Participation in Government Disability Advisory Bodies in Australia: An Intellectual Disability perspective

Patsie Frawley

Diploma of Teaching, Primary
Australian Catholic University, Ballarat 1985

Graduate Diploma of Special Education
Deakin University, Burwood 1987

Masters of Education, Special Education
Deakin University, Burwood 1997

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Doctor of Philosophy

School of Social Work and Social Policy
Faculty of Health Sciences

LaTrobe University
Bundoora, Victoria 3086
Australia

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ABSTRACT

This qualitative study examined the participatory experiences of people with an intellectual disability as members of government disability advisory bodies in Australia. These forums are one of the strategies adopted by governments to enable people with an intellectual disability to participate in the formulation of social policy. Such opportunities have arisen from progressive policy that frames people with an intellectual disability as full citizens with equal rights to inclusion and participation in society.

Little research has considered how people with an intellectual disability experience the participatory opportunities that have grown from this recognition of their rights. This reflects the more traditional focus on their status and participation as consumers and service users. The central question of this study is how people with an intellectual disability experience participation in government advisory bodies, and how such forums can be inclusive and meaningful.

This study positions people with an intellectual disability as the experts about their own experiences by relying primarily on their first person accounts of their experiences. Ethnographic and case study methods were employed including in-depth interviews with the central participants, document analysis, observation of the work of the advisory bodies and interviews with others involved in advisory

bodies. Analysis led to the development of a typology of participation that describes the political and personal orientations people have to participation. The study found that structures and the processes used by advisory bodies can mediate people's experiences; however more significantly, the experiences of people with intellectual disability are shaped by their perception of how they are regarded by others. Central to this is the efficacy of support based on the development of collegiate relationships, similar to the notion of civic friendship described by Reinders (2002), rather than support that is solely focussed on tangible accommodations

The study concludes that citizen participation bodies have not fully recognised the personal and political potential of members with an intellectual disability. It presents evidence that people with an intellectual disability are capable of this form of participation, can provide legitimate and informed perspectives on policy and can engage meaningfully, given full recognition of their capacity to participate as well as structures and processes that enable this.

STATEMENT OF AUTHORSHIP

"Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis for any other degree or diploma.

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CHAPTER ONE
INTRODUCTION

Introduction

This thesis describes how people with an intellectual disability participate in government disability advisory bodies in Australia. In these advisory groups, people with a disability, and others who are seen to have a role or interest in disability policy, are brought together to advise government ministers and other government officials about disability policy. Nine people with an intellectual disability, who are members of government disability advisory bodies in Australia, are the focus of this study. At the time of the study, they were the only people with an intellectual disability who were members of these advisory bodies. They became involved in the study because they wanted to tell their stories about participation and through doing this develop ways of achieving more meaningful participation.

Identifying the research need

Research often begins with insights gained through conversations and encounters with people and their experiences. This study had its beginnings in a conversation with Hannah a woman with an intellectual disability who was a member of a government disability advisory body. Hannah told the researcher that she did not feel that she was participating very well in this advisory body and she felt she was only there to make up the 'right mix' of people. She said that she

was "not respected for her abilities" in the advisory body. Hannah was expressing feelings of tokenism and talked about being unsupported and feeling unfulfilled in her role. She also said she felt less capable than her colleagues on the advisory body, did not always understand what was going on, and she felt unable to address any of these problems. The researcher noted that Hannah was feeling disempowered within this group and that she believed her capabilities were being overlooked. Neither Hannah, nor the management team of the advisory body, were addressing these issues at the time of this conversation.

The study grew from Hannah's accounts of her experiences and the researcher's interest in understanding what was happening for Hannah and others like her who were being sought to participate in these and other similar policy advisory forums. The researcher had worked in a disability advisory body, knew Hannah and other people with an intellectual disability in these roles, and through supporting self advocacy groups, knew that people with an intellectual disability were beginning to raise concerns about tokenism in forums that sought their input into policy.

Three key research issues emerged from Hannah's situation. Firstly, Hannah noted that she felt she was perceived differently within the group and this impacted on the opportunities she had to participate. She felt like she was treated differently because she was a person with an intellectual disability and people did not see her abilities. Secondly, she noted that she was not given the

right kind of support to participate, and finally, that it was a difficult environment for her because she did not always understand what was happening. However, she felt with the right support she could participate. Her situation raised questions about how people with an intellectual disability are perceived within government disability advisory bodies, what support they need to participate and how the structures of the advisory bodies and other factors impact on their participatory experiences.

Policy context for the study

Participation and inclusion are hallmarks of current disability policy; however there is little known about how people are participating in decisions about their own lives, decisions about policy that affects their lives and how they are participating in society. In particular, there is a lack of research on participation from the perspective of people with an intellectual disability who are the highest users of government funded disability supports and services in Australia (AIHW, 2007).

Schalock, Baker and Croser (2002) note that there is now a "transformed vision of what constitutes the life possibilities" (p. xii), of people with an intellectual disability. Disability policy supports this view by framing people with a disability as citizens with full citizenship rights and responsibilities. However, there is little known about the way these new life possibilities are being experienced by people with an intellectual disability, and if in fact the policy aims are being met through

the opportunities the policy enables. Chapter 3 gives an overview of this policy context. It notes that in western democracies, there are increasing expectations that people with disabilities will participate in making decisions about policy and funding; however neither social policy literature nor disability studies literature has fully considered the intellectual disability perspective on this form of participation.

A critical review of the literature presented in Chapter 2 also finds a gap in knowledge about this new role for people with an intellectual disability. Reasons for this knowledge gap are: studies are not based on the experiences of people with an intellectual disability; most research in the disability studies literature is about consumer participation not citizen participation; and what studies there are, are from the UK where self advocacy by people with an intellectual disability and government policy, has created a consequent increase in participation roles. The available literature suggests that there is both a suspicion about people's capacity to participate, and a number of barriers to meaningful participation in these and other consultative forums.

Significance of this study

Principles of participation noted as being central to current disability policy, are also enshrined in legislation that underpins this policy. The United Nations (UN) Convention of the Rights of Persons with a Disability (2006) articulates these participation rights and sets out ways people with disabilities should be

participating at local, state, national and international policy forums. However,

people with an intellectual disability are often not given the same participatory

opportunities as people with other disabilities. This is evidenced in Australia by

their low numbers in government disability advisory bodies (Frawley, 2006c).

The omission of people with an intellectual disability from participatory forums is

often decided on the basis that they would not be able to participate. The view is

held that 'others' including parents, carers, advocates or service providers are

better placed to represent them. This view is prevalent, despite advances made

by the self advocacy movement to have people with an intellectual disability seen

in their own right, and participating in all aspects of their lives. Stainton (2005)

notes that for people to participate they must be able to articulate their wants,

needs and choices. He goes on to suggest that for people with an intellectual

disability this is often "problematic" because:

> ..they do not use formal communication methods, or because their voice
> is suppressed through laws which declare them incompetent, through
> services which do not listen, or through having been denied the chance
> to develop self advocacy skills. (p. 292)

The self advocacy movement has a long history of standing up for the rights of all

people with an intellectual disability, including those who cannot articulate their

own thoughts. What is lacking however, is not only participatory opportunities,

but also an awareness of how to support the participation of those who can

represent the intellectual disability perspective in a meaningful way.

There is evidence that people with an intellectual disability can participate in policymaking and policy advice forums; however, most of this is based on their participation as consumers of disability services. In the UK in particular, this participatory role for people with an intellectual disability has grown through the implementation of the intellectual disability policy *Valuing People* (DOH, 2001b). People with an intellectual disability have participation roles in local service planning boards, making real decisions about services, policy and funding. Research from the UK on participation and self advocacy has shaped these forums and informed the development of a strong partnership and participation agenda in that country (Goodley, 1997; Grant 1985, 1997; Whittell & Ramcharan, 1998). This is further supported by a strong self advocacy sector, which is recognised as the collective voice of people with an intellectual disability, advocating on their own behalf.

In Australia, participatory opportunities for people with an intellectual disability are not as common, however they are growing. Unlike the UK, Australia does not have intellectual disability specific policy or large-scale support for consumer participation. Here, people with an intellectual disability have had some experiences of being consulted about disability policy, being involved in governance bodies in services, and are beginning to be engaged more frequently in government led consultations, reference groups and committees. However, there has been a lack of planned development of broader participatory

opportunities for people with an intellectual disability, including in government

disability advisory bodies.

These forums were chosen for this study because they are created by

government to engage people with a disability as policy advisors, not merely as

consumers of services. They are citizen participation opportunities, reflecting the

principles of disability policy that frames people as citizens and sets out their

rights to participate in all spheres of society. This form of political participation

broadens the way people with a disability are seen. It places them in roles that

reflect the view that they are more than users of disability specific services.

Currently, all members are appointed to government disability advisory bodies as

individuals, not representatives of a constituency. They are asked to provide

policy advice on broad whole of government social policy, and disability policy,

from their own experiences. For people with an intellectual disability, this is in

contrast to their experiences in policy advice and consultation, where they have

more commonly advised on policy or issues that directly impact on the rights of

people with an intellectual disability, and have normally done this with other self

advocates.

People with an intellectual disability are beginning to be 'at the table'; however,

they are there in lesser numbers than people with other types of disabilities and

can feel disempowered within them. This study aims to examine the participatory

roles of people with an intellectual disability and how they experience them. In particular it is interested in the question of how meaningful the experience is for them, and whether it fulfils their participation aims and aspirations.

Historically, research has not considered people with an intellectual disability as having a role in research that is about them. This study frames people with an intellectual disability as the experts; they are placed at the centre of the study to give their perspective as a way of learning more about these experiences. Research approaches described as partnership, participatory, collaborative and inclusive are beginning to emerge in disability research as the most empowering, when the aim is to involve people with an intellectual disability in a meaningful way in research about them (Chapman & McNulty, 2004; Knox, Mok, & Parmenter, 2000; Ramcharan, Grant , & Flynn, 2004; Walmsley & Johnson, 2003). From a political perspective, these approaches also model broader inclusive practices and support the self advocacy principle of "Nothing about us without us".

Chapter 4 discusses these approaches and presents some of the debates that are currently being held in disability research about the use of these approaches with people with an intellectual disability. It also details the approach this study has taken. In short, whilst it was not able to fulfil all of the requirements of inclusive research, it is an example of collaborative research that enables the research participants to inform and shape the study and have a more active role

in it. Also, it does not meet the aims of emancipatory research as it is discussed in disability studies; it was not devised, led and conducted by people with a disability, however, it did respond to an issue raised by Hannah, and enabled her and others who had similar experiences to further explore these experiences and gain some meaning about them.

The study is based on a view that people with an intellectual disability can participate in policy making, have a right to participate and, that knowledge about how this can be facilitated and supported is best sourced from their own experiences.

Research questions and thesis structure

The research questions were:

- What are the participatory experiences of people with an intellectual disability who serve on government disability advisory bodies in Australia?

- How are their experiences mediated by the mechanisms and structures of the advisory bodies?

- How can participation in government disability advisory bodies be inclusive and meaningful for people with an intellectual disability?

The study is situated within the social policy literature on citizen participation, and disability studies literature on intellectual disability; in particular on research about rights, inclusion and participation. The review of the literature in Chapter 2

finds that little has been written in either areas of study about citizen participation and people with an intellectual disability.

The policy context for participation and inclusion is outlined in Chapter 3, in which a comparative review is presented of disability policy that enables participation, in four western jurisdictions; Australia, Canada, the UK and the USA. These countries were chosen, because they have policy and legislative frameworks that highlight the citizenship rights of people with a disability, and support community, civic and political participation. Such policies provide some theoretical and contextual basis for the study.

Chapter 4 describes the research methodology, which was qualitative and used ethnographic case study methods to gather data. It also outlines the approach used to undertake a thematic analysis of this data. This iterative approach (Piantanida & Garman, 1999) was facilitated through close peer review in supervision and application of the significant prior knowledge of the researcher.

Chapters 5, 6, and 7 discuss the findings of the study through case studies of the nine people and their participation in the six advisory bodies. Each chapter presents a different dimension. Chapter 5 focuses on the people and their participation styles. It uses their experiences to describe what people with an intellectual disability bring to their roles in the advisory bodies, personally and as political players. Chapter 6 goes on to examine the participatory environments

and the structural factors within them that have mediated experiences of the participants. Chapter 7 considers the question of support, describing how people have been supported to participate and how these approaches have positioned people within the participatory environments, in particular how the question of empowerment is addressed by different support approaches. Finally, in Chapter 8, the three dimensions are discussed together focussing on how they interact and intersect for the people with an intellectual disability who are engaged in these citizen participation forums.

An analysis of the themes that emerged through the case studies, leads to a proposition about what is needed to support meaningful participation of people with an intellectual disability in advisory roles. Whilst the study engaged a small sample, the richness of the data and the attainment of information from the population of people participating in these roles at the time of the study, suggest that these ideas could also be used to address questions of participation support in other forums. What is proposed is a need for a multi faceted approach to supporting participation that is based on a fuller understanding of the personal and political characteristics, ideologies and orientations of people with an intellectual disability who have an interest in participating. This knowledge should then be used to develop the right environments to enable meaningful participation.

At the centre of this proposition is a conclusion that some people with an intellectual disability can participate in government disability advisory bodies, that these people are likely to have clear views about why they want to participate, and personal and political ideologies and experiences that shape their participation. They are more than, 'the person with an intellectual disability' at the table.

Summary

This introductory chapter has outlined the rationale for this study and its origins in Hannah's personal account of participation. It has also described why this study is important for people with an intellectual disability within the current policy context that frames them as citizens with full civic, political and social rights. However it also raised questions about how far current policy has come in supporting these rights. Participation and inclusion are terms referred to often within disability policy and legislation; however knowledge about how to achieve meaningful participation in practice is surprisingly limited.

CHAPTER TWO

A REVIEW OF THE LITERATURE

> The initial objection to us taking part was that we hadn't got the skills. Then we got involved and spoke up and they said we were unrepresentative. We hadn't really got learning difficulties. We weren't typical of disabled people. Or they'd say someone put us up to it! They just couldn't believe we can speak for ourselves. (Beresford & Croft, 1993, p. 18)

Introduction

Participation has a central role in discussions of citizenship and inclusion.

Disability policy in most western countries frames people with a disability as

citizens, therefore suggesting they have a right and responsibility to participate in

the social, civic and political spheres of society. Principles of inclusion have

informed these policies and disability practices that enable people to participate

more fully in their own lives. Increasingly people with an intellectual disability are

being invited to participate in a range of consultative and policy advisory forums

about services, and to a lesser extent in broader policy forums. This is a

relatively new and emerging role, which contrasts with their long history of

segregation.

Whilst people with an intellectual disability are increasingly being sought to

participate, neither the disability studies literature, nor citizen participation

literature adequately addresses the topic of civic and political participation of

people with an intellectual disability. Little is known about how people with an

intellectual disability participate, why they participate and what mediates these participatory experiences.

Few studies have been carried out from the perspective of people with an intellectual disability; however those that have discuss issues and experiences of tokenism, lack of support, and disempowerment. There is inadequate knowledge, particularly from an Australian perspective and an intellectual disability perspective, to shape practice in this area.

Citizenship and the right to participate

Citizenship and the social, political and civic rights and responsibilities that come with this status have become an important part of current disability policy in Australia, the UK, the USA and Canada (Victorian State Disability Plan, 2002 – 2012; Valuing People: A new strategy for learning disability for the 21st Century, 2001; In Unison 2000: Persons with disabilities in Canada, 2000). Therefore, an understanding of citizenship and how it applies to the lives of people with an intellectual disability is important to an examination of the implementation of these policies. Whilst in the mainstream, scholarly debate about citizenship and discussion of the concept and its relevance has abounded for centuries (Brett, 2001; Bulmer & Rees, 1996; Chesterman & Galligan, 1997; Dahrendorf, 1996; Marshall, 1950; Turner, 1993); there is less knowledge about how it applies to the lives of people with an intellectual disability (Armstrong, 2002; Carey, 2003; Ramcharan, Roberts, Grant, & Boland, 1997; Rioux, Bach, & Crawford, 1997;

Walmsley, 1991). Nor is there an understanding about how, and if, people with an intellectual disability value it in their personal or civic lives.

Citizenship as a focus for disability policy, is relatively new, and has come at a time when broader social policy and legislation is beginning to encompass notions of inclusion for all (see Charter of Human Rights and Freedoms, Canada 1995; Charter of Human Rights and Responsibilities Act, 2007, *Vic*, Australia). Stainton (2005) suggests that citizenship, along with the idea of rights, choice and self determination do underlie disability policies; however he notes its practical meaning in the lives of people with an intellectual disability, is still unclear. He goes on to say however, that this focus on rights and citizenship has created a shift in the way people with an intellectual disability are viewed noting we have shifted from, "…a paternalistic model, where *we* decided what was 'best for people', assuming *they* were incapable of making choices, or at least 'good choices' " (p. 290). Policies and practices based on principles of choice, self determination, inclusion and participation have supported this shift.

Citizen participation is a way that people engage with the policy making process and express their citizenship rights. However, Armstrong (2002) argues:

> Citizenship must be defined not simply in terms of equality of participation but also by actions, both individual and collective, of all those who struggle for their own participation. (p. 343)

He goes on to say that the challenge for self advocacy, and people with an intellectual disability in this movement is, to " [move] beyond a model of

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citizenship based on participation towards a model that contests disabling labels…in the pursuit of common political interests" (p. 342). Realisation of this goal is made more difficult when people with an intellectual disability remain isolated from the broader disability movement and in countries like Australia self advocacy is weakened by a lack of support and funding. However, Armstrong's argument suggests the need to look beyond participation to an engagement with broader issues that are the substance of inclusion. This, he recommends requires political action. The literature reviewed in this chapter also suggests that citizen participation is not the most effective way to gain this power and enable political action. Writers such as Goodley & Ramcharan (2005) whose work is discussed later, suggest that the move to consultation through government devised boards, might lessen the independent advocacy of self advocacy that was built on campaigning and other political action.

Contemporary mainstream literature on citizenship and social policy has drawn heavily on the work of T.H Marshall. He wrote from the 1950s to the 1970s about an expanded and more inclusive view of citizenship than had been developed in earlier times. He argued for a twentieth century definition of citizenship that added social rights and responsibilities to the existing areas of civil and political rights and responsibilities. Marshall defined citizenship as:

> …a status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties with which the status is endowed. There is no universal principle that determines what those rights and duties shall be, but societies in which citizenship is a developing institution create an image of an ideal citizen

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against which achievement can be measured and towards which aspiration can be directed. (Marshall, 1965 p.x)

Through this definition Marshall argued for, "… a fuller measure of equality, enrichment of the stuff of which the status is made, and an increase in the number of those on whom it is bestowed" (Marshall, 1965). In arguing this however, he also recognised the diversity of community membership noting that,

Some children are more able than others,...some occupations demand qualities that are rarer than others and need longer and more skilled training to come to full maturity, and …they will therefore probably continue to enjoy higher prestige. (p. xiv)

Many writers have critiqued Marshall's view of citizenship as a 'top down' view that too closely positions the person in terms of their relationship to the state. As Turner (1993) suggests this theory sees citizenship in terms of what the state owes the citizen and consequently what citizens owe the state. This, Turner argues, focuses too much on the active and public aspects of citizenship, and does little to develop an understanding of what it means for individuals in their everyday lives. Two questions emerge when considering this view of citizenship and what it means for people with an intellectual disability. Community membership is central to Marshall's idea of citizenship and, as community members citizens have a right and responsibility to contribute to society. The questions are whether people with an intellectual disability are recognised as community members and if so, whether they have the means to contribute.

Historically, and in some ways currently, people with intellectual disabilities have not been afforded full membership of society. They have been physically

segregated in institutions and segregated community based services (Rioux et al., 1997). Many people with an intellectual disability continue to be seen as incapable of participating or contributing to society or the economy; this questions their status as full community members and citizens (Reinders, 2002; Stainton, 2005; Young & Quibell, 2000). Positive accounts of inclusion and participation are not readily reported in the literature or the popular media.

Disability researchers and theorists have begun to debate these questions. Allison Carey (2003) argues that, " Disability has long been exempted from the study of citizenship…When discussed, disability was considered outside of the traditional conceptualisation of citizenship" (p.424). Schreenberger (1983) agrees that laws have placed people with an intellectual disability in a separate category; outside society. Others have suggested that whilst citizenship rights have been affirmed through disability legislation and policy, attainment of these rights is challenged by poorly resourced policy implementation, that has been characterised by the marketisation of disability services (Bigby & Ozanne, 2001; Oliver, 1996; Ozanne, 1998; Rioux et al., 1997). Ramcharan et al., (1997) agree that the current notion of citizenship in western democracies, is based on an equality of well being and that such well being, is dependent on entitlement and access to resources that reduce oppression and inequality.

Further to this debate, Carey (2003) suggests that a different view of citizenship for people with an intellectual disability is still evident in practice. This is

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particularly the case where legislation that is intended to be applied in specific circumstances, in particular in relation to supported decision making, is globally applied enabling control over all of a person's decision-making. This right to control is based on a view that the person, by way of their intellectual disability, is incapable and incompetent. Stainton (2005) adds that whilst disability legislation and policy has led to fundamental protection of rights, they have, "...to a lesser degree provided the positive supports necessary for the exercise of citizenship" (p. 290). Policy and legislation has gone some way to change the community view about disability; however these arguments suggest there is still further to go. In particular, they highlight the importance of questioning laws that reinforce the view that people with an intellectual disability are incompetent and incapable.

The question of capacity or incapacity underpins this review of citizen participation, as it appears that people with an intellectual disability need to be recognised as capable full members of the community, to be seen as citizens and therefore, to participate alongside other citizens in shaping the society in which they live. Simons (2000) notes that, there are many decisions made for people with an intellectual disability based on an assumption of incapacity and people need to be given adequate support to develop their own understanding of issues, before being judged as not having capacity. This lack of support, it is argued, can result in limited understanding of issues and can cause others to disregard their views (Beresford & Campbell, 1994; Beresford & Campbell, 1993).

In summary, for full citizenship to be attainable, the laws and policies that restrict citizenship rights and continue to disempower people with an intellectual disability need to be reformed, re-instating equality before the law (Basser, 2002; Carey, 2003; Rioux et al., 1997). Ramcharan et al., (1997) argue that these changes, along with entitlement and access to the resources that support full community membership, and active participation in the citizenry, would develop an 'included identity' for people with an intellectual disability in society. Without these, it is suggested that people with an intellectual disability cannot attain full citizenship status. If laws and the resources needed to implement them are not reformed, people's rights to participation will not be attainable.

Finally, writers from the self advocacy perspective call for more opportunities for people with an intellectual disability to set the agenda, self organise and receive the right support to be able to participate as citizens (Armstrong, 2002; Beart, Hardy, & Buchan, 2004; Chapman, 2005; Clement, 2003; Finlay & Lyons, 1998; Goodley, 2000, 2001, 2005; Romeo, 1996; Walmsley & Downer, 1997; Whitehead & Hughey, 2004). However, this literature has begun to question how well the self advocacy movement is understood and raises issues about what characterises the 'right support' in this context. These issues are re-visited later in this chapter and throughout the thesis, as they relate to the experiences of people with an intellectual disability who are engaging in citizen participation forums.

There is a lack of research on the way the concept of citizenship applies in the lives of people with an intellectual disability. What is reported suggests the ideal of citizenship has become central to disability policy without examining its meaning from the perspective of people with an intellectual disability. Beresford & Croft (1993) summarise this as the need for people with an intellectual disability to develop their own accounts, form their own judgments, and negotiate with others to challenge commonly held views about intellectual disability. Accounts of inclusion and participation and the barriers to this by people with an intellectual disability are beginning to emerge in some research. However, there remains a dearth of such research, particularly in countries like Australia where self advocacy is not well supported or adequately strong to develop opportunities and maintain involvement in this kind of work.

Forums for citizen participation

Citizen participation is defined in the literature as an important expression of citizenship rights and responsibilities, involving people in policy making who would not normally be involved (Patemen, 1970; Wolfe, 2002). Richardson (1983) defines it as "The ways in which ordinary citizens can or do take part in the formulation or implementation of social policy decisions" (p. 8). However, it is also critiqued as being tokenistic, disempowering and an end, rather than a means to an end in policy formulation (Arnstein, 1969; Patemen, 1970; Richardson, 1983; Van Til, 1984). Writers such as these also argue it is merely a way to legitimise existing policy (Arnstein, 1969; Patemen, 1970; Richardson,

1983; Van Til, 1984; Wilenski, 1986; Wolfe, 2002). Despite such critiques citizen participation has grown to be a commonly used policy tool of government. However, there is little known about whether it does meet the aim of having 'ordinary citizens' heard in policy making.

Barnes, Newman and Sullivan (2007) in their studies of citizen participation forums in the UK note that, "…there has been an explosion of participation forums" (p. 1). They argue these forums do not engage broad views to shape more representative policy. Moreover they suggest these "officially constituted" forums are drawing people into a new kind of governmental power that uses their voices to legitimate the government view. Barnes et al., (2007) note, "having a voice is an outcome [of participation] but is not enough to sustain participation over time" (p. 201). For participation to be meaningful and sustained, they argue the voices need to be recognised, respected and acted on, resulting in institutional change.

Findings reported by Barnes et al., (2007) reinforce the commonly debated questions about voice and power within citizen participation. Social policy literature has continued to ask how these kinds of forums can offer people a voice in policy making, and whether that voice will, or can be heard through existing citizen participation structures. Analyses of such forums have led to questions about the ability of citizens to influence government policy, particularly when managerial policy making is dominant. Reddel & Woolcock (2004) state,

" Diversity, complexity and engaging with the 'disengaged' are not easily accommodated given the dominance of managerialism and rational policy approaches" (p. 82). Questions about power, voice and representation are fundamental to a study of citizen participation.

Sherry Arnstein wrote a key paper on citizen participation in the late 1960s that sought to represent how citizen participation was developing. Her focus was on how power and decision-making were shared within such forums. Whilst this work has been heavily critiqued and questioned as being too simplistic a representation, it is regularly referred to in the literature. Her representation of citizen participation, called the 'Ladder of Participation' (Arnstein, 1969), described how certain approaches to and structures of citizen participation are disempowering and result in less, not more participation in policy making. She argued that "…what power holders achieve is the evidence that they have gone through the required motions involving those people" (p. 219).

Participation forums, she argued, have outcomes for those who constitute them that do not match the goals of those participating. Arnstein's work (1969) suggested that certain kinds of forums did not enable meaningful participation in policy making. She noted that advisory forums were highly tokenistic, and consultation on its own provides no assurance that people's voices will be heard. This representation of citizen participation suggests that some approaches are inherently tokenistic. This issue has neither been taken up nor disproved in the

literature. However, it remains relevant when considering the way people experience participation in these forums.

Richardson (1983), in her book on citizen participation argues that there are three major structural and functional barriers to meaningful citizen participation: They are perceived and experienced as a process of legitimation by governments without a shift in power; they are seen as a process of co-option by the system; the representativeness of participants is questioned, as it is merely the more organised, recognised, articulate, and easy to reach people who are invited to participate (p. 14). This critique agrees with Arnstein's view that the way forums are structured can determine the power of people participating to make real changes. However it also adds a question about the composition of such forums and whether they are truly representative of those they are trying to gain input from.

Despite critiques such as this there continues to be a commitment to this approach to policy making in western democracies and as Barnes et al., (2007) note, there are ever-increasing numbers of these forums at all levels of government and community. This reflects a view of democratic governance, that groups affected by policy decisions should participate in these decisions, and that citizen participation is a right and a duty of all citizens (Wilenski, 1986; Wolfe, 2002). The four themes consistently raised in this literature are; issues of tokenism, the question of power within citizen participation forums, the ability of

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these forums to engage with a representative voice, and how to support meaningful participation.

Little seems to have been done to address these issues in mainstream forums. Governments are increasingly consulting with end users of policies and community engagement is the cornerstone of social policy. Research strongly suggests this approach may not empower participants, may not lead to their voices being heard and used to formulate policy, and in fact might lead to more not less government power.

People with an intellectual disability participating: Having a real say
For at least two decades in Australia, people with an intellectual disability have been recognised as having a right to participate in decisions about their lives. This right has been enshrined in disability legislation and policy. Stemming from this, people have participated much more in individual planning dealing with their lifestyle, supports and services. This is often called Person Centred Planning (Cambridge & Carnaby, 2005), and has grown to be a common approach. More recently people have also begun to participate in service planning through membership of client councils in their services and other consumer participation forums. Also governments have begun to engage people with an intellectual disability in broader service planning and policy consultation.

There is a body of work from the UK that has analysed a range of participatory

forums and approaches to involving people with an intellectual disability in

service planning (Beresford & Campbell, 1994; Beresford & Croft, 1993;

Concannon, 2005; Croft & Beresford, 1995; Grant 1985, 1997; Redley &

Weinberg, 2006; Simons, 2000; Whittell & Ramcharan, 1998). The UK has a

policy system that differentiates between intellectual disability and other types of

disability in policy with a core focus on intellectual disability being through the

Valuing People white paper (DOH, 2001b). This policy has supported consumer

participation through a number of initiatives that will be discussed later. In

Australia, consumer participation by people with an intellectual disability has

grown; however there are few studies and little research about this form of

participation. Unlike the UK, Australia's formally constituted disability policy

forums at all levels of government focus less on service planning and more on

disability policy as part of broader social policy. Membership of these advisory

bodies includes people with a range of disabilities and in some instances, service

providers, peak bodies and government representatives.

One Australian study has been carried out on consumer participation forums

(Fullwood, Hodge, & Stanzel, 1993), however this study did not focus on the

experience of participation, but on an evaluation of the advisory bodies and their

outcomes. It found that participation was not well supported and that people did

not have training to participate. It made a range of recommendations about

strategies to support more inclusive, equal and meaningful participation that have not been implemented in subsequent advisory bodies and forums.

There are few studies that have sought an intellectual disability perspective on participation. Beresford & Croft (1993) have written about the consumer participation role and do include some insights from people with an intellectual disability. The opening quote of this chapter is a reflection on this role from a person with an intellectual disability. It reflects a view that they are not seen as fully contributing members who can participate, adding that they also feel unaccepted and not respected in these roles. Moreover, it suggests that there is suspicion, not only about their ability to participate, but also more disturbingly about their identity as people with an intellectual disability and their representativeness within such forums (Beresford & Croft, 1993).

This, I suggest is related to a lack of understanding about what constitutes a picture of the person with an intellectual disability in current times. As the earlier section on citizenship discusses, people with an intellectual disability have not always been recognised as having the capacity to be citizens. The view held by the person in the quote, is that when people with an intellectual disability take on representative and participatory roles associated with the acquired status of citizen, their capacity and right to represent the views of people with an intellectual disability and therefore their place at the table, is still questioned. Perhaps the current community view of what constitutes intellectual disability is

still one that is framed by incapacity. If this is the case, then paving the way for meaningful participation, is going to be difficult.

The work of Beresford and others over a decade ago (Beresford & Campbell, 1994; Beresford & Croft, 1993) drew on work of writers such as Sherry Arnstein to inform their critique of this emerging role for people with an intellectual disability. They suggest, that similar issues to those recognised by Arnstein (1969), were evident in the kinds of forums that were beginning to involve people with a disability. In particular they note: issues of power and the disempowering nature of these forums, tokenism, and lack of support for meaningful participation.

> First they must have the personal resources and skills to participate, then the organisational and political access to do so…People need to be offered support and skills to take part, combined with suitable structures and opportunities for involvement. (Beresford & Croft 1993 p. 51)

The literature on citizen participation in the mainstream, and emerging studies of participation by people with an intellectual disability, suggest that there are significant barriers to participation, at both individual and structural levels. Beresford and Croft (1993) highlight three areas: (a) access to suitably structured participatory opportunities; (b) personal skills and resources; and (c) support. They identify two different kinds of issues; the first suggests the need to examine structures and the second suggests the need to focus on the people who are participating. This second issue looks at what is needed to participate; the personal and political skills and knowledge needed to be effective in citizen

participation (Lucas, 1978; Wolfe, 2002). As noted there is very little research from either of these perspectives in disability studies.

Research on citizen participation involving people with a disability and disability organisations has covered both areas (Boyce et al., 2001); however as noted, it is scarce. There are few large-scale studies and only a small number that have focused on the experiences from the perspective of the people participating. Studies that have been completed, suggest that the structure of these forums is a major barrier to meaningful participation and the lack of decision making power remains a key issue (Redley & Weinberg, 2006; Riddington, 2007; Simons, 2000; Whittell & Ramcharan, 1998). They point to concerns about the intention and expected outcomes of this form of participation, noting that whilst they are set up to empower people within the policy making arena, albeit mainly at a service level, they do not meet this aim.

The late Ken Simons, from the Norah Fry Research Centre at the University of Bristol, devoted much time to working with people with an intellectual disability who were engaged in consultative and advisory roles in services and service planning (Simons, 2000). His work supports the findings from the citizen participation research that suggests a need to look at the people who are participating and how they can be engaged in the processes of participation. It highlights that people with an intellectual disability in consumer participation roles have limited access to the information they need to be able to participate

meaningfully and that people lack adequate supports to participate. Concannon (2005), also focusing on people with an intellectual disability in local planning of disability services in the UK, agrees that central to the question of meaningful participation, is access to real power within these forums. He argues that the structure of the forums and how they function does not give access to this power. His observation of meetings and analysis of participation by people with an intellectual disability concluded that whilst they were present they were not participating.

Todd et al., (1997) analysed the participation of people with an intellectual disability in the All Wales Strategy, an early example of large-scale participation of people with an intellectual disability in local disability service planning. They drew similar conclusions to Concannon (2005), reporting that despite people with an intellectual disability constituting 24% of those present at planning meetings, they made only 3% of contributions to discussions. Their study also found that despite the All Wales Strategy having aims of citizenship, and expectations that participation would lead to a shift away from a consumer identity to one of community membership, this did not occur (Todd et al.,cited in Whittell & Ramcharan, 1997).

In the UK, consumer participation by people with an intellectual disability has been fostered by the implementation of Valuing People (DOH, 2001b). People are involved in Learning Disability Partnership Boards (LDPB), that are

responsible for the planning, development and management of government funded learning disability services. Their membership includes people with an intellectual disability, carers and managers. Research has begun to emerge from the UK on these participatory forums. Carol Riddington is undertaking a study on how inclusive these boards are for people with a learning disability and family representatives. Her work is finding little evidence that the LDPBs are functioning as true partnerships between the lay representatives and the public agencies, with few examples of supportive relationships within the boards (Riddington, 2007). Two issues raised by this research are the lack of decision-making power held by these boards and the lack of active participation of the board members who have an intellectual disability.

Another initiative resulting from the implementation of Valuing People and the establishment of LDPBs is the establishment of Parliaments for People with Learning Disability (PPLD). People with an intellectual disability vote for representatives to these parliaments that meet regularly and then inform the LDPB. Elected members of the PPLD consult with a broader group of people with an intellectual disability and services through the parliaments. These parliaments are supported by government at the local level (Royal Borough of Kingston, 2007).

Redley & Weinberg's (2006) research on the PPLD of Cambridgeshire, used an interactional analysis from observations of meetings to determine how people are

interacting and what is impacting on these interactions. They conclude that

people with an intellectual disability are not interacting much or very

meaningfully. This is despite the parliaments being set up as inclusive

environments where structural barriers to participation have been addressed.

There is a strong focus on the use of 'jargon free' language and accessible

written materials. Redley & Weinberg (2006) note that these environments

ensured the voice of the MPs with a learning disability "..were honoured as the

primary spokespeople" (p. 27), however the parliaments still did not function in

this way.

> Our analysis has shown that the PPLD, though explicitly designed to
> honour the liberal democratic principles of political voice and
> participation, seriously faltered in its efforts to realise the principles in
> practice. (p.29)

They conclude that this failure was due mainly to the difficulties the people with

an intellectual disability faced "in situ" dealing with the interactions of the

parliament environment. This they claim could be improved by further reflection

on approaches to empowerment "…without thereby losing sight of their often

very real and serious needs and vulnerabilities" (p. 30). Their research found that

the parliaments had been devised to be fully accessible for people with an

intellectual disability, and in a practical sense they were. However, despite these

adjustments the reasons for poor participation they propose, was due to feelings

of vulnerability in these environments.

Redley & Weinberg's study raises an important question about the balance that needs to be reached between practical approaches to access, and addressing the social and interactional environment, or the group dynamic, so people feel they can have their say. In the PPLD accessible practices like easy English documents and using processes that enabled people to interject when they did not understand, were useful; however they did not address the way people felt about having a say. This suggests the need to think beyond practical means of supporting participation where adjustments are made to processes and information made accessible, to addressing people's needs to establish supportive relationships based on acceptance and respect. This also needs to be individualised. People need to feel that their input will be heard, respected and acted on so they can feel confident to have their say. Self advocacy has enabled many people with an intellectual disability to develop these skills, and the link between self advocacy and effective participation has been found in some research (Whittell & Ramcharan, 1998).

The third plank of participation in policy making in the UK is the Learning Disability Task Force. This is the forum where issues from self advocates can be presented directly to the government minister through a network of local and regional self advocacy groups and their representatives who report to two senior bureaucrats. This senior position is job–shared between a person with an intellectual disability and an experienced bureaucrat.

This three-pronged framework in the UK was devised to model equality, inclusion, joined up participation and representation; however, research about its effectiveness has not been released at the time of writing (Grant & Ramcharan, in press). It uses the strong self advocacy sector to have representation of people with an intellectual disability from the local level to the national level, and has devised accessible approaches to support this participation. However, as Redley & Weinberg (2006) found, people with an intellectual disability may still feel personally disempowered and incompetent within these forums. This question of empowerment is discussed in the literature as both a political and a personal aim in participation, and a required outcome of participation. Boyce et al., (2001) found that empowerment is what disability organisations and people with a disability want from participation. However as these studies have found, there are both structural and individual impediments to empowerment within citizen participation forums.

Empowerment

Meaningful participation, Arnstein and others have argued, is reliant on access to decision-making power within these forums. Arnstein's representation of citizen participation as the ladder of participation (Arnstein, 1969) is essentially about the redistribution of power to enable greater levels of control by the citizens or the governed in government. She notes "There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process" (p. 216). The question of 'real power' within

participatory forums is central to the study of citizen participation by people with

an intellectual disability. Arnstein's work is both a critique of the structures that

are used for citizen participation, and the decision making power they have within

the broader policy arena and about personal power, or how a person feels about

their capacity to participate and to achieve outcomes in citizen participation

forums.

Power to make the decisions and empowerment to have a say, are important

concepts raised here, however these questions have not been fully considered in

disability studies literature that addresses forms of consumer or citizen

participation (Boyce et al., 2001; Dearden-Phillips & Fountain, 2005; Redley &

Weinberg, 2006; Whittell & Ramcharan, 1998). There is a body of work on

empowerment as it applies more broadly to the lives of people with an intellectual

disability (Bayley, 1997; Brandon, 2005; Dowson, 1997; Goodley, 2001, 2005;

Hallahan, 1995; Ramcharan, Roberts, Grant , & Boland, 1997; Stainton, 2005;

Walmsley & Downer, 1997) that raises some related issues. In relation to the

broader question of empowerment Stainton (2005) notes:

> While definitions vary, the essence of empowerment is about enhancing,
> securing and/or legitimating the power of oneself, another, or a collective.
> For people who have been labeled as having a learning disability this is
> indeed a profound change – and challenge – to a society and service
> system which have on many occasions either inadvertently or actively
> sought to diminish, delegitimate, oppress and control those so labeled.
> (p. 289)

Empowerment is defined here as a process that can be personal or collective. It

is about legitimising the personal power people have and enabling this to be

used to gain more personal and collective power. Stainton's definition also notes that whilst it is understood in this way, for people with an intellectual disability to realise empowerment there needs to be attitudinal change.

Studies that have focussed on how people with an intellectual disability experience participation as consumers have found that participation practices have not always delivered empowerment. This is despite the view put forward that empowerment is an intended outcome of participation. Boyce et al., (2001) make this point from their study of Canadian disability organisations' participation in a range of policymaking forums in that country. Croft & Beresford (1995), in writing about consumer participation involving people with an intellectual disability suggest that on the contrary, disempowerment is a more common experience. Grant (1997) notes:

> New structures to involve users and families are established; multidisciplinary planning forums ….are designed; mechanisms to link individual, local and county strategic planning are put in place… [and] It is assumed that the involvement of users and families will somehow ensure that grass-roots ideas based on an appreciation of individual needs will inevitably…help to empower people. (p. 122)

This view suggests that whilst the structures can intend to be empowering, people can still experience feelings of disempowerment, a view also put by Redley & Weinberg (2006). Fisher (1994) cited in Grant (1997) adds that "..a right to participation remains a mere ideology unless matched by the means of making it a genuine experience of shared decision making" (p. 124). The means that Fisher refers to could be addressed at a structural and a personal level.

The key finding from the research is that empowerment should be the outcome of

participation, and that for this to occur structures must enable power through the

way they are formed and how they address decision making roles. In addition, a

feeling of empowerment should be experienced by people who are participating,

however this is not common. The research suggests this is due to both the

structures and to the way people with an intellectual disability are perceived

within these forums. The literature finds that people can feel incompetent and

have very little personal power because attitudes are still prevalent that see

people with an intellectual disability in this way.   Funding bodies committed to

empowering participatory experiences in the UK have developed guiding

principles for consumer participation, to ensure both the structural and the

personal power issues are addressed (Joseph Rowntree, 2003). However, there

is little research about the differences this has made or research about the

experiences people have in these roles.

Consumer and citizen participation forums that do involve people with an

intellectual disability normally have members with an intellectual disability, people

with other disabilities, parents, carers and often government officials. Whitehead

and Hughey (2004) raise concerns about the inherent power imbalance in these

situations and how this composition impacts on the way people with an

intellectual disability participate, noting "… isolation and degraded life options

imposed upon people with an intellectual disability is the result of often hidden

and unexplored dynamics of social power" (p. ix). These hidden dynamics are

likely to be significant for people with an intellectual disability when they are participating alongside others who represent social institutions that have had 'power over' them in the past. There is little research about how people experience interactions with people who represent services or government, however the research by Redley & Weinberg (2006) of the PPLDs did find that people with an intellectual disability felt vulnerable and unable to have their say, despite being supported to do this.

