I allow Harriet access to approach both members and workers at DJA to take part in the research and know that, in addition, participants will be required to give their individual consent.

If you require any further information please do not hesitate to contact me.

Yours truly

Gillian Meldrum
Executive Officer

APPENDIX C
MINUTES OF PROJECT GUIDANCE GROUP MEETING

Disability Justice Advocacy Inc

Project Control Group for Strategic Planning

Minutes for 1st meeting held Wednesday 28th January 2004

Present:	Sue Whiting Gillian Meldrum Harriet Radermacher

Topics discussed:-

Purpose of Group	HR outlined the purpose of the group. HR acknowledged that each member present has valuable knowledge and expertise, each acting as representatives: SW for the board members, GM for the staff, and HR for the university. This meeting, and any ongoing meetings, are to provide the forum for problem solving and raising questions regarding any aspect of the process.
Introduction to Research	HR outlined the motivation behind wanting to do some research with DJA. She explained how the research process may appear to be quite unlike what is understood about traditional research. The terms 'partnership', 'collaboration', 'participation' were explained as the guiding principles for the research.
Time line	The original timeline was reviewed and revised (see attached). The group decided that March would be a good time to set the planning day.
External facilitation	Getting an external facilitator was approved by the group. GM to contact Dymphna/Jill Lane about the possibility of being able to facilitate the planning day with regards to cost and availability. Need to enquire/consult with facilitator about their knowledge/familiarity with the strategic planning process.
VCOSS training	Discussed the value of a training day run by VCOSS for all board members to attend. This was unlikely to happen until

	March but was agreed that it was not essential for the strategic planning process.
Reviewing the archives	
	HR discussed reviewing the archives and questioned what documents would be useful and how to access them. GM stated that HC would assist with accessing the computer directory. The group agreed that HR would summarise the outcome of the last strategic planning meeting. GM queried how the process would ensure that all participants were informed about their choices.
Individual sessions	Discussed the value of carrying out individual sessions with all participants to ensure each participant has a voice in the process. This may enable some participants who are less able/more inhibited in a group environment to voice their opinions/understand the purpose of the research.
Board meeting	Decided to set aside one hour of the board meeting to introduce the research to all present. This would include an introduction by HR, a summary of the previous strategic planning meeting, and a report by SW on the progress of DJA since its conception. A timeline and expectations for the strategic plan will also be discussed.
Strategic planning content	
	70% of DJA's workload is individual advocacy. Many aspects (such as forms, process, privacy, confidentiality) have the potential to be addressed in the strategic review. This includes the 'why', 'how', 'who with' and 'when'. HR commented on the massive scope of issues to be addressed and queried how we were going to arrive at a focus.
Ongoing communication	
	The group agreed that email was the favourable form of communication. Any ongoing developments and queries are to be raised here.
Next Meeting	Board meeting Wednesday 11th February.

APPENDIX D
INFORMATION FOR PARTICIPANTS ON DEVELOPING A STRATEGIC PLAN

Developing a Strategic Plan

Agenda

Wednesday 11th February 2004

1. What is strategic planning?

Strategic planning has been defined as the process by which an organisation creates a vision of its future and develops the necessary structure, resources, procedures and operations to achieve that future.

2. Why have a strategic plan?

- to set and identify annual priorities
- to make achievable and attainable goals and objectives

for example..

Objective/Action Statement	Resources (existing and required)	Methods/Tasks required (by whom)	Timeline
To increase the public profile of DJA	Directory of services, advocates knowledge of service providers, allocation of budget	Post pamphlets/ newsletters to new and old service providers and invite them to AGM	To be completed with mailing of next newsletter

3. So what is the research?

- introduction to research
- focus on participation and collaboration
- everyone has valuable experience and expertise

4. What is the aim of the research?

- to develop a strategic plan together
- to reflect on what it was like to be involved in the process

5. What does it involve?

- individual contact with Harriet to highlight your priorities/ask questions
- attend strategic planning sessions on March 25th and March 31st)
- follow up contact with Harriet to talk about your feelings about being involved in the process

6. Who does it involve?

- you

7. Where do we start?

- establish a clarity of purpose
- need to build on previous findings/experience (eg last strategic planning meeting/ action plan from self-assessment)

DJA mission statement

> *To provide quality advocacy to people with support needs, who are in greater need, in order to protect and advance their well being, rights, and interests both individually and collectively*

8. What do you want to achieve through developing a strategic plan?

Who to contact?

There is a Project Guidance Group comprising Sue Whiting, Gillian Meldrum, Harriet Radermacher

- to manage/oversee process
- to address any issues/problems that arise

If you have any ideas, questions or comments please feel free to contact Harriet, Gillian, or Sue.

Harriet's contact details:- harrietrad@hotmail.com
0421 441 427 / 03 9419 2292

APPENDIX E
LETTER OF INTRODUCTION TO PARTICIPANTS TO RESEARCH AND STRATEGIC PLANNING

10 March 2004

Introduction to participants

Over the last few months it has become apparent that many of you feel that DJA needs a strategic plan. As a key person involved with DJA, your contribution will be invaluable towards making this an effective process that will impact on the future of DJA.