Australian disability advisory bodies have members with a range of disabilities, those with intellectual disability being the minority. This raises another power dynamic that is rarely addressed in the literature. There is an assumption made in these forums that people with disabilities are equal and can participate equally, particularly when the trend is to have membership that is solely people with a disability. A recent study on attitudes towards people with disabilities, by people with disabilities and others, has found that intellectual disability and mental illness are equally seen as the least accepted by both people with disabilities and the community (Deal, 2006). This finding raises an important question about solidarity and equality within cross-disability groups. Also, some literature suggests people with an intellectual disability have been left out of the social model of disability that has dominated disability politics (Chappell, Goodley, & Lawthorn, 2001; Dowse, 2001; Goodley, Armstrong, Sutherland & Laurie, 2003), which in turn has isolated them from this debate and the disability movement (Driedger, 1989). These hidden dynamics between people with different

disabilities could impact upon even the most well thought out participatory

processes. Studies suggest that empowerment to speak and have your say for

the person with an intellectual disability, can be mediated by who else is in the

participatory environment and how the person perceives their relationship with

them (Redley & Weinberg, 2006).

Overall the literature on empowerment and participation suggests that the

question of power, empowerment and equal and supportive relationships within

citizen participation, is central to enabling meaningful and less tokenistic

participatory experiences. However, there is a dearth of literature on how people

with an intellectual disability in these roles experience power dynamics or how to

address them.

Self advocacy and participation

Self advocacy is recognised as the collective grass roots social movement of

people with an intellectual disability. Goodley (2000) defined self advocacy as the

public recognition of the resilience of people with learning difficulties, which

changed the focus from what people were doing in self advocacy, to what self

advocacy represented. Others have defined self advocacy in terms of its

representation of self determination by people with an intellectual disability

(Armstrong, 2002; Beart et al., 2004; Crawley, 1988; Dybwad & Bersani, 1996;

Romeo, 1996; Whitehead & Hughey, 2004). Self advocates themselves have

defined it as follows:

Encouraging people with an intellectual disability to believe in and speak out about their rights. (Reinforce, 2007).

Its all about expressing yourself, getting to know people and sorting things out [Jon]. (Wyre Forest Self Advocacy & Tarleton 2005 p. 65)

It helps you get independent and it gives you a life [Emma]. (Wyre Forest Self Advocacy & Tarleton, 2005, p. 65)

Self advocacy is talking for yourself, going to meetings, not being dependent on other people to speak for you. (Armstrong, 2002. 335)

Research about self advocacy commonly draws together people's own stories of their experiences in self advocacy and how self advocacy as a movement has influenced the policy agenda (Mitchell et al., 2006, Armstrong, 2002; Atkinson, 1998, 2000). In countries like the UK, USA, Canada and Australia, where self advocacy has been developing over the last 30 years, self advocacy is an important social movement for people with an intellectual disability. It is also reportedly growing in other countries throughout Europe and Asia.

In the UK in particular, self advocacy has been noted as being central to participation of people with an intellectual disability in decision making about policy and service planning (Armstrong, 2002; Cooper & Hersov, 1986; Goodley, 2000, 2005; Goodley & Van Hove, 2005; Whittell & Ramcharan, 1998). However, in Australia, self advocacy has not developed along the same trajectory despite having similar beginnings (Fyffe, McCubbery, Frawley, Laurie, & Bigby, 2004; Romeo, 1996). Reasons for this have yet to be studied in the Australian context, although one potential factor is the absence of intellectual disability specific policy in Australia.

Recognising the link between strong self advocacy and meaningful participation,

has been important to policy makers and to self advocacy groups. This is

evidenced by the work in the UK on Learning Disability Partnership Boards,

Parliaments for People with Learning Disabilities and the Learning Disability Task

Force. These three kinds of forums draw their membership from the large

number of self advocates in the UK. Whilst the reported number of groups in the

UK in 1997 was 500 (Simons cited in Mitchell, 1997), this has grown substantially

with an additional £3m per year over three years provided for self advocacy and

citizen advocacy development through *Valuing People* (Goodley & Ramcharan,

2005). Some researchers have questioned the impact this has had on the

independence of self advocates and self advocacy groups (Goodley, 2001, 2005;

Walmsley & Downer, 1997; Whitehead & Hughey, 2004). However, it has meant

that more people with an intellectual disability are participating in this social

movement, closely linking them to opportunities to 'have a say' about policy and

practices that affect their lives.

Goodley (2005) raises a concern that the linking of self advocacy to boards set

up by government or through government funding, could weaken the

independence of the self advocacy voice. He asks,

> …Does the policy-led agenda and businesslike structuring of forms of
> self advocacy groups… correspond with the actions and ambitions of the
> existing self advocacy movement? To ensure that policy makers, service
> providers and professionals are not redefining self-advocacy in ways that
> are in contrast to those of the self-advocacy movement we need to
> engage with the ways in which self-advocacy groups respond to and
> promote the resilience of people with learning difficulties. (p. 337)

Goodley & Ramcharan (2005) note that campaigning has been a central focus and important activity of the self advocacy movement; however they note that government constituted forums are, "gaining ascendancy as the chosen means through which people with learning difficulties can use their power and voice" (p. 156). Others have also raised concerns about the close link between self advocacy and government (Armstrong, 2002; Whitehead & Hughey, 2004).

Despite debates about the independence and strength of self advocacy, there is a recognised link between the self advocacy movement and participation in policy making by people with an intellectual disability. This literature suggests that through self advocacy, people with an intellectual disability have gained their own voices, found ways of relating their stories and found their way into positions as policy advisors and policy activists. The place of people with an intellectual disability in these roles is important and self advocacy is, for many people, the way they gain the skills and experience to participate.

Central to the self advocacy movement is the recognition that it represents the collective view about life experiences of people with an intellectual disability, and enables people to come together to represent this common experience. Representation is a key issue when considering citizen participation and how to support a collective voice to be heard. Birch (1971), in a book about representation outlines three ways in which representation is understood; acting on behalf of or as an agent of a principal, being seen to share some

characteristics with a larger group, symbolising the identity or qualities of a

group, or being elected to put forward the views of a group. Self advocacy

enables all of these, therefore providing people with an intellectual disability with

a form of representation. This has been recognised in the UK, the USA and

Canada as discussed in the following chapter, where participatory forums

formally appoint self advocates as representatives of self advocacy and people

with an intellectual disability. However as noted in Beresford & Croft (1993), even

when people are appointed to participatory positions their representative role and

representation skills are not always recognised.

Supporting participation

A common criticism of consultative or advisory forums involving people with an

intellectual disability is that they are 'token', or not meaningful for those who

participate (Simons, 2000; Todd et al., 2000; Whittaker, 1993; Whittell &

Ramcharan, 1998). Some argue that this tokenism can be addressed by better

support; however the literature lacks studies of support in these forums. Self

advocacy literature, however does provide some review of support models and

approaches.

Simons (2000), in a study of the consumer participation experiences of people

with an intellectual disability in England, found that there is a belief by forum

conveners that some participation by people with an intellectual disability is better

than no participation. He found that this view is prevalent in situations where

there is inadequate attention to support, resources and training. Concannon

(2005) concurs with this view, adding that many people with an intellectual

disability lack the experience of being asked their opinion. This, he argues, is

problematic on its own, however when communication support and personal

support are not addressed, people with an intellectual disability are doubly

disadvantaged. Beresford & Croft (1993) suggest, "People need to be offered

support and skills to take part, combined with suitable structures and

opportunities for involvement" (p.51). Tokenism can be addressed, they suggest,

with the provision of both material and personal resources. Importantly they point

to a need to increase individuals' skills and confidence to enable them to

participate meaningfully; however they suggest this is more likely to occur where

people feel well supported and able to participate.

The self advocacy literature has discussed the self advocacy supporter or

advisor role and raises some concerns about how people are supported to

participate in their self advocacy organisations (Chapman, 2005; Chapman &

McNulty, 2004). This literature has concluded that along with the complexity of

this role as a mix between personal, and political or strategic support (Chapman,

2005), many practical support issues are not adequately addressed. Some of the

literature focuses on the practical aspects of participation, finding that people are

not adequately supported to participate in meetings and that the structure of the

organisations impacts on participation (Clement, 2003). Again, there is little

research on supporting participation. Whittaker (1993) in her overview of how

people participated in consumer participation meetings notes that beyond the practical support and changes to the participatory environment, people need commitment from the others in the group. This she argues can come from "thinking about people in new ways" (p. 325), along with implementing practical strategies that enable inclusion. In particular she points to the importance of inclusive language, effective chairing, allowing people to speak about their personal experiences, involvement of a skilled support worker and active listening.

Some self advocacy organisations have published handbooks and guidelines on supporting participation in meetings and/or on boards (Green Mountain Self advocates & ARC Vermont 2003; BILD, Simons, & Holman, 2000). These support the views put forward by Whittaker. Some suggest very practical approaches like using a 'traffic light' to indicate when information is not understood. This allows the person with an intellectual disability to hold up a red card if they need the meeting to stop, in particular if they need people to speak in a way they can understand, or to have a concept explained. Research referred to earlier by Redley & Weinberg (2006) suggests that even within environments that implement these practical approaches, people with an intellectual disability can still feel incompetent and lack the personal confidence to participate.

Work by Hans Reinders (2002), suggests that we need to go beyond the practical approaches of support to building supportive relationships with people

with an intellectual disability. This he calls "civic friendships". This concept is

referred to in more detail in Chapter seven, however what it implies has been

taken up by some other writers. They raise questions about the importance of

friendships and positive attitudes towards people with an intellectual disability

(Goodley & Van Hove, 2005; Whittaker, 1993; Yazbeck, McVilly, & Parmenter,

2004). This latter study by Yazbeck et al., (2004) undertaken using attitude

scales with respondents from a large scale survey in Australia, found that

"respondents reporting prior personal knowledge of a person with intellectual

disabilities consistently indicated that they held more positive attitudes than did

respondents without such knowledge" (p. 112). The implications of this and other

research, particularly life history work with people with an intellectual disability

(Atkinson, 1997, 1998, 2000; Atkinson, McCarthy, & Walmsley, 2000; Atkinson &

Williams, 1990; Traustadottir & Johnson, 2000), suggests the importance of

getting to know people, as a key to effective support.

Summary

It is apparent from this literature review that little is known about the participatory

experiences of people with an intellectual disability from their own perspectives.

Mainstream citizen participation literature gives some insights into issues

prevalent within participatory policymaking; however, this literature has not

included studies of people with intellectual disabilities. Within disability studies

literature, the focus has been on consumer participation, as this role is more

common, particularly in the UK where policy supports participation by people with

an intellectual disability in service planning. However, these participatory forums frame people as consumers or service users, and despite aims to broaden people's involvement as citizens in citizen participation forums, the literature suggests this has not occurred (Whittell & Ramcharan, 1998). Research of participation in Learning Disability Partnership Boards might well report progress towards this aim (Grant & Ramcharan, in press).

By far the most significant findings from the limited literature on intellectual disability and participation is the importance of support that focuses on enabling confident interactions by people with an intellectual disability in participatory forums. The work of Redley & Weinberg (2006), raised particular questions through its use of an interactional analysis of the PPLD, a participatory environment that was specifically developed to include the voices and views of people with an intellectual disability. Their findings when seen in a broader context suggest the need to address personal as well as structural barriers to participation. This is supported by the case studies of Boyce et al (2001) that advocate for a new framework for understanding participation involving people with disabilities that addresses the personal, structural and power differentials in these environments. This follows from a large body of citizen participation work that has raised issues of power and the disempowering nature of citizen participation forums; however it suggests a stronger focus is needed on the personal rather than the structural impediments to participation.

Citizen participation, although a contested approach to policymaking, does enable people to participate in shaping policies that affect their lives. This review of the literature highlights a number of important factors that need to be considered when questioning how and if this participation can be meaningful. Emerging from this research are themes about power and empowerment, questions about the way these forums are structured, issues about perceived tokenism, and questions about representation and representativeness. For people with an intellectual disability, the most compelling issue is the need to establish their rightful place at the policy making table. This issue centres on a debate about their capacity to participate. The literature indicates that there is a suspicion about this and a need to examine further how people participate and what supports or impedes their meaningful participation.

CHAPTER THREE

POLICY CONTEXT

> Clearly, the achievement of global human rights for all citizens is a matter of securing justice. While Governments as well as individual citizens bear a moral responsibility towards this goal, it should be "common sense" for civil society to recognize the human resource potential in all of its members. It is imperative that planners remain sensitive to the disability dimension. (United Nations, 2003-2004)

Introduction

Participatory policymaking forums in the disability sector aim to engage people with a disability and others to gain the 'disability dimension'. This is particularly evident in western democracies where participatory policymaking is used broadly by government. These approaches are supported internationally by the United Nations (UN) Convention on the Rights of Persons with Disabilities (UN, 2006a) which, at the time of writing had 118 signatories. In Article 29, the Convention sets out gaols for participation in political and public life, noting in particular the importance of voting and participation in non-government organisations, political parties and in organisations of people with a disability. The focus of these goals is equal access and equal participation.

Government constituted disability advisory bodies are forums where people with a disability can participate in the political and civic spheres of society. They have become more common in Australia at all levels of government with their numbers having grown in the past decade (Frawley, 2006a). These are the official forums

used by government to consult with people with a disability and other

stakeholders about the formulation, implementation and monitoring of disability

policy. However, as discussed in the previous chapter, little is known about the

impact of these advisory forums or the experiences of people who are members.

This thesis aims to add to this knowledge. A first step in understanding the

forums is to examine how they fit within the broader disability policy context,

understanding why they exist and how disability policies support participation by

people with an intellectual disability.

This chapter provides an overview of the emergence of this participatory

approach to disability policymaking in Australia and a review of the current

disability policy context. It compares this with the USA, Canada and the UK;

other countries that have citizenship, rights and participation as core goals within

disability policy. Stainton (2007) notes that these countries have a convergence

of structures and principles, based primarily on a rights-based approach. This

international perspective is given as a review, and to provide a contrast with the

Australian context.

The growth of participatory policymaking in Australia
Participatory forms of policymaking are based on a premise that they can bring

different views into the policymaking arena. A review of policymaking in Australia,

suggests that this form of policymaking began in the 1970s when there was a

shift from government provision of services, to non-government providers

(Yeatman, 1990). Along with this shift came a move to reform government administration with the Whitlam Government initiating a Royal Commission into Government administration (1976). These changes impacted on the way policy was developed and the place of the public in policymaking.

Yeatman (1990) argues, this led to a focus on democratic participation, and accountability being built into the policy process via local consultation and participation. Wilenski (1986) comments that this brought those affected by policy into the policymaking process. Dalton, Draper, Weeks & Wiseman (1996) suggest that since the adoption of more participatory policymaking approaches, to the present, other forms of public administration have developed, in particular more managerial and corporate approaches. However, they suggest that there is now an amalgam of approaches that all recognise the importance of participation, although each frames the role of individuals differently. For example, citizens can be framed as stakeholders, consumers, service users or individuals and seen as having individual, political or community power. Participatory policymaking engages people in any of these ways and brings a range of people into the policymaking process. Social policy literature calls these groups policy communities or policy networks (Bessant, Watts, Dalton, & Smyth, 2006; Considine, 1994, 2002).

Disability policy communities and disability policy networks engage in a number of ways in the making of disability policy in Australia. Individuals and

organisations participate in policymaking through lobbying, campaigning, being

consulted and through submitting to and presenting at Senate or other

government inquiries. Peak bodies and individuals who are seen as leaders or

key stakeholders, also develop relationships with government whereby they are

seen as having power and influence. People with disabilities are beginning to

take their place in these communities and networks, but as discussed later,

people with an intellectual disability are the smallest disability group present.

The social policy literature has criticised citizen participation for being tokenistic

and merely having people 'at' the table. It questions the power imbalances in

policy forums that place participants in policy legitimisation roles rather than

decision making roles (Patemen, 1970; Wolfe, 2002). Criticisms arise from

scepticism about the policy process itself, whether people are participating in

officially constituted forums or participating in these other ways. Questions of

power, equality of voice, the place of policy advocacy in the policy process and

access to decision makers are central to an examination of any aspect of

participatory policymaking. In summary, these critiques ask, 'Whose voice is

being heard'?

The Australian approach to policymaking reflects approaches in other western

jurisdictions and draws on the processes of citizen participation critiqued in the

literature in the previous chapter. The aim is, as Wilenski (1986), and Richardson

(1983) suggest, to involve people who are affected by policy, in the policymaking

process. Participation of people with a disability in policymaking in Australia is a relatively new phenomenon; it has grown over the past three decades with the emergence of rights based legislation that has affirmed their right to speak for themselves. Previously, service providers and other non-disabled people spoke on their behalf. This has changed markedly for people with physical and sensory disabilities as evidenced by their presence in disability led organisations and their high numbers in the disability movement.

Political participation: Representation and representativeness

In each of the countries discussed below, people with a disability, including people with an intellectual disability, participate in policymaking in a range of ways, other than disability advisory bodies. Most commonly they participate through advocacy organisations or peak bodies and the use of lobbying, campaigns and other advocacy activities. In addition, governments regularly 'invite' people to the policymaking table in government advisory bodies, as discussed in this chapter, and as members of reference groups or participants in targeted consultations. Boyce et al., (2001) suggest that this kind of participation is policy advocacy as opposed to policy participation, whereas Barnes et al., (2007) make the distinction between formal structures, which they call "officially constituted forums" of participation, and other policymaking activities, noting that the former sets up certain formal relationships between those participating and government.

Government disability advisory bodies like those discussed, are a particular type of policy participation forum that has been constituted by government to bring together people who have life experiences and/or professional awareness that can inform policymaking and policy implementation. They provide an opportunity for people with a disability to be seen beyond their 'client', 'service user' or 'consumer' role. They are seen as citizens, who have a place at the policymaking table of government, due to their life experience as people with a disability who share a place in the community alongside other citizens.

Goodley & Ramcharan (2005) warn that approaches that closely align groups with the policy makers through shared membership of forums, like the UK Learning Disability Task Force, may lessen the independence of participants' voices and weaken their ability to set the agenda. Boyce et al., (2001) raise a related question about representation and representativeness. They argue that formal policy participation in which individuals are appointed as an individual to represent a particular part of the population, is devised from a consumerism and market welfare basis and creates elite leadership roles. This approach, they call representativeness. They suggest that this approach looks for people who characterise particular categories or groups within society, and are representative of these groups. In contrast, where a person is seen to represent a collective or a group, they are providing representation from them. This Boyce et al., (2001) say is based on the "...politics of liberation, inclusion and equal opportunities" (p. 149), and holds different expectations about the way views and

issues are presented by the person making representation. They warn however, that the representation approach does not always work because individuals or groups represented in formal advisory bodies, may experience inhibited participation due to lack of power, information, and participatory skills.

These themes are explored more throughout the thesis; however the question of representation is significant as the Australian government advisory bodies, in contrast to those in other countries, require that people be appointed as individuals. They are not representing a collective voice, but are seen as being representative of the experience of intellectual disability. In the UK, USA and Canada, people with an intellectual disability are appointed to provide representation from self advocates and self advocacy groups; however in these countries there are also opportunities for individuals to represent their own views and experiences, and some examples of representativeness.

Rights-based legislation and policy: Enabling participation
Opportunities for participation have been enabled to some extent by rights-based disability legislation and policy. Stainton (2005) talks about an "architecture of rights based social policy" in current disability policy. He argues that a "coherent model is emerging with recognizable elements" which he notes are, "the related ideas of rights, choice, citizenship and self-determination" (p. 289). He notes these are evident in the more progressive disability policies in western jurisdictions.

This convergence of ideas and underlying principles have now been enshrined in the UN Convention on the Rights of Persons with Disabilities (UN, 2006a), discussed below. The UN had earlier covenants and conventions that specifically dealt with disability rights, for example the UN Declaration of the Rights of the Mentally Retarded [sic] (1971), followed by the UN Declaration of Disabled Persons (1975) and the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities (1993). A review of the range of UN declarations, agreements and measures over the past fifty years that pertain to disability show a steady progression towards a rights perspective and a dedifferentiated approach to disability (UN, 2003-2004). This is evident in the current Convention that adopts a multi-faceted definition of disability. The UN has an impressive history of leadership in progressing the rights of people with disabilities and reports suggest people with a disability are very encouraged by the current convention (Disabled People International, 2007). However, it is important to note that legislation of rights does not in itself lead to fulfilment of these rights (Nagler, 1993; Young & Quibell, 2000), and some things like friendships, attitudinal change and full citizenship rely on more than legislation to be fulfilled (Reinders, 2002).

Many other jurisdictions have incorporated disability rights within other Human Rights and Anti Discrimination legislation, these include, the Canadian Charter of Human Rights and Freedoms (1985), the Australian Human Rights and Equal Opportunity Commission Act (1986) and the State and Territory Equal

Opportunity Acts, the New Zealand Bill of Rights Act (1990) and Human Rights

Act (1993), and the UK Disability Discrimination Act (2005). Such legislation

brings disability rights into a human rights framework. In Australia, the state of

Victoria has recently passed the Charter of Human Rights and Responsibilities

Act (2006), which aligns with the new Disability Act (2006) and forms a clear

rights based legislative approach with a focus on freedom, respect, dignity,

choice, citizenship and self-determination.

For people with intellectual disabilities realising equal rights is perhaps an even

harder task given their lack of involvement in much of this legislative change. In

Victoria, self advocates were poorly represented in the legislative review process,

being represented by peak organisations without direct representation of self

advocates or self advocacy groups (Frawley, 2006b). Likewise, the consultation

process for the UN Convention (2006) boasts the highest level of participation of

any UN Human Rights convention, although the Ad Hoc Committee had no

representation from People First, the largest international network of self

advocacy groups of people with an intellectual disability (UN, 2006b). A recent

study (Deal, 2006) proposes that there exists a hierarchy of disability within the

community of people with a disability. This suggests that there is still a long way

to go to attain equality, respect and understanding for people with an intellectual

disability, not only in the society, but also within the disability community.

Intellectual disability and participation

One important mechanism for people with an intellectual disability to have a say about their own lives and policy that affects their lives is the self advocacy movement. However, there are still many people with an intellectual disability who are not involved in this movement and who are not supported to participate in decisions affecting themselves, or to be spokespeople for others. Some people with an intellectual disability do not have the communication skills, opportunities or capacity to participate; however, strong self advocacy and general advocacy can represent their needs. Self advocacy in particular is an example of what Yeatman (2000) calls 'disability led' participation. However, she notes that even with disability led participation there can be differences in power and voice. In particular she raises issues about the power differentials in such forums that bring together people with different disabilities, government officials and sometimes parents and carers:

> The disability-led model of participation also brings out the ways in which differences in power can either facilitate individual participation or work to suppress it. (p. 200)

Yeatman argues that individual agency is not the same as independence and that people who are dependent or interdependent, can have individual agency and should be recognised in this way. This, she suggests is important in establishing reciprocal supportive relationships to enable meaningful participation. She argues that good relationships built on recognition of a persons capacities and that address a persons dependencies can enable participation. Her main point being that dependence should not exclude a person from

participation. In a similar way, Stainton (2007) notes that difference is what

characterises disability and what he calls the 'difference dilemma' highlights the

difficulties faced when people with disabilities are given equal treatment when

they might need different treatment to be able to participate. Currently in

Australia, different experiences of disability are not consistently recognised in

legislation or policy. There has been a shift towards dedifferentiation. This

approach is characterised by a focus on the community as the place where

services and supports are based, and a move away from specialist services for

particular groups of people with disabilities, to generalist services and supports

(Tossebro, Gustavsson, & Dyrendahl, 1996). This approach is evident in current

Australian disability legislation and policy (Commonwealth Disability Strategy,

2000; Disability Act, 2006 *Vic*).

This is consistent with the UK social model, which underpins most disability

policy and legislation in western jurisdictions. Primarily, this model downplays the

importance of impairment, suggesting that a view of disability that focused on

differences and impairments led to oppression and isolation of people with a

disability. However, former proponents of this view are beginning to advocate for

more comprehensive understanding of disability that goes beyond the binary

debate of medical model versus social model. Shakespeare (2006) claims that

the rejection of impairment as put forward by the social model has not led to less

oppression for all people with a disability. In particular, he concedes that people

with an intellectual disability have not had equal gains from this approach. He

notes that the social model has failed to, "encompass the range of different impairment/disability experiences" (p. 55). He goes on to describe the approach he is adopting as one that recognises that:

> …Disability is always an interaction between individual and structural factors…The experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which she finds herself. (p. 55)

He suggests that amongst the intrinsic factors are: the nature and severity of impairment, individuals' own attitudes towards this, personal qualities and abilities and personality. In addition to social barriers, he suggests the extrinsic factors also include the "attitudes and reactions of others" (p. 56). Despite criticisms of the social model and some shift towards a more multi-faceted view of disability, current policy and legislation in western countries, including Australia, is still heavily influenced by and based on it.

Until July 2007, when the Intellectually Disabled Persons Services Act (1986) was repealed, Victoria was the only Australian State that had intellectual disability specific legislation, and hence specific policies and services for people with an intellectual disability. Currently, some supports and services remain primarily for people with an intellectual disability. In Victoria this has meant the passage of new legislation, the Disability Act (2006) that uses the following definition of disability:

> A sensory, physical or neurological impairment or acquired brain injury or any combination thereof, which, (i) is, or is likely to be, permanent; and (ii) causes a substantially reduced capacity in at least one of the areas of self-care, self management, mobility or communication; and (iii) requires

significant ongoing or long term episodic support; and (iv) is not related to ageing. (Disability Act, 2006 *Vic*, s3)

It also notes that this includes intellectual disability and developmental delay; however it excludes Autism and Psychiatric Disability if they are the primary disability. This legislation does not refer to particular disabilities requiring particular approaches, supports or services. Although, for people with an intellectual disability there are separate provisions for individual planning and for the use of restrictive practices that goes some way to recognising different needs in this area.

Participation is central to this new legislation, along with citizenship and self-determination. These are reflected in its goals of community inclusion, access, person centred planning, strengthening rights, providing better complaints systems and a focus on quality. Within each of these goals, active roles are identified for people with a disability. This legislation makes provisions for the Victorian Disability Advisory Council as a way of achieving participation in policymaking, noting:

> The Victorian Disability Advisory Council is a way for people with a disability to have a say in decision making on whole-of-government policy issues. Most Council members must be people with a disability (DHS, 2007).

The membership of this advisory body is to:

> (a) reflect the diversity of persons with a disability; and (b) reflect the cultural and indigenous backgrounds of persons with a disability; and (c) have appropriate skills, knowledge and experience in matters relevant to persons with a disability, including children with a disability; and (d) in so far as is possible have personal experience of disability. The Minister

must ensure that a majority of the members of the Victorian Disability Advisory Council are persons with a disability. (DHS, 2007)

A scoping survey undertaken as part of this study found that people with an intellectual disability are under-represented on this government advisory body and similar bodies in other States, Territories and in Local governments. The majority of places for people with a disability are filled by people with a physical or sensory disability (Frawley, 2006c). This trend has emerged despite people with an intellectual disability representing the highest users of government funded disability services nation wide (AIHW, 2003, 2007).

In contrast, participation by people with an intellectual disability in disability participation forums is higher in countries like the UK and the USA, as discussed later. In the UK there is intellectual disability specific policy and broad disability rights and anti discrimination legislation, and in the USA there is both intellectual disability legislation and broad disability rights legislation. This differentiated approach reflects the view put forward by Shakespeare (2006), that impairment cannot be ignored as it is significant to defining and understanding individuals' experiences of disability, and consequently their needs and the issues they face living in the community. This dual approach to legislation and policy allows for recognition of both the particular and the shared experience of disability. Specific needs and subsequently the services to support these are enabled; however broader rights and the shared experience of disability discrimination is acknowledged by the general disability rights and anti discrimination legislation.

People with an intellectual disability are afforded the same rights to participation

as all other people with a disability through disability legislation and policy in

Australia; however they are participating at lower rates in government constituted

advisory forums (Frawley, 2006c). As Yeatman (2000) and Stainton (2005) note,

participation for them is not a question of capacity but one of supports, and

recognising the need to establish ways of supporting participation through

relationships that address support needs and people's 'differences' and

dependencies, whilst not undermining their individual agency or capacity. In

addition, for those who cannot express their own views, it is suggested by

research discussed below, that a strong self advocacy movement is needed.

Self Advocacy and participation

Chapter 2 noted the importance of the self advocacy movement in disability

specific citizen and consumer participation in countries like the UK, USA and

Canada. In Australia there is no national self advocacy network and the self

advocacy movement has not developed as strongly as it has in the UK, the USA

and Canada. In these countries the self advocacy movement has set a strong

foundation for people with an intellectual disability to have a say in their lives,

have a say in their services and more recently in disability and community policy.

Hayden & Nelis (2002) note:

> The Self Advocacy movement was started by and for people with a
> developmental [sic] disability who wanted to advocate on their own

behalf rather than have others like professionals and family members speak for them. (p. 221)

A major part of this advocacy has been about having a voice beyond services; this is reflected in the goals and aims of self advocacy organisations. Self Advocates Becoming Empowered (SABE) is a national self advocacy group in the USA, Reinforce is a state-wide self advocacy group in Victoria, Australia and People First Norfolk is an English self advocacy group. Here they state their goals, aims and objectives:

> SABE will be a political power house to work on legislation that effects people with disabilities lives [by working on] Equal representation of self-advocates on Medicaid state boards; SABE presents at national governors and mayors conference on financial freedom, People First language, housing and accessible communication; Self-advocates will lead policy change; Lawmakers will recognize SABE and we will support their campaigns and educate them on our issues; More people at the table when they are making decisions about our lives. (SABE, 2007)

> Reinforce is a self advocacy organisation for people with an intellectual disability. Reinforce is here to assist, support and encourage independence for people with an intellectual disability. Reinforce promotes the rights of people with an intellectual disability to be upheld in the same way as everyone else in the community. (Reinforce, 2007)

> We give training, we provide information and give advice, we make videos, we work in the office, we work with others, we take part in steering groups, we organise and attend conferences, we organise and attend meetings, we sit on sub groups, we raise money, we campaign, we have fun. (People First of Norfolk, 2007).

Internationally the People First movement is the recognised umbrella organisation for self advocacy groups; however in Australia most self advocacy groups are not affiliated with People First. In the USA, Canada and the UK, People First is well established and connected through local, state/county,

national and international bodies. These networks have been used to formalise the participation of people with an intellectual disability in citizen participation forums in these countries and in local disability service planning boards. This is strengthened by disability legislation and policy that differentiates intellectual disability and focuses on services, supports and policy development for people with an intellectual disability.

Research in the UK has positively linked strong self advocacy to the increased participation of people with an intellectual disability in policy planning (Whittell & Ramcharan, 1998). In Australia, little research has been conducted on the self advocacy movement, (Fyffe et al., 2004; Romeo, 1996), and as already stated there is very limited research on how people with an intellectual disability participate in policymaking. Therefore it is difficult to draw any conclusions about the links between self advocacy and policy participation in Australia.

Historically, in Australia, self advocacy policy participation has mainly been through campaigning and lobbying for the rights of people with an intellectual disability. However, without formal recognition of self advocacy at a government level, through naming self advocacy as the body that represents people with an intellectual disability as it is in the USA, UK and Canada, they will still have to fight for their place at the policymaking table as a representative arm of people with an intellectual disability.

Participation and different levels of government

All levels of government in Australia have some form of government disability advisory bodies. They operate within terms of reference set by legislation or policy. The level of government and its legislation and policy responsibilities for disability funding and services primarily shapes the focus. In Australia there is clear delineation between levels of government for different areas of disability funding, services and supports. Thus, State Government advisory bodies have a focus on housing and support, education and transport, Local Government bodies focus on accessibility of public places and community activities, and the National advisory body focuses on income support and employment. One unifying concept is access, in particular access to the built environment, which is addressed by each level of government. This is primarily due to the provisions of the Federal Disability Discrimination Act (DDA, 1992, *Cth)* that recommend the development of Disability Action Plans to address this area (s 50 – 65).

Like Canada, Australia's governmental system allows for National, State, Territory, and Local Governments to operate autonomously in some areas. This is due mainly to the division of power between each level of government and their concomitant funding responsibilities. In Australia, there are shared policy areas. The Commonwealth, State and Territory Disability Agreement sets out those areas that are to be shared and those to be the separate responsibility of States, Territories or the Commonwealth. The establishment of new agreements can require protracted negotiations, often including disability advocacy groups

lobbying with both levels of government. The Commonwealth, State and Territory

Disability Agreement, states,

> …All parties are responsible for funding specialist services for people
> with disabilities: the Australian Government has responsibility for the
> planning, policy setting and management of specialised employment
> assistance; state and territory governments have similar responsibilities
> for accommodation support, community support, community access and
> respite; and support for advocacy and print disability is a shared
> responsibility. (FACSIA, 2002)

Local Governments have no legislative connection to the Commonwealth as their

roles and responsibilities are set out in State legislation. Most Local

Governments reflect State disability policy. In Victoria, there has been some

commitment by the State Government to work collaboratively with Local

Government in areas of community inclusion, and participation for planning

(Disability Advisory Council of Victoria & Municipal Association of Victoria, 2005).

However, Local Government disability advisory bodies, like the Municipal

advisory bodies in Canada have a very local focus and primarily advise on issues

of access and inclusion in local services and the community.

Different policy aims impact on the focus of the different government advisory

bodies. State Governments' disability policy and legislation in Australia differs in

each State. They are all based on similar rights-based principles, however they

are either whole of government focussed, attempting to lead policy change in all

government areas and the community or have a stronger focus on the

development of specialist disability services. Advisory bodies of governments

that have a specialist service focus are more commonly engaged in direct advice

and decision making about the direction of disability services and programs, where those with a whole of government focus do not tend to advise on disability service issues. For example in two Australian States in the same timeframe, residential institutions for people with an intellectual disability were being closed. The advisory body that had a disability service advisory role was closely involved in providing advice on the closure process, where in the State with a whole of government focus, the advisory body did not participate in the discussions about the closure or have a role in monitoring the process.

Many people with an intellectual disability are interested in improving disability services and supports, even when they are not specialist service users. This has been the focus of their self advocacy work, and underpins their interests in policy participation, as discussed later in Chapter 5. However, the policy focus, terms of reference and way the advisory body functions, may not engage them in debates about improving disability services, focusing more on broader issues affecting all people with disabilities like access to the community and its services, education, employment and income support.

Different participatory opportunities are associated with different advisory bodies. People's experiences of these different groups are discussed later in Chapters 5 and 6. However, people in this study did not always understand the different policy foci of different levels of government. Many of the people were not aware of the different policy and legislative frameworks that their advisory bodies

operated within. Participation in different kinds of policy advisory forums requires different policy knowledge and holds different expectations.

The current Australian disability policy context

The Australian legislative context includes Federal disability legislation that outlines the responsibilities of the Commonwealth Government in the provision of supports and services for people with a disability, (Disability Services Act, 1986 *Cth*). There is Federal Disability Discrimination legislation (Disability Discrimination Act, 1992 *Cth*) and Federal Equal Opportunity legislation (Human Rights and Equal Opportunity Commission Act, 1986 *Cth).* All States and Territories also have disability legislation and Equal Opportunity legislation. In addition, States like Victoria have recently developed Human Rights legislation (Charter of Human Rights and Responsibilities Act, 2007) that specifically outlines political and civic rights. This raft of legislation establishes a strong rights based foundation for disability policy in Australia.

All levels of government in Australia have disability policies that promote the full participation of people with a disability in the life of their community. They recognise that people with disabilities have the same rights, responsibilities and opportunities as all other citizens. The Commonwealth Disability Strategy (2000), which sets out the Federal Government's approach to disability supports and services, states the following principles:

Equity: people with disabilities have the right to participate in all aspects of the community including the opportunity to contribute to social, political, economic and cultural life; **Inclusion**: all mainstream Australian government programs, services and facilities should be available to all people with disabilities. The requirements of all people with disabilities should be taken into account at all stages of the development and delivery of these programs and services; **Participation:** people with disabilities have the right to participate on an equal basis in all decision making processes that affect their lives. (2000)

This strategy goes on to state that the outcome of diversity in social policy, in this case focussing on disability as diversity, is achievable:

…By involving people with disabilities in consideration of issues which affect them through inclusion on boards, advisory committees and reference groups. This is an efficient and effective way of ensuring that their needs are met at the time that policy is being developed and programs are being planned. (2000)

State, Territory and Local government policies also reflect this focus on citizenship and participation:

By 2012, Victoria will be a stronger and more inclusive community - a place where diversity is embraced and celebrated, and where everyone has the same opportunities to participate in the life of the community, and the same responsibilities towards society as all other citizens of Victoria. (State Government of Victoria, 2002. p. 7)

A society in which individuals with disabilities and their carers live as full citizens with optimum quality of life, independence and participation (NSW Government, 1998 p. 5).

The Disability Action plan will ensure people with disabilities have improved access to facilities and services and the opportunity to participate in community activities.(*Frankston City Council Disability Action Plan: phase one*, 2000 p. 5).

The focus of these government policies is community inclusion, equal and full citizenship and participation in the life of the community. Many Australian State, Territory and Local Government policies also focus on building the capacity of

communities to include people with disabilities. These current policies reflect a shift from a welfare to a rights framework for disability policy, and a shift in ways of understanding disability from a medical model or individual model, to social models (Oliver, 1996; Priestley, 1998), or as is currently debated (Shakespeare, 2006) and is reflected in disability measures (WHO, 2002), a multi-faceted model that recognises the inter-relationship between the individual and the social.

Notions of participation put forward in these policies are inclusive of citizen, community and political participation; however there is a strong focus on community participation. This is evident in the growth of community inclusion programs funded by all levels of government. These are primarily about physical access to community life, through improved streetscapes, community transport, access to buildings, and access and participation in community events. Local Governments in particular are involved in promoting community participation via their Disability Action Plans that outline how they meet the access and equity goals and objectives of the Disability Discrimination Act (1992). In contrast, little has been done in practice to support or develop citizen participation, beyond the establishment of government disability advisory bodies. In some States these bodies now have a formal status and are included in Disability Legislation (see Disability Act, 2006, *Vic*), however the opportunities they provide for participation are limited.

The Victorian government's *Victorian State Disability Plan 2002-2012* (DHS, 2002), has goals to increase community participation and accountability to people with a disability in planning. The government has funded a number of community inclusion and participation strategies including Rural Access, Metro Access and the Disability Advisory Council. The two access programs work within Local Government to increase participation of people with a disability in the community and in local planning through Local Government disability advisory councils. To strengthen the participation of people with a disability in service planning the disability services department launched the 'Active Participation Strategy'. This strategy noted that it:

> …. Supports people with a disability to exercise their democratic right to be involved and to participate in the decision-making processes that affect them and the communities in which they live. (DHS, 2004)

Active participation has been framed in this strategy quite broadly. It encompasses participation in the government department by inclusion of people with disabilities in departmental boards, in services and in the community. To support this strategy a reference group of people with disabilities was convened that advised on approaches to implementation of the strategy. Overall, it aimed to develop a participatory framework to enable people with a disability to have input into shaping their services and supports, being involved in governance of their services, increase participation in the community and enable participation of people with a disability in policy of the government disability department. However, few of these outcomes have been realised; an evaluation of the

strategy was undertaken but not published. Anecdotally, people with an intellectual disability who were involved in this study and had also participated in advisory committees of the Active Participation strategy, reported that they were frustrated by the lack of action from this strategy. This State Government approach to participation is an example of how participation has become an important plank of disability policy and reflects some of the difficulties that governments encounter when attempting to implement participation frameworks.

The notion of a formal forum, comprising people with a disability and others from the field, to advise government is relatively new in the Australian disability policy context. The earliest cross-disability advisory body was established two decades ago, however the majority of existing disability advisory bodies have been established in the past ten years, with most in the past five. This could be attributed to a greater focus on consultative approaches to policymaking within government broadly. However, in disability policy it is likely to be due to the shift from a welfare or medical model of disability, to a rights based approach that values the voice of people with a disability in decisions impacting on their lives. Some jurisdictions have been quicker to act on the policy principles of inclusion and participation than others.

The rights based legislation discussed earlier, has been in existence for a long time in this country, however commitments to the civil and political rights of people with a disability through increased participation in policymaking and

advice, have taken longer to be established across Australia. In 2004 the

Productivity Commission completed a review of the Federal Disability

Discrimination Act (DDA), (Productivity Commission, *Review of the Disability*

Discrimination Act 1992. Productivity Commission inquiry report, 2004) reporting

a number of findings about the impact of this legislation and recommendations

for changes. These appear to have acted as an impetus for the establishment or

re-establishment of disability advisory bodies, as between 2000 and 2005

advisory bodies at all levels of government increased, where existing ones were

reviewed and re-developed.

The review of the DDA by the Productivity Commission raised a number of

important issues about participation. First, it found that people with physical

disabilities have been helped more by the DDA than those with mental illness or

intellectual disability, (Productivity Commission, *Review of the Disability*

Discrimination Act 1992. Productivity Commission inquiry report, 2004 p. xxvi).

This confirms that people with an intellectual disability are not as present within

society and goes some way to explaining their low numbers in forums that seek

to represent the experiences of people with a disability. Second, the review

notes the importance of civic participation, but addresses it narrowly in relation to

voting and jury duty, rather than other forms of political and civic participation. In

Victoria, the development of the recent Charter of Human Rights and

Responsibilities Act (2006) concerned with civil and political rights, addresses

some issues raised in the DDA review about broader social and political

participation. Third, it raises the profile of Disability Action Plans, noting that they can be important in beginning to address access and equity issues.

This report also found that the DDA was a very under-utilised piece of legislation. Many of its provisions for development of rights based approaches had not been addressed in the first ten years of its existence. The review has had a part in the development of recent measures against discrimination including a focus by government on community, civic and political participation as ways of ensuring people with a disability are having a say about issues like access, inclusion and policy directions (Productivty Commission of Australia, *Review of the Disability Discrimination Act 1992. Productivity Commission inquiry report*, 2004).

The Australian disability policy context is characterised by a focus on participation and inclusion. However, the rights based approach put forward by both legislation and policy has not necessarily led to the same gains being made for all people with a disability. Community participation has had a stronger focus in these policies and hence, supports and programs have been established to ensure people have more opportunities to participate in the life of the community.

Civic and political participation has been narrowly defined in the DDA, subsequently government supported civic and political participation opportunities are limited to formal advisory bodies. However, people with a disability are increasingly becoming involved in policy communities and networks that directly

lobby government. As noted though, people with an intellectual disability are still under-represented in both the formal bodies and due to a lack of support for self advocacy, they are not as present in direct campaigning and lobbying as other disability groups. Compared with the other countries discussed below, Australia lacks a joined- up approach to citizen participation and also lacks strong consumer participation opportunities for people with a disability. In part this is due to the dedifferentiated policy context where intellectual disability is not addressed separately in policy or legislation.