The strategic planning dates are set for:-

Thursday 25th March, 11am – 2pm

Wednesday 31st March, 11am – 2pm

Strategic planning can be a lengthy process. Therefore before we go ahead it would be helpful to get some idea as to what you, as individuals, hope to achieve as a result of it. For example, this may be in the form of a plan of priority actions, a review of DJA's profile and whether it needs to change, or whether DJA requires a whole new way of working.

As many of you know, this strategic planning process is also a part of my university research. This means that as well as assisting with the process I am also interested in finding out about your experiences of being involved. For example, whether you feel that your opinion is valued by others.

Thus, as 'participants' in the research process, I will be contacting you before the planning dates to organise a time to explain what is involved and to ask you a few questions. It will also be an opportunity for you to ask questions and shape the nature of the research yourselves. This will take around 30 minutes. As part of this research I will also be asking for your consent to participate.

I look forward to working with you all in what I hope will be both beneficial to you and to DJA!

Kind regards

Harriet Radermacher

harrietrad@hotmail.com

0421 441 427 / 03 9419 2292

APPENDIX F
REVISED INITIAL INTERVIEW SCHEDULE

Introductory Interview Schedule

Welcome participant
Introduce myself
Explain background to becoming involved with DJA
Explain my role as assisting in strategic plan as part of my research
Explain notion of consent/permission, that it is voluntary, what will happen to data, confidentiality, anonymity
Explain need to record session and start recording

Strategic plan

Need to set agenda for strategic plan and what is said here will affect what is discussed at the planning day.

3 domains of questioning:

1. Expectations for strategic plan

- What do you hope to achieve by having a strategic plan for DJA? What do you hope the process will achieve?

  (eg. more direction, more unity/solidarity within DJA, better teamwork, an action plan for the next x years, a more accurate vision/mission statement/principles)

2. Views on current DJA performance

- How well do you think that DJA meets its current objectives?
- What things do you think are good about DJA?
- What things do you think are bad about DJA?

  (eg. Individual advocacy, systemic projects, team work, target group, organisational structure, resources, staff, board, networks, profile)

3. Future direction of DJA

- In what way do you want to see DJA change?
- What do you want for DJA?
- Where do you want DJA to go in the future?
- Where do you want to invest resources?

  (eg. Individual advocacy, systemic projects, team work, target group, organisational structure, resources, staff, board, networks, profile)

- Any other comments about the strategic plan?

Process

3 domains of questioning:

1. Role in organisation

- What do you see your role as a board/staff member as being?
- Why are you here?
- What is it that drives you to turn up every time?
- How are you involved?
- Is it meaningful to you? In what way?

2. Barriers

- What kinds of things stand in the way of you being able to say what you think/feel?

  (eg. not going to be taken seriously, people don't understand, don't follow what is going on, feel stupid, said too much already, feel embarrassed, it is inappropriate, feel scared, not enough time, too much effort)

- Have there been times when you have felt inhibited to speak? Why?
- Have there been times when you have felt lost and have not understood what has been going on/talked about? In what way?

3. Impact and value

- In what way do you have an impact on service delivery?
- In what way do you have an influence over decision-making?
- In what ways have you felt that you are valued in DJA?
- In what ways have you felt that you are not valued in DJA?

APPENDIX G
INITIAL INTERVIEW INFORMATION SHEET

INFORMATION FOR PARTICIPANTS

We would like to invite you to be a part of a study that aims to develop a strategic plan for Disability Justice Advocacy (DJA).

Participation in the research involves being interviewed for about an hour in a location convenient for both you and the researcher. The interview will focus on your expectations of the strategic plan, and your experiences of being a part of DJA. Interviews will be audio taped with your consent, but all information will be kept confidential.

Two strategic planning days will then take place at the end of March, which will incorporate what you have said in the first interview. A shared vision for DJA is expected to emerge, which will contribute to its ongoing success in providing advocacy to people with high support needs. Follow-up interviews will also be conducted to explore how you felt about being involved in the planning process.

While the researchers cannot ensure anonymity within such a small group, you will have the opportunity to discuss how we can make the research process safe for you. Should you consent to participate, you may stop the interview at any time, and will be invited to review and delete any information recorded. You may also ask questions at any time during the research process and raise any concerns you may have.

The interviews will be potentially sensitive, particularly in terms of your ongoing relationships at DJA. All efforts will be made to keep information confidential if you so desire, and you are welcome to change or delete any information recorded at any stage in the research process. You will be asked beforehand not to identify any particular individuals during the interviews so as to protect their anonymity also.

You will be able to contact Harriet at any point during this research process
to discuss any questions or issues you might have in relation to the research.
You can do so on 0421 441 427, or via email, harrietrad@hotmail.com.

APPENDIX H
CONSENT FORM

CERTIFICATION BY PARTICIPANT

I**,**

of

certify that I am at least 18 years old and that I am voluntarily giving my consent to participate in the study entitled:

A collaborative action research project with Disability Justice Advocacy (DJA) to develop a strategic plan

being conducted at Victoria University of Technology by:

Dr Christopher Sonn and Harriet Radermacher

I certify that the objectives of the study, together with any risks to me associated with the procedures listed hereunder to be carried out in the experiment, have been fully explained to me by:

Harriet Radermacher

and that I freely consent to participation involving the following activities:

- One or two audiotaped interviews about an hour in length each
- Two strategic planning sessions (3 hours each)

I certify that I have had the opportunity to have any questions answered and that I understand that I can withdraw from this study at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the information I provide will be kept confidential.

Signed: **.....** Date**:……**

Any queries about your participation in this project may be directed to the researcher (Name: Harriet Radermacher ph. 0421 441 427). If you have any queries or complaints about the way you have been treated, you may contact the Secretary, University Human Research Ethics Committee, Victoria University of Technology, PO Box 14428 MC, Melbourne, 8001 (telephone no: 03-9688 4710).

APPENDIX I
AGENDA FOR STRATEGIC PLANNING: DAY ONE

Disability Justice Advocacy Strategic Planning Forum

Day One

11	**1. Introduction** Welcome and Introductions ▪ History of DJA and it's mission, achievements and issues ▪ Overview of what want to achieve **2. The Strategic Planning Project and Emerging Themes** **3. What the world of advocacy faces** **4. Day's Plan** ▪ Overview of how day will proceed ▪ Small group formulation – group leaders, rooms to meet – reporting back	**Sue** **Harriet** **Gillian** **Jill**
11.30	**Small group discussions - External issues** ▪ Emerging issues - their impacts - what could be done - nominate 2 most important ideas - Group feedback	**Harriet and Jill**
12.30	**Lunch**	**Jill**

1	**Small group discussions – Internal issues** ▪ Emerging issues - their impacts - what could be done - nominate 2 most important ideas - Group feedback	**Harriet and Jill**
1.55	**Close of day** ▪ Commitment to provide notes from today ▪ Outline of next week ▪ Thanks for involvement	**Jill**
2	**Finish**	**Jill**

APPENDIX J
FEEDBACK FOR PARTICIPANTS FROM INITIAL INTERVIEWS

Strategic Planning Agenda

Feedback from initial interviews

Strategic Plan

Need to have more of a focus, direction…

- DJA has come a long way but we need to take the next step for what we are going to do in the future
- Need to have a clearer idea about what we (DJA) think we are on about
- This is the core of the organisation this stuff (the strategic plan), this is what it should all be about
- **If you don't have a shared direction/a plan for the whole organisation why do you bother?**
- Looking forward to it, no huge hopes or aspirations, but just the fact that we are doing it and knowing that we will get a finished product at the end of it is exciting

So this is about working together to get that 'finished product'…most of you talked in terms of having an 'action plan' or business plan

I have the minutes of last May's strategic planning day and it was noted that you wanted 'achieveable' outcomes. However there were no measures/methods explaining how this was to be done. Many of the issues raised were similar to the ones you have raised recently (eg need more links between IA and SA, website, more resources, consolidate and improve relationships between workers and btn workers and board, dedicated and funded transport worker, support for advocates and board). Now some of these have been done (eg website, supervision for EO) but in no systematic manner.

Great to have the opportunity to speak to each and every one of you to get individual feedback, and it has all served to shape the agenda here for today.

First of all I wanted to convey the many positive things that you said about DJA and what it does…

DJA Strengths

- A very supportive group
- Addresses individual needs
- Annual figures prove that DJA supports people in need and the figure rises each year
- DJA has come a long way
- The workers have a lot of energy
- We are pretty responsive, respond to everything, people do not have to wait long
- We are an important cog in the wheel of many systemic projects
- Not a lot of people that can provide advocacy to people with high support needs, and we do it, and we act within people's best interests
- We get good outcomes and doing the right thing by its clients
- DJA keeps moving forward

You all knew that what DJA does it does well, however most of you acknowledged that there was always room for improvement. We categorized the things that you said into specific issues and themes so that you could have a chance to discuss them today in a more structured way.

Issues/themes

External	Funding
	Target group – who do we serve?
	Publicity/raising awareness
	Sustainability
	Disability Sector
	Government policy
	Other advocacy services/collaboration/links/networks
Internal	Premises/resources
	Organisational structure/management/board
	Provision of individual advocacy
	Systemic advocacy/projects
	Methods of working/process/policy and procedure
	Standards/performance indicators
	Purpose of DJA/Vision

APPENDIX K
FEEDBACK FOR PARTICIPANTS FROM FIRST PLANNING DAY

DJA's Strategic Direction

Thank you for your involvement in Day 1 of the strategic planning process! You highlighted many areas for action and these have been recorded below. Please read through them and come with your ideas about when they should be done, how they are to be done, and who is to do them. We look forward to seeing you tomorrow for another exciting day of planning and action for DJA!

What we do?

ACTION	Review mission statement
ACTION	Explore what we do versus what we are called

With whom do we do it?

ACTION	Revisit 'target group' by board (People with HSNs are most vulnerable people, workload would be unrealistic if target group was broadened). Needs to be done in context of State policies, current opportunities in State Plan for some diagnostic groups eg CFS, MS, and the reality of access ie. who is out there to do advocacy?)

How do we do it?