The USA approach

In the USA there is overarching disability legislation, the Americans with Disabilities Act (1990) and legislation that specifically deals with developmental disability, which encompasses intellectual disability, the Developmental Disability Assistance and Bill of Rights Act (2000). This latter legislation specifically recognises self-determination rights and policy participation rights. Its goals include:

> [Provision of] opportunities to participate in, and contribute to, their communities; and support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities. (Developmental Disability Assistance and Bill of Rights Act, 2000, s.27 d & e)

This legislation also makes provisions for State (or Governors) Councils on Developmental Disabilities in each State. Their role is "… to engage in advocacy, capacity building, and systemic change activities" ("Developmental Disabilities

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Assistance and Bill of Rights Act," 2000). Importantly, this legislation names self advocacy as the movement where people with developmental disabilities can gain leadership and advocacy skills and links this directly to their participation in forums that educate policymakers and develop policies.

Nationally, there is a Presidents Committee for People with an Intellectual Disability. This was first established in 1966 and has grown and changed over time, now having a budget of US$498,000, thirteen ex-officio members who are heads of key government departments and organisations and twenty one 'civil members' (Department of Health and Human Services, 2007). Self advocates are named as key members of this council. Likewise, people with an intellectual disability are appointed to the Governor's Councils on Developmental Disabilities and through these make direct representation to State Governors. People with an intellectual disability are supported to participate by having access to a group of advisory members comprising self advocates and disability advocates.

Schalock et al., (2002) note in their review of intellectual disability in the USA, that the current strength in participation is due to: work in the 1950s through to the 1970s by parent advocacy and the civil rights movement that embraced disability rights, the supportive work of President J.F Kennedy on the rights of people with an intellectual disability, the growth of Congressional interest in disability, and adoption of the principle of Normalisation (p. 3). They argue that currently there is a strong disability rights framework and that intellectual

disability has a strong position within this, in particular through self advocacy.

They highlight that self advocacy gained ascendancy in 1990 with the first

national congress of self advocates and that the growth of this movement was a

catalyst for rethinking and growing intellectual disability activism that led to a

significant shift in how intellectual disability is viewed.

The system in the USA also enables people to present directly to government.

The Minnesota Governors Council on Developmental Disabilities established a

citizen participation training program for people with a developmental disability

and parents of children with developmental disabilities with a particular focus on

presenting to government: *Partners in Policymaking*. This program has been

running for twenty years and now operates nationally in the USA and

internationally. The program states its purpose as:

> Partners in Policymaking is designed to educate and empower its
> participants about current issues and best practices and familiarizes
> them with policymaking and the legislative processes at the local, state
> and federal levels (PIP, 2007).

This program has one module called "Making your case" which supports people

to:

> Tell your story effectively; Identify the policymaker who can help you;
> Communicate effectively with policymakers in person, in writing or by
> phone; Develop positive, on-going relationships with key policymakers;
> Organize others to tackle issues with broad community impact (PIP,
> 2007).

Partners in Policymaking promotes knowledge and skill development for active

citizen participation knowing that people doing the courses want to get their

voices heard beyond their services and in the policy arena. This is a unique

course worldwide and addresses a gap in education and training for citizen

participation for people with an intellectual disability. However, there is little

independent research on the outcomes of this program. One study (Johnson,

2007), a long term research of the program is being conducted; however the

findings are not complete and do not differentiate between reported outcomes for

people with a developmental disability or parents.

There is a lack of research about the efficacy of these approaches, and in

particular how people with an intellectual disability experience participation in

them. Also, there is a lack of analysis of disability policy outcomes and stated

goals of these advisory bodies. However, the USA approach does recognise the

representative status of self advocacy, enables participation in a range of ways

and has recognised the need for skill and knowledge development for meaningful

citizen participation.

The Canadian approach

In Canada, policies for people with disabilities fall under each level of

government; Federal, Provincial and Municipal (Government of Canada, 2006).

The guiding legislation for disability rights is the Canadian Charter of Rights and

Freedoms (1985) and the Canadian Human Rights Act (1977). Disability

advocacy groups have prided themselves on ensuring that disability has been

adequately covered within this legislation, noting that it was the first country to

enshrine disability rights within generic human rights legislation (Council of Canadians with Disabilities, 2007a).

Currently there is no national disability specific legislation, however the government of Canada is seeking to develop a National Disability Act (Government of Canada, 2006). This has led to debate by academics, disability advocates and peak bodies about the need for disability specific legislation (Gordon, 2006; Prince, 2007). The main concern raised is whether disability specific legislation does reduce barriers to participation and whether existing human rights and anti-discrimination legislation should be strengthened rather than creating separate legislation (Gordon, 2006).

In recent years there has been a number of studies and reports on disability policy and legislation (Human Resources Department, 2000; Human Resources Department, 1998; Gordon, 2006; Prince, 2001, 2002, 2004, 2007; Puttee, 2002; Rioux & Prince, 2002), fuelled mainly by concerns about existing gaps in legislation and questions about intergovernmental responses to disability (Puttee, 2002). Reports agree that reform is needed (Gordon, 2006; Puttee, 2002), with Puttee noting:

> With the need for significant reform apparent and with reform dependent on co-operation between federal and provincial governments, the way ahead seems clear: concerted, collaborative action on the part of federal and provincial government working with the disability community and others to fashion a wide-ranging reform agenda. (p.8)

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Provinces and Territories have a range of approaches to legislating for rights, services and supports for people with a disability and each Province and/or Territory has established policy to support their legislative framework. A report by the Canadian Government notes that disability is variously defined in the Provinces and Territories within human rights legislation, income programs, employment and education policy (Government of Canada, 2003). Ontario is one province with disability specific legislation, the Accessibility for Ontarians with Disabilities Act (2005) and the Ontarians with Disabilities Act (2001). The latter Act primarily addresses accessibility and will be repealed due to the development of the second Act. At Provincial and Territory levels there has also been significant debate about the need for disability specific legislation with Gordon (2006) noting that in Ontario there has been "mixed results" from their disability legislation. Prince (2007) raised similar concerns in a public lecture asking whether British Columbia needed to enact disability law.

Intellectual disability is not dealt with separately in policy or legislation. Definitions of disability are inclusive of physical, sensory and cognitive disabilities. Intellectual disability is included in this latter category. The multi-facted definition of disability put forward by the World Health Organisation, the UN and adopted by other western jurisdictions is used in Canada.

Citizen and policy participation occur at each of the three levels of government as well as within services. This participation has been primarily through policy

advocacy, organised by disability advocacy groups representing people with a range of disabilities (Council of Canadians with Disabilities, 2007a). Disability specific advocacy groups including People First of Canada, the national self advocacy organisation representing people with an intellectual disability, have also participated in this policy advocacy (People First of Canada, 2007b). There is a history of these and other groups coming together to advocate for change to legislation and disability policy (Boyce et al., 2001).

Formal policy participation is also available through government advisory committees. These have existed at each level of government, although currently there is no National level committee. Disability advocacy groups are lobbying for the re-formation of a National committee along with a National Disability Act (Council of Canadians with Disabilities, 2007). Currently at the National level Ministers responsible for a range of areas including transportation and revenue have formed time limited disability advisory committees. This is in keeping with the 'whole of government' approach to disability policy favoured within Canada. This approach is overseen by an Office for Disability Issues administered by a National Government department that has three Government Ministers.

Provincial and Territory Ministers responsible for disability in some Provinces and Territories have ministerial disability advisory councils, formed along the same lines as the Australian disability advisory bodies in this study. People with a disability hold the majority of places on these committees with other

representatives from disability policy and peak organisations, research and/or

disability services. The following aims are from a Municipal level advisory

committee:

> To provide the Minister Responsible for People with Disabilities with an
> ongoing consumer voice and advice on issues affecting individuals with
> disabilities; Advisory Committee members bring a wide range of
> nonpartisan views and experience with disability issues to ensure that
> the Minister hears the widest possible perspective; The Advisory
> Committee provides a cross-disability perspective on disability issues
> and not the perspective of the disability groups with which members may
> be involved. (*The Prince Edward Island Ministerial Advisory Committee
> on Disability Issues*, 2007).

The terms of reference note that the advisory committee does not duplicate other

existing policy advocacy activities by community advocates but has a broader

role in public policy advice regarding people with a disability. They note that to

meet these aims members need to be " not only cognizant of issues and

concerns of the disability community, but also need to be able to apply this

understanding within a public policy context" (*The Prince Edward Island

Ministerial Advisory Committee on Disability Issues*, 2007). These aims also

reflect the whole of government policy reform agenda outlined above, where an

inclusive community through inclusive public policy is the aim.

Policy participation can also occur within disability services, mainly within the

Community Living movement and services. These services are characterised as

being organisations 'of' not 'for' people with a disability. The focus is on

governance, employment and management by people with a disability. Stainton

(2005) refers to reforms to the governance of the community living services

division, in British Columbia. This division is responsible for an annual budget of $604 million (Canadian) for a range of disability services. The reforms have led to governance of these organisations being turned over to community based boards including designated places for people with an intellectual disability, named the self advocacy positions. The current legislation notes that of a membership of eleven, two must be people with a developmental disability (British Columbia 2004).

Participation of this kind does indicate that broader participatory roles are emerging for people with an intellectual disability in Canada. In British Columbia there is a second tier advisory committee that advises the Community Living British Columbia (CLBC) board. The current advisory committee has provisions for five self advocate members and five people who represent families of people with developmental disabilities (CLBC, 2007). This reflects a view that people with an intellectual disability can participate, however they are still under-represented in the decision-making roles within the governance boards. Stainton (2005) notes that this was due primarily to an argument about the capacity of people with an intellectual disability to participate at this level. Also, parents continue to be at the centre of services for people with an intellectual disability and share these advisory and governance roles. There is little research anywhere that has studied these dynamics.

At a local level, there are Mayoral Disability Advisory committees. These are formed by the Municipal Council and comprise of people with a disability, service providers and Municipal officers. Local and community issues of inclusion are their focus. Information about these committees did not identify the membership categories, or discuss in detail their modes of operating. From the available information they seem to operate in a similar way to the Local Government advisory committees in Australia.

In summary, the participatory opportunities for people with an intellectual disability in Canada seem similar to those in Australia with one marked difference; the identified place of self advocacy in these representative forums. Another important difference is the Community Living movement and through this the development of organisations *of* people with an intellectual disability. However, Stainton's (2005) discussion of Community Living British Columbia suggests there is still some way to go to enable people with an intellectual disability to have stronger participatory roles in the governance of these organisations. Although, they do represent a shift from the more passive involvement of people with an intellectual disability in consumer participation, in particular in comparison with the lack of progress in this area in Australia.

The UK approach

The UK has a longer history of actively engaging self advocates and self advocacy groups formally in the development of policy. A systematic framework

was developed in the 1980s, the All Wales Strategy (Office, 1991). Research

undertaken on this approach suggests there is a direct link between the

meaningful participation of people with an intellectual disability in service and

broader policy development, and their connection to self advocacy (Whittell &

Ramcharan, 1998). In addition, it supported the need for a clearer framework for

participation that links local action to State/County and National policy advice.

This strategy could be seen as a precursor to the current approach to intellectual

disability policy and approaches to implementing England's progressive

intellectual disability policy, supports and services.

The National policy for people with an intellectual disability is *Valuing People*

(DOH, 2001b). It was developed by government through the Department of

Health to reform supports and services for people with an intellectual disability in

England. A strong focus of this policy is the establishment of real opportunities

for people with an intellectual disability in service planning and research and

partnerships with people with an intellectual disability in every aspect of the

policy and its implementation.

Valuing People established Learning Disability Partnership Boards (LDPBs) in

each local area for local service planning, has established the Learning Disability

Research Initiative (LDRI) that involved people with an intellectual disability in

commissioning and doing research, provided over £900 000 (DOH, 2004)

funding for additional advocacy and self advocacy groups over two years and

established a government advisory group; the Learning Disability Task Force.

This policy has injected resources to support a renewed approach to

participation, choice, citizenship and control by people with an intellectual

disability in the UK. Partnership between people with an intellectual disability

and the policy makers has been evident throughout the policy development and

implementation phase. A companion document, *Nothing About Us Without Us*

(DOH, 2001a) was developed by the service users advisory group at the same

time as the policy was being developed. Research on the implementation of the

policy has begun to emerge through the Learning Disability Research Initiative

(Grant & Ramcharan, in press). In particular there has been research on the

Learning Disability Partnership Boards, discussed in the previous chapter and on

the participation of people with an intellectual disability in other aspects of policy

information.

As discussed earlier *Valuing People* has established a more formally constituted

joined-up approach that links people with an intellectual disability to government,

in particular through the Learning Disability Partnership Boards (LDPB),

Parliaments for People with Learning Disabilities (PPLD) and the Learning

Disability Task Force. The LDPB and the PPLD have been discussed in some

detail in the previous chapter. They are more like consumer participation forums

than citizen participation, however like the Canadian Community Living

organisations they do enable more significant decision making powers than other

service based examples of consumer participation. However, they do have policy

input into broader community policy like community safety and transport.

The Learning Disability Task Force is constituted as a government advisory

forum. It is made up of self advocate representatives from regional Learning

Disability forums. Local self advocacy groups nominate people for the regional

forums, which then nominates to the national forum. Representatives from the

national forum are appointed to the Task Force, which also has family/carer

membership and members from a range of organisations including Learning

Disability research centres, the Disability Rights Commission, the National Health

Service amongst others. The Task Force is co-chaired by a senior bureaucrat

and a self advocate who job share. The co-director who has an intellectual

disability is the first person with an intellectual disability in the UK to be appointed

to a senior government role (*Learning Disability Task Force*, 2007). The Task

Force and its management is part of the Office of National Director: Learning

Disabilities. It states its goals as:

> To be champion for change across England; To show how people with a
> learning disability should be part of everything that we do; To check that
> Valuing People happens everywhere; To report to the government on
> how things are going and what we think it needs to do. (*Learning
> Disability Task Force*, 2007)

In addition, the Task Force has two nominated 'champions' to represent groups

who have been identified as 'hard to reach', one for people with high and

complex needs and one for people from ethnic minorities. The Task Force meets

four times a year and each year concentrates on four issues that the members

identify as key to implementing Valuing People. In 2007 these were Health Care,

Post 16 Education, Independent Living and Employment. The Task Force

presents an annual report to Government on how Valuing People is being

implemented. Government formally replies to them and reports to Parliament

using information from the Task Force. All proceedings are in accessible

language and all information presented to them, used by them and developed by

them is in Plain English. They also employ a graphic facilitator to record the main

themes of the meetings. The minutes of the Task Force are publicly available on

the their website, further enabling people with an intellectual disability and their

self advocacy groups to stay connected to the issues being addressed by them.

There is no current research on the outcomes of the Task Force; however this

may come from research through the Learning Disability Research Initiative

(Grant & Ramcharan, in press). Regional participation networks have attracted

some interest by researchers, with the LDPB and the PPLD being the focus of

some emerging research discussed in the previous chapter (Redley & Weinberg,

2006; Riddington, 2007). Common themes from these studies include issues of

power and decision making and the question of equality of voice within these

forums (Redley & Weinberg, 2006; Riddington, 2007). Some regional *Valuing*

People support teams have established support and training networks for self

advocates who are members of LDPBs or PPLDs; however there is little

information available on how these operate and no current research that focuses on the experiences of self advocates in the networks.

The UK, through its intellectual disability specific policy *Valuing People* has been able to establish new and innovative practices in participation, partnerships, choice and control for people with an intellectual disability. These developments have been supported by a strong intellectual disability research agenda in this country where there are close research partnerships between universities, self advocacy groups, the Department of Health and philanthropic organisations that fund research. A central part of the research agenda is participatory, inclusive research with people with an intellectual disability where they have a key role in commissioning, developing, undertaking and reviewing research about intellectual disability.

Self advocacy groups are integrally linked to these opportunities in policy participation and research. This is supported by a strong network of self advocacy groups, research that has assisted in understanding more about how self advocacy works and how to support self advocacy, and the extra funding that has enabled the growth of self advocacy groups. Some research has questioned the impact this close relationship between the state and the grass roots self advocacy has had on the way self advocacy works (Goodley, 2005; Goodley & Ramcharan, 2005), in particular these papers question how it will affect the practices of campaigning that have characterised the self advocacy movement.

Again, research from the perspective of self advocates about these participatory experiences is lacking.

Summary

For people with an intellectual disability and people with other disabilities, participation in policymaking has grown from the rights based legislation and policy that is based on principles of inclusion, participation and citizenship. The United Nations has been a leader in developing this kind of focus through its conventions and declarations that support and advance equal rights and participation (*Declaration on the Rights of the Mentally Retarded Persons*, 1971; *The Standard Rules on the equalization of opportunities for persons with disabilities*, 2000; UN, 2003-2004, 2006a). However, formal approaches to participation devised by government, like disability advisory bodies, cannot be seen as the only way for people with a disability to participate in the formulation of policy that affects their lives. Many people will prefer to have their voices heard through other forums and by using alternative approaches, like lobbying and campaigning with their collective voice, formed in movements like the self advocacy movement.

Contrasting the Australian context with the USA, Canada and the UK, similarities are most evident between Australia and Canada, where disability legislation and policy is dedifferentiated, applying to people with a broad range of disabilities and focussing on community development to enable inclusion. The formal policy

participation opportunities for people with an intellectual disability in Australia are in cross-disability forums, where people are appointed because of their 'life experience' of disability.

In the USA and the UK, countries that do have intellectual disability specific policy and/or legislation, joined-up policy participation has grown for people with intellectual disabilities, supported by a strong self advocacy sector. However, there is no evidence in the literature about the impact this has on participatory experiences and outcomes from the perspective of people with an intellectual disability. Nor has there been any research that looks at the policy outcomes; however some of these questions may be addressed by the research coming from the Learning Disability Research Initiative in the UK (Grant & Ramcharan, in press).

The UK and to a lesser extent, the USA have been able to focus on processes that are tailored to issues that are relevant to the lives of people with an intellectual disability and to participation opportunities that directly relate to services and supports for people with an intellectual disability. In the UK the initiatives set up under *Valuing People* allow for people with an intellectual disability to have a voice about issues that concern them. Interestingly, many of these cross over to broader social policy issues, for example a current issue being addressed is community safety; however they are also able to focus on intellectual disability specific supports and programs. In the USA there has been

the development of civic and political training through *Partners in Policymaking.* This program specifically targets people with an intellectual disability who might need education on participation skills, to be able to participate equally alongside service providers and government officials. They have also ensured a strong link between self advocacy and participation opportunities, as have the UK.

This overview suggests that Australia has some commitment to policy participation for people with intellectual disabilities; however when compared to the USA and the UK it is clear that there is no national participatory framework that can bring the views of people with a disability through formal forums to Government. In particular, for people with an intellectual disability in countries like Australia, there are limited opportunities to formalise representation of issues through self advocacy to government.

Citizen participation for Australians with an intellectual disability is characterised by: lack of a joined-up participatory framework, little connection with self advocacy as a key representation arm of people with an intellectual disability, dominance of cross-disability policies and participatory forums, and a weaker self advocacy sector. When compared with these other countries, Australia appears to have a less sophisticated approach to participation, and participation opportunities that focus more on a whole of government approach to disability access, inclusion and participation than direct involvement in policy advice about disability services and supports.

CHAPTER FOUR

METHODOLOGY

Introduction

The study was designed to enable the experiences of people with an intellectual disability on government advisory bodies to be heard, described and understood and to develop from this a better awareness of citizen participation in disability specific forums, for people with an intellectual disability. The research problem is that people with an intellectual disability are experiencing feelings of tokenism when they are participating in policy consultations and advisory forums, and little has been done to acknowledge, understand and address this. People with an intellectual disability are increasingly being sought to participate in a growing number and range of these forums (Ramcharan & Grant 2001). They recognise the importance of this participation, but want to know how they can participate more meaningfully.

Research questions

The primary research questions addressed in the study were:

- What are the participatory experiences of people with an intellectual disability who serve on government disability advisory bodies in Australia?

- How are their experiences mediated by the mechanisms and structures of the advisory bodies?

- How can participation in government disability advisory bodies be inclusive and meaningful for people with an intellectual disability?

The research questions focus the study on the experiences of the people and see the structures as a secondary factor. Other studies on citizen participation outlined in Chapter 2, focus more on the structures and how they determine the power of the group (Arnstein, 1969; C. Barnes & Wistow, 1992; Boyce et al., 2001; Wolfe, 2002). This qualitative study focuses on the way the people have experienced their roles and particularly, their view of their experiences. The social and structural environments of the advisory bodies are examined, however they are not analysed separately from the experiences. The analysis focuses on how the structures and processes interact, intersect and impact on the experiences. Finally, the support approaches are examined to determine if people are empowered to participate through the support they receive.

Theoretical perspective

This study interprets the experiences of participation in government disability advisory bodies as told by the people who have participated. It aims to develop knowledge from their perspective that can be used to inform disability and social policy. The study is placed within a social constructionist theoretical framework that recognises that meaning is constructed by people within a social context (Crotty, 2003). This framework reflects the aims of the study. The study used a qualitative methodology, which Denzin and Lincoln define as:

> … Multi method in focus, involving an interpretive, naturalistic approach
> to its subject matter. This means that qualitative researchers study things

in their natural settings, attempting to make sense of or interpret
phenomena in terms of the meanings people bring to them. (p.3)

This suited the research aims, which were focussed on people's experiences and
recognised the importance of understanding these from people's own
perspectives.

The theoretical perspective reflects the view held by the researcher that people
with an intellectual disability through their experiences, can shape the way
supports, services and opportunities are developed for them in social and
disability policy. It also reinforces the stance that people with an intellectual
disability do have insights into their lives and experiences and can make sense of
them. Social constructionism is said to, "… emphasize [sic] the idea that society
is actively and creatively produced by human beings' (Marshall, 1994, cited in,
Crotty, 2003 p. 54). This study recognises the impact society and limiting social
attitudes have on the opportunities for people with an intellectual disability to
participate. However, it also proposes that these opportunities can be changed
and shaped by more knowledge about the abilities that people with an intellectual
disability have. It takes as a starting point, therefore, that research that uses the
told experiences of people with an intellectual disability can help shape social
change.

Research with people with an intellectual disability

The study is also broadly located within a methodological perspective that aims to give people with an intellectual disability an important and primary place in the research process. Currently in disability studies there are contrasting views about how best to achieve this.

The disability rights movement has adopted a position that all research about people with disabilities should be emancipatory. Barnes (2003), describes emancipatory research as representing the overt "politicisation" of research in which the researcher struggles for "transformative change" (p.6). Such change is seen as a direct result of the research and the research experience. This approach is value laden and concerned with the political outcomes of research and the research process (Ramcharan et al., 2004). This theoretical approach is commonly accepted by the disability movement, however it is less commonly understood, articulated or used by or with people with an intellectual disability. Primarily this is because people with an intellectual disability have not been part of the broader disability movement (Driedger, 1989). For example, Ramcharan et al., (2004) note, that although some would argue there is a growing convergence of agendas between the self advocacy movement and the broader disability movement, there is little evidence of this.

A further possible reason why this approach has not been taken up is the difficulty of applying its stringent expectations. These include that emancipatory

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research must ensure that people with a disability: develop and commission the research, control and critique it and be the researchers. There are inherent difficulties with transferring all of these requirements to research with and by people with an intellectual disability. Ramcharan et al., (2004) note that to apply this approach we would have to take a position that people with an intellectual disability can be represented by the broader disability movement who can engage in this approach, or that people with an intellectual disability can carry out the whole research process unsupported (p. 90). There has been much debate about the application of these principles and practices to research with people with an intellectual disability (Chappell, 2000; Ramcharan et al., 2004; Walmsley, 2001; Ward & Flynn, 1994). Chappell (2000) in particular has questioned where the interests of people with an intellectual disability are in disability research that claims to be emancipatory.

Research with and for people with an intellectual disability has been framed as 'inclusive' and principles such as those suggested by Walmsley and Johnson (2003) have informed its development. Studies have analysed the application of principles to practice (Grant & Ramcharan, 2006), employed these principles in research (Chapman, 2005; Johnson, Frawley, Hillier & Harrison, 2002a; Walmsley, 1991; Williams, 1999; Williams, Simons & Swindon People First, 2005), and considered how to support inclusive research, particularly the role of non-disabled research supporters (Williams et al., 1999; 2005; Chapman & McNulty, 2004; 2005). Most notably, in the UK, the Learning Disability Research

Initiative (2006) actively engaged people with an intellectual disability in commissioning research, reviewing research bids, participating in reference groups and undertaking research on the involvement of people with an intellectual disability in the research projects (Grant & Ramcharan, in press).

Inclusive research aims to ensure that people with an intellectual disability inform more research about intellectual disability. Also it has a commitment to seeking their perspectives in research that is about their experiences. This study was most concerned with the latter issue, giving voice to people with an intellectual disability through the research and gaining their perspective.

Although the methodological framework of this study is informed by the principles of inclusive research, it does not claim to be a pure example of the type of inclusive research such as that defined by guidelines developed in the UK, or the guidelines and requirements developed through this work (Department of Health, Learning Disability Research Initiative, 2007). Rather, this study is based on a key principle of inclusive research, that it gives voice to the people whose experiences are being studied, and gives as much power as is practicable to them to guide the research process (Walmsley & Johnson, 2003). More accurately, it is an example of collaborative research, a term which Marie Knox (1998) used to describe her research approach with six people with an intellectual disability about managing relationships. Knox, et al., (2000) suggest

that in collaborative research "An epistemological stance is adopted that sees the people as the experts, and the researcher or inquirer as someone who learns from these experts" (p. 49).

Research methods

Ethnographic and case study traditions are used in this study to elicit information that describes and explains the experiences of people with an intellectual disability, within the environments of the advisory bodies. The ethnographic tradition which uses in-depth interviews, observation and document analysis, was chosen as it enabled the researcher to be immersed in the micro environment where the experiences were occurring for this group, and to understand the shared meanings of these experiences through prolonged engagement with the research participants (Creswell, 1998; Hammersley & Atkinson, 1995). This particular approach to ethnography is described by Morse and Richards (2002) as a focused ethnographic study. Studies of this nature aim to, "elicit information on a special topic or shared experience…the topic is specific and may be identified before the researcher commences the study" (p. 53).

Hammersley and Atkinson (1995) suggest ethnography has four features: (1) an emphasis on exploring the nature of the social phenomena, (2) a tendency to work with unstructured data, (3) investigation of a small number of cases in detail, (4) analysis of data that involves explicit interpretations of the meanings and functions of what is observed, usually presented as descriptions (cited in,

Silverman, 2004 p. 56). This is done through observation, indepth unstructured interviews and document analysis. These methods are discussed in more detail later under data collection.

Morse and Richards (2002) suggest outcomes of an ethnographic study challenge commonly held assumptions about what is obvious, can reveal the hidden, overt, the implicit, and taken for granted (p.179). This study, through its focus on how the people with an intellectual disability participate in this political environment, casts this group differently from the way they are usually seen and thus reveals the complexities of supporting meaningful and equal participation.

Case studies are used in this research to reveal the personal and political perspectives of the people and to place their experiences within the advisory bodies of which they are a part, referred to as 'sites'. A case study approach is also used to examine the experiences of the central research participants within the specific environments, in which they are occurring, and to compare and contrast the perspectives given by people across the sites. Stake (2000) notes, "Case study is not a methodological choice, but a choice of what is to be studied" (in Denzin & Lincoln, 2000, p. 435). Here, the people with an intellectual disability and the advisory bodies themselves are being studied. Creswell (1989) calls this a 'bounded system', a case or cases that are bounded by time and place and can be a program, an event, an activity, or individuals (p.61). Stake (2000) notes there are a number of forms of case studies including collective and instrumental.

This study is more characteristic of an instrumental case study which are examined mainly to provide insights into an issue (Stake, 2000). Such case studies facilitate an understanding of a broader phenomenon, not just an insight into the actual experiences that are being studied. In this research, the case studies provide insights into the implementation of principles of participation as a way of including people with an intellectual disability in decisions about policy and practices that affect their lives. They also enable an analysis of the way people with an intellectual disability are perceived and understood within such participatory environments.

The researcher in the research

A number of important issues must be considered about the nature of the research relationship in this study. In particular, the role of the researcher needs to be considered. Morse and Richards (2002) suggest that the qualitative researcher should not deny that they know a lot about the study and that prior knowledge is part of what they call the process of 'abstraction', which is crucial to the development of understanding that occurs in a research study. They note however, that this is neither positive nor negative; it simply exists and therefore needs to be acknowledged. Darlington and Scott (2002) note that often in qualitative research the roles can be blurred, and that researchers need to be clear about their roles and carefully consider questions of ownership of the research and its findings. When considering the position of researchers in collaborative research Knox et al., (2000) note that the researcher is placed as

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the learner. Such views suggest the need for qualitative researchers to consider, and be clear about, their closeness to the topic, the people involved in the research, and how and if this will impact on aspects of the research.

These issues were addressed in the conduct of this study, mainly through a relationship of trust that was built between the researcher and the participants. This trust derived from the researcher's long association with some of the participants and a commitment to working from an advocacy stance, typified by equality of relationships and 'standing beside' those you are advocating for and with. Half of the primary research participants knew the researcher, as did many of the secondary informants. As a result, there was some potential for confusion or misunderstanding of the role or identity of the researcher and whether the researcher was seen as an insider or outsider. At one time in the study this issue was raised with the researcher by a secondary informant who noted that the researcher could not be seen as objective in the study given her past experience in one of the sites. The orientation of this study was from the perspective of those who directly experienced the phenomenon, therefore the issue of objectivity did not come into question, as the researcher was not evaluating the efficacy of these forums or developing a study based on any predetermined notions about these forums.

To counter this view, the researcher ensured that through the communication about this study and the way it was conducted, it was made clear that the

researcher was positioned as a facilitator, enabling the voices of the people with

an intellectual disability to be heard and supporting them to reflect on and

interpret their experiences. It was essential that the study enabled the researcher

to maintain the role of 'active learner' and facilitator, rather than a collector of

observable data to prove or disprove a predetermined theory or hypothesis.

The researcher recognises that the data that has been made in this study is

affected by the researcher's identity. As noted earlier, it is commonly accepted in

qualitative research that the researcher and their attitudes, values, ideas and

prior knowledge are very evident within the research. However, having a

closeness to the people and the topic also supported a more collaborative

approach and facilitated the sharing of information and the use of an advocacy

stance in the study.

Research design

The study took place over a three-year period. The central participants were nine

people with an intellectual disability who were members of six government

disability advisory bodies in Australia. In addition there were thirteen secondary

participants who were other members of the advisory bodies, or acted in a

support or managerial role to the advisory body, or the central participant (more

details are given in Table 3 and in the following sections). Data was collected

through interviews with the central and secondary participants, observation of

advisory body meetings and document analysis. Morse and Richards (2002)

refer to this process of data collection in ethnography as data making. This invokes a picture of research as a growing and evolving process, which reflects the way data was collected in this study.

A thematic analysis of the data was undertaken as the data was being made and was used to inform further data collection. Piantanida & Garman (1999) refer to this as an "iterative, cyclical" process. Data analysis is discussed in more detail later under data treatment.

Sampling and recruitment

In qualitative research the sampling methods vary depending upon the methodological approach being used. The research methods used in this study; ethnography and case study, similarly aim to study experiences in situ, using the voices of those who share the experience to highlight characteristics of the phenomenon they are experiencing. The sampling method used in this study was purposeful (Morse & Richards, 2002; Rice & Ezzy, 1999) and the following two approaches were employed. Criterion sampling was the main method where the criteria for the central participants was, that like Hannah, they were people with an intellectual disability who were members of government disability advisory bodies in Australia. To find all of the people who met this criterion, a snowballing sampling method was also used. Rice and Ezzy (1999) suggest that snowball sampling is useful when the people are hard to reach, not easily identified through other means, and are themselves well networked.

The decision to base the study on the experiences of people with intellectual disability who were members of government advisory bodies was made in response to the initial conversation with Hannah. It was clear that she was experiencing a 'problem' that could be examined through research, however it would require finding more people like her and locating the study within these public bodies. The decision was also a practical one as locating it within advisory bodies enabled the study to more closely reflect her experiences and to 'contain' the research and focus it on this one kind of participation. In making this decision the study would become caught up in negotiating with advisory bodies and addressing the issue of consent with them.

The first recruitment strategy aimed to locate potential participants through advisory bodies and gain consent from these advisory bodies to be involved in the study as study sites. The researcher knew many of the potential participants with an intellectual disability, and whilst the research could have progressed without the formal involvement of the advisory bodies, it was decided that members of the advisory bodies and those who managed them and supported people's participation, would form an important part of the collaborative approach. However, difficulties were encountered with this original recruitment plan. Letters were sent to the advisory body Chairpersons to introduce the study, ask that they assist in locating potential participants, and to request the participation of advisory body personnel in the study. A consent form was

attached so it could be read at a meeting and signed by the Chairperson if the group agreed to participate (Appendix 7). At this stage the study began to encounter forms of gatekeeping (Silverman, 2004). Some advisory bodies did not respond and others noted that they could not or would not pass on information to people, as they did not usually distinguish between group members by their disability. Bringing the research to the attention of people with an intellectual disability they felt, would conflict with their normal practice.

The issues raised were unfounded, as there is publicly available information about each of the government advisory bodies that includes the names and biographies of members. Some websites also publish the strategic plans of the advisory bodies and meeting minutes and reports. However, this initial unwillingness to participate by some advisory bodies led to the use of the alternative strategies outlined below, and a reappraisal of the participatory nature of the research.

After encountering these difficulties, the researcher decided on the snowball sampling method. The first research participant self selected into the study as she identified the research problem in her conversation with the researcher. A further conversation with Hannah led to her identifying some more potential participants. She used her networks to talk about the study and along with the researcher, invited these people to a briefing meeting. This led to a total of three people agreeing to join the study. These people also agreed to talk to the

managers of their advisory bodies to request that they consider the invitation to participate, sent earlier by the researcher. Each advisory body subsequently completed the consent forms to be involved as study sites and to put forward secondary participants for interviews. As discussed later, not all of these groups agreed to observation of meetings.

The next step was to conduct a phone and email survey of every Australian State and Territory government disability advisory body. This survey asked if the advisory body had members with an intellectual disability, and if so, whether they would be willing to provide this person with information about the study. Through this method one additional research participant was located. The advisory body that she belonged to passed on the information about the study to her and she contacted the researcher expressing an interest in participating. The researcher had a number of phone conversations with her discussing what would be involved in participating in the study and sent her information and consent forms. This first phase of recruitment only located four people who fitted the criteria within three advisory bodies.

It was clear there were not a large number of people who met the study criteria, and whilst large numbers were not required for statistical purposes, the research was aiming to gain rich and thick descriptions of the participatory experiences. For this reason the criteria for inclusion was broadened to include Victorian Local

Government advisory bodies. Victoria was chosen because it is where the researcher lives and would minimise travel costs and maximise access to the study sites. Also, at the time of the study there had been a recent growth in the development of disability advisory bodies at a Local Government level in Victoria. A phone and email survey as described above, was completed with all seventy-nine Victorian Local Governments asking whether they had a disability advisory body, and if so whether there were members with an intellectual disability. At the time of this survey only forty-six of seventy-nine Local Governments had disability advisory bodies.

This located three additional study sites and five more central research participants, resulting in a total of nine central research participants and six study sites. Three different levels of government disability advisory bodies were represented enabling some comparison of these sites (Table 1). Using Stake's (2000) definition of case studies, there would be numerous ways of focusing this study as a case study. The cases could be the nine individuals individually or as a group, the three different levels of government advisory bodies represented, or the six sites together or as separate cases. Creswell (1989) calls this a 'bounded system', a case or cases that are bounded by time and place and can be a program, an event, an activity, or individuals (p. 61).

Information and Consent

Mindful of the need to inform the people directly about the research in addition to using the advisory bodies to distribute information, a number of processes were used. Most importantly, the researcher was aware of the close networks of some of the research participants. In two locations there were two groups of three people who knew each other and had already begun talking about the research. When the researcher contacted these people to provide them with more information, they suggested group meetings. Briefing meetings were then held in two locations with two groups of participants. Three people attended each session. This enabled people who knew each other, and knew about the research, to come together to talk about it and then go away and talk to each other if they wished.

These briefing sessions were followed up with phone calls, some initiated by the participants, and face-to-face individual meetings. People who did not have a connection with either of these groups met individually with the researcher. In these instances the written information and consent forms were used. Only one person requested these forms in an alternative format of words and pictures (Appendix 6). Others asked to have the forms read to them and each person was encouraged to talk it over with someone else; either a friend, peer, or support worker, before giving their consent.

The people with an intellectual disability in this study were a group of articulate, independent and experienced individuals. They shared a number of characteristics as people with an intellectual disability but differed in how they experienced life as people with an intellectual disability; what supports they needed to live their lives, how they perceived their needs and their identity. Having an intellectual disability did not exclude them from making their own decisions, planning their own lives or deciding the direction of their lives. It was assumed that each person, given the right support and appropriate ways of accessing and understanding the information about the research could give informed consent about their participation.

Overall, the aim was to clearly inform potential participants about the research so they could freely decide whether to participate and then carry out the research so it would do good and avoid harm (Freedman, 2001; Griffin & Balandin, 2004; Mc Carthy, 1998; Stalker, 1998). The key issue was to provide enough information in a form that could be understood to enable informed consent. Factors considered were: the researcher's knowledge of the people, the best way for each person to receive and process information, and providing enough time and the right environment for the information to be heard, discussed and questioned.

Each potential participant had very different reading skills and ways of accessing and understanding information. The researcher knew some participants, so building a rapport and communicating with them was easier than it was for

people who were not previously known to the researcher. The decision was

made to focus on engagement processes that suited each person. Information

and consent forms were developed (Appendix 4 & 5). Each research participant

was able to sign the consent form, however this did not occur until each person

had attended a briefing meeting and at least one face-to-face meeting with the

researcher. For most participants, there were at least three meetings or

discussions before they were asked to provide their signed consent. Griffin &

Balandin (2004) note that "Consent is an interactive construct and will vary

according to the complexity of the information presented, whom it is presented

by, the effort put into communicating it, and the setting in which the information is

conveyed" (p.69).

Confidentiality

Confidentiality and anonymity were two key concerns in the study as there were

only a small number of potential participants and the forums being studied were

public forums. The decision was made after prolonged discussion with the

research participants to change their names and the names of the forums. This

was despite some participants wanting to be named and recognised through the

research. For them the study was an opportunity to make changes; however, the

secondary respondents required some anonymity due to the public roles some of

them held.

Smaller qualitative studies that use a small pool of participants and provide rich,

more personalised data presentation methods like narrative, are likely to be less

anonymous (Griffin & Balandin, 2004). However this is balanced by the tools of

qualitative researchers for masking the identity whilst not compromising on detail

and richness. Much oral history research does not attempt to be anonymous and

in this kind of research with people with an intellectual disability, being identified

has been an important aspect of doing the research (Atkinson, 2000; Atkinson et

al., 2000; Atkinson & Williams, 1990). This has also been the tradition in

participatory action research which has been used successfully in studies with

self advocates and self advocacy groups as a form of advocacy (Chapman,

2005; Ward & Trigler, 2001). People with an intellectual disability are also

becoming active in setting the research agenda, doing their own research and

being commissioned to do research (Ramcharan et al., 2004). In these instances

their identity as a group of people with an intellectual disability is central to the

research being undertaken (Gramlich et al., 2002; Gramlich, Snelham, &

McBride, 2000).

Participants and Study Sites

In keeping with the aim of this research, to focus from the perspective of the

people with an intellectual disability 'up' and 'out', it was appropriate to formulate

the cases around the people. This, Stake (2000) describes as a collective case

study, an instrumental case study extended to several cases. The collective

approach to case study in this research portrays both what is common and what is particular in the participants' experiences. Whilst all nine people shared some characteristics, a focus on their particular experiences enabled specific examples of participation to be identified. Also, whilst the six sites and some particular sites had a number of things in common, they also had specific differences. Common characteristics were the level of government; however the study shows that even within those that shared this characteristic there were significant differences in the way they were structured and functioned (Table 2).

Table 1 Research participants

Research Participant (names changed)	Age/Gender	Advisory Body (name changed)
Hannah	43/Female	Southern
Andy	50/Male	Southern
Jana	50/Female	Central
Karla	40's/Female	Northern
Kieran	40's/Male	Seascape
Martin	21/Male	Hilltown
Phillip	50s/Male	Greentown
Tyler	20's/Male	Greentown
Christine	21/Female	Greentown

Table 2 Study sites

Study site	Level of Government	Number of members* and assigned positions ( )	Number of members with an intellectual disability
Central	National	15 People with a disability (10), Parents (4), Service providers (1)	1
Southern	State	13 People with a disability (10), Parents (3)	2
Northern	State	17 People with a disability (13), Parents (1), Service provider/advocacy (3)	1
Seascape	Local	11 People with a disability (4), Service providers/community members (4), Organisational/peak body (3), Ex officio (2)	1
Hilltown	Local	11 People with a disability (5), Carers (5)	1
Greentown	Local	12 People with a disability (12)	3
	N = 6		N = 9

*Membership numbers accurate in 2005

The secondary respondents were identified through their roles with the advisory bodies of which the central participants were members. These people were either employed to support the people with an intellectual disability, manage the advisory bodies, or were other members of the advisory bodies, in particular people who had formal roles such as the Chairperson. These research participants were chosen either by the central respondents, or were identified through their role. For example if people had support workers they were interviewed regardless of whether the respondent with an intellectual disability identified them as a secondary respondent (Table 3).

Table 3 Secondary respondents

Study site & Research participant	Respondent/s (names changed)	Position	Role
Central Jana	Sandy	Support worker	Participation support
Southern Hannah & Andy	Sandy	Support Worker	Participation support
	Raelene	Advisory body Chair	Chairing meetings, setting agenda, liaison with government and disability sector
	Candy	Manager Advisory Body	Strategic support
	Mary	Administration support	Administration support, transport and payment
Northern Karla	Nancy	Support Worker	Participation support
	Arthur	Chair person	Chairing meetings, setting agenda, liaison with government and disability sector
	Diana	Advisory body member	Advisory body member – person with a physical disability
Seascape Kieran	Georgie	Social Planner	Management and support of the advisory body
	Ellen	Advisory body member	Representative from a tertiary institution
Hillside Martin	Kate	Disability access worker	Management and support of the advisory body
	Mary	Chairperson	Chairing meeting and setting the agenda
	Stella	Advisory body member	Parent of an adult child with an intellectual disability
Greentown Phillip, Christine & Tyler	Carla	Disability access worker	Management and support of the advisory body
	N= 12		

What eventuated were three types of involvement from the advisory bodies; remote involvement, supportive and open involvement and active involvement (Frawley, 2006c). One site was undergoing restructuring at the time of the study, resulting in a lack of engagement with the research; this is described as remote involvement. This site and another one did not agree to any form of observation and were reluctant to provide secondary participants for interviews. Three other sites were supportive of the study and assisted the researcher with meeting times and recruitment of secondary participants. This kind of involvement is described as open involvement. Only one site was actively involved in the research. This was characterised by regular contact, invitations for the researcher to attend and observe a range of meetings and regular email contact sharing documents and information relevant to the study. This is discussed in more detail later in the chapter in relation to the limitations of the study.