ACTION	Explore possibility of a merger with another organisation (opportunity to share physical resources and running costs, but might compromise sense of identity and specialist nature of our service)
ACTION	Make more links with government
ACTION	Make more links with generic services
ACTION	Explore potential/links with Disability Advocacy Resource Unit (esp as a one stop shop for referrals)
ACTION	Marketing to government, individuals and agencies (esp making sure that people with HSNs know we are around)
ACTION	Look at links between employees and employers

ACTION	Clarify the roles and responsibilities of the EO and the Board, including the relationship with one another
ACTION	Look at internal communication systems
ACTION	Explore the links between what issues arise in individual advocacy and the systemic projects that we take on, and how advocates/board make choices about what systemic projects are taken on
ACTION	Explore when and if to say 'NO' and what to do when SA issues arise without warning
ACTION	Need a planned approach to funding. Look at options to get more $s (eg charging for service, fundraising, national lobbying, alternate sources of $s, State funds -how do we get it?)
ACTION	Recruit more members

What do we need to do it?

ACTION	Explore the options for increasing the expertise of the board (eg training for board, support for board, support for EO, invitations to local government/agency reps to act as non-voting members or consultants) while maintaining 'grassroots'
ACTION	Create an opportunity for staff to look at the operational procedures, and revise why things are done in certain ways
ACTION	Implement more of a structure in how things are done without being too prescriptive
ACTION	Set standards and performance indicators to ensure quality in what we do
ACTION	Look at other models - are we working in the best way? No increases in funding in line with other rises (in rent, wages etc.)
ACTION	Look at support for advocates

Where do we do it?

ACTION	Allocate worker time to look at this big need to move premises

APPENDIX L
AGENDA FOR STRATEGIC PLANNING: DAY TWO

Disability Justice Advocacy Strategic Planning Forum

Day Two

11	**Introduction** ▪ Welcome ▪ Review of last week ▪ Overview of what want to achieve **The Strategic Planning Project and Emerging Themes** **Day's Plan** ▪ Overview of how day will proceed ▪ Small group formulation - group leaders, rooms to meet - reporting back	**Sue** **Harriet** **Jill**
11.15	**Whole group discussion** ▪ **What we do?** ▪ **With whom do we do it?** – what could be done – how could it be done – who should do it – who needs to know – what's most important? ▪ **Report Back**	**Jill**
11.30	**Small group discussions** ▪ **How do we it?** – what could be done – how could it be done – who should do it – who needs to know	**Harriet** **and Jill**

	– when should it be done – what's most important? ▪ **Report Back**	
12.30	**Lunch**	
1	**Small group discussions** ▪ **What do we need to do it?** - what could be done - how could it be done - who should do it - who needs to know - when should it be done - what's most important? ▪ **Where do we it?** - what could be done - how could it be done - who should do it - who needs to know - when should it be done - what's most important? ▪ **Report Back**	**Harriet** **and Jill**
1.45	**Close of day** ▪ **Commitment to actions and agreements** - Adopting plan - Setting priorities - Reviewing progress ▪ **Thanks for involvement**	**Jill** **Sue** **Gillian**
2	**Finish**	**Jill**

APPENDIX M
LETTER TO DJA STAFF

13 April 2004

Dear

RE: STRATEGIC PLAN AND FOLLOW-UP INTERVIEW

Thanks again for all your work in making the strategic planning days such a success!

All your comments and ideas have been compiled into a strategic action plan (a summary sheet and more detailed plan are enclosed). I hope that you will find time to look over it, and check to see that it is a correct record of what was discussed on the day.

The Board is due to look over it at their next meeting on Wednesday 14 April. If you have any amendments or comments you would like to make, let me know and I will feed them back. This includes identifying their level of priority (eg. ongoing, high or low).

Expect to be contacted by Harriet at some point soon for a follow up interview. This will involve talking about your experiences of the strategic planning process – be they good or bad!

Remember that this is just the beginning! It is your responsibility to make sure that the actions you identified now get done.

Congratulations and best of luck with steering DJA towards a more positive future!

Harriet and Jill

APPENDIX N
REVISED DRAFT STRATEGIC ACTION PLAN

Disability Justice Advocacy

Strategic Action Plan

March 2004

ACTION	WHO	WHEN	PRIORITY	REVIEW
1. Review purpose, mission statement, constitution, principles and priority settings				
1.1 Explore funding options (see if State and Trusts fund these projects)	Gillian Harriet	May Board Meeting 2004		
1.2 Find worker/student				
1.3 Set up a working group				
2. Revisit target group				
2.1 Read and review constitution. Make recommendations for change	Gillian	July 2004		
2.2 Read policies				
2.3 Review Commonwealth performance planning				
2.4 Find out about innovative grants info from DHS website	Margaret	April 2004	ongoing	

ACTION	WHO	WHEN	PRIORITY	REVIEW
3. Explore possibility of a merger				
3.1 Set up an informal conference with other advocacy services to discuss feasibility of a merger			high	
3.2 Put merger ideas to the advocacy network	Gillian			
3.3 Explore possible services/agencies who don't have conflict of interest with DJA				
3.4 Discuss what a merger would mean for DJA - devise questions for both staff and members to answer	Staff / Board			
4. Make links with government				
4.1 Invitations to join us on the Board eg local government reps				
4.2 Invite Commonwealth Government worker (new project officer		July Board meeting 2004		

	being appointed in June) to Board meetings twice/year				
4.3	Invite State worker (eg Clare Thorn) to Board meeting to provide info about how we can qualify for State funding	Peter G Gillian	July/August 2004		
	ACTION	WHO	WHEN	PRIORITY	REVIEW
5.	**Establish marketing plan to link with other services i.e. network**				
5.1	Get assistance to construct plan (eg from Interact Foundation)			low	
5.2	Decide what links should be and then which organisations to pursue				
6.	**Secure recurrent funding**				
6.1	Explore what projects the State will fund recurrently	Gillian and Margaret	July 2004		
6.2	Talk to Commonwealth re election, and how a merger would impact on DJA's funding	Gillian	By May Board meeting 2004		