Data collection

The main data collection method with both the central and secondary participants was interviews. A narrative, semi structured approach was used based on the work of Booth and Booth (1998) (Appendix 8) and is discussed in detail below. Other methods included observation and document analysis. These methods are also outlined in the following section. Table 4 sets out from whom data was collected and the approaches used for each data type.

Table 4 Data collection methods

Participants	Method	Number/ duration	Approach
People with an intellectual disability who are members of government Disability Advisory Councils.	In-depth face to face interviews	2 to 3 x 2 hours with the central research participants	A narrative, semi structured approach using an 'aide memoire' as a framework to the interviews. (Booth & Booth, 1998). Interviews audio recorded
Management staff and other members of the study sites. (eg Council Chair, other ordinary members)	Face to face interviews (individual or shared)	18 x 1 hour at 6 sites	Semi structured interviews. Audio taped
*Support workers	Face to face interviews	3 x 2 hours at 2 sites	Semi structured interviews
Participants of full Council meetings or other Council activities (forums, working groups)	Observation	2 x up to 2 hours at 3 sites	Naturalistic observation in the natural settings of these activities. Researcher notes.

*Only three sites employed individual support workers. In one site this support worker supported two people. This same support worker also supported a person in a third site

Interviews

Interviewing people with an intellectual disability, like interviewing any informants requires above everything else, a good rapport and a flexible, comfortable and safe environment (Minichiello, Aroni, Timewell, & Alexander, 1995; Perry, 2004; Walmsley & Johnson, 2003). All of the research participants were articulate and able to convey their thoughts and feelings freely and easily in the interviews. Open ended, semi structured questions using life review methods as described below, resulted in a conversational interview environment and mainly long answers with some 'yes' 'no' responses.

The purpose of the interviews with the central participants was to enable them to talk about their experiences on the government advisory bodies. The interviews

were semi structured using what Booth and Booth (1998) called an aide memoir to guide the conversation (Appendix 8). They describe the aide memoir as a framework, checklist for marking off material covered, and for pinpointing topics for further discussion. It also acts as a reminder about information to be collected, contains some direct questions, and guides the free ranging conversation of the interview. This approach is based on life review methods, which is part of a narrative approach used where people are invited to reflect on and appraise their past experience from their standpoint in the here and now (Birren & Deutchman, 1991). It is characterised by: the interviewer's prompting and questioning being driven by storyline determined by the informant, interviews not being intended to produce factually accurate or verifiable accounts of lives, people re-construct their past in light of their present sense of who they are. Booth and Booth (1998) note, "Memories constitute one of the building blocks of identity and the meanings people give to their own past are intimately bound up with the image they choose to present to others" (p.17).

According to Booth and Booth (1998), this approach to interviewing is suited to working with people with an intellectual disability because of some identified problems they can have such as: remembering details, inarticulateness, not being able to talk at length or with a great deal of detail about events, temporality and poor recall, in particular remembering dates and details, and unresponsiveness with open ended questions. This more conversational

approach prompted by an aide memoir enables flexibility, and as they suggest the interviewer has to work harder at "listening beyond" the individual.

Dorothy Atkinson has undertaken a large amount of life history and narrative work with people with an intellectual disability and notes the importance of using narratives. In her work they are normally full life stories, which she claims can act as important counterbalances to other accounts of the lives of people with an intellectual disability (Atkinson, 2000). Atkinson also claims that this approach treats people as the 'expert witnesses' they are to their lives and to the broader story of intellectual disability (Atkinson, 2000). In addition, life story work enables people to develop a picture of themselves and through this, and the reflexive approach used in life story work, develop a fuller sense of who they are and have been in the world.

This study does not claim to go this far as it did not develop life stories with the central participants; however, narratives were written collating information from each interview for each person. These narratives formed an important part of the reflexive and analytical process undertaken with the research participants and in the broader process of analysis. Importantly though, for some people in the study it was the first time they had heard parts of their own story read aloud. Andy noted " That sounds good, that's me and my story".

A total of nineteen interviews were conducted with the central participants (Table 5), each person was interviewed a minimum of twice, and three people were interviewed three times. Each interview lasted between one and three hours. They were held in various locations selected by the research participants but predominantly in their homes. Four people arranged alternative venues to fit in with their work or advisory body meetings. These four people really enjoyed the social aspect of the interviews, which normally included a lunch or coffee before, after, or during the interviews. One person requested ongoing social catch-ups where they provided the researcher with some updates on their participation in the advisory bodies, however these were not counted in the number of interviews. In addition, three other people maintained regular contact with the researcher by phone, email and catching up at other meetings or events over the duration of the study.

Interviews with the secondary respondents used a similar interview framework to that used with the central research participants, to maintain some consistency across interviews; however they differed from each other (Appendix 9). The differences in focus were primarily determined by the role of the informant, their closeness to supporting the central research participant, and their knowledge of the advisory body. The interviews discussed the role of the person, their knowledge of the central participant's involvement in the advisory body, their views about the person's participation, descriptions of how they worked with or supported the person's participation, and their evaluation of how the person

participated and how well the advisory body supported this. A total of eighteen secondary interviews were conducted. At least one secondary respondent was located for each of the nine central participants, however for one person there were four secondary respondents and others had either two or three (Table 5).

All forty-one interviews were recorded and transcribed in full by the researcher. For the central participants the complete set of interviews was collated in one document and a summary narrative was written for each person. These were stored using Nvivo software for retrieval and analysis. The secondary interviews were transcribed in full and also stored using Nvivo software.

Observation

Ethnography uses direct observation in the 'natural setting' as a key research tool. Morse and Richards (2002) note, "Observing is the most natural of all ways of making data, but observing unobtrusively is extremely difficult" (p. 96). Darlington and Scott (2002) concede that observation has its strengths and limitations, noting its strengths as: affording access to events as they happen, requiring little active effort on the part of those being observed, being time efficient, and not requiring the research to be 'set up' as is needed with interviews. It is also sometimes perceived to be more 'objective' than interviews, with the setting not being controlled by the interviewer. Concerns about observation as a research tool have been discussed in detail in a number of qualitative research texts (Creswell, 1998; Darlington & Scott, 2002; Denzin &

Lincoln, 1994; Gillham, 2000; Holloway & Jefferson, 2000; Morse & Richards, 2002; Patton, 2002). For this study the key factors impacting on the use of observation were: the types of forums being observed, the impact of the observer on the group, and the lack of data obtainable by this method. In this study, observation of the advisory body meetings did not form a large part of the data collection. In three sites it was not used, although for another site it was used a number of times and was more participatory (Table 5).

The first consideration was the types of forums that were the focus of this study. The advisory bodies are not generally understood to be 'open forums', as they are government appointed groups. These types of settings are known as "closed or private settings…where access is controlled by gatekeepers" (Silverman, 2004, p.57). Gaining access to these settings is reliant on agreement or consent from the group. In all but one advisory body in the study, consent was given for observation of meetings. At one site, Southern, however, it was not deemed appropriate to have an outsider observe meetings where government policy was being discussed. Consent was not given for the researcher to attend any meetings of this group or observe their work.

The second issue, the impact of the observer, was a key factor in considering the use of observation in this study. Silverman (2004) describes this as the researcher "finding an identity" and notes that "...observers may change the situation just by their presence" (Silverman, 2004, p.58). Again, textbooks on

qualitative research and ethnography address this issue in detail. Atkinson and

Hammersley (1994) outline four problematic features of fieldwork identity as:

whether the researcher is known to be a researcher by all of the those being

studied or only by some, or by none; how much, and what, is known about the

research and by whom; what sorts of activities are and are not engaged in by the

researcher in the field; and how this locates her or him in relation to the various

conceptions of category and group membership used by participants; what the

orientation of the researcher is, and how completely he or she consciously

adopts the orientation of insider or outsider (cited in Silverman, 2004, p.58).

When direct observation was used the researcher role or identity was carefully

considered, this required decisions about levels of participation. Spradley (1980)

outlines five such levels of participation observers can take in qualitative

research: non-participation, passive participation, moderate participation, active

participation and complete participation (cited in Darlington & Scott, 2002 p.77).

In this study it was generally considered inappropriate for the researcher to take

on any observation role that involved active participation, although at one site,

Greentown, the researcher did take on a moderate participation role. This was

due in part to the formative stage of this group and the nature of the research

role as shaped by the research participants at this site. The researcher entered

the site knowing that it was in the early stages of development and that the group

expected the researcher to have input, rather than take on an outsider role. In

keeping with the collaborative and inclusive research criteria for this study, the

researcher agreed to this role, and the researcher identity was clearly formulated within this context. This included the group asking the researcher to provide feedback to them that they could use to develop their terms of reference; it also involved consultation with the advisory body manager on a regular basis. This was defined by her as a form of professional development that enabled her to draw on the themes emerging from the research at this site and implement them as needed. In this way, the research at this site reflected principles of action research.

In one other site, Seascape, where the researcher attempted a non-participant observation role, the member with an intellectual disability was so focused on the researcher's presence that they did not participate in the meeting being observed. Throughout the observation period they focused their attention on the researcher in various ways: turning to the researcher to make a point, offering the researcher cups of tea, directing their comments and questions about agenda items to the researcher, and asking the opinion of the researcher as they saw the researcher as an 'expert' on the issue.

Whilst it is accepted that completely unobtrusive observation is unlikely in any instances where the group knows they are being observed, as ethically they should, in this research it was assessed that observation could at best provide a 'snapshot' of the environment, as opposed to a clear insight into how the person with an intellectual disability participated. As such, the possibility of an observer

being unobtrusive was unlikely and therefore the use of observation was limited.

Whether a researcher chooses to undertake observation or not, they are still

present within the study. The presence of the researcher was very clear in this

study. To ensure all research participants knew of the closeness of the

researcher to the study, the researcher disclosed their prior involvement in one of

the study sites and where relevant, disclosed their prior working relationship with

research participants.

Finally, it was clear that the type of data obtainable by observation was not as

important to the research as what was 'made' through in-depth discussions or

interviews. Observation, when it was used, enabled the researcher for instance

to count how many times the person with an intellectual disability participated in

the forum through speaking, and to witness firsthand how the person with an

intellectual disability interacted with others in the meeting, and how others

interacted with them. As Darlington and Scott (2002) note, the researcher as

observer is:

> …limited to observable social phenomena. Internal processes of
> cognition and emotion cannot be observed…Observation alone cannot
> tell us why people do the things they do or what the particular activity
> means to them. (p.75)

Knowing how the people with an intellectual disability felt about their experiences

was very important to this study. This was another reason for relying heavily on

in-depth, informal interviews as the primary method of inquiry.

Fieldnotes were used to record observations. These included details about

seating positions, participation activities by the central research participant and

interactions between other people present and the central research participant.

The meetings were recorded using a digital audio recorder, however some

material was not recorded at the request of those present at the meetings. These

recordings were not transcribed; however the full recording was stored on the

researcher's computer and replayed to verify and clarify points from the

fieldnotes. Key observations were stored in Nvivo for retrieval and analysis.

Document Analysis

The six sites in this study had similar kinds of documentation that were relevant

to understanding how they operated and their mandate. However, access to the

documents in some sites proved difficult due to interpretations about the

availability of these documents to an 'outsider' which meant a full set could not

be obtained for each site. In all six sites the terms of reference of the advisory

bodies were obtained, along with policy documents or legislation that set out

these terms of reference. These formed the basis of a description of the way the

advisory body operated, the functions of the advisory body and the structure of

the group (see Chapter 6 and Appendix 3). Meeting minutes were made

available except by Southern advisory body. These were reviewed to describe

how meetings were conducted, the length of agendas and how and when the

person with an intellectual disability was referred to within them. Other

documents retrieved and used to describe the way the advisory bodies worked

were: annual reports, position papers, strategic plans or workplans, briefing papers, and in one advisory body, Southern, a short series of newsletters and an evaluation report of the advisory body.

Analysis of these documents allowed both within-case analysis, where the work of the advisory body could be described and analysed in detail through these documents, and cross-case analysis to compare and contrast themes across sites (Creswell, 1998; Stake, 1995, 2000; Yin, 2003).

Data Analysis
Narrative and case studies
Ethnography and case study both rely on the 'findings' being reported using a narrative approach. The use of narrative, Booth & Booth (1998) note can: provide an inner view of the person, work as a means of making what might be abstract more tangible by grounding it in the lived experience of the research participant, and bring the individual and their experiences into view. They also suggest that narrative forms of reporting act as, "…a bridge between the individual and society by giving access through people's lives to structural features of their social world" (p.5). These approaches fit the aims of this research study and enabled the researcher to 'tell it how it was' from the perspective of the participants. Drawing from the ethnographic research tradition and, in intellectual disability research the life history approach (Atkinson, 2000; Booth & Booth, 1996; Goodley, 1996), this study builds rich and thick descriptions of people's experiences.

The multiple data collection methods resulted in a range of data 'made' as described in the previous section, reflecting Morse and Richards (1998) definition of data development. Data were stored using Nvivo software, and for each person who was a central research participant, they were collated as a narrative. Detailed study site overviews were written for each advisory body (Appendix 3) and key details were collated in a table to enable comparisons (Appendix 1).

The development of each person's story was a first step in analysis of their experiences and the themes emerging from the perspectives they gave. Punch (1998) notes that much social research data occurs naturally in story form and it should be treated as a story in analysis, highlighting that data analysis that segments, codes and categorises information is valuable; however, it can also lead to fragmentation. In this study the data started from conversational, informal interviews based on a life review approach. The transcripts were long and sometimes the respondents answered questions, or reflected, in one-word responses. In the tradition of oral history, a number of different methods were used to bring the narrative together from the interview data (Atkinson, 1998; Perks & Thomson, 1998; Walmsley & Atkinson, 2000). The process of joining these up in a narrative allowed a fuller story of the person and their experiences to emerge.

Atkinson (1997), notes that life stories are accounts and products in their own rights, and through her life history work with people with an intellectual disability,

she has successfully used them to illuminate personal and cultural insights into the life experience of intellectual disability. However, in this study the narratives act as a backdrop to the study and as a way of grounding the study in the experiences of the people. The case studies that were developed from these narratives place the stories of the people within the stories of the advisory bodies.

Through the case studies the people are described, and their experiences portrayed within the advisory body environments. The case studies also present specific experiences and describe these in situ. They are also used to provide a snapshot of the advisory bodies and the way people participated in them.

Thematic Analysis

Three data analysis approaches were used in this study. The first was based on the development of narratives for each central research participant , and reflection with them on what emerged from their stories of participation, as described above. The second approach was an analysis of the study sites through case studies written for each site. These case studies brought together information from the document analysis and from the narratives developed with the central participants. This approach enabled an analysis of the structures and how people participated in them. Finally, through a process of abstraction described in detail later, conceptual categories were developed from the key

themes that led to the development of a series of propositions about what

mediates and supports meaningful participation for people with an intellectual

disability in government disability advisory bodies. This approach to analysis is

described broadly as thematic analysis.

This analysis was ongoing throughout the study, and was linked to a number of

methodological processes, in particular ones that are associated with

establishing trustworthiness in the research (Denzin & Lincoln, 2005; Lincoln &

Guba, 1981). These included: prolonged engagement with the study and the

data, peer debriefing, member checking as discussed below, and focusing on

and using the thick descriptions developed from the data to reflect on the themes

that were emerging. Analysis began early in the research process and took place

initially as the focal point of regular supervision sessions. This form of peer

debriefing was ongoing over the course of the study and used written excerpts

from interviews, narratives and case overviews to focus the discussions and to

aid in the development and debate of emerging themes.

The data was analysed and re-visited in a process of cyclic analysis. Piantanida

and Garman (1999) describe this analysis as "cycles of deliberation" (p. 1),

which is characterised by being cyclical, iterative, deliberative and discursive.

The analysis was ongoing and took place in the following ways: themes were

identified, summarised and written from the text and then discussed, reflected on

and further developed through supervision sessions and other peer review

mechanisms including presentations at conferences (Frawley, 2006a, 2006c). As such, the data analysis in this study was characterised by discussion, debate, writing of stories and overviews, and some coding and categorizing using Nvivo. Formal coding however was a minor method due mainly to a desire not to segment the data through this process. Also, this approach is less likely to be able to include the research participant in analysis of themes.

Throughout the interview phase that spanned two years of the study, member checking was used with the central research participants. At each session and between sessions the researcher discussed the kinds of themes that were emerging. Some of the research participants would phone the researcher asking, "How is the project going"? At these times the researcher would discuss the most recent thematic developments and sought clarification and views from the research participants about these. At the second interviews, the researcher read the narratives back to the informants. These then formed the beginning of subsequent interviews and often took up a predominant theme that had emerged. Finally, through some journaling, intensely focused supervision sessions and discussions with research participants, a reflexive process was developed which served to fine-tune themes. These were subsequently discussed with the central research participants.

In the tradition of life history work, much of the data was left to speak for itself through the rich and thick descriptions in the form of detailed excerpts of

interviews that feature in Chapters 5, 6 and 7 of the thesis. Ramcharan et al.,

(2004) when discussing analysis in participatory research with people with an

intellectual disability, note, that in most cases it is the non-disabled people who

support people with an intellectual disability to do research, who lead and do the

analysis of the research. They argue that narrative on its own, or other stories

that emerge from some participatory research would not have policy relevance

without some form of rigorous analysis. However, as outlined here, through

reflecting and checking with people with an intellectual disability throughout the

research, they can participate in forming ideas and challenging views that

researchers glean from research carried out with them and about their

experiences.

The thematic analysis also drew on elements of grounded theory, moving from

the descriptions of what was occurring in the study sites, to a more abstracted

interpretation of the core meaning of what was occurring. Charmaz (2006) notes

that in their original statement of this method, Glaser and Strauss (1967), "invited

their readers to use grounded theory strategies flexibly" (p. 9). She goes on to

say that in light of this she has come to see three elements as important, "having

an emphasis on examining processes, making the study of action central, and

creating abstract interpretive understandings of the data" (p. 9). Morse and

Richards (2002) also describe a process of abstraction in the treatment of

qualitative data made from ethnographic research methods. Key aspects of this

approach are, conceptualisation from rich data, and articulation of

understandings that are developed as a result of the researcher's insight, which is gained from their closeness to the research data and their prior knowledge and work in the research area. This prior knowledge or 'a priori' encapsulates the skills, knowledge and experience of the researcher both within the research and prior to it.

Whilst the usual process of coding associated with grounded theory was not used, the grouping of themes and refinement of these over time, led to the development of conceptual categories. A theory is not developed, however a series of propositions are put that are based on findings developed through this analytical process. These are discussed in Chapters 5, 6 and 7. Table 5 outlines the full data set that was used in the analysis.

Table 5 Complete data set per central research participant

Research participant	Advisory body	Data collected
Andy	Southern	2 x group briefing 3 x individual interviews 4 x secondary interviews
Hannah	Southern	2 x group briefing 2 x individual interviews 3 x secondary interviews
Jana	Central	2 x group briefing 2 x individual interviews 1 x secondary interview
Phillip	Greentown	1 x group briefing 2 x individual interviews 2 x secondary interviews 2 x observation
Christine	Greentown	1 x group briefing 2 x individual interviews 2 x secondary interviews 1 x observation
Tyler	Greentown	1 x group briefing 2 x individual interviews 2 x secondary interviews 1 x observation
Martin	Hilltown	2 x individual interviews 3 x secondary interviews
Karla	Northern	2 x individual interviews 3 x secondary interviews 2 x observation
Kieran	Seascape	2 x individual interviews 2 x secondary interviews 1 x observation
		Total number of interviews **41**

Limitations

All studies face challenges in their development and beyond. In qualitative

studies, there are always questions about the ability to generalise from small

samples and questions of representativeness. However, these are

counterbalanced by the richness of data, transparency of data treatment and

reporting style.

In this study the sample size is small; however it represents a complete sample of people with an intellectual disability participating in government disability advisory bodies in Australia at the time of the study. Silverman (2004), notes that in qualitative studies it is important to choose cases carefully, but most importantly to choose on the basis of relevance to your questions. In this study the questions were focused on a phenomenon that is specific to a small number of sites and a small number of people.

Finally, as discussed earlier, the study was also limited methodologically by the lack of participation from some study sites. Early study designs envisaged a more participatory and perhaps active research methodology; however without the same or very similar levels of commitment across sites this was not possible and would have led to inconsistencies. In particular it challenged the collaborative nature of the research, with the most remote site providing no collaboration.

Variable support and involvement of secondary participants in the advisory bodies produced challenges; however the research participants with an intellectual disability were very active participants, regularly contacting the researcher to talk about how the study was going and to provide updates relevant to the research. Their enthusiasm enabled the research to proceed in a somewhat collaborative way.

There is much to learn about doing inclusive research with people with an intellectual disability. Approaches that do not isolate or intimidate the person with an intellectual disability or adversely affect their inclusion and participation in research need to be considered. These underlying issues of inclusive research are not often raised in the research; however, people with an intellectual disability are beginning to take on more active roles as research partners in inclusive and partnership research projects. In the researcher's experience, this participation can be hampered by organisations that 'gatekeep' as discussed earlier, but also by the concerns held by people with an intellectual disability about the outcomes of their involvement in the research. In this study, the people who spoke more critically of their experiences were concerned that they did not want to jeopardise their positions by "saying too much" about their experiences. This was managed by ensuring anonymity, but most importantly letting them know that what they said would not be fed back to the managers of their advisory bodies.

People with an intellectual disability are often still suspicious of people who they see as having authority. Building a trusting relationship is the most important aspect of any form of inclusive or collaborative work with people with an intellectual disability. For some this is harder than others because of their past life experiences.

Summary

This research has employed different techniques to examine the participation of people with an intellectual disability in government advisory bodies. It has used an analytical approach to gain an understanding of what is occurring and to develop explanations and knowledge about this phenomenon. Significantly, the methods outlined enabled a collaborative approach to the study with a group of people who in the past have had few opportunities to gain insights into their experiences and to use these to advocate for changes. The following chapters present and discuss these ideas

CHAPTER FIVE

PERSONAL AND POLITICAL ORIENTATIONS TO PARTICIPATION

> The justification for a democratic system in the participatory theory of democracy rests primarily on the human results that accrue from the participatory process. One might characterise the participatory model as one where maximum input (participation) is required and where output includes not just policies (decisions) but also the development of the social and political capacities of each individual. (Patemen, 1970 in Richardson, pg 43)

Introduction

This chapter introduces the nine people who are at the centre of this study. Their

experiences are represented here using the pseudonyms of Karla, Jana, Andy,

Hannah, Martin, Kieran, Phillip, Christine and Tyler. This chapter draws on their

experiences of participating in government disability advisory bodies to develop a

description of why they participate, how they participate and what shapes the

way they participate. Their personal and political orientations are presented in

this chapter in a typology of participation orientations. In these roles, people were

involved in shaping, advising on and discussing policies that in some way would

impact on their lives and the lives of other people with an intellectual disability.

The way people approached their participation is described using a typology.

This was developed using the explanations people gave about why they

participated, what their expectations were for their participation and what they

brought to the role. An analysis of these found that the people had personal and

political ideologies that informed their views about the roles, how they wanted to participate and their expected outcomes. The commonalities of these informed the development of the typology where three types of orientation to participation are described: democratic, professional and communitarian.

The findings presented in the form of the typology highlight that people with an intellectual disability that come to these roles, do have some basis for their approach to participation beyond their identity as a person with an intellectual disability. They have 'agency[1]' as individuals; they are people who have personal experiences that shape their views, and they have formed these views and expressed them in ways that can be described as political. They have ideas about what they can achieve through participation and views about how they can do this.

Introducing the people

Two things bind these people: they are described either by themselves, the service system or the advisory bodies they belong to as having an intellectual disability, and they are all members of government disability advisory bodies in Australia. The two characteristics are linked because these kinds of policy-

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1 "Our capacity to be self-aware, to know what we are doing, to give good accounts of why we have done what we have done, and our will to act" (Bessant et al., 2006)

making forums look for members who have a personal experience of disability, and attempt in most cases to have a 'cross-disability' representation, therefore looking for people with different experiences of disability. They belong to three different levels of advisory bodies and as explained in Chapter 4, they are involved in this study because at the time of the study they were members of either State/Territory, National or Victorian Local Government advisory bodies and they were people with an intellectual disability.

Karla, Andy and Hannah belonged to State Government disability advisory bodies; Jana was a member of a National body and Martin, Kieran, Phillip, Christine and Tyler belonged to Local Government advisory bodies. Hannah and Andy were in the same State advisory body and Phillip, Christine and Tyler were in the same local advisory body. The people in the same advisory bodies knew each other and some others knew of each other through self advocacy networks.

Through the interviews with the researcher each person talked about their experiences in these advisory bodies and their broader life experiences, jobs they had done, and committees and consultations they had been involved in. They were a group of experienced and articulate people with an intellectual disability whose stories indicate their knowledge, drive, and commitment to better lifestyles and opportunities for people with an intellectual disability. Table 6 gives an overview of some of their life experiences and participation experiences.

Table 6 Overview of respondents and their participation experiences

Life experiences /Service use Living Situation	Democratic Orientation	Professional Orientation	Communitarian Orientation
Past	Institutionalisation (Karla), Lived with family (Jana & Kieran)	Institutionalisation and supported community living (Andy) Lived with family (Hannah)	Institutionalisation (Tyler); With family (Phillip, Martin and Christine);
Current	Living independently (Karla and Jana) Living with family (Kieran)	Living independently (Andy and Hannah)	Supported community living (Tyler & Christine), Family (Martin), Independently (Phillip)
Employment/ Program involvement	Sheltered employment (Kieran) Part time work (Jana), Employed in Advocacy (Karla)	Employed in Advocacy (Andy and Hannah) Other employment (Andy)	Unemployed and no day service (Martin) ; Community disability and education programs (Christine & Tyler), Self employed (Phillip)
Participation experiences			
Self advocacy	All current and active members of self advocacy	Both current members of self advocacy group	Current but not active members of a self advocacy group (Christine, Tyler & Phillip).
Other…	All regularly involved in policy consultations through self advocacy	Member of national peak body for people with an intellectual disability (Hannah) Member of disability service board (Andy) Both regularly involved in policy consultations through self advocacy	Participated in some policy consultations and reference committees (Christine, Tyler & Phillip)

Democratic orientation: Participation as a right

Karla, Jana and Kieran are described as having a democratic orientation to participation. They are actively connected with self advocacy and see their role on government disability advisory bodies as an extension of their self advocacy role. They see participation as a right, and believe that through their participation, they will enable more people with an intellectual disability to get onto these kinds of advisory bodies.

Case Study 1 Democratic orientation: Jana, Karla and Kieran

> **Jana** is in her late forties, she is married and lives with her husband in a house they own. She grew up with her family, went to a mainstream primary school, a special school and then onto an Adult Centre for people with an intellectual disability. She left the Adult Centre and got a job in a pay office, a job she describes as a "normal job in a normal place", but it didn't last. She became more involved in self advocacy around this time, joining committees and getting some work with the self advocacy organisation in the office because she knew how to type and do office work. Her involvement with self advocacy became a key focus of her work. Over the next fifteen years she became involved in campaigns ran by the self advocacy movement, mainly about closing institutions. She also joined research reference groups about different things to do with being a person with an intellectual disability. She worked with a researcher to write about her life as a woman with an intellectual disability. Jana calls herself a self advocate. She is someone who is known by people in the government department for disability and she is often invited to go to consultative forums or join groups that meet about certain policies. She is on the committee of two self advocacy organisations, she goes to their meetings and is involved in the work they do. She has been on one government disability advisory body.
>
>
> **Karla** is in her late forties and has lived in institutions before moving into the community, where she now lives in a flat on her own. When she moved into the community she didn't want to have anything to do with people with an intellectual disability, she just wanted to get out and about and live her life. She heard that a friend of hers was involved in a self advocacy group and she wanted to see her friend so she went along. She soon found out that the self advocacy group were talking about

things that interested her, particularly getting institutions closed and making life better for people in the community. It wasn't long before she became involved in the campaigns and lobbying they were doing and then she got a place on a self advocacy committee and became the chairperson. Through this she was appointed to a government disability advisory board where she was talking about intellectual disability to the government and service providers; this was in the 1980s. When she finished on this committee she started working in disability rights, where she still works running workshops on legal rights. Karla is very well known and is often invited to join groups, give presentations and sit on different advisory committees; she has completed two terms on a government disability advisory committee and is also sitting on another one that is not about disability. Karla likes to do this work because she thinks that other people learn from her that people with an intellectual disability can have a say and should be invited to have a say.

Kieran is in his early forties, he works full time in a sheltered employment service and lives with his family. Kieran went to a special school until he was about seventeen. He started to be interested in talking to other people about disability and rights when he began attending a self advocacy group. He used to drop into his local group, even though he was shy, he wanted to see what they were doing. Through this he heard about a lot of things that were going on and that he thought needed to be fixed up. He started learning about disability rights through this group, then he was invited to go to the 'peer facilitation' program ran by the government disability department. He loved that program where he met a lot of other people with an intellectual disability and learned about the Disability Standards[2]. He decided to run workshops back at his workplace and another local service about the Standards, he says he is a 'trained presenter'. Around this time he was elected onto the committee of the self advocacy organisation and on the workers' committee at his workplace. Through the self advocacy organisation he heard about the government disability advisory body. He

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[2] In the late 1990s in Australia the Commonwealth Government Disability Department and State Government Disability Departments developed Service Standards that governed the way funded disability services provided their services. These Standards are predominantly about the rights of disability service users and the responsibilities of service providers.

has been on it for a few years now and likes to get things done, particularly about access and inclusion for people with a disability in his local community. Most of all he likes to show other people that people with an intellectual disability can get involved and have their say about things that affect their lives.

Goals and expectations: Representing, educating and growing the voice

I've lifted the umbrella open so they can see what people with an [intellectual] disability can do. Lift the umbrella up so they can see what it there...Oh this person with a disability has got good thoughts and ideas and brain and opinions. *Kieran 10/05*

The people with a democratic orientation express the importance of using their position as a way of supporting other people with an intellectual disability to have a say and to educate others that people with an intellectual disability have a rightful place at these policymaking tables. They express this almost as a duty to be a good role model for other people with an intellectual disability. Jana in particular recognises that there are not enough people with an intellectual disability participating in self advocacy and therefore they are not getting the opportunity to participate in other forums. Karla also sees that through her participation she is teaching other people with disabilities that people with an intellectual disability can participate and have a say.

I find that what I get out of council is I am teaching people about people with an intellectual disability. And I find that people with other disabilities will listen to me. *Karla 02/06*

Like Karla and Jana, Kieran also shares the view that because he has a position of importance on a government advisory body, he has a duty to be a good role model for other people with an intellectual disability and to educate others, that

people with an intellectual disability are capable of participating. His pathway to participation was also through self advocacy, an identity he strongly relates to. Kieran is very clear that other people could have the same opportunities as him but many do not. He recognises that many disability advisory bodies do not have people with an intellectual disability on them and thinks they should:

> It would change if I went to another Council and if they weren't giving a fair go with the intellectual disability people I would ask, I would soon give them the rev up and say they can do it. Don't shove them under the mat they are not roots under the tree. People with all disabilities can do it *Kieran 10/05*

Karla, Jana and Kieran have held positions on many policy and disability organisation committees and have been policy activists through self advocacy. They are seasoned participants in government led and devised consultations and advisory roles. Jana notes that there used to be more lobbying and protesting but now the government invites people to be on reference groups. She understands that is the way the experiences of people with an intellectual disability can be heard and she wants to be a part of it.

Jana, Karla and Kieran all say that overall their participation on the disability advisory bodies is positive, although Karla and Jana do refer to some structural barriers to their full participation, which are discussed in Chapter 6. They all strongly identify with self advocacy and have goals to get more people with an intellectual disability involved in disability advisory bodies and consultations. They are like ambassadors who, through their positions feel they have been delegated to represent their 'people'. They clearly see themselves as people with

an intellectual disability within these roles and draw on their life experiences and connection with self advocacy to put forward an 'intellectual disability' perspective. Jana notes that she has encountered some problems with performing this role as the organisation has not clearly articulated or formalised it:

> I don't really know what my role is on the [disability advisory council] all I know is they put me, they say I am representing [a geographical area] but I don't know it myself. I haven't really got roles. That's where I don't know and I don't really know who to report back to. Nobody bothered to tell me what my role was… I don't know, self advocacy groups I reckon [I am representing] because I, at the [disability advisory council] I speak about what the self advocacy groups are up to. *Jana 04/06*

Jana also notes that she has had difficulties communicating issues to self advocacy groups and getting their feedback and input to take to the disability advisory body. She thinks this is because she does not formally represent any group, self advocates do not know about the disability advisory bodies, and nobody within self advocacy is supporting her to make these connections. Despite the lack of clarity about her representative role, Jana continues to make the connections herself. She does not want to be seen as an individual having her say about the policy issues addressed on the disability advisory body, she wants to represent self advocates. Likewise Kieran sees himself as a representative of the local self advocacy group on the disability advisory body. He was approached when another member of the self advocacy group left the disability advisory body and was put forward by the self advocacy group to be the representative. Like Jana, his role as a representative of this self advocacy group

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is not formalised but it is implied by the connections that are made between the two groups.

The key participation goals of those with a democratic orientation are: to be strong and informed representatives, to increase the number of people with an intellectual disability who are directly involved in these roles, and to educate 'others' that people with an intellectual disability can have a legitimate and strong voice in these advisory forums.

Self advocacy : A collective identity

> I would like to see all the groups get back their funding, I would like to go out to the country and talk to groups….to get more people with intellectual disabilities involved in advocacy. *Jana 11/05*

Jana says she is a strong self advocate, and she has an intellectual disability. Jana's identity as a self advocate has come from her recognition that many of her life experiences are the same as other people in these groups; she went to a special school and to an Adult Day Centre:

> It used to be called the mentally retarded or handicapped children in those days and that's the way they were treating us like. *Jana 11/05*

Jana notes that at this centre she had to put her hand up to go to the toilet even though she was an adult and then a 'teacher' would accompany her to the toilet, even though she did not need help. Jana has seen many changes in the way services understand intellectual disability over a number of years. These experiences had a significant impact on how she perceived herself and on her

views about how things should be for people with an intellectual disability, she

explains:

> In the olden days when I was there in the 70s we made moccasins, it was like, basically it was like a school because we, they treated us like kids…Oh it was OK but it was, it was OK but it wasn't that good, the way they treated you….I left there when I was about 24 or 25…in the 80s it started to change. So we all went out on day groups swimming, some teachers took us swimming, gardening and that and we did college, like getting an education and that…I did numeracy and literacy at [a TAFE college] there we did typing, that's when they had type writers back then and we did cooking and sewing and spelling and electronics. *Jana 11/05*

These changes led to Jana moving out of home and getting a job doing clerical

work in a transport company. It was also around this time that she discovered

self advocacy. Although Jana was living independently and had work, she

realised that through self advocacy she could meet other people with an

intellectual disability and add her voice to the concerns raised by others about

how services, the community and government departments understood

intellectual disability:

> Well a friend of mine she was at [the adult centre]. She was already involved with [the advocacy organisation] and [Jana's husband] was involved with them. And she told me about it one time and she took me over to one of their meetings years ago when they used to run meetings at Sth Park in the early years and then I don't know what happened, they had their AGM and I signed up to be on their committee…It was just an impulse. The first advocacy organisation I was involved with sort of gave me the skills and that to work in other organisations and then there was another group started up and they were looking for a self advocacy worker. So I applied and I got the job but basically doing everything, doing the newsletter, going out to talk to groups and that. Yeah advocacy is what I was good at in those days. I am heavily involved in advocacy....if they [other people with an intellectual disability] see we can do it then they can just do it too. All they might need is some training to do things or to help in training in what they want to do. *Jana 04/06*

These insights into Jana's life confirm that she strongly identifies as a person with an intellectual disability, and most importantly a self advocate. This term is perhaps a more positive term to use to describe yourself if, as Jana outlines, in the past other labels used to describe you have led to negative experiences or people responding to you in a negative way, like Jana's teachers did at the centre for 'mentally retarded children'. She uses intellectual disability and self advocate interchangeably, recognising that to be one, a self advocate, you have to be the other; a person with an intellectual disability. This view is strongly held and understood in the Australian disability context where self advocacy is implicitly understood as referring to a collective of people with an intellectual disability engaging in issues about rights (Fyffe et al., 2004; Romeo, 1996).

Like Jana, Karla also strongly identifies as a person with an intellectual disability through her involvement with self advocacy. Karla did not always want to identify as a person with an intellectual disability or associate with people with an intellectual disability, particularly after she had left an institution to live in the community. However through self advocacy she found a social and political niche that led to employment and the opportunity to develop and share advocacy skills:

> I didn't have any interest in joining groups of people with an intellectual disability. I wanted to be like everyone else because I had always lived with people with an intellectual disability. I started in self advocacy because there was a person with an intellectual disability who I knew from an institution and I wanted to see him, he was in self advocacy and I wanted to catch up with him. I met two people and then I started a self advocacy group, my friend had told me about good things he had done. It taught me how to work with people with an intellectual disability, how to

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work in a legal service for people with an intellectual disability, helps to talk to people with an intellectual disability in a way they can understand it in the right situation, and things like that. It helped me to stand up for myself and helped me to advocate for other people, which I might not have been able to do. *Karla 10/05*

Karla expresses the view that institutionalisation has been and to some extent still is the biggest issue in her life and closing institutions remains her central focus. In addition, she notes that she cares a great deal about people who have the label 'challenging behaviour' and that she would like to work to change the attitudes of service providers and policy makers about what this really means. She is very articulate about this issue, reflecting the more progressive view of intellectual disability research that challenging behaviour is the best way people have of communicating in environments that challenge them. She suggests that she might shift her focus from self advocacy to this issue. She has a sister with an intellectual disability and regularly visits her in her residential support service:

> I now want to get involved with people with high support needs. I have a sister with high support needs. [In relation to people with high support needs and who are labeled as having challenging behaviours].. you have to get to understand their communication, you have to understand people with communication needs. They don't need programs. I think a behaviour is a communication. It's about getting a message out. It's very hard when professionals think they know. I think it's a lot of crap. *Karla 02/06.*

This shows Karla's closeness to and affiliation with the needs of all people with an intellectual disability. She is focussing on a very specific issue that is not usually addressed by self advocacy and recognises the need for changes in how this term is understood and used. She believes that through her position she can

advance this view and do something for a group of people who are absent from the public gaze and therefore from the policymaking arena.

Karla's approach reflects an awareness of her representative role, knowing that people with higher support needs are not going to get the same opportunities she has to affect the way others understand intellectual disability. She comments that once she interrupted a government Minister who used the term 'challenging behaviour' and set this Minister straight about the misuse of this label and what it really means for people who cannot communicate. She is using her position, to bring a hidden and often forgotten issue to the attention of policy makers, to get changes for people who are themselves unlikely to be able to have direct representation to government Ministers. Karla wants long-term change; the issues she puts forward are based on the experiences of many people with an intellectual disability that she has contact with through her self advocacy work and through her contact with people in residential services. She sees that she has gained from policies like deinstitutionalisation and that she now has a role to get change for those who still rely on disability support services.

> I am a person with a disability and I take things on personally especially about deinstitutionalisation. As a person with an intellectual disability I don't let council get away with things. *Karla 10/05*

Karla and Jana have used funded disability services and they aim to represent the issues faced by this large group of people to policy makers. They use their networks, their work in self advocacy and their past experiences to inform their

position. Whilst these two women are on different advisory bodies and have very different life experiences, as people with an intellectual disability they have a shared understanding of the strength of a collective voice and the importance of using their experiences and networks to be heard in these forums. The work that Karla and Jana do as people who can represent other experiences of intellectual disability, highlights the importance of this form of representation, but also raises the importance of the network, connections and collective voice that is self advocacy.

Kieran became involved in self advocacy after he heard the local self advocacy organisation give a talk at his workplace.

> I used to drop in and say hello when I was, I used to be shy and never go much and they said come in and I said no, no. It took me courage for me to get in the door and I got in and now I have been there ever since. *Kieran 10/05*

One thing led to another for Kieran. Through his involvement with the self advocacy organisation he heard about some training called 'peer facilitation' that was ran by the State Government disability department:

> When I was going to Talking Up [the self advocacy organisation] there was this conference that was coming up in town and we stayed at the [hotel] and that is how I got involved in [the peer facilitation]. *Kieran 10/05*

Through the peer facilitation training Kieran learnt about rights and about the disability standards and he used his position on the workers committee at his workplace to talk about the standards and run workshops on them. Through his

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involvement on the self advocacy committee he then heard about the disability

advisory body and when there was a vacancy he applied and was appointed.

Kieran has gained an identity and participatory opportunities through his

involvement with self advocacy. He admits that at times he has moved away from

the self advocacy organisation but notes that this was due to the way the non-

disabled people in the organisation took control of information:

> I used to be with [on the committee] of Talking Up [self advocacy
> organisation], I resigned from there, Oh it was a bit stressful too…if you
> want to know something the coordinator wouldn't tell you much.
> *Kieran10/05*

When he distanced himself from the group he realised that he also lost contact

with the issues, and the key reference point for his work on the advisory body, so

in a later interview he noted that he had returned to the self advocacy group.

However, he returned with a new approach where he decided what he would do

in the organisation. The self advocacy organisation knew what he was doing on

the disability advisory body because they received the minutes, so Kieran had re-

established this important connection but on his own terms.

Kieran's experience suggests that the connection with self advocacy is important

and perhaps adds meaning and relevance to his citizen participation role;

however it also suggests that participation in self advocacy can be problematic

and disconnection from one can affect participation in the other. It also highlights

issues about the roles and control non-disabled associates have in self advocacy

and how this can impact on the participation of people with an intellectual

disability within them. These issues are well documented in other research on

self advocacy (Beart et al., 2004; Chapman, 2005; Fyffe et al., 2004; Goodley,

2000, 2001; Whitehead & Hughey, 2004) and discussed in Chapter two. It is

evident, from the perspectives on participation from those with a democratic

orientation to participation, that self advocacy has played an important role in

their lives. Through self advocacy they have learnt participatory skills, had

opportunities to participate, learnt through shared experiences about the issues

facing a broader range of people with an intellectual disability, and formed and

maintained strong personal connections. For some it was where they first

articulated their struggles as rights and recognised that they shared some

experiences with other people who were also struggling for their rights.