7. Identify priorities for systemic advocacy				
7.1 Seek guidance from other agencies eg attend VDAN workshop to identity priorities for sector	Lachlan Margaret GIllian	VDAN May meeting 2004		
7.2 Look at statement of purpose/ guidelines for priority of access to guide direction/choices for systemic work	Board	By June Board meeting, 2004		
ACTION	WHO	WHEN	PRIORITY	REVIEW
7.3 Identify other groups/organisations that deal with specific systemic issues		June 2004		
7.4 Identify a liaison person				
7.5 Contact/networks/ support other groups in their systemic work (to share responsibility for addressing systemic issues) eg DSHA				
7.6 Make a checklist in order to identify priorities				

7.7 Find out from other organisations how they prioritise their systemic work	Every staff member to contact one organisation			
8. Make safe and accessible transport campaign sustainable				
8.1 Apply for funding (trust/ State grant) to get a project worker to lobby government to have a permanent transport worker	An advocate (Niki?)	July 2004	high	
ACTION	WHO	WHEN	PRIORITY	REVIEW
9. Increase expertise of Board				
9.1 Invite guest speakers for Board to ask questions				
9.2 VCOSS info kit (contact Frances)		May 2004		
9.3 Explore what needs to be done in order for Board members to become more proactively involved 9.3.1 Extend Board member activities	Sue	August 2004	High	

outside of Board meetings 9.3.2 Board members to take on systemic projects 9.3.3 Board members to exchange resources with other orgs eg VALID				
9.4 Make it a project including: 9.4.1 Ongoing training for Board 9.4.2 VCOSS training inc review/clarify role of Board members/EO 9.4.3 Ask members what help they want 9.4.4 Review strengths	Gillian Harriet	May 2004		
ACTION	WHO	WHEN	PRIORITY	REVIEW
10. Improve operational procedures (EO to coordinate)				
10.1 Look through operational	All staff at	June 2004		

	procedure and provide feedback on problem documents and procedures - ID shortfalls/ solutions	staff meeting and to report to Board			
10.2	Collect information about systems				
10.3	Improve ownership of information by getting staff involved in feedback loop				
10.4	Oversee operational procedure	Gillian and student	December 2004		
10.5	Undertake appraisal of EO	Board	July Board meeting 2004	Low / medium	
10.6	Improve internal communication system eg devise system inc regular staff meetings	Kerry	End of May 2004		
10.7	Increase support for advocates eg talk to advocates individually about what support they need	Gillian	By May Board meeting 2004		
10.8	Set standards for individual advocacy	All staff at staff meeting			

10.8.1 Revise and collate referral forms and other forms 10.8.2 Contact other organisations about process of referral /intake				

APPENDIX O
SUMMARY OF STRATEGIC PLAN

Disability Justice Advocacy

Strategic Plan – A summary

March 2004

MISSION STATEMENT

To provide quality advocacy to people having higher support needs who are in greater need, in order to protect and advance heir well-being, rights and interest, both individually and collectively.

Statement of commitment to plan:

- The strategic plan will be officially reviewed and revised by the Board at 6-monthly intervals. The next review date is the December 2004 Board meeting

- An update of ongoing actions will be a standard item on every Board Meeting agenda

- The strategic plan, in particularly item 10 regarding operational procedures, will be regularly revisited at staff meetings

- The Executive Officer will provide the link between staff and Board discussion

Strategic Direction and Action Statements

What do we do?
1. Review purpose, mission statement, constitution, principles and priority settings
With whom do we do it?
2. Revisit target group
How do we do it?
3. Explore possibility of a merger
4. Make links with government
5. Establish a marketing plan with other services i.e network
6. Secure recurrent funding
7. Identify priorities for systemic advocacy
8. Make safe and accessible transport campaign sustainable
What do we need to do it?
9. Increase expertise of Board
10. Improve operational procedures
Where do we need to do it?

APPENDIX P
FUNDING APPLICATION TO INTERACT FOUNDATION

INTERACT FOUNDATION - COMMUNITY CONNECTIONS PROGRAM

APPLICATION FORM

CONTACT PERSON

Gillian Meldrum, on behalf of Disability Justice Advocacy Inc.

WORKPLACE

Disability Justice Advocacy Inc
266 Johnston Street
Abbotsford
VICTORIA 3067

CONTACT DETAILS

03 9416 3488
0412 027 532
gillian@justadvocacy.com

DESCRIBE THE ORGANISATION YOU ARE SEEKING SUPPORT FOR

Disability Justice Advocacy (DJA) is a community-based organisation set up in 1989 to provide quality advocacy to people with high support needs associated with a physical disability. DJA works towards justice and inclusion for people with a disability, focusing on their fundamental needs, rights and interests. DJA is governed by a Board of elected members, all of whom have high support needs associated with a physical disability. Funded by the Commonwealth, DJA provides 70% individual advocacy and 30% systemic advocacy.

DJA is located in Abbotsford. It is managed day to day by an Executive Officer, who oversees the work of 3.6 EFT staff. During the 2002-2003 financial year DJA received 172 requests for information and referral. This is an increase of 41 over the previous year. Of the 112 people supported with advocacy over the same time period, half were new referrals.

WHAT IS YOUR CONNECTION WITH THIS ORGANISATION

I am the Executive Officer of DJA.

HOW LONG HAVE YOU BEEN INVOLVED WITH THIS ORGANISATION AND HOW DO YOU CURRENTLY SUPPORT IT?

I have been involved with DJA for 7 years. Before being appointed as the Executive Officer in July 2002, I worked as a full time advocate. My role is to work with the Board and other employees to ensure the organisation pursues its purpose and is managed efficiently and effectively. While the governance of the organisation rests with the Board, the executive officer has both a management and leadership role. Key functions of my role are the development and maintenance of constructive and consultative internal relationships within the organisation and ensuring positive relationships are fostered with the community and the government. It is also my responsibility to implement the Board's policy decisions and ensure the Board is kept properly informed. I am directly accountable to the Board and ultimately to the members of DJA.

WHAT KIND OF SUPPORT ARE YOU SEEKING?

We are seeking funds to cover the costs, or part costs, of a strategic planning process for DJA.

"This is the core of the organisation this stuff (the strategic plan), this is what it should all be about."

"If you don't have a shared direction/a plan for the whole organisation why do you bother?"

"Looking forward to it, no huge hopes or aspirations, but just the fact that we are doing it and knowing that we will get a finished product at the end of it is exciting."

(Participant comments made prior to the planning process)

In March 2004 we carried out a strategic planning process for the organisation. This has been well overdue, and it is expected to be pivotal in DJA's ongoing success and development. In our commitment to DJA we felt it was important to invest both time and resources to do the job properly. We were fortunate enough to have a student on placement with us to coordinate the planning process. To ensure its smooth and efficient delivery on the day,

we also sought the services of an independent and experienced facilitator, Jill Lane.
It was a lengthy, but worthwhile process involving all of our current Board members and staff (see list of participants attached). Each participant was informed about the process and interviewed prior to the event in order to develop an appropriate agenda that met everyone's needs and expectations. The strategic planning process itself took place over two half-day periods (6 hours in total). Spreading the process over two days enabled the student coordinator and the facilitator to collate the information from the first session, and to provide feedback to the group prior to the second session. It also gave participants time to absorb and reflect on the proceedings.

Considering the recent challenges facing the organisation (eg funding constraints, staff burnout, inappropriate premises, variable expertise of the Board) it was deemed necessary by the Board to go ahead with the strategic planning process as soon as possible. In the light of this, as well as being informed by Interact Foundation that it would be possible to make an application for funding following the event, we proceeded.

By assisting us financially Interact Foundation will not only have made the planning days possible, but will also have been integral in ensuring the future sustainability of DJA. We now have a draft strategic plan for DJA (see document enclosed). This document is a valuable product from our days of planning, and has the capacity to steer us in a positive direction. However it is just the beginning. We acknowledge that it is now our responsibility to ensure that the actions identified are properly followed through and implemented. As part of our commitment to success, we have agreed that the plan will be subject to review twice a year.

We believe that this planning process has not only provided DJA with a strategic direction, but it has strengthened our internal relationships. Furthermore, many participants commented on the value and importance of being able to pause in their daily routine and take time out to reflect on the bigger picture. While we realise that Interact Foundation prefers to allocate funds to more action-orientated projects, your investment in our strategic plan will indirectly lead to a broad spectrum of advocacy related activities. Hence, your support will have an infinite number of ongoing positive repercussions for our organisation.

For the breakdown of the costs incurred, please see the attached document.

IF YOUR APPLICATION IS SUCCESSFUL, HOW WILL THE ORGANISATION ACKNOWLEDGE OUR SUPPORT?

If our application is successful we will gratefully acknowledge your support both in our quarterly newsletter, in our new website (which is due to be launched in May 2004), and in all other upcoming publications.

STRATEGIC PLANNING COSTS

ITEM	COST
Facilitator (Services Quality Australia)	$1200
SCOPE attendant care support @ $28 per hour for 6 hours	$168
Catering (12 people for both days)	$110
Taxis for Board members to attend strategic planning day	$150
	$1628

APPENDIX Q
FOLLOW-UP INTERVIEW SCHEDULE

The aim of us sitting down here today is to talk about how you felt about being involved in developing the strategic plan for DJA. And about what you think of the action plan itself. It also gives you the chance to say what you really feel about the whole thing and how you think it could have been done better, whether you think it will be useful etc.

1. Strategic planning research process

Firstly, I want you to think back to when I first came to DJA (March last year) and all that has happened relating to the strategic plan until now…just to refresh your memory, this sheet (hand over sheet) outlines the main stages involved (run through stages)

- In what way did you feel involved in the process/ part of the process? (active or passive, decision-making ability, informed, planning)
- What kind of words describe how you felt about being involved? (eg did you feel frustrated, hopeful, unhappy, energised, uncertain, excited, confused, inspired?)
- Did you feel like you had a choice about being involved?
- Would you have wanted to be more involved? In what way?
- What would have encouraged you to be more involved?
- What do you think was good about the process? What stands out?
- What was not so good about it? What were you unhappy with?
- If you could have done things differently, how would you have done them? Is there anything you would have changed?