The people with a democratic orientation to participation have used self

advocacy as a springboard to these advisory positions and they use the skills

and networks they have developed through self advocacy to be included in these

policymaking forums. All became aware of the disability advisory bodies through

their advocacy networks and were supported by non-disabled supporters of self

advocacy to apply for their positions.

Summarising the democratic orientation

This group of people share a strong commitment to getting more people involved

in and aware of these advisory and consultative forums. They are aiming for a

stronger voice and one that is more representative, or at least is speaking from a more informed position using their connections with self advocacy to inform their opinions. As Jana indicates this is not always easy in these forums because people are appointed to the more formal advisory bodies as individuals not representatives of groups. Despite this administrative barrier they continue to see themselves as representatives of self advocacy and work from this experience and perspective. Like Jana, Kieran sees himself as a self advocacy representative on his Local Government advisory body as he was appointed through his self advocacy group, however it is a loose connection with no formal reporting lines. Likewise, Karla is a well-known self advocate in her State and uses her contacts with self advocacy to voice the experiences of a broad range of people with an intellectual disability.

The democratic approach of these people has meant that they assert the experience of people with an intellectual disability as a collective experience, which is common within self advocacy and the disability movement more broadly. It also means that they attempt to provide a perspective beyond their own experience to a broader experience of intellectual disability, which is evidenced by the range of life experiences of this group and the range of issues they provide opinions on; employment and the Disability Support Pension, (Jana), deinstitutionalisation and the experiences of people with challenging behaviour (Karla), and roads, road crossings and footpaths (Kieran). Whilst this is a broad spectrum of issues, each person has asserted their opinion from what they know

through life experience, through the issues and opinions expressed in their self advocacy groups or through finding out directly from other people with an intellectual disability. Their experience as self advocates and their ongoing connection to the self advocacy movement is referred to often by these people indicating that it is significant to them.

It is argued here and discussed in more detail in the concluding chapter that there is an important link between self advocacy and the citizen participation role for people with an intellectual disability. This supports findings from research in the UK (Whittell & Ramcharan, 1998). Some studies suggest that self advocacy itself is in need of strengthening to ensure it can actively support this kind of participation and representation through informed and connected members (Armstrong, 2002; Fyffe et al., 2004; Goodley, 2001; Whitehead & Hughey, 2004). It is noted by these writers that it is not what self advocacy is, but how it is recognised and supported within the disability policy sphere that impacts on its effectiveness.

Professional orientation: Participation as a status

> Before I was known no body wanted Hannah, now that everyone knows that I can do the job everyone wants a piece of me. *Hannah 09/05*

The people with a professional orientation to participation have also come through the self advocacy movement; however they have moved beyond it to define themselves as leaders in the intellectual disability arena. There are two

people whose similar approaches to participation led to defining their orientation as professional. Both belong to State Government disability advisory bodies and both are employed by advocacy organisations as educators, group facilitators and project workers. Whilst sharing these characteristics their life experiences as people with an intellectual disability differ quite markedly from each other, but they have both pursued similar opportunities for employment and representation on advisory forums.

Case Study 2 Professional orientation: Hannah and Andy.

Hannah is in her mid forties she lives with her husband and has spent almost twenty years in self advocacy, mainly working in self advocacy organisations as a project worker. She grew up with her family, went to a special school and then onto sheltered employment. Hannah found out about a local self advocacy organisation through a group at her work. She joined the group and before long she was on their committee. She was employed by this organisation to support other self advocates to learn how to stand up for themselves and to have their say. Things 'snow balled' from then on; she became well known because she attended a lot of meetings with the government disability department and started to be invited by them to join consultative groups and attend meetings about policy. This meant she became even better known and led to her being invited by the government department to present at forums. She has presented at conferences, spoken to Parliament, and is invited to talk to business and the government at various forums to do with disability. She has experience on two government disability advisory bodies and chairs a national forum for self advocates. She is a project worker for an advocacy organisation where she runs sessions with people with an intellectual disability in disability support services. She is not actively involved in self advocacy any more and does not go to self advocacy meetings apart from the one where she is paid to run the forum.

Andy is fifty-one, he lives on his own in a rented flat and has part time jobs in self advocacy and as a gardener. He lived his early life in institutions, being moved around a lot. Finally he was moved out of an institution into a group home but that ended up being almost as bad as the institution. He was moved from there because he was 'too good' to

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be in supported accommodation. His family helped him to move into a flat and now he looks after himself. When he moved out he went to adult disability services and employment support services. Through these he was invited to join committees becoming a 'client' representative. Later he joined other disability organisation's committees and became involved in an advocacy organisation. He started out on their committee and then moved onto running a forum for people who were on client committees in disability support services. Being involved in this advocacy organisation also meant he had access to information about what was going on in disability services and what the government were doing. He started going to meetings with the government department, being invited because of his association with the advocacy organisation. He was invited to attend forums and consultations. He has never really been involved in direct lobbying or campaigning, preferring to be 'behind the scenes' and having his say through consultative forums. He loves politics and listens to it on the radio, he reads the papers and keeps up with what is going on through his contact with the advocacy organisation. He is well known in the disability area but is not well connected with the 'grassroots' self advocacy movement. His main interest is institutional closure and whenever he gets the chance he raises this at forums and meetings. He has been on a government disability advisory body for two years.

Both Hannah and Andy are in paid employment within advocacy. They have both pursued a range of jobs in disability; sessional lecturing, research work and project work. They both talk about their participation on the disability advisory bodies as 'work' and count it amongst the jobs they do. Hannah and Andy are well known and have developed part time careers through their involvement in disability advocacy.

Goals and expectations: Employment and professional contact with people in power

> Well I am employed by the [State Government Department] on the advisory council. *Andy 09/05.*

Hannah and Andy's primary aim is to hold positions on advisory bodies and other forums and committees as employment, to be able to participate alongside other

people with a disability and disability professionals as equals, and to have contact with people who they perceive have the power to make changes. They do not connect with other people with an intellectual disability to inform their views, preferring to express positions and opinions that they have formed individually.

They approach their roles as people who are employed to do this as a job, which is how they see others who are paid to participate. This approach distinguishes them from self advocates and disability services users who are invited to participate in consultation forums but are not paid for their participation. Andy says, "Of course ...its not the money it's the, its[the] occupation I suppose you would call it". However, being paid is important to Andy, he comments that when he was first approached to apply for the position on the advisory body he was not interested because he did not want to go to more "boring" meetings, but when he was approached a second time and advised that he would be paid he accepted. He says the pay is important because other people who have jobs in the disability sector and attend the meetings are paid by their employees when they attend. Andy does not have a full time employer and needs payment by the advisory body to recognise it as work. As Andy notes above, he equates his appointment on the Government advisory body with being employed by the State Government. Hannah also defines it as work and the pay supplements her disability support pension.

Andy and Hannah are career people who believe they have a right to be employed in the disability sector. This right is one that has been hard fought by self advocates whose claim, 'Nothing about us without us' includes the professional arena of the disability industry. There are few other positions available within the sector for Hannah and Andy as involvement in self advocacy groups as active members does not pay. Both Hannah and Andy have been successful in gaining employment through participatory roles and increasingly in advisory roles in research or as researchers. However, they still make a distinction between themselves and other 'disabled' and 'non-disabled' professionals:

> In the new advisory body [made up primarily of people with a disability] I ….suppose I felt stupid. They were professional and would think because I had an intellectual disability I couldn't do it. *Hannah12/06*

Proximity to the decision makers and people in power has been very important for both Hannah and Andy. They recognise that this contact is unlikely to happen for other people with an intellectual disability and value the opportunity it gives them as individuals to be known by people with power. Hannah notes that the position is important because she can meet with Ministers, reporting very positively about a time when she had this close contact through her role on the advisory body,

> With [the Minister].. you could ring her office, all right you might have a bit of trouble getting to talk to her but she returned your calls, or if you emailed her she had time, like she could be in a busy meeting and you could be in a meeting and she would stop and come and talk to you…. we had a dinner, we had a social dinner where she could sit down and talk to all the members of [the disability advisory body]. *Hannah10/05*

However over the four years in this role Hannah also learnt that contact with

Ministers was not always guaranteed, but at least in this role she was closer to

the decision makers:

> The problem is you can't always get to the Minister's advisor even on the [advisory body] but it is easier than when you are an outsider. The …chairperson can meet with the Minister and put up our ideas but people with a disability still get walked over. *Hannah 12/05*.

Andy laments that direct contact with those in power does not happen often

enough. He notes that the Minister had only attended one or two meetings in his

time on the State advisory body and members of the advisory body rarely get to

make decisions.

> I don't think I have been at a [advisory body meeting] where we have been asked to make decisions…I don't think the [disability advisory body] makes decisions. …Some Ministers are full of promises and some Ministers are there and say we will do this, we will do that, [the Minister] has only been once to a meeting…We don't know what the Minister is going to do. *Andy 02/06*

Andy defines his job on the advisory body in similar terms to what he thinks a

politician's or advocates job is:

> Well I guess it's not my voice, the people who I am speaking up for…I am speaking for the whole lot and I am taking those issues to the Minister, that's right. …I am just wanting to sit around the table I mean over coffee or over lunch, yeah and just have an informal chat...What can I do for you, what is the problem? *Andy 02/06*

For Andy it is a new experience to be the person who is meeting with the

decision makers, despite being involved with an advocacy organisation for over

ten years, Andy has very few opportunities to speak on his own behalf. The non-

disabled professionals in the advocacy organisation have this role and Andy's

role is to accompany them to meetings and forums. Participating as an individual on the advisory body is very important to Andy.

Appointment to these roles gives Hannah and Andy status, recognition and some contact with decision makers. They see the staff that support these bodies and the other members as their colleagues; however as Hannah indicates above, she does not feel like their equal. She wants to be seen as a professional however she feels incompetent in relation to the 'real' professionals. Andy also notes this difference between himself and others on his advisory body:

> My knowledge is not as good as other people's; oh I think a lot of people with disabilities haven't got the education, or haven't got the knowledge. Because I haven't been to school… I haven't been to TAFE, I haven't been to uni [sic] to study. *Andy 09/05.*

Their appointment to these positions has provided an opportunity to 'work' in the sector but as they indicate they still feel incompetent in comparison to their 'colleagues'. It has also given them the opportunity to have contact with people in power; however as Andy notes this does not happen as often as he would like.

Leadership and status: An individual identity

Hannah sees herself as a leader and has pride in the fact that she is singled out to do things that other people with an intellectual disability do not get asked to do, like presenting at conferences and participating in leadership. She says she "doesn't feel sorry" for people with an intellectual disability and she "likes to help them". Hannah worked her way up in self advocacy organisations to positions where she could work alongside the non-disabled staff, primarily as a trainer.

She has been very successful in gaining positions on committees, reference groups and advisory bodies in her own right. Over a period of time she became more involved in these forums and left the self advocacy group where she had been employed for ten years, moving away from the grassroots involvement in self advocacy, no longer attending meetings or participating in campaigns. As she says earlier, Hannah became 'known" which coincided with this shift away from self advocacy.

Hannah enjoys the accolades, the payment and the side benefits like travel and going to functions. She wants to be seen as an individual with something to contribute. In particular, Hannah enjoyed the opportunities that came with her appointment to the disability advisory body, particularly being promoted as a 'leader':

> I got my leadership then [the chairperson] made me like a co-chair. She said "sit next to me and learn from me". If I didn't understand it she would [ask] did I get that? It was business talking but it was still like friends. *Hannah12/05*

Andy is in a similar position to Hannah but he has not been quite as successful in gaining appointments to reference groups, advisory committees, consultative groups and working parties in his own right. Often he has attended these meetings with the manager of the advocacy organisation that employs him as a project worker, rarely being appointed as the sole representative from this organisation. Like Hannah he has a long history of working in self advocacy;

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however he has never really participated at the grassroots level, saying he

prefers to "work behind the scenes".

Andy likes politics and has enjoyed being at meetings with senior departmental

staff, community leaders and Ministerial staff, although as noted above he thinks

the Ministers should attend more meetings. Despite this he talks enthusiastically

about a meeting he had with the Minister's advisor:

> Yeah I had a meeting with him at Parliament house a few weeks ago [to]
> give the Minister advice…to tell the Minister if [they] have not heard
> about …there's a brand new CRU [Community Residential Unit] ..and I
> believe it is overcrowded…also about closing institutions. *Andy 09/05*

Hannah and Andy have had direct contact with people they perceive as having

positions of power in their roles on the advisory body. Through this they have felt

like they too have had important status. Their involvement in these advisory

bodies has also led to new experiences; Hannah talks about being asked to

present at conferences, noting that she achieved things she had never

considered were possible:

> I worked very closely with the… chair person for twelve months and I
> went to [two Capital cities]…..I went to [Capital city] and done two
> courses …and this year I am going [overseas to a conference]. Going to
> that, thinking oh no I'll never go [overseas] …and talk to 300 , 400 people
> about disability because I think oh no I could never do that.
> *Hannah/12/06*

Succeeding as individuals and taking their place alongside other professionals is

a measure of their individual success. They do not feel like they have to identify

with a group to have this success, Hannah notes:

> It was good just representing myself on the [disability advisory body], not an organisation because I didn't have to report back. *Hannah 12/06*

And Andy notes:

> Well I am a person with a disability and I am a normal citizen. I still can live like normal people…no different to any other people in the community [but] to be on the [advisory body] you have to have a disability, that is how the system works. *Andy 09/06*

Summarising the professional orientation

Hannah and Andy are not disability service users and do not rely on disability policies or the funding that comes from these to live their lives. They have little direct contact with people who do rely on services; when they do they are usually in training or facilitation roles imparting their knowledge and skills rather than standing beside them in a self advocacy way. As trainers, consultants and researchers they have taken on professional roles in the disability sector alongside non-disabled professionals who also have these roles. They have embraced the opportunities that these roles have offered them as individuals.

Foremost Hannah and Andy see their positions on government advisory bodies as jobs and they approach them as individual employees doing their work. They believe they have to work as professionals in these roles. They form their own opinions about key issues and are often known to repeat their 'script' when asked to have input. For Andy this 'script' is about closing institutions and for Hannah it is about putting information into Plain English. Hence, Andy says he does not say much about other issues at meetings.

Their appointment to these roles has marked important changes in their identities, from self advocates or self advocacy workers to leaders and professionals employed in the disability sector alongside other professionals. Andy wants to use his position on the government advisory body to have private meetings with the decision makers where he can push for institutions to be closed. It is likely that Andy is modelling himself on people he has worked with, in particular professional advocates whose work involves a lot of meetings with government representatives. Andy has never had the opportunity to engage with these decision makers this way in his self advocacy work, always accompanying the professional advocacy worker. Hannah refers to herself as a "leader"; she wants to be seen for her abilities, not her disability and to be accepted as a friend or colleague to other members of the advisory body and the staff who support the advisory body.

Hannah and Andy have moved away from the collective reference point of self advocacy to this professional approach to representation. However, Hannah and Andy recognise that in their roles they do not have much power or influence, and as individuals, they do not always get the support they need to participate in the way they believe they should. Andy says, "If you don't ask you don't get told. That's very true".

Andy and Hannah have not established autonomous ways of working in their positions on the advisory body because they are not used to working this way.

They are more used to having their work arranged for them and being advised or instructed on how to carry it out. Andy talks about 'hoping' that the support staff will arrange meetings for him with the Minister. Hannah 'hopes' for a group who sees her as she sees herself, as a competent leader who is their equal. At one time in her role of the advisory body she did feel accepted in this way; however that was when she perceived members of the group as her friends and colleagues and they treated her well, in her eyes. Both Hannah and Andy participate as individuals and have created their own way of doing this. Neither report very positively on this experience, however neither has asked for changes nor worked towards a different approach, preferring to continue as they are. Hannah is very critical of the forums she is involved in and questions the way she is perceived within them.

In Chapters 6 and 7, the basis for this professional framework is discussed in more detail where it is argued it has been developed by a combination of the terms of appointment, how people have interpreted these, how they have been supported to participate, and how they identify themselves within these roles. As individuals with an intellectual disability they have drawn stronger links with the professionals in the sector however they do not always feel that they are, or are perceived to be equal to them or equally capable of participating in the same way as they do:

> On the [council] there is only myself and one other [person with an Acquired Brain Injury] and the rest are carers, parents so it's been a little bit difficult but I am holding out. *Hannah 11/05*

This professional approach to participation sees people participating in their own right, occupying "socially valued" roles alongside other professionals. In this way it fits with the goals of Normalisation and Social Role Valorisation, which were to enable participation of people with a disability by aligning people with an intellectual disability with non-disabled people or other valued disabled people. However, Andy and Hannah's accounts in this chapter and later in Chapter 6 illustrate that they are not fully participating and they do not feel like equals within these participatory environments.

Communitarian orientation: Participation as community involvement

> Oh it is going to improve our community….cause there is so much stuff around here that needs doing, so we have just got to try to improve it, it may take time but we will get there eventually….in my opinion it is about time we got this community up to line. *Christine 08/05*

There are four people whose views about their participation indicated a common approach that is described here as the Communitarian orientation. All four live in country areas and belong to Local Government disability advisory bodies. These people have a commitment to improving their local communities and enabling better access and inclusion for everyone.

Case Study 3 Communitarian orientation: Phillip, Martin, Tyler & Christine

> **Phillip** is in his late fifties and lives in a rented flat on his own. He likes to be busy and over the years he has been self-employed in a range of jobs. Phillip hasn't had much to do with disability support services,

preferring to do his own thing. He did get involved in a day service and through that was appointed to a committee of another service. He has had a few of these appointments but finds it hard sometimes because he doesn't like it when decisions are made without proper consultation with everyone. Through his connection with a self advocacy organisation he found out about the 'peer facilitation' program. He loved doing this program because he got to spend time with his 'peers', other people with an intellectual disability. He was really disappointed when this program stopped and the government disability department didn't do anything to bring them all together again. This was the first time Phillip had ever been involved in anything like this and he saw it as a great opportunity for people to get out and talk to others about their rights. He has been on the local advocacy organisation committee and through this he has become pretty well known by the government disability department. This has led to him being invited to consultative forums and meetings held by the department about different policy issues. Phillip says he gets sick of going to meetings and not seeing anything being done, he can't see the point of it. Phillip wants to see more people get involved in having a say about things for people with a disability. He is a lead person in the Local Government disability advisory body and works closely with the coordinator of this group to get more people involved.

Martin is in his early twenties. He doesn't have a job and lives at home with his parents. He went to a mainstream primary school and secondary school. He is a volunteer in a community group and a volunteer with kids with disabilities in a recreation program. He has been to TAFE doing work preparation programs and would love to get a job in his town. Martin has never belonged to a self advocacy group and apart from some people at the TAFE he doesn't know many other people with an intellectual disability. He became involved in the government disability advisory body through a person who knew him and knew about the group. Martin likes to be a part of his community and thinks that people need more support to be able to get involved. Sometimes he thinks the disability advisory group should help to raise funds for things that people in the community need but he has learnt that this is not their role. He sees himself as helping out in this advisory body and making sure that things get done. Martin never misses a meeting and is good at remembering what was supposed to be done from the last meeting. He doesn't have much to say but likes to be involved and to learn about what is going on, particularly hearing from guest speakers.

Tyler is in his mid twenties and lives in a flat on his own. He has lived in many different places including an institution for people with an intellectual disability. He was much younger and much more independent than the other people in the institution and was placed there because he was homeless and had some difficult behaviours. He ended up moving into the community but with very close supervision and support. Now he just gets help with shopping and budgeting. He is really busy in the community with programs in art and music with other people with disabilities. Tyler also attends some classes on reading and money at a community-learning centre for people with a disability. He became involved in advocacy when he was being helped by an advocacy organisation to move into the community. Through this group Tyler became interested in being on boards and committees. The advocate also invited Tyler to meetings about disability policies and issues and told him about the 'peer facilitation' program ran by the government disability department on the Disability Standards. This got Tyler involved in having a say about the rights of people with a disability. Tyler's main interest is getting people out of institutions and helping them move into supported services in the community, and he would hope that more people could end up living independently.

Christine is in her mid twenties. She grew up in her family and went to local schools. When she left school she became involved in disability support services to do courses in numeracy and literacy. Around this time she also became involved in arts and music. Christine shares a house with another young woman with an intellectual disability. They receive support from an outreach worker for cooking and budgeting. Christine also did the 'peer facilitation' program and through this and her connection with the local advocacy organisation started running some courses on the Disability Standards for people with a disability. This is when she started thinking about the rights of people with a disability. She has never been involved in any self advocacy campaigns but has been to a lot of forums and groups that the government disability department ran. She usually finds out about these through the advocate at the advocacy organisation, she says he thinks it is a good idea for her to get involved because she lives independently and can talk about this. Christine really carers about the people who live in institutions and making sure they can be a part of the community, but thinks the community has to get a lot better before people like those from institutions can live happily and easily in the community.

Participating from a communitarian orientation means that this group identify more as community members and have a very local focus in their roles. All four people in this group feel very strongly about their communities; three are from the one community and the fourth is from another smaller community. There is a strong local flavour to the way they see the issues and the solutions to these.

Goals and expectations: Contributing to a changing community

> I am rapt with what the [advisory body] is doing…Yes, to me I'm going up and down like a kangaroo because I can see something at the end of that little hole. *Phillip 12/05*

Phillip's main goals are to bring people together and get things done. He talks about his many friends with a disability who do not participate in the community and he thinks this is because they haven't been involved in forums about community inclusion. His other goal is to remedy this and bring more people with an intellectual disability into forums like the ones he has been involved in. He thinks that is the only way they will see themselves as part of the community and the community will see them as legitimate community members.

Christine and Tyler, have a lot of contact with people with a disability through the supported day services they use and their community arts activities. They talk about these 'other people with disabilities' often and refer to their needs when talking about what they want to achieve through their policy participation:

> My main, well one of my main interests is to get people from umm institutions into 24 hour care then back into living independently get them in the community a bit more. *Tyler 11/05*

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Tyler also notes that he should use his experiences to make the community aware of the problems people with a disability face, in services and in the community. He has had a lot of experiences where his rights were not recognised, and he can talk about it whilst many other people cannot. His main goal is to share his experiences with the community so they can have some insight into what it is like for people with a disability when they are not accepted:

> Doesn't worry me what it is because as I said earlier they are just like everyone else, they shouldn't be set aside as they have been in the past. I get to see the enjoyment on the people's faces that there is someone wanting to get their information out. *Tyler 11/05*

Christine sees her role mainly as a connector and communicator. Through her roles on the disability advisory body, other consultation committees and her community arts activities, Christine has contact with: three disability services, a community drop in centre, a community radio station, Local Government and the State disability department. She works across these to raise issues, talk to people with disabilities, and talk to disability service providers and the community about the barriers that are standing in the way for all people with a disability. She is very keen on changing the community's view about people with a disability through being seen as a member of the community.

> Because I reckon it's important for those people to know out there what I can do.. But yeah I reckon, that's why I am involved with these meetings if there is anything that has to come back to here [community program/service]…I can come back [and talk about] how we can improve it and all that stuff. So that's why I am involved because.. I don't want to see them [other people with disabilities] left out if we are not around they are going to be stuffed.. Yep trying to get them out in the community. *Christine 08/05*

She talks about, "our community". By this she means the shops and the services

in the town and the disability specific services and activities she accesses, in

particular a community drop in centre used primarily by people with a disability.

Her involvement with this centre is as a service user and a support to other

people who attend. This is her community and she wants more people with

disabilities who are, "stuck in their services" to get out and participate in this

community. Through this participation she believes the broader community will

become more accommodating of all people with disabilities.

Martin's goals for participating are about having something to do, helping out as

a volunteer and learning about issues from other people. Martin participates in

two community volunteer groups and the advisory body. He sees them all as

volunteer roles and talks about them as the same kind of activity. He likes to hear

about the issues in the community and enjoys it when the group has guest

speakers. Some of the issues he remembers being addressed by the advisory

body are: safety in public toilets from Neighbourhood Watch, footpath safety from

a woman with a disability with young children, and access to taxis for people with

a disability and older people in the community. Martin talks about physical access

as an issue he wants to address:

> Easier access into buildings as well for people in wheelchairs. There's a
> couple of places where they have had to put ramps in…the banks. *Martin
> 09/05*

He does not use a wheelchair or have any mobility needs but from his

involvement in the disability advisory body he has met many other people with

physical disabilities and he has become attuned to their needs. He also notes that he is very well known in the community and he thinks that is why he should be involved in things like the disability advisory body.

The people with a communitarian orientation have mixed goals but primarily their participation is about changing the community through their presence in the community, through volunteering, and through advocacy and advisory forums. Each of these people are members of advisory bodies where the membership is solely people with a disability. They are small, local groups that function in a semi-formal to informal way allowing for the members to set the agenda. This enables these people to focus on their immediate community and its needs and to decide what needs doing and how they want to address the issues.

Community members: A shared identity within their 'community'

> Everyone in the whole of Australia they have all got a disability, it doesn't matter who you are, you might not look like you've got one but everyone has got a disability …*Christine 08/05.*

Christine, Tyler, Phillip and Martin are actively involved in their communities. Some, like Christine and Tyler are also disability service users and are identified as this by the advocacy organisation they belong to and by the people who promote their involvement in the disability advisory bodies. However, they recognise that compared to the other people who live in residential services and institutions, they are community members. Martin lives a very isolated life apart from his three volunteer commitments. He has attended TAFE but when he

finished those courses he returned to his daily schedule of helping out at home and going to his voluntary jobs. He is well known in the community, with his sister commenting that "everyone knows [Martin]"; however he does not have any friends or a social life outside his voluntary work. Phillip, whilst well known in the community, is not very active in it. Most of his time is spent doing odd jobs like mowing and collecting bottles. He gets paid to do this work by a few different people around the town. His strongest connection to the community is through the people who employ him to do odd jobs. Outside of this work his social contact with his friends is through an advocacy group.

These four people all expressed that first and foremost they were members of their community with many of the same needs as other community members. They recognise that as people with an intellectual disability they face barriers to participating in the community. They have experienced this themselves and have learnt more about it through hearing about others' experiences. Their motivation to participate primarily comes from an interest in community membership and addressing the social barriers that stand in the way of full community involvement. They want employment, housing and a social life in the community and to be able to use the disability services that are available to support them when needed.

Phillip has lived in the one town all his life, where he is a well-known identity. As he puts it:

> For a little while about 12 months ago I had a go at possibly shifting to Woolsford and a few people in the town threw their arms up in the air and said No, No, No, no way known. *Phillip 09/05*

He feels like he belongs in this town and has connections with people that help him live his independent life. Phillip's participatory career is based on him having been 'headhunted' to join consumer committees, a State Government policy advisory committee and a self advocacy committee. A local self advocacy organisation put him forward to join the advisory body, and over time he became known by the government disability department workers and Local Government as a person who likes to have a say. He is also known for his commitment to getting things done; particularly things that apply to his local area.

Phillip does not use disability services, but knows lots of people who do and thinks they should get more involved in the community. These are Phillip's friends, he has grown up with many of them and unlike him they have continued using disability services throughout their lives. Phillip sees it as his responsibility to get them involved in committees and groups that are making decisions about how things are done for people with an intellectual disability. Some of the "wrongs" he sees are, people who live in a nearby institution not being able to participate in the community and footpaths that people in wheelchairs can't use. Phillip says the way he likes to work is, " Not here are some problems what are we going to do about them, but when are we going to do them?"

The community is the reference point for this group and through participation on advisory forums, work, disability services, volunteer roles and connection to advocacy groups, they feel they are belonging, contributing and engaging in the community. Through their community presence, they also feel they are able to educate the community about disability and the needs of people with a disability in the community. Martin also found that through his work in the community with other people with a disability he was able to learn more about the barriers people with different disabilities faced.

Summarising the communitarian orientation

Unlike the other two types of participation orientation the communitarians have positioned themselves within a community context, rather than a self advocacy or professional, individualist context. Their aims are community participation for everyone and through their work on the disability advisory bodies they see that they are both participating and acting as change agents. Christine, Tyler and Phillip are clearer about these goals, while Martin views his involvement as an extension of his volunteering role where he participates because he is a concerned and committed community member; it is not about promoting himself.

Participating in the advisory bodies they believe, enables them to raise community awareness about disability, and through this change the structures of the community and community attitudes so everything is more accessible to people with a disability. In this way they are ascribing to a view that is put forward

by the social model of disability, as discussed in Chapter 2; that disability is constructed by disabling societal barriers and the aim is to change these barriers that disable people. They are also working within a participatory framework that sees participation as a means to an end through supporting change via community capacity building.

A typology of participation orientation

The following table (Table 7) presents the key factors that define each form of orientation. The development of this typology draws on work from Wolfe (2002) and Boyce et al., (2001) who suggest that it is important to consider the reasons why people participate from both a personal and political perspective, and that it is people and the structures that they participate in that forms citizen participation. The typology (Table 7), includes four dimensions: participation goals and expectations, reference points for participation, how people see themselves, and their view of participation. This final dimension could also be seen as their political perspective on participation.

As discussed in the sections above, these people were able to articulate the dimensions of their participation. They knew what they wanted to achieve, how they wanted to achieve it and what they considered to be the reasons for participating. Similarities, where they occurred, were used to group them under one of the three participation orientations. The typology provides a way of describing and understanding these similarities.

Table 7 Participation Orientation Typology

Participation Orientation	Participation Goals and Expectations	Reference point for participation	Identity – how they see themselves	Notion of participation
Democratic	Increased involvement of people with an intellectual disability in participatory opportunities. To be a role model to other people with an intellectual disability. To educate 'others' that people with an intellectual disability can participate.	Self advocacy Direct life experience of a broad range of people with an intellectual disability represented through self advocacy.	Self advocate Person with an intellectual disability	Participation as a right
Professional	To be recognised as a leader with an intellectual disability. To have contact with people in power. To be a spokesperson and to be paid to do this.	Own life experience as a person with an intellectual disability and ability to succeed as an individual.	Question label of intellectual disability as applying to themselves.	Participation as a status symbol
Communitarian	Raise community awareness, change community attitudes, address social and structural barriers to community inclusion	Own life experience and shared experience of disability.	Person with a disability – associated with difficulties with learning	Participation as a role for community members.

It is suggested by this typology that people come to these roles for a number of reasons. Wolfe (2002) makes nine claims about why participation might be valuable. These are: to assert individual and political rights, to express freedom, to engage in civil society, to express oneself, to contribute to a system of self government, to connect the voluntary sector with government, to build trust and

social capital, for individual self development, to develop social bonds within community. The typology presented above suggests that the people in this study were participating for some of these reasons. For those with a democratic orientation it was about empowerment for themselves and all people with an intellectual disability through participating, and attainment of a civil and political right. Those with a professional orientation were participating to attain what Wolfe (2002) has called "individual self development" and those with a communitarian orientation aimed to create a certain kind of community and through their participation to express themselves as a community member. Most of the reasons for participating could be seen as 'means to end' rather than an end in itself. People are participating because they want to see something change through their participation, either something personal or political.

This study also suggests that each orientation has a different political basis. The people with a democratic orientation share a belief that participation is a right and that more people with an intellectual disability need to be participating or at least be represented in participatory forums. Their reference point is self advocacy. Most of the people in this group learnt their skills of participation through their involvement in self advocacy and still have strong connections to the self advocacy movement. They are people with an intellectual disability who have lived their lives in a time when rights based disability legislation and policy were introduced, following a time when they were not seen as people with rights, were segregated and were silenced. This analysis suggests that their past

experiences and the policies that were dominant throughout this time have had an impact on what they see as the reason for participating. They have a rights based framework for determining their action.

Hannah and Andy who are described as having a professional orientation have come from the same era as those with a democratic orientation, they have in their past engaged as self advocates, also working from a rights based perspective. However, they have distanced themselves from this in their participatory roles on these disability advisory bodies and have now embraced a professional approach to their participation, modelled on the non-disabled professionals they work alongside. The analysis here suggests they have been influenced by another important principle that developed in disability policy at the same time as the rights based approach was developing; the principle of Normalisation. Their views about their participatory roles, and how they have been positioned in these participatory forums as professionals alongside other disability professionals, reflects this philosophy. They have attained the 'socially valued role' of an appointed member on a government advisory body and as such have achieved normalisation. Their goal was to be accepted as spokespeople amongst other people with disabilities. They have been appointed to these positions as individuals, not representatives of any organisation and they participate as individuals who are 'known' in their own right as leaders.

The group with a communitarian orientation have primarily lived their lives in the community. They have experienced community integration and aim to be employed in the community. Their participation goals reflect their views of themselves as community members and more than people with an intellectual disability. They recognise that there are barriers to the full participation of people with a disability in the community and aim to address these through their participation. Community inclusion and community participation are their goals. Their underlying belief is that by participating they are changing the community and showing that people with an intellectual disability can be community members. They see themselves and other people with disabilities as people who belong in the community but because of the way society or the community is constructed can have difficulties participating. Changing these attitudinal and structural barriers is important to them. This view reflects the UK social model of disability (Barnes, French & Swain, 2003; 1999; Boxall, 2002) and the range of disability policies that have been based on this model. Whilst none of the people in this group articulated their stance or approach as a reflection of this model, it seems that it has impacted on the way they see themselves, their participatory goals and their orientation to participation.

Summary

Being a person with an intellectual disability is a different experience for different people, it cannot be assumed that people can represent 'an' intellectual disability perspective in their participatory policymaking roles. People will bring to these

roles their own life experiences, their own views about what is important for people with an intellectual disability and themselves and their own political orientation. Such factors will shape their participatory aims and their ways of participating.

The typology presented in this chapter aims to recognise the personal and political contexts that have orientated people to their way of participating. It suggests that the people with an intellectual disability in this study are basing their participation on something more than their individual experiences of life as a person with an intellectual disability. They have a broader basis for their participation which comes from their past participation experiences, their notions of what participation is about, their life experiences, their political views about intellectual disability, and their identity as a person with an intellectual disability. Importantly, they are seen as having 'agency' and being able to draw on their own views and the experiences they have had as individuals and as people with an intellectual disability to inform the way they participate.

This supports research by Yeatman (2000), who suggested the importance of recognising that people with an intellectual disability can have individual agency and express this through participation. It also enables a new view of people with an intellectual disability to be formed and recognised that can transform the way they are seen, supported, and worked with in participatory roles (Schalock et al., 2002; Whittaker, 1993). They have particular political ideologies that inform their

participation goals and expectations, and personal views about what participation in advisory bodies can achieve for them and others, personally and politically.

The three orientations suggest that there are some similarities in styles, goals and approaches to participation. However, the analysis suggests that it is likely that these have formed through a mixture of the opportunities people have had to participate and the way these experiences have shaped their views about themselves and about what people with an intellectual disability can achieve. A proposition is put in this chapter that different disability principles and philosophies of practice and policy could also impact on how people see their roles, form their expectations and decide on their aims. The three models or ideas about intellectual disability that it is suggested have had some impact on how people see themselves are: the rights based approach, the principle of normalisation and the UK social model of disability. Each of these are evident within current disability legislation and policy, as discussed in Chapter 3.

Disability studies literature is beginning to affirm that a multi-faceted view of disability defines the way we see disability today (Shakespeare, 2006). This view has been shaped by the past thirty years of questioning and reviewing what makes sense and what can assist in both understanding disability and responding appropriately to the supports and opportunities people with a disability need to live their lives. Definitions of intellectual disability have also changed over this time and likewise, we have come to a time where a more

multi-faceted view is dominant. This view accepts that functioning can be impacted by a combination of capacity, ability, and opportunity, and that these factors coexist and contribute to the overall experience of having an intellectual disability (Fyffe, 2007).

When considering how people with an intellectual disability participate in policymaking and advisory forums, it is important to accept these complexities and then see how the participatory environments mediate the experiences. In Chapter 2, the literature on citizen participation indicated that there is a range of structural characteristics about citizen participation that impact on its effectiveness and efficacy. However, as noted by Freeman (1983), "It is important to emphasize...that factors in these structural dimensions do not act alone but are mediated through the agency of individuals" (in Boyce et al., 2001 p.26). This chapter has given some insights into the individuals and their agency, as people with an intellectual disability participating in a political environment.

CHAPTER SIX

DISABILITY ADVISORY BODIES: STRUCTURE, FUNCTION AND THE PARTICIPATORY EXPERIENCE

> Where … participation is perceived solely in terms of structure and operation, then agencies will preserve inherently disabling relationships and achieve perhaps no more than tokenism. (Drake, 1992 p.276)

Introduction

This chapter examines how the structural characteristics of government disability advisory bodies, and the way they function, mediated the participatory experiences of the members with an intellectual disability. This perspective is developed through: the evaluative reflections of the people with an intellectual disability as they described their participation, observations of the way the advisory bodies functioned, and document analysis of the work of the advisory bodies. The structural factors considered include: the level of government and policy context, the terms of reference, the membership composition, and the way the 'business' of the groups is carried out. Each factor is outlined in Table 8. The combination of the way the advisory bodies are structured, the processes they use, and the way they function were used to determine a level of formality. These are set out below.

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Table 8 Indicators of level of formality

Advisory body	Formality	Govt' level	Roles	Membership	Meetings: frequency, duration, agenda & minutes
Northern	Highly formal	State	Determined by legislation	Appointed by government (formal application process)	Monthly -1 day 12 – 15 point agenda with briefing papers and reports (over 50 pages) 2 page minutes 10 + policy groups
Central	Highly formal	National	Determined by government policy	Appointed by government (formal application process)	Quarterly -2 days Lengthy agenda with briefing papers and reports (more than 20 pages) Dot point minutes Some working parties as needed
Southern	Highly formal	State	Determined by legislation	Appointed by government (formal application process)	Bi-monthly 2 – 3 hours Lengthy agenda with briefing papers and reports (more than 20 pages) Dot point minutes Some working parties as needed
Seascape	Semi formal	Local	Outlined in terms of reference developed by government policy worker.	Formal application process. Selected by government policy worker and formally ratified by Council	Monthly 2 hours 4 – 5 point agenda Minutes 2 pages mainly dot points.
Hilltown	Semi formal	Local	Outlined in the groups aims and objectives	Expression of interest	Monthly 1 – 2 hours 4 – 5 point agenda 2 page minutes
Greentown	Informal	Local	Developed by group	Responded to open invitation	Irregular meetings 1 – 2 hours 4 – 5 point agenda 1 page minutes

Highly formal structure and function

Northern, Central and Southern are examples of highly formal disability advisory bodies. Two are State Government bodies and one is a National body. Their terms of reference, membership composition, aims and modes of reporting are outlined in legislation and/or government regulations. They meet regularly and formally, using formal meeting protocols; however people do not vote on decisions, as these groups have recommendatory powers. Agendas are shaped significantly by government policy and government can request that they undertake particular reviews, consultations or other work. In these instances they develop position papers or reports for government. Normally this involves some broader consultation with people with a disability and the disability sector. Each of these groups report formally through a government Minister to their respective level of government. The Chairpersons have regular meetings with Government Ministers and/or their advisors. People appointed as Chairpersons are normally high profile public figures, appointed for their public work or expertise in disability and/or social policy; most also have a disability.

Meeting agendas in the highly formal advisory bodies are large and meeting papers distributed to members before the meetings are sometimes up to more than fifty pages; they include briefing papers and reports. Meetings are normally long (from 3 hours to 2 days) and meeting procedures formal. Members are paid sitting fees and out of pocket expenses, travel is arranged and meals are provided at meetings.

Semi-formal structure and function

Hilltown and Seascape operate in a semi-formal way, they are Local Government

bodies that have formal terms of reference that are developed by the Local

Government workers and are ratified by the Local Council. They are connected

to the Local Government through a Councillor; in Seascape this Councillor is also

the Chairperson of the advisory group. Hilltown advisory body reports to a

particular Councillor through a Community Advisory Group, which is another

formal advisory group to the Local Government. Both Hilltown and Seascape

have a formally appointed Chairperson and they set the agendas in consultation

with the members and the support worker. The 'mood' and 'tone' of the meetings

is very conversational and friendly. They normally start with a meal or

refreshments and an update from each member about their activities since the

last meeting:

> They are evening meetings but they are from 6.00pm to 7.30pm and we
> always provide food. The first thing is people come in and start talking
> informally then get themselves cups of tea and coffee and sandwiches
> and so on. *Field notes 11/05.*

These two advisory bodies do not make decisions about policies or programs,

their aims and functions are primarily about community awareness raising and

monitoring of the Local Government Disability Action Plans. They do not develop

formal reports on issues and tend to approach their work in ways that the group

can manage. The support worker for Seascape outlined how she engaged the

group to monitor the Council's Disability Action Plan; the formal framework for the advisory group.

> She takes each objective and presents it to the group who then talk about whether it has been achieved and what progress has been made, each person then allocates either a 'tick' a 'cross' or a 'question mark' to indicate whether it has been achieved, not achieved or still requires work. In this way they are fulfilling their role to monitor the plan but it does not dominate their work or require formal processes to evaluate the outcomes. *Field notes 11/0.*

Both advisory bodies are characterised by their 'low key' modes of operating, their focus on community awareness raising, limited formality for addressing their aims, and a friendly, 'low key' atmosphere at meetings. People support each other and enjoy the social aspect of their meetings and of belonging to these advisory bodies.

Informal structure and function

Greentown is the least formal of the six advisory bodies. They have two tiers of membership; a core group of people who regularly attend meetings, and a broader network of people who are connected to the group but do not necessarily attend meetings. The majority of the core group are people with an intellectual disability; however over time a small number of people with other disabilities have joined. They developed their terms of reference and began without any formal link to the Local Government. The Mayor attended their first formal meeting, however they do not have a formal reporting arrangement with Council.

Greentown operated from the group 'up' and is facilitated to do this through the resource of the Local Government worker. This worker had specific views about the best mode of operating. This was based on her knowledge of the history of consultation with people with a disability in this local area, and local 'disability politics'. Her views included: that a formal group that only operated via their 'around the table' meetings would not work because it would be difficult to form such a group that was representative of the various disability groups in the town, the main aim was to have people with a disability participating in policymaking, monitoring and advice because in the past disability services had dominated these roles, and there should be a range of ways of participating based on the interests of the individuals. Initially there was no formality, no meetings set, no terms of reference and no formal membership categories or processes for becoming a member. Overtime the group sought some formality through the development of terms of reference. They began to have meetings and the core group grew to be more representative of different disability groups. Despite this move to a more formal approach, the advisory body remained informal, as they did not alter their processes or procedures regarding membership, agenda setting, and management of their work or reporting.

Experiences of participation

Experiences of participation vary greatly among the nine people with an intellectual disability in this study. Their length of time on the advisory bodies ranged from over five years for Kieran to a few months for Phillip, Christine and

Tyler. Hannah had been a member for four years and was just finishing her term at the beginning of the study, however, she was later appointed to another government advisory body.