2. Strategic planning days

I want you to think back now specifically to the planning days. Think back to your own role/contribution to those days

- How satisfied were you about your own involvement/participation?
- In what ways would you have wanted to change your level of participation?
- What made it difficult for you to get/feel involved?

3. Strategic planning document

Think back to before the planning day, and to when we sat down for our first chat like this. I asked you what you hoped to achieve by the end of the planning process. You said…

- In what way do you think that this has happened?
- In what way do you think that it hasn't happened?

Here's a copy of the strategic action plan which you should have...

- (In all honesty) have you even had a chance to read it?!
- In your view, is it an accurate reflection of what was talked about on the day?
- Do you feel like your ideas have been included in it? In what way do you feel that you have contributed towards shaping the document?
- Is there anything that you feel is missing, that you would want to change, or that you wanted to include at the time that is not there? Why was it not included at the time? (eg didn't think about it then, not enough time, wasn't written down etc.)
- I want to know how you feel about the action plan. What are your thoughts about it in terms of how it will be used and what will happen with it?
- How do you think it will affect the future of DJA?
- Was it worthwhile?
- How is it going to help the work of the Board?
- *(outline statement of commitment)* in what way do you think this is enough to make sure the actions actually get done?
- What do you feel are your responsibilities in relation to the action plan? (if any?!)

Highlight tasks allocated to participant

- How do you feel about your own tasks? Do you feel like you are going to be avle to do them ok/in time?

Do you have any questions, suggestions, comments about any of the work we've been doing?

Thank you very much for your time and commitment. I hope you have found it to be worthwhile. My involvement with the strategic plan itself is now over, and the document is the property of yourselves and DJA. You have a hard copy of the most recent version, but it is a living document and will be subject to change. If you would like an electronic version please let me know.

I will be working on analysing the data, and writing up my thesis until the end of the year. As I have said before you are welcome to have copies of the interview transcripts both for your interest, and to check their accuracy. You will also have access to the final report. I hope to write a summary of the findings specifically for DJA.

APPENDIX R
FOLLOW-UP INTERVIEW INFORMATION SHEET

STRATEGIC PLANNING STAGES

1. Developing initial idea for having strategic plan
2. Receiving letter of introduction
3. Attending initial interview
4. Getting feedback from interviews re. issues
5. Attending planning day 1
6. Feedback from planning day 1
7. Attending planning day 2
8. Receiving draft strategic action plan
9. Reviewing strategic action plan
10. Attending final interview

APPENDIX S
EMAIL TO DJA TO PROPOSE ONGOING INVOLVEMENT

----- Original Message -----
From: Harriet Radermacher
Sent: Friday, March 11, 2005 2:55 PM
Subject: strategic planning guidance group!

Hello Hello members of the strategic planning guidance group!

As Gillian now knows, I have been accepted onto the doctorate program of my uni course which means that my thesis is still ongoing. This means that there is an opportunity to do some more work with the strategic plan.

Having been a whole year (??!!) since the strategic planning days it might be quite timely to organise a kind of review and I'm wondering if you might be interested in me facilitating a kind of feedback session. This would include me presenting a kind of summary of the findings from your interviews, an opportunity for all of you to reflect on the strategic plan so far (what is working/not working/good/bad etc.), and where to go from here.

Let me know what you reckon or any other ideas and comments you may have.

I look forward to hearing from you!

Harriet

APPENDIX T
FEEDBACK OF FINDINGS TO DJA

Harriet's back!

Thanks again to everyone for taking part. Here is some general feedback about your experiences of the strategic planning process, and what we might learn from the process. This is with a view to working out where we might go from here…

General feedback:

- Everyone generally happy to be involved in the strategic planning process and agreed that it needed to be done.

- Most people thought the process was good but that it could be improved.

- There were mixed responses about the usefulness of the action plan. While most agreed that it was good to have actions written down, some people were concerned with: (1) the lack of detail; (2) the unequal distribution of tasks; (3) that it was unrealistic; and (4) whether it would be used.

What were the key issues?

- The issue of *time* came up a lot: "I think it tackled too much in too short a time." Decisions were rushed and ill-informed, and the process of deciding which items were or were not to be included was unclear.

- Everyone has *different perspectives*, understanding, experiences, roles, aims, expectations and personalities. General feeling was that everyone (Board, advocates, project workers, admin workers, and membership) should be involved, and yet many people noted the challenges involved in meeting everyone's needs and accommodating for these differences.

- Most people said that they found it hard *to say what they wanted*. This was for a variety of reasons e.g. fear of hurting feelings, of not being listened to, of not being understood, or just wanting to listen to what others had to say.

What can we learn from this?

- Allocate sufficient *time* and *resources*
- Ensure there is a clear *focus*
- Need *commitment* and *motivation* from everyone involved
- Need to think carefully about *who* should be included
- Provide *support* and *training* for the Board
- Ensure *fair* and *clear decision-making* processes
- Think about ways in which to create a *safer environment* for people to be heard

What's the next step?

- It is now one year since we sat down and created the strategic plan which may be a good time to reflect on some aspect of the plan.
- Harriet has been given the opportunity to extend her research and this means that she is available to work with you again in some way.
- *Taking on board what we learned from the process last year*, think about what might be useful for us to explore together.
- Some options might be to:

    1. Identify what is currently working and not working in the strategic plan and/or construct a plan of action with a timeline
    2. Identify one action plan item and flesh it out use as an example of good practice
    3. Select and explore a key issue/theme from the research (e.g. support for Board, org structure, policies and procedures, Board-staff communication)

Whatever option we choose, we need to identify *who* is to be involved, *what* we are aiming to do, *why* we are doing it, *how* it's going to be done, when and where.

APPENDIX U
DJA WORKSHOP AGENDA

Wednesday 11 May 2005, 10-12pm

1. Introduction and overview of agenda (5mins)

2. Opening activity (15mins)

Everyone gets into pairs and takes it in turn to talk to each other about (1) their most funniest/memorable moment at DJA and (2) their most challenging moment. We then get back as a big group, and each partner has to feed back to the group about what their partner has said. (A good activity to encourage people to listen and talk to each other!)

3. Setting the context – Training for the Board in the Strategic Plan – where are we at? (HR) (10mins)

Look at the strategic plan where it relates to 'increasing expertise of the board'. Go over the points - What did we mean? Have we achieved our goals? If not, why not?

4. Training for the Board – what does a Board member need to know? (SW) (30mins)

A little background about how training for the board has been raised again and again as an issue, and why it is so important (or get others to say why it is important!). Aim is to get people thinking about what being on a Board means and the skills that are required. Give copies of the board requirements to everyone and go through all the points, ensuring that everyone knows what they mean and that they are indeed important. Ask people, in light of the requirements, what they see as their strengths and weaknesses.

Break (15mins)

5. Making an application for funding (PG) (30mins)

Peter can give a brief overview of what a funding application involves (and where he is up to so far). Having identified people's gaps in knowledge in the first part, we can try to focus on identifying some priorities for training and feed this into the funding proposal. (This workshop could even be written about in the funding proposal to add to its credibility?!). And I suppose that as Peter is leading the writing of the proposal he will be in the best position to know what else needs to be done, and we can try to allocate some tasks to people. How are we going to see the successful completion of the funding application?

6. Individual commitment (10mins)

Write down individual commitments/tasks on a card for people to take away. Clarify as a group what is the next stage.

7. Evaluation. (5mins)

Has this been useful? How could we have done it better?

APPENDIX V
NOTES FROM DJA WORKSHOP

Notes from DJA Workshop (11-05-05)

Part 1 – Systemic Advocacy

As accommodation is the most common reason for individuals seeking advocacy at DJA, the group focused on DJA's involvement with 3 systemic projects working on this issue. The advocate involved with each respective project identified their strategic focus – answering the key question 'What is the role of DJA in this project?'

1. Young People in Nursing Homes (YPINH) (Kerry)

(To be completed by Kerry)

2. Community Living Alliance (CLA) (Niki)

- To promote awareness of the accommodation needs of all people with disabilities, and thus broadening the focus of the group away from just intellectual disability

- To advance opportunities for people with disabilities to be trained and employed to work with others coming out of institutions

- Building networks at a regional level to promote the exchange of information

3. Eastern Region Neighbourhood Co-op (Kerry/Sue)

(To be completed by Kerry)

ACTION: At the next meeting identify the strategic focus for the other accommodation related systemic projects including:

(1) Attendant Care Action Group; and

(2) Aids and Equipment.

Part 2 – Training for the Board

To introduce the topic the group discussed how training for the Board has been an ongoing issue for a number of years, but has never actually happened.

Funding proposal

Gillian noted that there are three good reasons for funding such a project, and that these reasons should be emphasised in the proposal. The reasons are: (1) it is

innovative and unique; (2) there is a realistic need; and (3) it will be the leader in training courses for people with disabilities.

Budget/Project Worker

Peter raised the need to itemise the budget. However, Gillian noted that if the proposal stated that DJA is planning to employ a project worker, then it will be their role to identify appropriate trainers and identify the training needs. The group went through the list of requirements of Board members (as prepared by Sue). It was agreed that 'understanding legal and fiduciary duties' and also 'understanding the importance of working together inside and outside of Board meetings' was also important and should be added to the list.

Board Turnover

Sue noted that the turnover rate of the Board would impact on the project proposal, and it was noted that it needs to be an ongoing project so that all new board members can benefit from the training.

Training Content

The training program does not need to reinvent the wheel. The project worker can use what is already out there (e.g. Becoming the Boss). The group also discussed ideas for where to look for training. This included Council for Adult Education (CAE), local Neighbourhood houses, VCOSS, and TAFE.

Working in Partnership

The group also talked about working in partnership with others to run the training, and identified the need to find out how other organisations provide existing training for their Boards (e.g. ACL, AMIDA, Reinforce - Villamanta, CAUS have advisory committees).

ACTION:

Lachlan	-To approach the Board at the Ivanhoe Drop-in Centre for ideas
	-To ask Julie at Reinforce about their training/possible partnership
Peter	-To ask TAFE contact for advice/a referral
Harriet	-To check own potential resources about training for Boards
Sue	-To ask Cath at ACL about their training for Board
Gillian	-To find VCOSS funding proposal and send to Peter