Most were relatively new to this kind of role and those who had served for longer periods at the time of the study had no previous experience in such broad policy advice forums. All had experience in other consultative forums; these were mainly information forums conducted by government on particular policies. Some had experience on reference groups or management groups and Phillip had been a representative on a statewide policy group. Karla was the only person who had past experience in a similar disability policy body; she was also a member of a broader social policy advisory body that was not focussed on disability. All had past experiences of attending meetings although few had been members of cross-disability groups.

The people in the study had various reasons for participating. These were very personal for some people like Karla and Andy who wanted institutions to be closed because they had lived in them and knew how bad they were. For others like Martin who saw it as an extension of his volunteerism, it was a way of contributing to the community. People like Kieran wanted to participate to change attitudes about intellectual disability and to show others that people with an intellectual disability could participate. For Hannah it was a job and a way to be recognised as a leader amongst other people with a disability. Tyler and Christine wanted to be spokespeople for other people with an intellectual

disability and achieve community living for everyone. Chapter 5 discusses these 'reasons for participating' as part of their orientation to this form of participation. It is argued in Chapter 5 that this orientation was formed from their own personal experiences and their past experiences of participation.

Overall, the participants in this study are people who knew what they wanted to do in the roles, could see benefits for themselves and others through their participation, and used their past experiences and views to inform the way they participated. However, most of the nine people in this study struggled with the policy content of their work on these advisory bodies and did not refer to this as their main focus. Some note in the following section that the main thing they got from the participation was an opportunity to learn about what was going on, rather than to influence it. Few of the participants described in detail what they did in this role preferring to describe how they felt about what they did, what they liked or disliked about their role and what helped or hindered their participation. The following sections examine what it was like for these people to participate in these advisory bodies and how the participatory environment, in particular its level of formality, mediated these experiences.

Participating in a highly formal policy focused environment
Case Study 4 Highly formal: Northern disability advisory body

> **Karla** walks into the large meeting room on the top floor of a city office building, it is 9.50am the meeting started at 9.30am. She is late, everybody else is already seated. She walks in and loudly apologises for being late, saying "I slept in" and laughs. One person jokes back, "you shouldn't say that you should say the lift is not working". Everyone says hello. Karla takes a seat next to her support worker Nancy. The

Chairperson chose this spot for her at the start of the meeting. When everyone settles back down the Chairperson recaps for Karla. The room is open and light and there is tea and coffee set up at the back. There are seventeen people in the room including two sign language interpreters. Five people are in wheelchairs. The Chairperson works from the agenda, inviting various people to discuss points. There are twelve agenda items and an information pack of sixty-eight pages. (Karla received this the previous week and went through it with Nancy the day before the meeting). The Chairperson starts with information sharing which he calls 'gossip' and invites Karla to start. Karla has a quick whisper to Nancy and then talks about having only two more meetings to go until her term finishes and also shares some personal information about her father. Nancy whispers to her, then Karla also adds some information about Young People in Nursing Homes, a project that recently received funding from the Federal Government. In the first half an hour of her being at the meeting Karla has asked one question, presented information once, had two chats with Nancy and asked another speaker for clarification of an issue. The meeting goes until 4.00pm with breaks for morning tea, a buffet lunch and afternoon tea. There are two guest presenters and the last hour is spent in working groups; one on housing which Karla participates in. During the day Karla takes a couple of naps, continues to chat to her support worker, cries once while talking about institutions and has something to say another fourteen times (comments about what other people are saying or asking questions). At lunch Karla chats to a few different groups of people and laughs with them. By the end of the day she is tired but still able to concentrate and have her say.

Karla is a member of the Northern Disability Advisory body. She is a very friendly and talkative person and by her own admission "very emotional" about issues to do with people with an intellectual disability. She has been a member for four years and at the time of the study was coming to the end of her term. Karla notes that one term is not long enough for a person with an intellectual disability as it "took a year to know what council was doing". Karla reports that she will be sad to leave the advisory body. The current Chairperson also reports that he values Karla's input and tries to ensure that she is able to participate by giving her

opportunities to speak about things he knows she can speak about. Overall her

experiences have been very positive, although in the beginning she had some

difficulty participating. She managed to engage a support worker who understood

her needs and met with and supported her in a very personal way. This and a

Chairperson who actively engaged Karla in meeting discussions led to what

Karla described as "something [I] love". Karla describes what it has been like for

her:

> In the early stage it wasn't easy because I didn't understand everything
> on the council and I didn't understand what their goals were and what
> their philosophy was and what they meant to do and things like that so I
> found it really hard in the beginning. And then I got to understand it a bit
> and then it got easier and easier. When I very first started on there and
> things like that it was very hard for me because I, the things were going
> too fast and too quick and I didn't understand the big picture very well
> even though I did have someone to explain it to me….My eyes go like
> this [crosses eyes] I get so frustrated in the meetings, I have to leave, it's
> pushing my buttons, the system doesn't know what it's like. This is not
> about me, it's about people in institutions. *Karla 02/06*

Karla was described in the previous chapter as having a democratic orientation

to participation. She has strong connections to self advocacy and a firm

commitment to deinstitutionalisation. This issue drives her participation and whilst

it has taken her a long time, she does feel like she has placed this on the agenda

and been able to progress the need for community living, through her

participation on the advisory body. This formal forum has set some challenges for

Karla, however Karla has participated and has felt that she has had her say, and

has shaped the advisory body to some extent.

> I think for the disability council, I think that as a person with an intellectual
> disability being on this council every person has taken an interest in the
> issue of people with an intellectual disability, or people with a disability

being in institutions or things like that…It's tiring emotionally and physically. *Karla 02/06*

Like Karla, Jana has been described in the previous chapter as having a democratic orientation to participation. She became interested in the government disability advisory body after hearing about it through a self advocacy group and having a friend who had been on one. Jana has been involved in self advocacy for over twenty years and she explains that she felt she could do more, or something different on a government advisory body:

> I am heavily involved in advocacy… Yes and [I am in self advocacy] to see whether they are getting their rights…[The advisory body] No that is a bit different. They focus on all kinds of disability issues like mainly the pension for a start, what they are doing to people's pensions and that and focus on carer's issues. They focus on all range of issues across the network… I speak about what the self advocacy groups are up to. I also went over to [another State] last year in September. The [advisory body] paid for me to go and I presented at the self advocacy conference for the whole weekend. Well I wanted to try, I wanted to try something new in my life. I wanted to see whether I can do it. It's good experience for me, I like meeting new people... umm I feel important. And I never felt like I was important before but now I do...I am finding out first hand because we have representatives from the Department who come and talk to us about the pensions and other things. *Jana 11/05*

Jana has enjoyed the opportunities this advisory body has presented, she talks about meeting new people, travelling to different cities and enjoying the social side and being paid. However she also notes that the meetings are long (held over two days) and tiring:

> Over two days, it's full on they are very long days, um the first day, Thursday is from nine to five and the second day if it is in [another city] it is nine to three because people have to catch their flights to get home, but if it is in [another city] it is nine to four... On Thursday night after the meeting we always have a conference dinner...and we always relax but

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on the Friday I am glad, people are glad to get home, they are very tired [laughs]..It is good, Umm I am learning new things, I am understanding… Would it be bad to say [I like] the money? *Jana 02/06*

Jana talks about how she participates and that at times the information is hard for

her to understand even with the help of her support worker:

I am learning and sometimes I do understand what is going on…yeah because I suppose, because the [advisory body] is, umm is good because they like to inform people with disabilities what is going on… Some information I do [understand] and some I don't. That is why I take [my support worker] with me and she explains...yeah I read it that's why [I understand], whatever I don't understand, [my support worker] always has a copy because they send her a copy too. And if I don't understand it she reads it to me or she brings her own stuff, and we go over it. Well it would be better [if they were in Plain English] then I could understand what I am reading. Some of the minutes is easy for me to understand and some get very complicated. It went over my head. Like I couldn't even follow what the whole [meeting] was about. They didn't have it in Plain English they didn't have it easy, if they want people to participate they have to make it understanding for people too. I wish there was an easy meeting to go to that you could understand. And also they should, look, they should really cut down the minutes so it is easy, like have them simple, the language. Also, they are very long days... It is mostly good because you can understand what people are talking about. They slow down … (*Jana 02/06*).

Jana also talks about the way the meetings are chaired and how this helps her to

participate, but most importantly she feels comfortable in the group because

people have been friendly to her:

We go around the table and everyone can have input, what do you think of this? Someone presents then after people present, then we go around and say what do you think of this? and people have their say. He [the Chairperson] gave people a fair go, people put up their hands and that, and people would say "hang on wait your turn", this person is there, first it's [Jana] or this person and that... [my friends]. There is [names member], she's from, I think she is from Adelaide with her gorgeous blind dog, what's his name? oh I have forgotten her dog's name again. And there was another lady, [names her], she is from Western Australia I

think, no umm somewhere and she was telling me about her pet snake [laughs]… *Jana 11/05.*

Others who participate in the highly formal advisory bodies have not had such positive experiences. Hannah is a member of Southern Disability Advisory body. She was told about the advisory body by her self advocacy group. She applied with the help of an advocate, had an interview with the Minister's advisor and a senior manager from the State Government disability department and was appointed. Hannah enjoyed the orientation period, which included meeting the Minister, attending drinks and other functions. Hannah felt very excited about her new role, however after a short amount of time, she became despondent and began doubting her ability to perform the role:

> I thought it was going to be easy, no sorry, interesting and I thought I might be able to change attitudes of government people and make them look at people with a disability in a different way and it has taken me four years to get people with a disability heard [to] listen to people with a disability. But it hasn't always been smooth sailing because I have had to fight to get heard. Even now I don't get heard. *Hannah 12/05.*

Hannah has been described in the previous chapter as having a professional orientation to participation. She aims to work alongside other people with and without disabilities as an equal, however when she started on the advisory body the secretariat supporting the advisory body asked her to do a reading test to establish her support needs and to see how she could participate.

> I was a little bit upset when I got my position because I got put in a little room to ask me could you read this bit of paper to prove that I was capable enough to be on the [advisory body]. I had trouble from the start. I already was appointed to be on the [advisory body]. She [the secretariat staff] didn't know how to treat a person with a disability so she got me in

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a little room and she said could you read this bit of paper and I said what's this bit of paper about and she said I just want to check that your reading ability is all right …*Hannah 11/05.*

Hannah's participatory experiences were very reliant on how she felt within the group and how she felt the secretariat staff, the Chairperson of the advisory body and other members, perceived her. In Hannah's second term on the advisory body, her frustrations with her participatory experience continued, even though she was now more experienced and had also undertaken some leadership training. Her main concerns were that the meeting information was not written in Plain English, and she felt that the new members and the new staff did not understand her, or support her as well as others had in the past:

> Because we have a new [manager] and we have a new chair and they just don't treat me with any respect. The first Minister was like she would roll up her sleeves and get her hands dirty, if there was something about disability she was there, the second Minister didn't want to know and the third Minister we've had it's like …we don't even, we have found [it hard] just trying to get to see the [manager]. With the new [members, minister and managers] I don't have the support of colleagues. The new [advisory body] is different because there are parents and people who I thought didn't want me to be there. I just don't get on with the Chair and it's like I just feel there are some people [there] now that don't like me and because I am out spoken they don't like that, they want someone who is going to sit there and not be outspoken and I am not one of those people. I am feeling frustrated because I feel I am not being appreciated and they are not using me for the abilities I have got. *Hannah 04/06.*

Hannah's story illustrates the complexities of participating in a very formal environment where the expectations are high. People are expected to read and understand complex policy information and then form their own opinions about it.

However, Hannah was unable to read, or understand the information and even with a support worker, she had limited access to the materials on which she was expected to base her opinions. Hannah's experiences also highlight the importance and complexity of establishing working relationships with a broad range of people; Government Ministers and their staff, Chairpersons of the council, other members and secretariat staff. In Hannah's case this mix of people changed many times in four years, she formed good relationships with some, and with others felt unsupported. Hannah's story indicates that positive experiences of participation in these kinds of groups can often depend on the relationships you form, as much as your ability to have a say about the policy issues. Hannah felt this very strongly. She had positive experiences when people she could access surrounded her, who understood her, and engaged with her. She had less positive experiences when she had a weakened support network, felt she was not accepted and was unable to establish a working relationship or 'friendships' with the range of people she saw as her colleagues.

Andy like Hannah has a professional orientation to participation and he too wanted to be able to participate alongside others. He wanted to be seen as their equal; however he had real difficulties concentrating and understanding what was being discussed at meetings. He blamed himself for not participating well enough:

> Oh I think sometimes, oh well, sometimes I don't listen very well …I am not taking enough interest in what they are talking about. What else?, I am not taking enough time. *Andy 09/06.*

In this role he expected to be able to meet with the Minister and the Minister's advisor and was concerned when this did not happen very often. He expected to be able to tell the Minister what his views were and found the regular meetings "boring", however he attended them because he was getting paid to and he saw it as his job. Andy also felt that he was not as well prepared for meetings as the other members noting that he had "no training, no nothing" when he was appointed. He goes on to note again that compared to the others he felt less experienced:

> Yeah I think they have [more experience] they go to a lot more meetings than I do. *Andy 09/06.*

He reflects that another person did not participate in meetings saying, "she used to just turn up and sit there" suggesting that if it was all right for her then it should be all right for him, but he felt that others were judging him if he did not participate.

Both Hannah and Andy have many years of experience as self advocates and in a range of roles where they represent the views and experiences of people with an intellectual disability; however in these formal policy focussed forums they can feel incompetent. They each recognise how things can be better in these environments; Karla highlights the importance of establishing a strong supportive relationship with a support worker, Hannah notes the importance of feeling respected as an equal and being promoted and supported to take on active roles. Jana and Hannah raise the issue of access to information and Andy highlights

the difficulties of not having direct and regular access to the policy makers and the issues he experienced because of lack of training.

The formality of the groups and the scope of their work have impacted on the participatory experiences of these people, and only some have felt confident to make changes to their environments to enable more positive experiences. Karla and Jana who have been described as having a democratic orientation to participation were able to work out ways of participating based on their past experiences, and by getting appropriate support. They continued to struggle with the accessibility of the information and saw this as a systemic issue that needed to be addressed beyond these advisory bodies. Others like Hannah and Andy who have a professional orientation to participation, did not want to focus attention on themselves because they did not want to lose this role that they felt was very important and that 'employed' them as professionals.

Jana and Karla made allowances for the formal participatory environment and worked 'around' some of the barriers inherent within them, there is not a lot of evidence that the environments adapted adequately to the people. Issues like inaccessible information, long meetings, a lack of training and orientation, and for some, a lack of supportive relationships internally and a lack of connection with external networks, impacted on the input people had and the outputs they experienced.

The most striking mediating factors apparent from these accounts were in relation to accessibility to information and how people felt they were regarded. Jana and Karla had problems with understanding information, however they both also felt that they were well regarded and were able to participate. This view was based on their perception that others respected them and with support, they could manage the information. Andy and Hannah however expressed strongly that they felt less capable and less competent than other members. This, Andy ascribed to his lack of education and training, whereas Hannah believed people were not giving her a chance to participate and to show and use her abilities.

Participating in semi formal locally focused advisory bodies
Case Study 5 Semi formal : Seascape disability advisory body

> The meeting venue was at the Seascape Council Chambers. The meeting room was large with a long wide meeting table taking up most of the space and a side table set out with tea, coffee and sandwiches. When Kieran and I arrived people were mingling with each other, having a drink and something to eat. People greeted Kieran as he entered the room and he began to introduce me to the other members. He found a place for me to sit then offered me a coffee and something to eat.

> After about ten minutes everyone seemed to have arrived and the Chairperson (a Councilor) sat at the head of the table and said that they should start the meeting. There were eleven people at the meeting; one was the advisory body worker from the Social Planning Department and one was another Council employee who was presenting to the meeting. There were two people in wheelchairs and one person with a guide dog. Kieran sat at the end of the table where he could see everyone and was facing the Chairperson. He explained to me that when he Chairs the meeting he sits at the head of the table. There is an agenda of six points (two business items; Mobility access and the Disability Directory). The minutes from the previous meeting are also tabled (two pages, eight items, all dot point notes).

> The first agenda item is 'welcoming' people and Kieran introduces me to everyone there and asks me to explain what I am doing. The Council employee who is a guest speaker is also introduced. An attendance sheet is passed around and Kieran writes his name, asks me to write mine and then he writes the name of the visually impaired person. The previous minutes are discussed and Kieran 'seconds' them. One item is the progress report on the Disability Action Plan, Kieran asks what a progress report is and the Chairperson explains and others add in information about the work they have done on this to remind Kieran what the item was about. During the meeting Kieran voiced his agreement on one item, put his hand up to have a say about another item and gave some feedback on a photo shoot he had been to for a Council event. The meeting was over in one hour and two people offered Kieran a lift home. Kieran told me on the way out that he really enjoyed the meeting. *Field notes, 0406.*

Seascape and Hilltown are Local Government groups. Their main aim is to raise community awareness about disability and to address issues of access and inclusion for people with a disability in their community. They place value on the personal experiences of the people with a disability; the expectation is that people will use their personal experiences to inform the work of the group. People are encouraged and supported to link these experiences to the broader policy objectives.

Both advisory bodies have been described as semi formal in the way they operate and the scope of their work. They have meetings, however these have a social and conversational tone. People share a meal and refreshments and are given time at the start of the meetings to catch up with each other. There are formal agendas and minutes, although these are kept brief and meetings normally take one to two hours. People are not paid sitting fees; however a light

meal and refreshments are provided at meetings. Seascape has formal terms of appointment outlined in their terms of reference, which allows for a three-year term and re-appointment beyond one term. Hilltown does not have terms of appointment; people are appointed based on an expression of interest and can remain members until they wish to resign.

Kieran is a member of the Seascape Disability Advisory body. He is really enthusiastic about his work on the advisory body and has been a member for a number of years. He is the Deputy Chairperson of the advisory body often chairing the meeting when the Councillor does not attend. He also likes to be involved in community activities organised by the Council like running a community awareness day on the International Day of Disabilities. Kieran's involvement in the group gradually increased over time. At first he attended and didn't say much, then after awhile he gained confidence and put his name forward to become Deputy Chairperson:

> I just sat and watched then one time they asked who would like to be voted to be chairperson and I put up my hand and said I would like to give it a go. It's a good role; it gives you self-confidence that you can do it… If I can do it then somebody else can do it. Down Syndrome people can do it, if someone can't speak they should be on the committee. They might [have to] print a little bit of paper out or have their signs but they can do it. *Kieran, 10/05.*

At Seascape, the Council is linked to the advisory committee through the Chairperson who is a Councillor. Kieran recognises the importance of this connection:

She [the Local Government Councilor who is Chairperson of the group] can umm take things back and she knows that people with a disability [have raised them], yeah and she can say "this is what can be done" and that and "the umbrella is open and I can see. *Kieran, 04/06.*

Kieran feels like an important part of the advisory body. He says that the group's real strength is everyone listens to each other, supports each other and if more time is needed the Local Government worker helps the group to plan to get their work done:

Yes, I let them know I have got something to share, and I listen to them yes. There's good communication, there is no one left out sort of. For someone with a disability it works. Someone is always there for you to help you if you got stuck or something, someone will always be too happy to help you, yeah that is why I am on it for a long time. We talk, if its one thing that might take a bit longer we will plan a meeting for that and we might talk about that one thing on a different night. Then we stick to that and we talk about it. *Kieran, 10/05.*

Kieran's participatory experiences on Seascape disability advisory body are very positive. He participates alongside everyone else, talking about his own experiences and working in with other members to get things done. He participates in much the same way as the other members and feels able to ask for help within the group if he needs it. He enjoys being able to have input into issues. Many of these come from the experiences of the group members; Kieran is easily able to relate to these because they are about his community. One example is where Kieran has used his position on the advisory board to raise issues about a pedestrian crossing near the TAFE he attends:

Well I've been on about getting a crossing at the back of the railway station across to the TAFE because it's hard to get across there, the cars zooming. I've been fighting that for a long time …It actually got somewhere…I actually got action happening…They are going to get a bypass over so people can walk across over to the other side, to TAFE.

Yeah, I have been fighting and fighting and been on their backs, and keep on their backs about it and if you don't keep on their backs about it nothing will be done unless you keep on and on. So I fight for that [for people with a disability]...Yeah and especially elderly people too. *Kieran, 04/06.*

The semi-formal mode of operating suited Kieran's style, he knew the rules of participating and relied on these when chairing the meeting, but they did not stifle his participation. Kieran has been described in the previous chapter as having a democratic orientation to participation. The structure and way that Seascape advisory body functioned also seemed to suit this orientation. Kieran was able to participate, bring his and other's issues to the group, was supported by other members and learned from them and their experiences. He provided feedback to his self advocacy group through the minutes; these are accessible and relevant to his colleagues in the self advocacy group who also live locally. Kieran's participatory experiences are positive. He has gained personally from his involvement and has directly impacted on the issues as evidenced by his work on the pedestrian overpass.

Martin is a member of the Hilltown Local Government disability advisory body. As discussed in Chapter 5, Martin does a lot of voluntary work and he sees his role on the disability advisory group as an extension of this. He has been described as having a communitarian orientation to participation. His main aim is to be involved in community activities and to learn from other people about issues. He

is also interested in letting the community know about the issues faced by people

with a disability:

> Yeah they have got that [community awareness day] on the Thursday. I think they are going to hand out folders with the different things. And I am going to clean out the back of my bike because I can fit quite a few on each side of my pack. *Martin, 08/05.*

Martin really likes the meetings when there are guest speakers because this is

an opportunity to learn about different issues:

> Yeah talk and like umm, talk about what we want to happen. Last meeting we had someone from the taxi, the local taxi group, because there are not enough taxis for people with a disability to call a taxi to go down the street or something. Also we need easier access into buildings as well for people in wheelchairs. There are a couple of places where they have had to put ramps in. It's pretty good. To learn different things, yeah and you get to hear about different things that happen. We talked in different groups, things that we want done in the community, one of the other people in the group, yeah like a couple of people say a lot but I just listen in mainly. *Martin, 08/05.*

Hilltown disability advisory body relies on the members to bring issues to the

meetings and to use these and upcoming events to set the agenda. Their role

includes monitoring of the Local Government Disability Action Plan, which can

guide some of their work. As Martin notes, they often have guest speakers about

issues like transport or physical access in the town and these speakers often

raise issues that the group use as a focus for future meetings. There is a strong

personal and local focus in the Hilltown advisory body. Martin talks about

individual members, their disability and the challenges they face in the

community, and how hearing about these helps him understand more about what

needs to happen to make the community more accessible. The group are

encouraged by the Local Government worker to focus on these personal and local issues; however she guides some of their work by suggesting and organising particular guest speakers or raising particular local issues with them.

Martin notes that sometimes he doesn't know what people are talking about, but he feigns understanding by looking at his notes and taking his glasses off. He thinks this looks like he cannot see what is on the page, rather than not understanding it. He can read, however only small amounts of information and only if he has enough time and it is not in complex language. He does not understand all of the written material that he gets in the advisory body. Martin remembers what has been discussed at meetings by reading the meeting date. The meeting minutes are written in Plain English by the Local Government worker; however Martin is still not able to read them in detail.

The semi-formal advisory bodies described here are places where the members with an intellectual disability can learn about issues through other people's experiences, bring their own experiences and issues for discussion, and together the group works towards changes that impact on many people in the community. Martin talks enthusiastically about the other members of the group, their disabilities and what the issues are for them:

> Yeah like one of the people who actually comes …she is in like a wheelchair, electric wheelchair. [Mary] is in a wheelchair and another one comes and she is in a wheelchair. She has got a umm one of these dogs. Like [Molly] she comes down she used to bring her special computer that she has 'cause she has a Braille one. *Martin, 08/05.*

Participation in these two semi-formal groups goes beyond the meetings. People participate in community awareness days, information sharing inside and outside the group and engaging with guest speakers. Both Martin and Kieran reflect very positively on their participation in these groups. They both say they feel like they are learning and are contributing.

An analysis of these semi-formal advisory bodies finds the way they are structured and their modes of operating connects people to the work personally, enables social links to form, and results in policy outcomes that mean something to the members. People are recognised for their own skills and interests and they are connected with each other and with the broader community. Also, the processes are straightforward. Decision makers are accessible to the groups and the members can see the impact of their decisions and advice; there is an immediacy of the policy outcomes. Such advisory bodies appear to be equally accessible and participatory for people with an intellectual disability as other members.

The informal and developmental participatory environment
Case Study 6 Informal: Greentown disability advisory body

> The meeting room is in a community centre. There are eleven people at the meeting; all people with a disability apart from the two Local Government workers. There are two large plates of sandwiches on the table and one of the Local Government workers is busy getting people drinks and helping others with the food. The group has grown since the last meeting, there are quite a few new faces and two of the original group aren't here. Most of the people at the meeting are people with an intellectual disability but three more people have joined who do not have

an intellectual disability and do not attend any of the disability services in town.

The Local Government worker starts talking to the group and explains how it came together. She said it was about things that were important to people in their community and things going on in Council and how to get involved. She introduces Phillip and says he has taken up a leadership role in the group. Phillip tells everyone that it is important that they speak up. The Local Government worker goes on to talk about the two other groups that this group could keep in touch with; one is a regional disability advisory group and one is a project group looking at participation within the government department. They talk about getting a representative from the regional group to come to their meetings; Phillip says that is a good idea and "the sooner the better, more chance to understand".

The Local Government worker talks about having a Councillor who will come along too. The group then talks about what that person's role would be and said they would be welcome but they wouldn't make decisions, just listen and take things on board. Everyone wants the representative to be the Mayor because he could make decisions. The discussion moves onto a report from Council about fixing things up around the town. Phillip and some of the others talk about the need to fix up some pedestrian crossings, to clean up the streets from rubbish and dog droppings, to clear bushes and trees that are hanging over footpaths and to do something about the lack of accessible taxis. They then talk about membership and Phillip says it is better than the smaller group and he is pleased to see his friends at the meeting. People talk about different people who might come along and ask the Local Government worker to send them some information. The meeting finishes after about an hour and the group stay around chatting while people get taxis and lifts organised. *Field notes 03/06.*

Phillip, Tyler and Christine are members of the Greentown disability advisory

group. It had not been established for very long when they first became involved

in this study. They had met a few times with the Local Government worker and

had begun to talk about why they wanted to form the group. Phillip was one of

the key members, where Tyler and Christine were less involved from the start

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and wanted to drift in and out of the group depending on what was going on both in their own lives and in the community. They were more interested in doing things like talking to other people with disabilities and attending community activities than attending meetings. Phillip's experiences are outlined below, as he was more actively involved in the work of the group during the study.

Phillip wanted to get involved in this group because he was concerned that there were a lot of people with an intellectual disability, including many of his friends, who didn't seem to get much of a say or get out and about much in the community. Phillip has past experiences of participating in different forums and thought it would be good for others to do this too. Through his previous experiences he learnt about the importance of having a say and he wants more of his friends to have this experience. Phillip had become frustrated with one committee because the meetings were in the city and he felt that the issues had nothing to do with him. He decided to resign from it because he didn't think it was achieving much and certainly nothing that helped him or his friends in their town. He had also given up on the service committee because he felt like he was a "token gesture" as they seemed to make decisions without consulting him.

As a member of Greentown disability advisory body, which as outlined above, used a 'bottom-up' approach to its development, Phillip was part of a group that determined how it would form, its composition and its terms of reference. Phillip, like many of the members of this group, had some significant barriers to

participation. He cannot read at all, he hasn't had a lot of exposure to disability policy and he has not used many disability services. His interests come from his experiences of living in the community independently, being supported to be self-employed, and his contact with an advocacy service.

Phillip has been supported by a range of people in the community throughout his life. He defined his work on the advisory group as a way of showing these people that he was able to give something back to a community that had supported him. As discussed in Chapter 5, Phillip was motivated by helping other people with disabilities to participate in forums that could change the community. His participation in Greentown advisory group enabled him to do this.

Phillip had an idea for getting more people involved. He wanted to find out what people with a disability in the area thought about participation and what kinds of forums they would like to participate in. He decided to do a survey but was unable to do it by himself. The worker supporting the group described how she supported Phillip to do this:

> Phillip talked to me about what he wanted in the survey and I suspect that he felt a bit uncomfortable because he is unable to read and write so he was happy for me to just take the notes, put something together then give it back to him. I read it back to him and he said he was happy with that. He said it reflected what he wanted included in the survey. The aim of the survey was to find out from people what it was that stopped them from participating, what they were involved in, what they enjoyed about participating. We then gave it to the other members of the group to have a look at, Phillip trialled it on a couple of people too and got good feedback so we decided to send it out. So we sent the survey out … I think we only got about 20 responses. *Carla 09/06*

Whilst the response rate was low, Phillip still felt that this was an important starting point for the group, and the information was used to invite people to the first meeting. It also assisted in the development of a database of people who were interested in participating. The advisory body uses this list to inform people about upcoming forums and participation opportunities. Most importantly, for Phillip it engaged some of the people he was hoping would become involved. At the first formal meeting of Greentown advisory group Phillip pointed his friends out noting they were new members who were there because he had got them involved through his survey (*Field notes 05/06*).

Phillip wanted to be an active member. He had previous experience of attending meetings where nothing happened and people just talked. He said he had seen enough of this when he was on the board of a service and when he went to the statewide meetings. Phillip worked with the Local Government worker to establish himself at the centre of this new group. At the second Greentown disability advisory group meeting Phillip was the Co- Chairperson. This meeting brought together the Mayor, a State Government disability department representative, eight members of the group and a representative from a regional disability advisory group:.

> Phillip said afterwards over coffee that he was "rapt" about the way things were going with the Greentown disability advisory group. I suggested that he was a leader in the group but Phillip said, " I am not a leader", people like the advocate and the Local Government worker were leaders. I challenged this and said that Phillip had been there from the

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start, he brought in other people, he got more members involved and he was committed to keeping it going so that younger people with disabilities can start to get involved and take over when older people like himself are not around any more. *Field notes 05/06.*

The success of Phillip's participation rests significantly with the vision of the Local Government worker. She helped Phillip and the other members to develop the roles for the advisory body and gave them information about the range of ways they could participate in policymaking and advice. She did this with the knowledge that Local Government wanted a disability advisory body, but in the past, these forums had only attracted disability service providers.   This worker acted as a conduit to the policy context of their work; however she did not expect the group to have a firm grasp of the issues, nor did she see this as essential to their participation. She noted that Phillip, Tyler and Christine were not aware of this policy context:

> I would be really surprised if they [the members of the advisory body] knew we had a Community Access and Inclusion plan…I don't know if they would even think it was something that they had a role in actually driving. I'd like to shift that but I don't want it to look like this [refers to a diagram of a group sitting around a table]. *Carla 09/06.*

Lack of policy knowledge was not seen to be a barrier to participation in this informal advisory group. The Local Government worker preferred to support the group to determine their own agenda. At the first formal meeting the group screened a video they had made. The Mayor was at the meeting, watched the video and said he would present it to Council. The video depicted a number of places around the town where people were having difficulty with access; these included a busy street outside an intellectual disability day service, uneven

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ground near a railway crossing and some local shops with steep stairs. The Local

Government worker noted that she did not think the "roads, ramps and rails"

issues were the main ones for this community; however she supported the

groups work on the video and understood the importance of this to them.

For Phillip participating on this advisory body was a very positive experience and

one where he could determine the way he would participate:

> Well I think more so the [Greentown] …group because it is hands on, I
> don't have to go to [the city], I can come here when I want…And I think if
> one person sees me on this reference group and thinks, hey, what is he
> doing there I could do that. That's my niche yes and I am not saying to
> them deliberately, I want them to see my involvement, I want them to see
> my reaction and when they have seen how much and why, "Come here
> you" , they will come on board. *Phillip 09/06.*

This informal advisory body offered a significantly different participatory

experience than Phillip had in the past in more formal groups. It was not locked

into a set agenda, they were able to determine what their priorities were, and

most importantly, they could come and go from the main forum and still be

connected to the advisory and consultative work through the network. This

flexible membership arrangement recognised the often-complex life styles of

people with an intellectual disability. Christine and Tyler drifted in and out

because they had issues associated with accommodation and support over this

time and were less able to contribute to a policy-focussed forum. This group

were heavily dependent on the Local Government worker to support their work

and to support the way they worked. When this worker left, the group became

less active, however Phillip maintained an interest in bringing the group together

and sought opportunities to do this until a new worker was appointed. This issue of sustainability of groups and the importance of consistent support is covered in the next chapter.

This informal and developing advisory body created its own structure and developed its own functions, albeit from the informed perspective of the Local Government worker. Members like Phillip were integrally involved in creating it from the ground up, as a way of responding to their disenchantment with other advisory forums, and their interest in doing something locally. The meeting described at the start of this section did not have an agenda, however subsequent meetings had agendas and minutes because the group wanted them. The role of Chairperson was rotated, because Phillip was going to be the Chairperson but decided everyone should have a go. Agendas started to reflect the interests and experiences of the people as well as responding to requests from Local and State Government for input into policy.

The group also planned for involvement in local events. They established links with the Local Government by inviting the Mayor as the Council representative. They also established links with state and regional advisory groups by inviting representatives of these groups to attend meetings and sharing minutes. They chose what issues they responded to and how they presented their advice. Issues and advice were connected to experiences and the outcomes were quite immediate, as evidenced by the video that was developed between their first and

second meetings. Overall, this developing and informal advisory body enabled

people to participate in ways that they formed through their interests and skills.

The Local Government worker formed the strategic connections; however the

people in the group decided how to address issues. Whilst they were locally

focused, their connections with other advisory bodies at a regional and statewide

level enabled them to link their work to a broader policy agenda.

Mediating factors: Level of government and terms of reference
A number of structural dimensions have been raised in the case studies and it is

suggested that they mediate the participatory experiences of the members with

an intellectual disability. They talk about the way the meetings are conducted, the

issues being discussed, and the approaches used by the advisory bodies to give

advice, as impacting on the way they participate. However, many of these issues

are inherent in the type of advisory body and are determined by their terms of

reference, which in turn is normally set by the level of government and guided by

its particular policy responsibilities.

As discussed in Chapter 3, in Australia each level of government has different

responsibilities in relation to policy, services, and supports for people with a

disability. There are separate and in some instances overlapping responsibilities,

for example advocacy is funded by the Commonwealth and State governments.

In addition, the Commonwealth or Federal level of government also funds the

State level to provide certain services and the State funds the Local level. Also,

each level of government funds generic services that impact on the lives of people with a disability like health, transport and education.

There is a large range of policy areas and funding arrangements that are related to disability policy. Disability advisory bodies are charged with providing policy advice across these, which can be complex and confusing. Members of the advisory bodies with an intellectual disability did not always have detailed policy knowledge or awareness about the complex arrangements of different levels of government and their responsibilities for different areas of disability policy and funding. This often led to frustration when their advisory body was dealing with issues that they did not see as relevant. There was not always a 'good fit' with their interests and the goals of the advisory body as determined by the policy focus.

The highly formal bodies as discussed were State and National government bodies, whereas the three less formal bodies were Local Government. The people with an intellectual disability in this study did not actively choose which level of government advisory body they would join. They were either approached to apply for a particular group, or were supported by someone to apply for a publicly advertised position. Whilst the differences in levels of government are apparent, the people with an intellectual disability in this study did not have a clear understanding about the policy parameters of the various advisory bodies or the different policy responsibilities of different levels of government they were

advising. Phillip had switched from a State government disability department

advisory group, to his Local Government advisory group, because he determined

the latter to be more relevant to him and he would not have to travel to the city to

attend the meetings. He did not say that this was because of a more relevant

policy agenda; however he realised that in the local one he could talk about

things around his town and get changes to these. The policy context of the

advisory body meant that Greentown advisory body could talk about access to

the community and advise on issues like safety, footpaths and ramps.

The terms of reference point to the policy focus as discussed above, and to the

scope of the advisory bodies work. The wording of these terms of reference also

point to the focus of the advisory body: 'be a forum', 'provide advice', 'and

participate in programs'. They also indicate the flow of work; using words like

'referred from the Minister', 'requested by the Minister' or 'seeks from the

Minister', indicating that the scope and direction is not self-determined. The study

found that the roles and functions are not always clearly articulated to the

members with an intellectual disability. A number of the people were not aware of

the terms of reference or that they outlined the work of the advisory body. Most

people had not read these or couldn't remember seeing them:

> I don't know what my role is, nobody has told me what my role is. To
> represent self advocacy from [the State] I suppose. I don't know. *Jana*

The membership composition is normally outlined in the terms of reference of an advisory body. All government disability advisory bodies in the study had members with some form of disability; most had a mixture of people with a disability, service providers, and peak body representatives. These cross-disability groups bring people with a disability together based on their shared experience of disability. This membership category is based on an assumption that the shared experience binds the group and enables them to inform policy from this basis.

Only a small number of people with an intellectual disability were members of government disability advisory bodies and as indicated earlier in the thesis, the six advisory bodies in this study were the only ones identified from a survey of Australian State/Territory, National and Victorian local disability advisory bodies that had members with an intellectual disability. This lack of direct representation by people with an intellectual disability was justified as discussed earlier by the view that they did not have the capacity to participate in such forums, or 'others' were better placed to represent them. People with physical and sensory disabilities fill the majority of positions available for people with a disability on these government advisory bodies. Whilst physical and sensory disability groups may have more presence within the community through their work and community participation, people with an intellectual disability remain highly dependent on specialist disability policy to support their lives. Being the only

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person with an intellectual disability on a cross-disability advisory body was a

mediating factor for some people with an intellectual disability in this study:

> On the [advisory body] there is only myself and one other [person with an
> Acquired Brain injury] …[and people with physical and sensory
> disabilities], the rest are carers, parents so it's been a little bit difficult but
> I am holding out. *Hannah 12/05.*

For others like Martin and Kieran on the local advisory bodies that were less

formal, the range of disabilities represented was a positive factor, as they gained

insights into the issues through these people's experiences. Members were

setting the agenda through the issues they brought to the table, and through the

policy context set by the Local Government disability plans that have a focus on

access and inclusion. In the State and National advisory bodies represented in

this study, the agendas were set by the policies. Northern advisory body had a

dual focus on disability services and making policy across government more

inclusive, so Karla could comment on issues that were important to her, like

closing institutions, and improving services and supports for people with

challenging behaviours:

> I am finding the hardest being on [advisory body] because one, being the
> only person with an intellectual disability, two I know there might or could
> be other people with disabilities who have been institutionalised and
> things like that but I feel so alone about the issue and things like that
> *Karla 02/06.*

Greentown advisory body started as a group of people with an intellectual

disability and broadened over time to include people with other disabilities. The

policy worker had noted that one of the problems in this area was that people

with other disabilities had felt that intellectual disability service providers had

dominated earlier groups, and they were unable to compete with them in setting

the agenda. When it was people with an intellectual disability themselves at the

table, they begun to set an agenda that was relevant to people with a disability

that lived in that town: the focus became the community and inclusion and

access to the community. This suggests that equality of voice can be attained in

cross-disability groups if people can connect with the issues and feel that their

experiences are relevant and will be heard. Advisory bodies that have cross-

disability representation need to examine their policy agenda and determine how

to develop these links and ensure it can be relevant to the members. For smaller,

less formal groups, it appears that being able to set the agenda from the shared

experiences around the table is important for equality of participation and voice.

Participating in meetings

> When I very first started on there and things like that it was very hard for
> me because I, the things were going to fast and too quick and I didn't
> understand the big picture very well even though I did have someone to
> explain it to me and things like that. *Karla, 02/06.*

Three key factors were found to determine how an advisory body functions; what

it is required to do which is normally set out in terms of reference, how it

interprets these requirements, and the style and approach of personnel involved

in managing the work of the advisory body. These factors combine to shape the

overall approach of the advisory body, described here as its level of formality. For

the people with an intellectual disability in this study, the most significant factors

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were how often meetings were held, the procedures that governed meetings and the way they were chaired.

The terms of reference of disability advisory bodies normally outline the minimum requirements for frequency of meetings, reporting and other procedural issues. The six advisory bodies in this study differed in each of these areas with frequency of meetings showing the greatest variance; Central met for two days every two months, Southern and Hilltown met each month for two hours, Northern met monthly for a day, Seascape met every two months for two hours and Greentown did not have set times for meetings; these were determined by the group after each meeting. Whilst the majority of the work of the advisory bodies was completed at these meetings, some also had working parties, portfolio groups and project groups that focussed on specific policy or program issues. This mode of operating was more common in the larger more formal advisory bodies like Northern, Central and Southern.

Meetings of all of the advisory bodies were formally chaired, had agendas and minutes that recorded discussions and action. The three Local Government advisory bodies made a particular effort to provide this information in Plain English, a format more accessible to people with an intellectual disability, and often materials were provided in other formats for people with sensory disabilities. The more formal advisory bodies, Northern, Central and Southern did

not make this adjustment for people with an intellectual disability however some noted that they tried to present all material in 'plainer' language.

As noted above the meeting duration varied from two days to two hours. Some of the advisory bodies paid attention to the need for breaks whilst others were less focussed on this need. Generally, people spoke to the meeting through the Chairperson; however in the meeting observations it was noted that this was not closely monitored with a degree of free discussion taking place.

In each of the advisory bodies a person was nominated as the Chairperson, however in Greentown this role rotated amongst the group with different people taking on the role. The Chairpersons' role included setting the agenda, often in consultation with members and government representatives, and running the meeting. Additional roles of the Chairperson included: liaison with government Departments and the relevant Minister, monitoring of the work or strategic plan, public presentations on behalf of the council and management of the overall work of the council (usually in collaboration with support staff). This role had significant status in the State and National advisory bodies and is a Governor in Council or Ministerial appointment. The people appointed as Chairperson in these advisory bodies were high profile people in the community and were both people with a physical disability.

In Seascape advisory body the Chairperson was a Councillor. The member with

an intellectual disability noted that this was a positive thing because the

Councillor could take issues back to the Mayor and the rest of the Council having

heard them directly from people with a disability. In this same advisory body the

member with an intellectual disability was the Deputy Chairperson a role he often

performed, as the Councillor was not always able to attend meetings:

> Yeah, I am Deputy Chair, They said "Who wants to be the Deputy chair person?" and I put my hand up. [My job is] to read the minutes and ask people have they read them and would they like to go through them. Then ask them who wants to accept the minutes then they are tabled then we go any apologies, umm then any business from the previous meeting any business then general business arising any general business like you want to add something or improve it… You have got an important role to make sure they follow to make sure it runs properly. It is a responsibility too...it is a good role, gives you self confidence to see that you can do it. *Kieran 09/05.*

Only one other person in the study held a position of responsibility on the

advisory body. She was appointed as a Chairperson of a working party. Through

this role she was able to focus on one policy issue and take responsibility for its

outcomes. She reflected very positively on this experience.

> I was Chairperson of the [policy] working party. Chairing the [policy working party] the Department had to email me and not [the secretariat]. It had to be me not [them]. And like getting on my high horse to them and saying, look you are not doing your work, why aren't you doing it….That was one of the highlights. *Hannah 02/06.*

As illustrated here there was a degree of difference in how the advisory bodies

operated. Each of the people who were members of the more formal advisory

bodies noted difficulties with understanding the information (agendas, briefing

papers) and concentrating for long periods of time.

> The real reason why I don't want to go is because it is very difficult to get
> your head around and I feel bored and half the stuff that they talk about
> goes over the top of my head and even when [the support worker] has a
> go with me I still have trouble understanding. *Jana 12/05.*

Members with an intellectual disability noted the meeting environment and how it

was managed as a significant factor; however much of what they raised was

about the way they were supported to participate. This included issues about the

support relationship, making adjustments to meeting procedures, access to

information, training, and the different challenges to support in these

environments. Support is discussed in following chapter.

Summary

As indicated in this section, advisory bodies have different levels of formality and

the scope of their work varies greatly. For some their approach is influenced by

their interpretation of their role, for others it is about how they have formed and

operated over time. Such characteristics of the advisory bodies were not well

understood by the members with an intellectual disability. In most cases they did

not know how their particular advisory body had been established, what its terms

of reference were and how they could participate in setting the agenda. Members

of the advisory bodies with an intellectual disability described participating how

they thought they were supposed to. They based their way of participating

primarily on personal and political orientation to the role as discussed in Chapter

5 and on their past experiences of participation in similar forums. Some people

discussed their feelings of frustration with the advisory bodies and their own

participation experiences, others reflected feelings of contentment, pride and

happiness with what they achieved.

Whilst this study did not set out to evaluate the effectiveness of this participation,

either from the perspective of the people with an intellectual disability, or the

organisations, this chapter does raise some questions about expectations and

outcomes of participation from these two perspectives. As Pateman (1970) notes

there are personal, organisational and policy outcomes from citizen participation.

Output, she claims is not just about the decisions made, it is also about what

happens for the people participating and the organisations along the way.

Overall, it can be argued from the insights into participation put forward in this

chapter, that the more formal groups presented more difficulties for people than

the less formal groups. Difficulties included: access to materials, understanding

and relating to the policy context and the agenda, forming supportive and equal

relationships, and lack of direct access to the policy makers. Karla's more

positive experience in the more formal advisory body hinged upon the support

relationships she was able to build and the positive regard that she knew others

had for her:

> I think every person on council respects me.. every person on that
> council has treated me as a human being no one has said "oh we are not
> working with [Karla] because she is a person with an intellectual

disability", or they have never said that people with an intellectual disability should not be on council, never said that and so forth, not since I have been on there. *Karla, 02/06.*

The less formal participatory environments of Hillside, Seascape and the mainly informal Greentown advisory group provided a very different participatory environment for the members with an intellectual disability. Martin, Kieran and Phillip were active in the work of the group, understood what their roles were and performed these confidently. They found the participatory forums to be places where they could both learn about issues, and other people's experiences, and provide their own insights into the issues. The less formal groups had more direct access to the policy makers they were advising and more control over the agenda.

The case studies presented in this chapter indicate that people with an intellectual disability can participate in government advisory bodies; however the structures and processes that govern the way they work mediate their experiences. This analysis has found that supporting people to more fully understand how they can participate, and what they can have a say about is important. This can be done through people on advisory bodies supporting each other and sharing information, experiences and knowledge. Also, people indicated that they had not received training to participate and that in the main, information was not accessible and there was a lack of active support. Such factors can be described as the processes used rather than the structures themselves.

CHAPTER SEVEN

SUPPORTING PARTICIPATION

> Empowerment is a process. Power is not given to people nor is it earned. It happens as a result of a constructive, meaningful activity that leads people to be more knowledgeable, skilful, informed and aware than they were before.(Worrel , 1998 in Goodley, 2000 pg 8)

Introduction

Chapters 5 and 6 have discussed two interrelated factors that impact on the participatory experience of people with an intellectual disability in government advisory bodies: the personal and the structural. The former recognises the importance of knowing who is participating and what they bring to the role, the latter recognises that the participatory environment, as determined by its structure and processes, will also impact on how people participate.

The literature on participation as discussed in Chapter 2, points to the need to consider these factors when questioning how citizen participation works; however there is a third factor that underpins these two. Many writers have discussed the power dimension in relation to this form of participation, suggesting that people need to have 'real power' to be able to participate meaningfully. Here they are referring to both operational power through decision-making roles and responsibilities, and personal power that comes from having the skills, knowledge, confidence and capacity to participate within these complex participatory environments. The disability literature talks about this dimension as

empowerment. It suggests that in participatory environments, people with an intellectual disability need to be supported to gain access to the skills, knowledge and experiences that will empower them personally, and through their participation, will be empowering for them and for people with an intellectual disability (Boyce et al., 2001; Goodley, 2001; Grant 1997; Ramcharan, 2006).

Participation support is discussed in this chapter as a conduit to personal power for the people with an intellectual disability who are participating in government disability advisory bodies. Some argue that through citizen participation individuals have the power to influence the policymaking agenda, however this power is only attainable if there is meaningful participation. Barnes et al., (2007) note that this participation comes when citizens have the means to participate and "through this participation become better able to engage with the complex issues that form the substance of policymaking" (p.35).

The support approaches discussed in this chapter are analysed from a stance that all three dimensions; the personal, structural and support dimensions interact to both shape and mediate the participatory experience. Empowerment is at the heart of this analysis. This chapter presents how people are supported in the advisory bodies and discusses the outcomes of this support, considering to what extent the support approaches can and do empower the person with an intellectual disability to participate.

Firstly, the challenges of citizen participation for people with an intellectual disability are discussed. This is followed by a description of the approaches to support in these advisory bodies, case studies of how support is experienced by the people with an intellectual disability, and perspectives on support from those who provide or manage it. An analysis of these factors leads to a discussion about how support is framed for people with an intellectual disability in advisory bodies.

Support for citizen participation: Challenges for people with an intellectual disability

The people in this study are negotiating a role that many people without an intellectual disability struggle with. The literature on citizen participation discussed in Chapter two identifies a range of issues faced by people who participate in these forums. Some of the challenges are personal and some are political, structural, or based on common problems of group dynamics (Arnstein, 1969; Reddel & Woolcock, 2004; Richardson, 1983; Wolfe, 2002). For people with an intellectual disability there can be additional issues and challenges to participation. The literature on consumer participation discussed in Chapter 2 suggests some of these challenges are: access to power, experiences of tokenism, access to knowledge and skills, and the impact of presumed incompetence, where it is believed that people with an intellectual disability simply cannot participate at this level and their place at the table is an end in

itself (Concannon, 2005; Drake, 1992, 2002; Simons, 2000; Stevens & Ibanez, 2004; Welsh & Office, 1989).

Meaningful participation relies on a number of factors: a clear understanding of your role, access to information, knowledge of the issues, skills for participating, having the means to participate, and feeling like you will be listened to and that your input is valued (Beresford & Croft, 1993; Mc Namara et al., 1993; Simons, 2000; Stevens & Ibanez, 2004). People with an intellectual disability generally have difficulty accessing information, gaining and retaining knowledge, and negotiating complex relationships in social situations. The nature of intellectual impairment means that people have difficulty with cognition, problem solving and developing and articulating their thoughts (Fyffe, 2007; WHO, 2002). However with support, many people with an intellectual disability can have their say and articulate what is important to them, both within their personal lives and more broadly.

Through self advocacy and with support from allies and skilled support workers, people with an intellectual disability are increasingly having their say in a meaningful way, however research on support models and approaches for supporting people in civic and political activities are scarce. Some research has looked at the self advocate supporter role (Chapman, 2005; Goodley, 2000) and how this role impacts on the way people with an intellectual disability participate within self advocacy. This research suggests that the support role is crucial;

however there are difficulties with how it has been established and used within these forums. In particular it raises questions about how to engage people with content that is hard for them to understand without influencing their input. Stainton (2005) also raises some important questions about support when considering how to support people with an intellectual disability to identify and articulate their claims in a rights based policy environment. He notes, "If people are to be empowered to control their own lives then they need to be able to articulate their wants, needs and choices" (p. 292). However, he makes it clear that this is problematic for many people with an intellectual disability and there needs to be a range of ways of supporting this participation. In particular he discusses the need for people to have supportive relationships in all areas of their lives.

Equality of opportunity to participate

Citizen participation forums like disability advisory bodies are complex participatory environments as discussed in Chapter 6; however they are required to be inclusive. Disability discrimination legislation (Commonwealth of Australia, 1992) requires that at both structural and individual levels barriers to full and

equal participation are addressed through making 'reasonable adjustments[3]' to enable people to reach the same notional starting line as others (Productivity Commission, *Review of the Disability Discrimination Act 1992. Productivity Commission inquiry report*, 2004). This concept of the 'same notional starting line' provides a basis for looking at the kind of support needed to participate in these advisory bodies. The literature suggests there are inherent problems with these forms of citizen participation that impact on all people who participate. Such problems are acknowledged in this study; however it is focusing on the particular experiences of people with an intellectual disability and whether the support they receive does allow them an equality of opportunity for participation.

Supportive relationships

People in this study reflected regularly on their feelings of acceptance, equality and belonging within the advisory bodies. People like Hannah and Andy shared their feelings of incompetence and inferiority noting that they did not feel equal, and for Hannah she felt shunned and disregarded, whereas people like Kieran, Karla and Jana noted feelings of acceptance, respect and belonging. Their feelings are inherently personal and rely on the person's own interpretation of the

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[3] Disability Standards established under the DDA (1992) require " a person or body dealing with persons with disabilities to put in place reasonable adjustments to eliminate as far as possible, discrimination against those persons" (DDA, 1992, s 31 1(a))

group and personal dynamics within the groups, however, they do have a strong and pervasive impact on the person's participatory experiences.

Whilst discrimination legislation can provide a framework for addressing physical and structural barriers, there cannot be the same level of proscription for personal or attitudinal barriers. Also, feelings of being valued or respected are very personal and hard to articulate beyond how a person feels. However, people with an intellectual disability who have not always felt respected and accepted, like some of the people in this study, can recognise negative attitudes and moments of rejection. Hannah interpreted these experiences through people not actively engaging her in conversations at meetings, an incident where the Chairperson overlooked her for an invitation to an event, and when people spoke over her at meetings. Hannah also referred to some of her colleagues on the advisory body and management staff, as her 'friends' and noted that when these people left she felt isolated and alone. Interestingly, none of these were people with disabilities; Hannah did not form any bonds with people with other disabilities on the advisory body.

Conversely, Kieran spoke about positive experiences where his colleagues had informal conversations with him that made him feel welcomed and included, they listened to him when he was chairing meetings and they supported him when he needed help in the meetings. Jana spoke enthusiastically about her colleagues, recollecting personal things about them like where they were from, what their

disability was, and the kinds of pets they had. She reflected that there was a personal bond and connection to these people. Karla also noted that she felt well supported by her colleagues, particularly at times when she became emotional in meetings, and she felt that people did respect her.

Disability researchers have written about this issue in a range of ways. It remains that people with an intellectual disability do have small social networks and their participation in planning boards and advisory bodies will broaden their network of contacts. However, these environments and the relationships formed within them are different from social friendships, formal support relationships and work relationships. Reinders (2002) calls them civic friendships, which intersect between the personal and the civic lives of people. He notes, "...people with an intellectual disability need allies and buddies, not only in their private lives, but also in the formal world of their institutional roles" (p. 4). This is increasingly relevant when people with an intellectual disability are beginning to spend more of their time in these civic roles with people with other disabilities and professionals.

The self advocacy literature talks about 'allies', 'supporters' and 'advisors', (Chapman, 2005; Clement, 2003; Goodley, 2000; Goodley & Van Hove, 2005; Hayden & Nelis, 2002; Williams, 1999; 2005). Within self advocacy such roles are sometimes formalised through employment arrangements and payment; however often they are voluntary. There are some similarities between these

roles and the support worker roles in government advisory bodies, discussed below. However, 'civic friendships' as described by Reinders (2002), better describes the broader supportive relationships that are evident in some advisory bodies; these provide both practical and personal support.

The case studies discussed below describe this range of overlapping roles. Often the person with an intellectual disability will view the support relationship as more personal than professional; however the environments they are in are work environments, and as discussed in the previous chapter, some of these work environments are very formal. Other members of the group also provide support; however the case studies highlight that underpinning such relationships is the question of acceptance, and how people feel others regard them. In the following case studies, people reflect on their support relationships and generally on the support they receive to participate. What is evident is the complexity of the support relationships within the environments, and the need to consider the many layers of what support means, particularly within cross-disability participatory environments.

Types of participation support within disability advisory bodies
The following table outlines the kind of support people were given, why this type of support was provided, how it was provided, and what it was aiming to achieve. Insights into support discussed below, were drawn from: observations of advisory body meetings, interviews with people who provided and managed the support,

and from the participants with an intellectual disability. Analysis of their descriptions and the observations found there were five approaches to support used in the advisory bodies: individual, shared, collegiate, specialist and procedural. These are outlined in Table 9 and the following case studies.

The 'focus of support' outlined in the last column draws on work undertaken by the Joseph Rowntree Foundation that found such factors as described here, as important for meaningful user involvement in disability organisations (Joseph Rowntree Foundation, 2003). The factors that support should address, according to this guideline are: access to information, knowledge development, engaging with the participation process, forming relationships with stakeholders, and skill development. As noted in chapter 6, there were significant gaps in the way advisory bodies addressed the question of accessibility to information and the research participants reported a lack of training for participation. This chapter looks more closely at how the support provided addressed such aspects of participation. Table 9 indicates that most support models addressed access to information in some way, but few focused on knowledge or skill development. The other gap was in support for building relationships with others; in particular there were no examples where people were supported to build relationships with people outside the advisory bodies to inform or support their participation. They were not supported to build or consult with a network of people who could inform their work.

Table 9 Approaches to participation support

Type of Support	Advisory Bodies	Goal	How it is provided	Focus of support
Individual	Central Northern Southern	Support the individual with an intellectual disability to participate in the meetings	1:1 support provided by a support worker employed on an 'hourly' basis.	Access to information Knowledge development Personal/emotional/moral support
Shared	Seascape Hilltown Greentown [Through the secretariat in Southern, Central and Northern]	Support all members to participate and to support the functioning of the advisory body.	One worker or a number of staff are assigned to the advisory body from the relevant government department.	Access to information Forming/building relationships with stakeholders Engagement with the participation process
Collegiate	Seascape Hilltown Greentown	People supporting each other	People working together as colleagues within the advisory bodies. Evident in groups where shared support was the key approach to support.	Building supportive relationships within the group Engagement with the participation process
Specialist	Greentown	Provide short term, additional support or training.	Bringing in external trainers or advisers on specific topics or skills.	Access to information Skill development Knowledge development
Procedural	Northern Central Hilltown	To have meeting procedures that are accessible and inclusive.	Normally facilitated by the Chair and/or secretariat to eliminate procedural barriers to participation	Access to information Engagement with the participation process

Individual support

This is typified by a one-to-one support arrangement where a support worker is employed to work alongside the person with an intellectual disability. Individual support was the primary approach to support in the Northern, Central and Southern advisory bodies. These are described in Chapter 6 as 'highly formal' participatory environments. The people with an intellectual disability in highly formal advisory bodies were the only members with access to this type of support. In each case the person found their own support worker and together they negotiated the nature of this support.

Four of the people in the study had this form of support: Karla, Jana, Andy and Hannah. At the time of the study Jana and Andy were using the same support worker and Hannah had used this worker in the past. Hannah had decided to work without a support worker in her second term of appointment noting, "I didn't want a support worker because I felt having a support worker was a put down a bit because I was growing and I thought it put me down a bit".

The following three case studies give an overview of how this approach to support is negotiated and managed by the people with an intellectual disability and their support workers. Each arrangement works differently depending on how the person with an intellectual disability has defined their needs, the resources available for the support, the relationship between the support worker and the person, and to some extent, the view the support worker has of their role.

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Case Studies of Individual Support

The first case study introduces the support relationship between Karla and

Nancy. Karla was a member of the Northern disability advisory body; she was the

only member on this advisory body with an intellectual disability and the only

person who used a support worker to support her participation. One other

member of this advisory body used sign language interpreters; no other

members used external supports. Nancy and Karla were interviewed together to

talk about the support model they use and how it worked for them.

Case Study 7 Individual support: Karla and Nancy

> Nancy supports Karla at the day long meetings that are held every two months. She also spends time with Karla before meetings to go through the meeting papers and normally 'de-briefs' with Karla after the meetings. They get along very well and when they were interviewed Nancy and Karla joked with each other and worked in a very flexible and informal way to prepare Karla for the upcoming meeting.

> **Karla** The first person I had was a friend. She knew what I needed, but then the bugger went and got a job didn't she? I had to look for someone else. People I asked would have done it with bells on the tree but they were working. I asked Sally from the secretariat if she knew anybody and she said she had a friend who might be interested. I asked if she had ever worked with people with an intellectual disability but she hadn't.

> **Nancy** I am the support worker. In my previous job [in a gallery] I was used to producing things in Plain English. Sally thought we [Karla and I] would like each other. She thought some support workers had their own agenda and I was agenda free.

> **Karla** She doesn't put words in my mouth. It's about time, commitment and putting things in communication I can understand. Before the meeting we get a package of information. Nancy goes through it and picks out the main points. I want to go through the Chair's report because some things that happen at [Northern Disability Advisory Body] affect me personally, I need emotional support, that's the issue. In [the] meetings it's really hard. Nancy had to get used to concepts so she could translate to me. In the beginning it was hard.

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Nancy I provide emotional back up, pep talks. Karla gives me instructions and doesn't let me talk too much and get too involved. Sometimes we step out [of the meeting], it goes in waves. The secretariat doesn't question the time we use; it's about three hours a time.

The second case study of individual support introduces Sandy, Jana's support worker. Sandy had also supported Hannah in the past and worked as Andy's support worker as discussed below. Jana was the only person on her advisory body who had an intellectual disability and she was the only person who used an individual support worker. No other members used external support workers. Jana and Sandy were not interviewed together.

Case Study 8 Individual support: Jana and Sandy

Sandy attends meeting with Jana three or four times a year. They are long meetings that go for two days and they usually involve travel and staying overnight away from home. They also include some social functions like dinners or evening presentations.

Jana Some information I [get] and some I don't. That is why I take Sandy with me and she explains. She comes and sits down with me at the meetings and she takes notes on what is really important, umm if there is anything really important, before the meetings if there is anything important I want to say she will write it down and remind me to bring it up when it is the right time, and that and yeah she takes notes and whatever I don't understand she will explain that to me.

And before the meeting we meet and go over the agenda and the minutes…yeah I read it that's why, whatever I don't understand, Sandy always has a copy because they send her a copy too. And if I don't understand it she reads it to me or she brings her own stuff, and we go over it. The minutes are not really that accessible to understand. No they are really complicated I think I have raised this once with them I think I said the minutes should be in Plain English and that. They said they would try. Well it would be better, then I can understand what I am reading.

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Sandy I think …it is quite intimidating to speak up and the issues fly so fast and at such a level. I find it very tricky because usually the support worker role I have done is with advocacy groups and there is this agenda that you are clearly supporting them on, or going with self advocates and you have met and you have a plan of action. I think it is quite a limiting role and for me, it's generally, if people want things in Plain English I will do that but I will go through the stuff before the meeting but I find that quite limiting. As I said there is so much. You can see people kind of phase out after the first two or three sorts of things. For Jana she just wants someone to take notes and go through [the papers] and I will raise things and say "this is an issue you might be interested in", and also I think sometimes clarifying things like , I'll have note books and if any questions are raised "well let's write them down" and [talk about] when [she]should raise it. ...So I will write the questions down in the points for discussion book. Jana says, "I don't want you to speak" [in the meetings].

Case study 9 outlines how Andy and Sandy work together. Andy has known

Sandy for a long time and asked her to be his support worker after his first

support worker had to finish up because of other work commitments.

Case Study 9 Individual support: Andy and Sandy

Sandy attends the bi-monthly meetings with Andy. The meetings normally go for between two and four hours. Andy and Sandy meet up immediately prior to the meetings to go through the meeting papers, they do not usually have any other contact in between meetings.

Andy It's really hard especially if Sandy isn't there with me, she wasn't there last week...I do need that information. [She] just goes through the agenda [before the meeting] at the coffee shop around the corner [laughs] just go through it pick out the important things that need to be asked.

[Andy notes that Sandy is not always available because she has got other work and when that happens he tries someone else but last time he did that she wasn't available either]We meet an hour before something, like an hour before the meeting and umm we go through the agenda and the things we are going to be talking about and umm then

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we just go up [to the meeting]. She writes down notes, we make a time later on and we go over what has been said. I think it [having a support worker] encourages you to have a say, [having] a person there who is willing to participate and help you. Sometimes I don't listen very well. I am not taking enough interest in what they are talking about.

[Andy talks about the meetings and that Sandy doesn't help him in the meetings. He also says that he doesn't want to stop the meeting or ask questions or have Sandy do this]

Well I just want to see the meeting flow on, if you are going to stop the meeting ..they will go all day. They are boring.

Sandy With Andy he has got the three issues and we talk about how to get that on the table, what is the best way we can think about it. If I was going to do it properly, and I don't do it properly by any means because [of] all of the other commitments…it would probably take much more resources than they are prepared to pay once you work through things. I don't have a chance to [go through all of the papers], we do it together. Sometimes I try to sit down and quickly scan it all before I go. Certainly with Andy we have trouble coordinating times because he works as well...so I scan through them all before I go because we often meet just before the meeting which is not great, but sometimes we do match up [with what the issues are]

The focus and impact of individual support

Individual support, as it is described in the three case studies above, is primarily focused on access to information and personal or 'moral' support. The nature of the support relationship was determined primarily by what was negotiated between the person with an intellectual disability and the support worker, with no formal input from the advisory bodies. Neither of the support workers had contracts, job descriptions or an agreed number of hours. Sandy notes:

Well it is very interesting…because I think everybody [advisory body members] has signed a confidentiality agreement and they have not even thought about me. I've not signed anything. *Sandy,02/06.*

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Negotiating the support role was an important task and usually undertaken by the support worker and the person with an intellectual disability. The staff from the advisory bodies did not have any input into the parameters of the role or how it should be undertaken. Sandy's quote above indicates that this lack of involvement left her to manage herself and there was no supervision or support for her role.

A key focus of the support roles was to ensure the people had access to the information in a format they could understand. This included interpreting written information into Plain English[4], however, the support workers noted that this was a very big task and they did not always have the time or resources to do this with every piece of information. The advisory bodies did not produce information in Plain English; however they had provided written information in Braille and large print for other members and did provide sign language interpreters for people with a hearing impairment. Nancy and Sandy mainly relied on talking through the agendas and verbally summarising what was in larger documents, highlighting points that might be of interest to the people they were supporting. Both Nancy

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[4] This is the term used by self advocates to describe the type of written information they can access. There are no standards for this however it is common to use less formal, summarised language with some pictures. For an example see www.changepeople.co.uk

and Sandy commented that they rarely had time to read through all of the documents.

Current Disability Discrimination legislation in Australia and other Disability legislation (Disability Act, *Vic* 2006) requires that people be able to access information in formats that meet their needs, and that adjustments be made to enable access. For the people in this study, Plain/Easy English documents could be seen as a 'required adjustment', however, access to this format depended on the ability and availability of a support worker to translate the papers provided to all members. Some research has found that a large number of people with an intellectual disability cannot read and that those who have some literacy skills do not understand what they have read (Carr, 1988 as cited in Poncelas & Murphy, 2006). In the current study seven of the nine people interviewed could read some material whilst two people could not read at all. Most noted they needed help with written information, and they all preferred information written in Plain or Easy English. For these four people "Plain English, Less Jargon" was a chant that they have used within self advocacy, to heighten understanding of how formal language can be inaccessible for them, creating a barrier to engagement with information that impacts on their lives. However, in the advisory bodies they were denied access to a form of language they could read and understand.

People like Hannah continue to lobby for Plain English, however in her role on the Southern Advisory body she was unable to make this happen. She noted with

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concern, that when she was appointed to the advisory body she was submitted to

a reading test. She believed this was discriminatory, as other members were not

submitted to this test. Importantly, this also suggests that the advisory body

'expected' a certain level of literacy and assumed that Hannah would not have

this, nor was this expectation outlined in the selection criteria for the position:

> The [member of the secretariat] that was there…didn't know people with a [intellectual] disability, didn't know how to treat a person with a [intellectual] disability so she got me in a little room and she said "could you read this bit of paper" and I said "what's this bit of paper about"? and she said "I just want to check that your reading ability is all right to be on the [advisory body]. *Hannah, 09/05*

Hannah felt that the advisory body should have adjusted the way they presented

information so she could access it, rather than requiring that she be able to read

at a certain level. Hannah referred to this incident many times in our interviews,

noting that she felt it set her apart from the other members, and made her feel

that she was being judged differently from them.

Karla, Jana, Andy and Hannah all noted that the information was hard to

understand and that they did not always know what it meant, even with a support

worker to interpret it.

> It is very difficult to get your head around and I feel bored and half the stuff that they talk about goes over the top of my head and even when [Sandy] has a go with me I still have trouble understanding .*Jana, 02/06*

> [Sandy's job was] taking notes for me and putting my notes in Plain English, and that was fine, [she] was good but I never ever got to [have time to] meet with Sandy. It was always like an hour before the meetings so I was rushed, so if I was having a meeting at 10 I would have to meet Sandy at 9 so I never really had that time. Because a lot of people thought that because I have an intellectual disability that [I] couldn't keep

everything inside my head for a month …so [we had to] do it on the day. *Hannah, 02/05.*

Andy found it difficult to understand the information but tended to blame himself for this, noting that it was because he "did not listen well enough" or "didn't have the education" to understand the information.

The content of the documents could also challenge the support workers. For Nancy who did not have a background in disability work, the content was sometimes unfamiliar, meaning she was not able to provide background information or examples to make it easier for Karla to understand. Karla noted that it was difficult for Nancy because she did not know the 'concepts' being talked about. For Sandy, who had many years of experience in supporting self advocates, there was some tension between simply interpreting the information and providing a commentary on it. She found it difficult to understand this support role because it was different from what she did as an advocacy support worker:

> Usually the support worker role I have done is with advocacy groups and there is this agenda you are clearly supporting them on, but with the [advisory bodies] it is quite a different thing...it is just information coming in…there has been issues and I will say, "I really think you should be addressing this, and then I ...sort of pulled back from going too far…because I think I am just putting my agenda there so I have to divorce that advocacy support worker thing. *Sandy, 02/06.*

Sandy noted, the 'advisory body support worker' role is unclear and it is quite different from the work a person does in advocacy support. There is a lack of clarity about it and how to perform it. Sandy and Nancy did not know each other and had not discussed how to perform their roles, however they had both

developed their roles and interpreted them quite narrowly. They indicated that they were essentially left to their own devices to negotiate the roles with the person they supported. The outcomes were a focus on taking notes and verbally summarising big documents, providing personal or emotional support and debriefing after meetings. Both Nancy and Sandy also noted that the people they were supporting generally did not want them to "talk" in the meetings. By this they meant they did not want the support worker to have their own say. Karla and Nancy did chat to each other or whisper throughout the meetings that were observed, however Karla usually initiated this.

The case studies suggest that it is important for people to be able to define their own support needs and negotiate the way this support is given; however there are gaps in the way the support is provided. Also, it is very difficult for people to articulate their support needs, particularly when some might want to mask their needs so they do not have to use supports and better fit in. Defining supports in these environments can also be difficult when people are unaware of the roles and the complexity of participating in advisory bodies. Most commonly, people did not fully understand the issues that were being discussed at the advisory bodies. The support they received gave them some access to the information but rarely enabled them to understand it in a way that enabled them to feel confident about having a say. Barnes et al., (2007) note the importance of being engaged with the issues that are the "substance" of policymaking. Most people in this study talked about being 'bored', having information 'go over their heads', and

'not knowing' what particular issues were about, despite having access to individual support to enhance their access to the policy information. This raises the question about the level of knowledge that is expected and needed to be able to actively participate in advisory forums equally and meaningfully. It also suggests that this individual model of support could be strengthened by a more thorough approach to enabling meaningful access to information.

There was one example in the study where people were provided with specific education or background briefing in a format that they could understand. The manager of Southern disability advisory body noted that access to and understanding of the often-complex information posed a challenge for many members of the advisory body. To address this, Southern advisory body had 'pre-meeting' briefings that any members could attend, however these only continued for around six months. The advisory body manager describes this approach:

> When I started with the [advisory body] I was aware of the extreme diversity and I was unperturbed by it. I wanted to ensure everyone felt happy and that people felt that they could make a contribution and to ensure the secretariat equipped them to do that. I wanted people to be able to generalise beyond their own issues and engage in a range of issues in a broader way. For the first 6 months I developed briefings in Easy English and established a process where people could attend "pre-meeting" meetings and briefings. As the secretariat we can only do so much, and then it plays out in the two hour meeting every two months. We try to make sure it is action and task focused. We try to make sure it relates to the [disability policy] and is as functional as possible. *Candy10/05.*

This practice did not continue in this advisory body, due mainly to the resources required to maintain it.

Finally, the case studies show that people needed or wanted 'moral support' or 'emotional support' to be able to participate. Sandy noted, "For one person it was like, 'well I just feel more secure with you there'", and Andy said, "to have [Sandy] there gives me confidence in a way". In Chapter 5, some people talked about feelings of difference and incompetence within the advisory bodies. Andy noted that everyone else was more educated, Jana said that people with physical disabilities who had been to university knew more than her, and Hannah suggested that others could not see her abilities, just her disability. Hannah talked about how she sought support from within the advisory body to manage this, but was encouraged to employ an individual support worker as it was not seen as appropriate for her to use her colleagues, or as she saw them "friends" to provide this support:

> Because I am supposed to have an intellectual disability and other people didn't…because I said at that time [names two other members who she knew through previous work] on the [advisory body] with me and I knew these two ladies well I said "I won't need someone outside because I know [them]"she [the secretariat worker] said "oh no you can't have them" …I was told I couldn't have [them] because [they] were there with their own hats on. So in that time, I did get a support worker but [the two other members] were always helping me. *Hannah, 02/05.*

Hannah is referring here to accessing support from her colleagues. This approach is discussed later as collegiate support. It was not evident within the

highly formal advisory bodies but was more common where people did not have an individual support worker.

The individual support approach is able to offer people short periods of individualised attention, however as the case studies suggest there are some limitations with this role. Namely, the onus for making information accessible is with the support worker who may not have the skills or time to do this properly, there is little or no responsibility taken by the advisory body to manage or monitor these roles, and they do not enable supportive relationships to build between the person and other members, as support is seen as the full responsibility of the support worker. However, it seems that they are able to provide important 'emotional', 'personal' or 'moral' support to people who, as indicated by this group, can feel incompetent and inferior in cross-disability forums.

Shared support is discussed in the next section, however this approach was also used in the highly formal advisory bodies where it was provided by a paid secretariat. Such staff had specific administrative or policy work roles with the advisory body. They also provided some personal support to members, particularly in relation to travel arrangements, payment advice, organising sign language interpreters or attendant carers. Mary was an administration worker with Southern who provided this kind of support to all members of the advisory body; here she describes her role.

I suppose I see my role as just to make them comfortable enough so they can ask for information or they get all the information they need to be able to participate fully on the council. Because council members are all very different, different ones need different support. I just had an issue yesterday; one of our members had a seizure and yeah so, yeah just supporting her to get through that. Make sure she gets home and goes to bed. Yeah and also for some council members I am more of a support worker and I will say, "this is here" or "come and sit next to me" at the meeting. "If you want ring me during the week". I would probably like to see some of the members have more support. I suppose to cognitively understand I think some of the members have support workers who I presume, look after that bit because I don't think I can do that part. Some members I think really need a lot of support - just when you get to the meetings, to remember the meeting is on and some guidance in terms of what will be discussed at the meetings. *Mary, 10/05*.

This example suggests that in the highly formal bodies there was a need for the two types of support; individual and shared, however there was no communication between the people providing each type of support, nor as mentioned earlier any monitoring of its effectiveness.

Shared and collegiate support

There were three Local Government advisory bodies that used shared and collegiate support: Greentown, Hilltown and Seascape. They did not have access to additional funds to employ individual support workers and normally used the one resource of a Council employed policy worker to perform a number of support roles. This worker did administrative work, including writing and distributing the minutes and supporting the Chair to develop the agenda. They also organised and facilitated the meetings. The 'shared' support worker also liaised with the Local Government representatives and ensured the work of the advisory body was linked and reported to the government. In addition they

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provided support to people at the meetings to ensure they could participate, this

could include sitting next to a person to turn pages or clarifying information on the

agenda.

In Hilltown and Seascape advisory bodies, the members also supported each

other. They helped with reading the agenda, clarifying information, and gave

each other support with practical things like turning pages or getting drinks.

However, as Kieran outlines below, it was mostly about 'being there' for each

other and knowing that others could be approached to help out. This type of

support was not formally developed or expected. Moreover it seemed to be an

extension of the informal environment of these advisory bodies as discussed in

Chapter 6. The lack of resources for individual support could be one factor that

led to the development of this approach; however it is more likely to have evolved

from the way people understood their role within these semi formal, mutually

supportive forums.

Case studies of shared and collegiate support

The following case studies provide some insight into how shared support and

collegiate support were used in these Local Government advisory bodies.

Seascape and Hilltown are used as the primary examples as Greentown also

employed other support approaches discussed later. The first case study shows

how Georgie, the policy worker at Seascape advisory body, defined her role and

how Kieran felt about the support he received from Georgie. It also introduces

the view of a co-member of the advisory body.

Case Study 10 Shared and collegiate support: Seascape

Georgie works with Seascape disability advisory body as part of her role as a social policy worker at Seascape Local Government. The majority of her work is 'behind the scenes' organising the meetings and the agenda. Kieran is the only member with an intellectual disability on the Seascape advisory body; he is also the Deputy Chair.

Georgie. The role of the Council staff member is basically to support the function of it [the advisory body] and so that role is … actually taking and distributing minutes, making sure they are forwarded onto Council, providing background information about what is going on [to the advisory body] and also developing the agenda in association with the Chair. The way in which I provide support to individual members and so on, I don't know exactly how to put it. You try and have conversations with everyone rather than talking at them. I think that is one of the most important ways of supporting everyone there. They are evening meetings but they are from 6.00pm to 7.30pm and we always provide food. The first thing is people come in and start talking informally then get themselves cups of tea and coffee and sandwiches and so on.

Ellen is a co-member who is a representative from a local tertiary education centre.

We do make adjustments mainly with the complexity of the information and the detail. [The Local Government worker] is good, Kieran sits next to her at the meetings. It is a small committee of 6 to 8 people. We meet from 6.00pm to 7.30pm and have a small agenda. We don't have much background reading it is really just the minutes and the agenda. Sometimes we have extra documents but we have one month to read it. I assume Kieran has outside and existing support in his life to help him with this. He might even choose not to read it and wait for the discussion. I think not having a support and not changing things for him normalises it and gives us all the responsibility to include him. We always discuss the information before we do a task. We are aware of his needs and know him well.

Kieran I might get a little bit stuck so I get some help from Harry, Oh he's on the [advisory body] Yeah he'll help me if I don't understand something, he'll help me read it out, because he used to be the

Chairperson. He sort of knows how it should go. Meetings are pretty all right but sometimes if I get stuck he helps me.

Ellen and Georgie both raise important points about this approach. In particular, Ellen sees it as creating an inclusive environment and puts forward that other more individualised support models could lead to some segregation or could frame Kieran as 'different' within the group. This approach she suggests, normalises his involvement. In particular, she suggests that the group feels a responsibility to be inclusive and offer extra support where it is needed. Georgie focuses more on the processes and suggests that focusing on these can alleviate support needs for everyone. Kieran highlights that through the two approaches he felt supported and able to call on different members to provide him with different levels of support. The shared support focuses mainly on making information accessible and setting up a flexible, accessible environment where people have time to talk about and understand issues, as discussed by Kieran.

The collegiate support approach enabled supportive relationships to be built and through these created the same 'notional starting line'. Seascape used the people on the advisory body as a support resource for each other, enabling people to share their expertise, knowledge and skills to support access to and understanding of information and to support each other to engage with the process of providing advice to the Local Government. The one paid worker was able to focus their attention on policy and strategic support, working with the

Chairperson and the advisory body to develop an agenda and work program that was linked to the policy context. This worker had also created a more flexible, less formal environment as discussed in Chapter 6. This she suggested, along with a personal approach through 'having conversations' with people, was the key to supporting active and meaningful participation.

Case study eleven, outlines the way support was provided to Martin in the Hilltown advisory body as described by the Local Government policy worker Kate and Martin's co-members Stella and Mary. It suggests, that in this small semi formal participatory environment where Martin is the only member with an intellectual disability, there is a strong sense of collegiate support. In particular, she noted that this group functions in a way that was based on the members having a high regard for each other and being supported to work to their own agenda by the Local Government policy worker.

Case Study Eleven Shared and collegiate support: Hilltown

Kate is the Local Government policy worker for a larger Local Government that includes the shire of Hilltown. She has responsibility to run a range of advisory bodies in this Local Government area including three disability advisory bodies. In Hilltown she has supported the group to develop based on their views about what a disability advisory body should look like and what it should do. Martin's co-members Mary and Stella introduced here, offer a very personal insight into the support approaches used in Hilltown.

Kate. My role is to give information [to the advisory body], to liaise [with the advisory body and the Council] and to facilitate their work. The majority of people cannot look at the big picture so they need to be supported to think beyond the individual issue to the broader issues The

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biggest struggle is to make sure every member has meaningful participation. [My job] is to mobilise people with a disability...they [the advisory body] are a flexible group that is based and led by the group who are connected to the community. I need to think about what Martin's agenda would be because the current agenda is very strongly about physical access. It would probably be about presence in the community and community awareness

Mary We are a democratic group. Martin is an extremely valued member of the group. He is not lacking in confidence and he is an incredible participant at meetings. He doesn't get any help at the meetings and he rarely misses a meeting. He has something to say about most things on the agenda.

Stella I think Martin reminds us that he is the type of person we are working for. Without us working [with Martin] we might not have informed input. Martin gives the group feedback, it is not always on the topic but sometimes it is. At the meetings he comes in with his bag with all the books/minutes in it. He is very organised and connects with this information. He is very helpful.

Hilltown was a semi formal advisory body that Kate, the Local Government worker, said developed "from the group" ,who came together wanting to "do some work". Her role was to develop these kinds of groups in two or three areas and she notes that each one developed differently:

> There are groups in [two larger towns] too but they have less people with a disability and more service providers. *Kate, 05/06*.

Martin was able to name every member of the group, their disability and the kinds of issues they brought to the meetings, however, as Kate and Stella noted, he did not always understand what the issues were about nor how they connected with the "bigger picture". This was not seen as problem within Hilltown, as his presence on the advisory body enabled other members to be aware of the issues, and understand how they could impact on people with an

intellectual disability. In this way, he acted as an important colleague in the group. As discussed in Chapter 5, Martin was a community-focussed person who liked to be able to connect with other people and through these relationships develop his awareness of issues. He also liked to do what he could to support the work of the groups. Kate notes:

> Martin is a key part of the group. He comes every month and he is well connected to the group. *Kate, 05/06.*

And Stella highlights the importance of having a person like Martin in the group to raise community awareness of a range of disability issues.

> Martin is a community member. He likes it when there are things to be done, handing out information etc. He likes to be seen and to be involved. He is well known, everyone knows him and sees him. *Stella, 05/06.*

Hilltown was a small advisory body that placed value on the personal experiences of the members and their presence within the community. As noted by Kate, they worked like a community group. A major part of this was using the skills of each group member to get the work done. Martin "helps out" both at the meetings and in community awareness campaigns. The other members accepted this and supported him to do this by nominating him for these roles. Both Stella and Mary also noted that Martin helped everyone at the meetings; people who needed assistance with getting their wheelchairs into the room, or assistance with getting drinks and food. In return, other members helped Martin to understand what is on the agenda by linking it to the tasks that he might be able to undertake that were related to the particular issue.

Hilltown is an example where both shared support and collegiate support are used, however the focus is primarily on collegiate support as the support staff, Kate, did most of her shared support 'behind the scenes' with a focus on making the agenda relevant to the members. She did not attend every meeting expecting the Chair, Mary, to manage the meetings and report back. Her role was somewhat removed compared to Georgie's in Seascape; however they both had a key focus on engaging the members through linking their work with a broader policy agenda and making this agenda relevant to the members. Both advisory bodies valued the personal experiences of the members and saw the members as a resource to each other.

The focus and impact of shared and collegiate support

Shared and collegiate support focus on building supportive relationships within the advisory body and engaging people with the participation process. The case studies suggest that their strongest outcome was building supportive relationships where members felt responsible for supporting each other, recognised each other's strengths and needs, and provided each other with practical and 'moral' support. The combination of the shared and collegiate support approaches enabled the paid support staff to focus on engaging the members with the policy context of their work through linking their agenda with the policy agenda. Kate reflected that she needed to think more about what

Martin's agenda might be and how she could ensure this could be linked to the work of the advisory body.

Kieran and Martin knew and were able to give examples about the kind of work their advisory bodies were doing, reflecting the stated aims of addressing community access and community awareness raising. They talked about footpaths that had been made level, development of a segment for the local paper about access and inclusion, involvement in a Disability Awareness day, talking to their Councillor about what the advisory body had achieved in a year and Council's responses to some of their work. They seemed engaged with the work they were doing and with the people they were working with on the advisory body. They were very happy with their roles and as Kieran noted, he had remained on the advisory body for a long time because he felt comfortable, accepted and useful.

A combination of the shared and collegiate support models, and the semi formal nature of these advisory bodies, worked together to enable people like Kieran and Martin to participate in a way they saw as equal to other members. It was based on strong individual relationships and a supportive group dynamic that allowed each member to feel supported by other members and the group as a whole.

Shared support was primarily a response to a lack of resources being available to engage individual support workers and to have a range of staff employed to support the work of the advisory body. However, as indicated in these case studies, it did seem to empower the group to develop their own agenda and work directly to it. Similarly, collegiate support grew out of a lack of access to other resources; the main resource in the group is the members. People in these advisory bodies show a keen interest in each other and have developed relationships with each other based on an awareness of each other's experiences of disability. This 'knowledge' of each other fostered an environment where people did seem to care about each other and want to help each other. There were no evident feelings of inferiority or incompetence associated with the need for help expressed in these forums. Both Hilltown and Seascape advisory bodies appear to be places where people feel supported and work collaboratively. Both Martin and Kieran expressed their feelings of equality, shared experiences of participation and most significantly they expressed that they could and did participate equally alongside the other members.

Procedural support

Procedural support was introduced in Chapter 6, where the modes of operating were discussed. This section raised issues about the type and amount of information that members were required to read and comprehend, the style and duration of meetings, how the meetings were chaired and how the level of formality of the group impacted on the participatory experience. The following

section discusses some similar issues but from a support perspective. Procedural support was less about what was changed or adjusted and more about facilitation of participation through the way others like the Chairpersons, engaged the person using the procedures of the meetings. As evidenced in Case Study thirteen, it was also about setting up and supporting different procedures, in this case a separate consultative forum, to enhance participation of members with an intellectual disability.

Procedural support combined a practical approach; making adjustments to normal meeting procedures that aimed to enhance participatory opportunities for everyone, and targeted practices that aimed to include members with an intellectual disability specifically. The case studies presented below are from the perspective of Chairpersons of two of the formal advisory bodies. The people supporting participation recognised that part of their role was to make meetings and the work of the advisory bodies inclusive for all members. Both also noted that that there were specific ways that they as Chairpersons aimed to support participation of members with an intellectual disability.

Case study twelve is of Northern disability advisory body. Karla is the member with an intellectual disability, she had an individual support worker who attended each meeting with her and met with her in between meetings to talk over the agenda items and business. This was a very positive and effective support relationship, as discussed in the earlier section on individual support; however, it

was strengthened by the active support that the Chairperson provides. The case

study below highlights some of the approaches as described by the Chairperson.

Such approaches were also evident when the researcher observed the meetings.

The Chairperson had a very active approach to engaging Karla, inviting her to

have input on particular agenda items and asking for her comment on others.

The case study focuses on the Chairperson's perspective on his support role.

Case studies of Procedural Support

Case Study Twelve Procedural support: Northern disability advisory body

> Arthur, the Chairperson of this advisory body has a physical disability although they have not used specialist disability services throughout their life. They came from the public sector and have a high public profile. Here the Chairperson talks about their focus on supporting all members to participate but in particular how Karla is supported.

> **Arthur** has been the Chairperson of Northern Advisory Body now for three years. He says "it has been an interesting roller coaster ride…. in terms of [my] naivety about the disability sector, [the Minister was looking for someone who] could present a different perspective or they could sell what the council was doing and lift its image, or profile in the community and not to be inward looking". He has a particular view about the role of the Chairperson saying,"[It is] not to be the mother or father but at least to provide subtle leadership or to be a catalyst. The main aim is really to lift the profile and press the importance of disability at all levels, in the community and society".

> Arthur recognises that not all members can or do have the same level of knowledge or awareness of issues or the same capacity to participate, "I mean the argument in theory is that anyone that sits on a council like this or any other board has responsibilities; equal participation, equal contribution and in theory I think that is plausible and I agree with it but in reality that is not practical. My view is if you have someone with intellectual disability and we do [Karla].. I have a role to sometimes pull the brakes on and devote…more time in terms of explaining, I have to put the brakes on sometimes and slow down, and enunciate quite clearly what we are on about, where we currently are, where we are going to, how we are going to get there and if you put it into a context it is fine"

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A focus of this Chairperson's role has been working out ways to actively support Karla's participation. They have supported this is a number of ways; "When Karla wants to ask a question that capability has to be put in place… you have to set the framework for that, the climate for that to occur [and], having set the climate it then pays dividends for all". Arthur also changes the pace of the meeting and allows Karla to stop the proceedings, Karla says , 'oh sorry I am slow' or, 'I am sorry I don't get this' or 'my helper has gone through this but I still don't get it', all of us, whether we have an intellectual disability or we don't… sometimes need to stop during a meeting, an all day meeting on complex issues, to stop and reappraise and revisit and come back.

He also recognise that Karla changes the pace and mood of the meetings by her emotional responses to some issues. Arthur says it is important for the group to realise where she has come from and what her experience of disability is and to learn from this. Arthur manages this by giving Karla forewarning of agenda items that might evoke an extreme emotional response and allowing her the opportunity to leave, or stay and have her say then move on. It is the his view that "Whether we don't get through an agenda simply because we spend too much on a particular item, which in theory would be of benefit to Karla, then maybe the irony is that because of that it is greater benefit to everybody, the agenda can wait until the next time". He feels the best way to support Karla's participation is to, "work from a mechanism of mutual respect, growing respect and we have got to take time".

Case study thirteen is of Southern Disability Advisory Body. It overviews how the Chairperson and the secretariat supported participation for people with an intellectual disability, by altering some procedures and in particular, by setting up a consultative forum with the members with an intellectual disability and self advocates from the community. It provides insights about what people perceived were the challenges to participation for this group and what they believed could support more meaningful participation, beyond the provision of an individual support worker, as addressed earlier.

Case Study Thirteen Procedural Support: Southern disability advisory body

Southern disability advisory body at the time of the study had two members with an intellectual disability. There is a Chairperson, Raelene who has a physical disability and who like the Chairperson of Northern has not used specialist disability services throughout her life. She has also come from the public sector and have a has a high public profile. Southern is supported by a paid secretariat, Mary is an administration worker and Candy is the manager.

Raelene One of my jobs is by the end of a term or two these people should be able to join any advisory committee about anything to do with government… I don't want it to be a training ground because I want to get on with the job; on the other hand it is inevitable [that it be a training ground for participation]. I try to make the meetings extremely realistic: They start on time and if people are late too bad, they end in two hours because normal advisory councils [do not] go for more than two hours. I make very few concessions [because] they operate at the top [end of the policy area]. I try to make concessions that are democratic and reasonable, this is for [members with an intellectual disability] and also for others. They are, and are not training grounds for learning the skills of citizen participation.

This Chairperson held the view that the advisory body should focus on barriers in the community that exclude people with a disability. She thought the overall approach should be like an advocacy model where the advisory body is advocating for change to these barriers to employment, education and transport. She believed the support approaches used within the advisory bodies should match the broad advocacy model and should support people to use and learn advocacy skills. As a result, she supported the use of individual support workers who came from advocacy support and could actively support members with an intellectual disability to put forward issues and advocate for change; this could include direct participation by the support worker to model advocacy skills. As a result of these views Southern disability advisory body supported the members of the advisory body with an intellectual disability and other members to hold a consultative forum with people with a disability from the advocacy and self advocacy sector.

Mary We organised the self advocates forum and it was the first time I had ever seen [the members with an intellectual disability] just shine. I was just amazed I thought that was really good. And now [they] are really rapt in that idea and want to keep meeting with the Minister, and the

Chair now wants to meet with the self advocates and do 'pre-meeting' briefings with them and the Minister's advisor.

Candy [There are three ways we have supported people] Engaging with the individuals, finding out what they are interested in, and helping them to 'self select' to be on relevant working groups; supporting them to build relationships with relevant groups that they can gain insights from, and linking them with their broader constituency through consultative forums with self advocacy and advocacy groups.

A number of procedural support strategies are evident in the case studies. The Chairperson of Northern employed different levels of support; they talked about developing a 'climate' of participation and putting in place a 'framework' to create Karla's capability to participate. The first approach was about managing the group dynamics, and knowing Karla well enough that the Chairperson could predict and then manage her input, particularly around issues that they knew she was highly sensitive about. The second required direct and active engagement of Karla by, developing agenda items for her to participate in and then inviting and supporting her to do have the input. Arthur, the Chairperson asked questions and provided spaces in the discussion for Karla to have her say, if she didn't he posed questions for her response. Thirdly, he managed the pace and intensity of the meeting by "putting the brakes on" and "revisiting" issues throughout the meeting. This Chairperson noted that all of this was worthwhile because it often enabled other people to catch up and participate better and it enabled all members to have a better insight into an issue from Karla's perspective. The style of chairing was very active and planned. Arthur did not leave anything to chance when it came to supporting Karla's participation.

Case Study thirteen gives a very different perspective on procedural support. The Chairperson of this advisory body held the view that people had to participate in a way that would be expected of any person who was a member of any advisory body. They did not alter their style of chairing to engage particular members, however this Chairperson did recognise that some members were participating as a way of learning the skills to participate. She believed that a 'model' of participation could be developed using a broad advocacy approach to guide the way the advisory body worked and then to match support to this model. Her approach was to engage people in the 'top end' of the policy discussions and to expect people to engage with the issues the way an advocate would. The idea was that people were supported to have input from an advocacy stance. She believed that as the Chairperson she modelled this, and that other members also used this approach. The end point was where the advisory body through the Chairperson lobbied Ministers to take on the advice. However, there was little evidence of this approach being used and the support worker, Sandy noted that to the contrary, she was unable to use this approach in her support role.

The Chairperson and the secretariat both noted the positive impact of the self advocacy forum that was set up to connect the members with an intellectual disability with their broader constituency of self advocates. This forum took place once and despite its apparent success, was not repeated. Also, both Hannah and Andy noted they were waiting for the secretariat and advisory body manager to arrange another one and arrange subsequent meetings with the Minister and

their advisor. None of these strategies had eventuated. Therefore, despite the

Chairperson expecting a certain model of participation and support it was not

occurring. The members with an intellectual disability relied solely on their

individual support worker who did not feel there was an advocacy model being

used in this advisory body. This case study suggests that sustainability of more

robust support models like this one is problematic, despite their apparent

effectiveness.

The focus and impact of procedural support

The approaches in Southern disability advisory body focused on broad

procedural models whereas the approached used in Northern disability advisory

body was more active, personal and targeted. Both examples show the

importance of the Chairpersons' approach and style, which is another 'human

factor' that has to be considered when analysing these participatory forums.

Karla spoke affectionately about the Chairperson of Northern advisory body. Both

Karla and the Chairperson talked about joking with each other and this mutual

respect was evident when observing the Northern disability advisory body

meeting; the Chair asked Karla if she had any "gossip" to share with the group

and throughout the meeting they engaged with each other in a very light hearted

and friendly way.

In contrast, Andy and Hannah who were members of Southern advisory body

noted the lack of a 'personal' relationship with the Chairperson; Hannah

complained that she did not feel like the Chairperson knew or understood her and Andy noted that the Chairperson talked too much. However both Andy and Hannah spoke very positively about the secretariat support and the manager of the advisory body. Again, the people with an intellectual disability focussed mainly on the relationships they had built with the various staff and the Chairpersons rather than reflecting on the outcomes or the more strategic approaches explained by the Chairpersons. This theme continued to occur in the analysis of their experiences and appears to be more important than the 'practical' or 'strategic' approaches to support discussed in this chapter.

The case studies presented here indicate that procedural support can be effective, however in these cases the person with an intellectual disability did not drive it. As indicated here, it relies on the style and the views of people in other roles, like the Chairperson and the secretariat and management staff, to plan and implement these approaches.

Greentown advisory body: A composite model of support
Greentown was the only advisory body that used some form of external specialist support for the group. They engaged a consultant to observe their meetings then ran a session on participating in meetings. They also engaged an arts worker to help them develop a video. Some other advisory bodies engaged external consultants for strategic planning and developing and supporting working parties, however none of these addressed practical skills. Greentown also used shared

support and to a lesser extent collegiate support. Also the policy worker acted as

an individual support worker for some members, meeting with them between

meetings and supporting them to read and understand information. Greentown

advisory body did not have a large amount of written material as a number of

members could not read. The policy worker relied on discussions with the group

and short combined 'agenda and action point' documents for meetings. She also

employed a number of procedural support approaches, including rotating the

Chairperson role, having short meetings and supporting the members to develop

materials in video format to present to the Local Council.

Case study of a composite model

Case Study Fourteen Composite support: Greentown advisory body

> Greentown advisory body is a Local Government disability advisory body
> that was established to develop a model of direct representation by
> people with a disability at a local level. In particular, it was the aim of the
> worker responsible for this group to move the consultation focus away
> from disability services to people with a disability. A series of meetings
> were held to bring people with a disability together, with the aim of
> establishing the group. During these meetings it became apparent that
> people with disabilities other than intellectual disabilities did not feel
> represented in previous consultations, as intellectual disability services
> dominated previous consultative groups. The aim of establishing a new
> Local Government advisory body was to change this focus and to
> concentrate on supporting the Local Government inclusion and access
> plan.

> The Local Government worker held a view that the group needed to
> establish itself rather than have predetermined membership categories
> and terms of reference. This resulted in a core group 'self selecting' to be
> members of the disability reference group. There were five people who
> attended the first meeting and all of these were people with an
> intellectual disability who were closely connected to the disability
> services that had dominated previous forums. The worker, along with
> one member, developed a range of strategies to bring in the perspective

of people with other disabilities including distribution of a survey to people who had attended the previous open meetings. Phillip, one of the members wanted to develop the survey but he cannot read or write so the Local Government worker talked to him about what needed to be on it and from this discussion wrote the survey.

People on Greentown disability advisory body do not have individual support workers. There is the one Local Government worker and plans to employ another part time worker to support the group. Members do not have official roles but share roles like chairing meetings. In their first year of operation the group identified that they needed some extra support to be able to do their work, this resulted in some formal training on participating in meetings. They also engaged the support of a local arts worker to help them develop a video about problems with roads and footpaths in the town. Members of the advisory body featured in the video and the end product was screened at an advisory body meeting with the Mayor.

The focus and impact of a composite model

This combination of support approaches was the result of a range of factors

including, a lack of resources, the view held by the Local Government worker that

the group should determine how they wanted to work, and the fact that the Local

Government worker saw facilitation of the group as her role. Greentown advisory

body believed that their primary role was to advise the Local Government on

better access and inclusion for people with a disability, as such they did not focus

on policies but tangible issues. The Local Government worker had broader goals

for the group, in particular she hoped that through focused local work the group

would become interested in, and more aware of, the common issues of transport

and community inclusion and be able to engage in policy advice at a regional and

statewide level on these issues. To facilitate this, members of regional and

statewide disability advisory bodies were invited to meetings and formed links

with them through information sharing and networking. Some members of Greentown disability advisory body had been representatives on these regional and statewide groups but had become disillusioned and decided to focus on the local issues.

The case study of Greentown disability advisory body illustrates how a number of support approaches can work together to support participation. At the time of the study there was little evidence of collegiate support due mainly to the changing membership of the group. However, most of the early members knew each other and those who joined the group seemed to settle in quickly with the other members, despite there being two distinct membership types; people with an intellectual disability who were the largest in number, and a smaller group of people with physical disabilities.

Outcomes of support: Empowerment?

Empowerment is an expected outcome of citizen participation for people with a disability (Boyce et al., 2001). At the beginning of this chapter empowerment was defined as a process of constructive and meaningful activity that results in more knowledge, skills and an increased awareness. Support has been framed in this chapter as a conduit to power for people with an intellectual disability within these disability advisory bodies, because without support they may not have the same 'notional starting point' as other members of the groups, therefore having less power in the participation arena.

The support approaches discussed in this chapter focused on a range of outcomes: access to information and knowledge, skill building, relationship building, and engagement in the participation process. Overall, the most beneficial outcome from the perspective of people with an intellectual disability was where they were supported to build supportive and equal relationships with colleagues, thereby 'feeling' more competent, better regarded and more capable of participating confidently. People with an intellectual disability were most critical of support that did not help them understand the issues or engage with them in policy discussions, in particular they were critical of the lack of support to access information in formats that they understood.

The case studies suggest that the most positive support approaches were shared and collegiate because they led to strong supportive relationships. Through these relationships people did become more engaged with the issues at hand because they were based primarily on people's own experiences. This was particularly evident in Seascape and Hilltown where Kieran and Martin could speak about issues that had been addressed and who they related to in the group. However, policy workers were more concerned with connecting people with the 'bigger picture' policy issues through the locally focussed work and engaged a number of procedural support approaches to enable this. The most effective example of this was the 'pre-meeting' briefings developed by Southern and the consultative forum also developed by Southern; however these approaches were not sustained.

Active procedural support as evidenced in Northern disability advisory body was also effective when paired with the strong and personal individual support that Karla received from her support worker. The Chairperson of Northern disability advisory body gave examples of well planned and executed support approaches used to develop what he called a 'climate' of support and a 'framework' for enabling Karla with the "capability to participate". The individual support approach described by Karla and Nancy was very flexible, personal and active. These two approaches did result in Karla participating meaningfully as evidenced by her own assessment of her participation and the Chairperson's.

Very individualised and isolated support as experienced by Andy, Hannah and Jana did not seem to result in more active or meaningful participation. They did not feel connected to the rest of the group, were not confident about participating and did not show great awareness of the issues, despite having an individual support worker. Their support worker Sandy, was very critical of this approach indicating that it was not valued by the advisory bodies and was not well enough resourced. She was a very experienced support worker, however despite having the knowledge and skills to support people she did not feel she was able to use them in this approach.

Sandy suggested an alternative approach, similar to the consultative forum used by Southern, however she said it needed to be ongoing and set up as a formal

reference group for members with an intellectual disability. Using this model, people would be supported to develop a reference group of peers or other self advocates that they would consult with on a regular basis about the policy issues being addressed. This would result in a more collective viewpoint being put across by the members with an intellectual disability. This is the more common approach used within self advocacy and is evident in some citizen and consumer participation models in the UK and Canada, as discussed in Chapter 3. The member would then be able to participate in the advisory body discussions and would be doing this from a more informed basis. This approach would require a change to the terms of appointment. All members are currently appointed as individuals, not representatives of organisations.

The composite model of Greentown employed a number of different approaches, most notably; engaging specialist support to address skills based activities like how to participate in meetings and making a video. This was the only example where skill development was the focus of the support. There was a notable lack of skills training to support people to learn how to participate, how to speak in public, how to communicate their views or develop and present their views. The Chairperson of Southern suggested that this advocacy model was their aim, however there was no training or mentoring support provided to assist in this skill development. In the UK, this skills training and mentoring happens within the strong and well-resourced self advocacy sector, and in the USA it is evident

within self advocacy and also through recognised participation courses like *Partners in Policymaking.*

Neither forms of training outlined above exists in Australia. People with an intellectual disability lack participation training opportunities, unless they organise them themselves, or access some of the leadership courses that are beginning to become available. Such courses have identified the skills needed to participate and are shaping their courses to address such skills; however they are primarily cross-disability courses and have yet to provide research findings on the outcomes for people with an intellectual disability. One research project was completed in Victoria that formed the basis for the development of a disability leadership course (Johnson, Frawley, Hiscoe & Strong, 2002). It recommended a range of approaches to supporting both leadership and participation opportunities including training, mentoring and the development of leadership networks of people with a disability. However, many of the recommendations were not addressed and the existing cross-disability leadership course that is modelled on a community leadership program, remains the only formal disability leadership program in Australia (Leadership Plus, 2007).

Summary
Support that leads to empowerment is lacking within the advisory bodies. The focus on individual support does not result in people having more knowledge of the issues, good access to the information, close engagement with the

participation process or strong and equal relationships with colleagues. Each of

the six disability advisory bodies in this study differed in their approach to, and

understanding of the participatory role of the person with an intellectual disability

and therefore the support provided. For some it was about ensuring that the

person could understand the information they were dealing with, and have an

equal opportunity to have a say within the forums. This was often 'addressed' by

employing a support worker to work 'one on one' with the person with an

intellectual disability. Others saw the advisory body as a model of an inclusive

environment, these preferred to work as a group and provide support to each

other and address procedural barriers to participation. The approaches in most

cases were linked to other factors of the advisory body; whether it was formal or

informal, what personnel and budget were available and the broader goals of the

group that related to inclusion and access.

Overall, support approaches that actively engaged the person within the group

and the meetings and connected them with other members appeared to be more

empowering. However, none of the support approaches resulted in people

having in-depth knowledge, or awareness of the issues being addressed by the

advisory bodies. The approach that came closest to this was the collegiate

approach whereby members could recall issues through their connection to

individual members' experiences. Support to access and understand information

was lacking in all approaches, as none of these used, or had the resources to

provide ongoing training, briefing, or consultation that led to meaningful engagement with the policy information.

The analysis presented in this chapter suggests that the most empowering support connects the person to other people and through these relationships connects them to the policy issues. For many people with an intellectual disability, these 'other people' will be other self advocates, and their networks will be established through self advocacy organisations; however as noted these are not well developed in Australia. In addition, it also suggests the need for more active support as provided by the Chairperson of Northern advisory body and a more thorough approach to supporting access to and understanding of policy information.

A lack of participation training for people with an intellectual disability in Australia is also raised and the importance of connection to a better-resourced self advocacy network to source and receive this kind of training and support. Finally, as raised in Chapter 5, participation support as outlined in this chapter, needs to acknowledge the past personal and political experiences, ideologies and orientation of the people participating and shape supports that reflect these. In turn, the participatory environments would begin to be shaped by the orientation of the people participating and the kind of support they needed to participate. The structures would change as a result of this understanding of participation and approach to participation support.

CHAPTER EIGHT

CONCLUSIONS

> Hey, no that's not right, how do they know we can't do it? Of course we can do it . We are above the trees, up to the sky how do they know we can't do it? Of course we can do it . Hey they think we don't know but we can know. Give [us] a chance to prove that they are wrong. [We] have got the power. If I can do it then somebody else can do it. Don't shove [us] under the mat [we] are not roots under the tree. People with all disabilities can do it. *Kieran*

Introduction

Since the 1980s, some people with an intellectual disability have been

participating in advisory and consultative bodies at various levels of government.

Much has been written arguing for the importance of their participation, and

efforts have been made to facilitate it. However, little is known about how the

people themselves have experienced their participation. The focus of this thesis

has been an analysis of people's experiences and the processes that are in

place to enable and support their participation.

The literature reviewed in Chapter 2 put forward a number of issues about citizen

participation by people with an intellectual disability. In particular, research that

has attempted to report the perspective of people with an intellectual disability

suggests that people feel incompetent, and that this is based on them not having

a valued role in such forums (Beresford & Croft, 1993). In addition, research on

the consumer participation role of people with an intellectual disability has found

a number of obstacles to participation, in particular in relation to understanding information and feeling empowered to have a say (Grant, 1997; Whittell & Ramcharan, 1998; Simons, 2000). Other writers noted that despite efforts to address tangible barriers, people with an intellectual disability could still feel disempowered and incompetent within such forums (Redley & Weinberg, 2006).

The literature calls for a "profound change" (Stainton, 2005) and new ways of thinking about and supporting people with an intellectual disability (Whittaker, 1993) to participate. However, there is a dearth of knowledge drawn from people's experiences, and little research about the way people are participating in the increasing range of advisory and consultative roles they have. Despite this lack of knowledge, policy that has participation at the fore has forged ahead.

Orientation and representation

Historically, people with an intellectual disability have not been afforded a central place in research, nor have they readily been seen as being able to reflect on and use their experiences to shape policy and practice. This has changed over the past three decades, with the emergence of a rights based framework, and more attempts to include people in all aspects of their lives. However, as Stainton (2005) argues, "Traditional ideas about competence and capacity are…proving difficult to reverse" (p.294). This study attempts to add to knowledge that can support this reversal. It has found that the people with an intellectual disability who were participating in government disability advisory bodies had the individual

agency to do this, and were capable competent people with particular personal

and political orientations to participation. Like other people who engage in such

forms of citizen participation, people with an intellectual disability base their

participation on their life experiences, and their political views and ideologies.

The people in this study formed their stance in different ways, but what they had

in common was clear reasons for participating, preferred approaches to their

roles and the capacity to participate. A typology of participation orientations was

developed to describe how and why people participated.

People had varied reasons for becoming involved in advisory bodies and brought

their own views and a preferred approach to them, however there was a common

purpose, which was, to represent the intellectual disability perspective. For those

with a democratic orientation this was seen as a right and expressed from a

collective perspective, for those with a professional orientation it was more

individualised and based on themselves as leaders, and for the communitarians

it was an expression of community membership. For each, there was an

opportunity through this participation to represent issues they or other people

with an intellectual disability experienced.

At the heart of this motivation was a belief in the right to participate, the right to

be seen as an equal with others whose voices were being heard, and a right to

engage in shaping policy that affects the lives of people with an intellectual

disability. The study concludes that each of the nine people in the study have

agency; they are able to form their own opinions and they have a stance from which they act. However, these two factors alone do not ensure they will have meaningful participation. Their membership on the advisory body realises their right to be there, however without effective support and recognition of their capacity as evidenced by their ability to form and express legitimate policy views, their participation may still be experienced as token. All the individuals had a presence on the advisory bodies where others saw them as representing an intellectual disability perspective, but it was those who were supported as a colleague of other members, that had more meaningful and positive participation experiences.

Despite their representation aims, they were not formally appointed as representatives to represent a collective voice of people with intellectual disability. In some advisory bodies**,** the appointment process was very explicit that they were not representing people with an intellectual disability; rather as an individual they were to embody and be representative of the intellectual disability experience. As a result, they were not formally connected to a constituency, and for some who did not create their own connections, they and their views, were disconnected from the broader and collective voices of people with intellectual disability. However, each person engaged with the issues in a way that reflected their representation aims, expressing needs and views about policy that were beyond their own experiences. For some this was expressed from a self advocacy stance and for others, through a spokesperson role.

Advisory body co-members and the managers of the advisory bodies also saw them as representing the collective intellectual disability perspective. They noted that the people with an intellectual disability gave them a unique insight into what is important for people with an intellectual disability, reminded them of the needs and life experiences of people with an intellectual disability and enabled their views and the views of policymakers to be informed by these insights. Without people with an intellectual disability on such advisory bodies, this view would be missed, or as is the case in a number of advisory bodies surveyed as part of this study, provided by service providers, families or advocates. Arguably such people have their own informed perspective. Whilst this may be a legitimate one, it is not one formed through life experience of intellectual disability, or shaped by a collective view from collective experiences of people with an intellectual disability as articulated by them.

The study does not suggest that others do not have a legitimate place at the table. However, it argues that people with an intellectual disability have a legitimate place at the table alongside such people and should not be overlooked because 'others' are seen to be more capable of representing them. People with an intellectual disability can participate equally when they are recognised as having the capacity to do this. The study shows that this participation can be even more meaningful when people with intellectual disability participate alongside others who despite their different perspectives, none the less respect

the views of people with an intellectual disability and are willing to lend them collegiate support.

Representation is an important plank to meaningful participation. It is clear however, through the analysis of people's participation experiences that being appointed as an individual is not the same as representation. This distinction is discussed in the literature by Birch (1971), who finds that the two are sometimes confused. The people in this study had representation aims, however it was difficult to enact them when people were appointed as individuals. In some instances, people created their own ways of being a representative, by maintaining their links with self advocacy, reporting to their self advocate peers and reporting their collective ideas back to the advisory bodies. One person was supported by the advisory body to do this, but predominantly, people were appointed and expected to act as 'individuals'.

People who did not have a connection to a constituency, and were not supported to create this, expressed feelings of isolation and frustration, particularly when advisory body agendas appeared irrelevant to them and to the issues raised by self advocates. In comparison, where people could connect with a constituency, their participation appeared to be more informed. One support worker also noted this as a significant barrier to providing support for participation. She put forward an alternative model similar to that used in USA, Canada and the UK where

people are appointed as representing self advocacy and through this role, act more as spokespeople (Learning Disability Taskforce, 2007).

This research has found that there is some apprehension about enabling and supporting a representative role for people with intellectual disability on government advisory bodies in Australia, in favour of a more individualised approach that sees each person as representing their 'personal experience of disability'. Where people are appointed as individuals who embody the characteristics of the identified type of disability, it is assumed that they will be divorced from particular agendas or the machinations that create division between people in particular groups. However, as the people in this study have shown through their own accounts of their participatory experiences, they have the potential to be capable and competent in representation roles, based on personally informed and strongly established political orientations.

Supporting participation through changing structures and building supportive relationships

Feelings of tokenism were at the heart of the concerns raised by Hannah, whose questions about participation initiated this research. She was concerned that her participation in the government disability advisory body did not mean anything more than her filling a seat at the table as the designated 'person with an intellectual disability'. Other people in this study also raised feelings of tokenism in their discussions about participation experiences. Phillip noted that he left one

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advisory group because he felt like the token, Andy noted that he did not say much because the Chairperson spoke most of the time, and Hannah was concerned that she was not seen for her abilities. However, people like Karla, Kieran, Martin and Phillip, when he moved to Greentown advisory body, talked very positively about their experiences, suggesting they did not share these feelings of tokenism. The basis of their positive views was that they were listened to, able to put forward their ideas, and they felt that others respected them and valued their input.

The literature on citizen participation also raises this issue of tokenism; however it focuses mainly on factors within the participatory environment as developing tokenism (Arnstein, 1969; Richardson, 1983; Wolfe, 2002). In particular, how the participatory bodies are structured within a policymaking context, how they function as determined by often narrow terms of reference, and what decision making power these terms of reference give to those participating. Whilst this study found some structural factors to be important and described how they mediated the participatory experience, by far the most significant factor was how people felt others regarded them. These findings suggest that such feelings of acceptance and being valued by others lie at the core of enabling positive and meaningful participation for people with an intellectual disability.

Furthermore the positive participation experiences described in this thesis were largely brought about through supportive relationships with other members and

staff of the advisory bodies. This suggests it is important to define support more broadly as an experience or relationship, not just a tangible, practical adjustment. Those people, who described positive experiences of participation, reflected on the relationships they had that created these experiences. They recognised that their capacity to participate was acknowledged by those around them. Karla had a support worker who used her close and insightful knowledge of Karla as a person, to inform how she supported her to participate. Kieran, in Seascape was appointed as the Deputy Chairperson. This enabled him to manage the pace of the meeting and more closely focus on the agenda, and openly ask for clarification of issues when he needed this. He also had close and collegiate relationships with co-members who recognised his skills and supported him when he needed assistance understanding information. Phillip, who had experienced tokenism in the past, found an advisory body where he was a leader; however, this is not how he saw himself. He was supported to bring together other people who had not been noticed as potential participants and encourage them to participate. Through this, his capacity to lead and to motivate others was supported by a local government worker who recognised his capacity and was able to provide the practical supports to overcome his inability to read.

In contrast, those people who described more negative experiences reflected that they did not feel respected and included, and compared to others in the advisory bodies, felt less capable. They tended to blame themselves and their lack of skills and knowledge, or looked within the environment for structures and

processes that inhibited their participation. Commonly they reflected that they did not understand their role, or were not able to perform it because they could not understand the information, and lacked the right kind of support to interpret and use the information.

Tokenism, it is argued here, is experienced when people are not recognised for their capacity to participate, and supports and processes are developed and used that further isolate the person, rather than include them. This study has described nine very capable people whose participation demonstrated that they were indeed able to form a stance, and engage in the policy participation opportunities they had. At the core of building positive experiences was what Reinders (2002) calls civic friendships. He suggests these grow where, "…people live and work together in the pursuit of shared ideals. It is a mistake to think that we have achieved the goal of inclusion by creating new institutional roles for our clients as citizens" (p.3)

Within the context of government disability advisory bodies, this would require that people's ideals are recognised and used to inform the agendas, and that there is a sharing of people's views within the advisory forums. As this study suggests, appointing people with an intellectual disability to the institutional role of 'policy adviser' or consultee, cannot on its own meet participation aims. People reported positive experiences where they were supported to have their say, listen to other people's experiences and learn from them, set the agenda based on the

issues they knew were relevant to people in their networks, and use these networks to create a shared agenda with others on the advisory bodies.

In summary, the most empowering, positive experiences were evident in advisory bodies where people were known well, respected, and supported within the advisory body in a collegiate way. Their views were valued and their orientation to participation acknowledged and used to engage them with the agenda. Some of the advisory bodies were very formal structures and others were informal. However, it was their processes and modes of operating, rather than their structures that mediated people's participatory experiences. Certain impediments to participation were noted, and did include issues that could be addressed by making adjustments; in particular to the way information was provided, translated and used to support people's understanding of the policy context of their work. However, in most instances where there were supportive relationships these tangible barriers were overcome without significant adjustments or difficulty.

This does not suggest that barriers should not be addressed; however, it does caution that narrowly defining support as dealing with tangible barriers only can overlook the real benefits that can be found in the development of strong collegiate relationships. This is evidenced in the study where resources were used to provide individual support that resulted in one paid support worker taking full responsibility for supporting the person's participation. In three such instances, the support worker was unable to make all of the information

accessible and reflected that her role was tokenistic and resulted in token participation.

Across all six sites there was a lack of formal training or mentoring support to enable people to participate; where it did exist it was on an informal basis, dependent on the initiative of individual members. In the formal advisory bodies where individual support was the primary approach, people were dependent on their individual support worker for all their support and training needs; however, neither support worker interviewed in this study performed this role. Formal training and development of mentoring roles as are established through programs like *Partners in Policymaking* in the USA, (Minnesota Governors Council, 2007) and in some self advocacy groups with self advocacy advisors in the UK (Chapman, 2005), are lacking in Australia and in Australian government disability advisory bodies. In addition, the lack of attention to making information accessible evidenced in this study, suggests that access for people with an intellectual disability is not well understood.

A proposition from this study is that those people with an intellectual disability who do have an interest in participating, hold participation aims, and have well formed personal and political views are likely to be capable of participating given the right support. This, it is argued, comes from a willingness by others to form and maintain collegiate relationships that are based on an acknowledgement, not only of the persons right to be participating, but also their ability to participate.

Moreover, that this is aided by strong connections to a constituency who can inform their participation. It is proposed that representation roles supported by connections to self advocacy are more beneficial than merely appointing people because they represent a 'personal experience' of disability.

In summary, the study finds that the mechanisms to enable participation and inclusion of people with an intellectual disability in policy advice forums are still hampered by views that people with an intellectual disability are incapable of this level of participation. In addition people are further isolated by narrowly defined supports and a focus on adjustments that do not increase participation or change views about people's capacity to participate.

Conclusion and implications for practice

This study indicates that rarely can the personal, political and the practical be separated when considering the life experiences and supports required by people with an intellectual disability. No longer is it acceptable to compartmentalise disability as individual, medical or social. Writers including Priestley (1998) and Shakespeare (2006) have questioned the 'either or' debate about models and understandings of disability and argue for a more multi-faceted definition and approach to understanding and supporting people to achieve equality, inclusion and participation. In the context of this study, this multi-faceted view of disability would lead to a more informed approach to support and more meaningful participation. The suggestion made in this study is that to fully

understand the experiences of people with an intellectual disability who participate in policy advisory roles, we need to start with the personal and acknowledge people's capacity and agency and how this shapes them politically.

Participation in government disability advisory bodies has focussed this study on a particular role and particular environments to examine one aspect of the broader question about inclusion and participation. The challenge within the government advisory bodies was to develop an inclusive environment that enabled everyone to participate in a meaningful way. However, experiences shared by the people in this study, reflect the complexity of the intellectual disability perspective and experience, and the difficulties expressing this in such forums. Hannah's experiences of being given a reading test to establish her capacity to participate, Andy's view that he shouldn't ask questions even when he had a support worker there to help him, Martin's feigning of understanding by pretending he couldn't see the writing on papers, and Karla's concern about responding emotionally to issues raised in meetings, reflect this complexity. Some approaches to support, even if they are well intentioned and individualised, can leave people feeling incompetent and less worthy of their place at the table than people who do not have an intellectual disability.

Further, the lack of recognition of self advocacy as a representative voice of people with an intellectual disability creates tensions and difficulties for people with an intellectual disability who are used to representing a self advocacy

perspective in consultative and advisory forums. Unlike other people who are members of these cross-disability advisory bodies, they are unlikely to have strong personal or professional networks that they can draw on to inform, legitimise and develop their views. For most, their membership of self advocacy organisations fulfils this role. When terms of appointment actively discourage the use of this network to inform their participation, they can feel less competent and less sure of the views and positions they are putting forward. Individual support relationships or collegiate support relationships cannot replace this network and the need for people to connect with it. However, a strong self advocacy sector is needed to fully support people to act as its spokespeople. This and a representative framework that appoints people as self advocate representatives is needed along with more active support and opportunities for people to access skills, knowledge and opportunities to participate.

Implications for policy and practice

The final research question asks how participation can be made inclusive and meaningful for people with an intellectual disability? Already this chapter has outlined the main findings, which highlight the need for a multi-faceted approach to developing more meaningful citizen participation experiences. In addition, it also argues for the development of a framework that has a strong focus on representation and connects people with an intellectual disability through their networks and through people who can represent these, to policy makers.

Currently, Australian government disability advisory bodies are created by different levels of government with very little collaboration or cooperation between each level. The State and Territory advisory body Chairpersons have a network, which meets to discuss activities and shared issues. However, there is no mandate for them to communicate with each other and no opportunities for other members to meet or to report. As already noted, people are primarily appointed as individuals without a framework of accountability or connection back to a constituency. In other countries like the UK, formal frameworks have been established to connect people with intellectual disabilities, through local self advocacy groups to regional and national policy advice forums, and ultimately to politicians who are making policy decisions (Learning Disability Task Force, 2007). Whilst some have criticised this approach for tying self advocates and the self advocacy movement too closely to a government devised policymaking approach, it does at least form connections and some accountability. Self advocates and self advocacy groups are still able to act as policy activists through campaigning and being recognised as legitimate stakeholders in other policy advice forums, this is one way that connections can be made from the personal to the political.

As depicted in the figure below, representation has been found in this study to be an important plank for supporting meaningful policy participation by people with an intellectual disability.

Figure 1 Components of meaningful participation

Structure
Processes
Modes of operating

Personal/Political
Ideologies
Approach

Support
Adjustments
Relationships

Representation/Self Advocacy
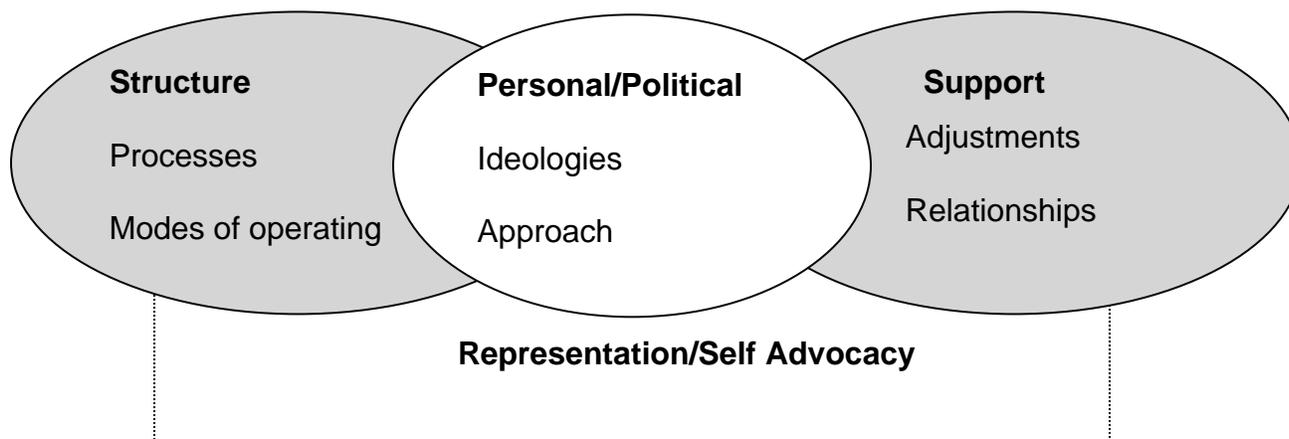
Writers like Wolfe (2002), Boyce et al., (2001) and Barnes et al., (2007) ask the

question why people participate in these kinds of forums. They suggest that it

can be a means to an end or an end in itself, it can be for self development or to

transform policy and create social change through participation, and it can, or as

Boyce et al., (2001) suggests, should be about empowerment when involving

people with a disability. In this study people reflected that they participated in

these forums for a range of reasons, but most significantly because it was an

extension of their role as known spokespeople for people with an intellectual

disability. The combined personal and political orientation to the role is a

significant factor that was not well understood or acknowledged by the advisory

bodies. However, through this study the importance of it is articulated. This

political orientation needs to be supported by a process that reflects representation.

In Chapter 3, the policy context for this new and emerging role of citizen participation for people with an intellectual disability was outlined. It is clear that in Australia, whilst there are policy statements in disability policy regarding all forms of participation and in some, specific mention of civic and political participation, there is a lack of a coherent participatory framework. As discussed in chapter 3, countries such as the UK and Canada have developed comprehensive participatory and representative structures to enable citizen participation by people with intellectual disabilities. In contrast Australia has adopted a more ad hoc approach not based strongly on representation.

Two issues arise from this analysis; firstly the need to develop a strong systematic participatory framework supported by policy, and secondly to engage more people with an intellectual disability in the existing forums in more meaningful ways. An overarching issue is the need to ensure that people with an intellectual disability are given the opportunity to connect with each other and with the issues that matter to people with an intellectual disability. In addition, they need to be appointed as recognised representatives who can gather the issues from their constituency and through a range of advisory forums and roles, voice this view in the policymaking arena along with other groups and people who have shared ideals about disability reform.

Participating was not an end in itself for the people in this study, but an important means to an end for them and for the broader population of people with an intellectual disability. The people in the study talked about using their position to educate others about the capacity people with an intellectual disability had to participate. Kieran talked about "Lifting the umbrella" so others could see the potential that people with an intellectual disability had in these roles. It was also a way to raise issues that were hard to raise; Karla said that she was there to challenge views about the needs of people with higher support needs who could not be there to have their say. Also, people recognised that they had an important role that was connected to people in power and they wanted to use it. Andy said that it was not his voice but the voice of other people with an intellectual disability that he wanted to use to talk to the Minister. These are insightful views about political and civic participation. They have come from the in-depth study of people who are political advocates, spokespeople and people with an intellectual disability.

This study has shown that by engaging seriously and at length with people with an intellectual disability about their experiences of participation, much can be learned. They are serious political players who are in positions where they can influence policy directions. However, the meaningfulness of their participation is dependent on a changed view about their capacity to participate, and development of structures, processes and supports that reflect this view. Whilst

their achievements and disappointments may not be so different from the feelings of many people who engage in citizen participation, the intellectual disability perspective on citizen participation has not been heard before.

Within a policy context, that is increasingly dedifferentiating the disability experience, this study argues for a particular approach to supporting citizen participation of people with an intellectual disability. This recognises their different experiences, their particular way of engaging with issues and their own collective voice. It also clearly recognises the ongoing struggle people with an intellectual disability have to be taken seriously, and to be respected for their capabilities as policy advisors and political players. Whilst social and structural barriers do exist and can inhibit people's experiences, by far the most pressing need is to realise and respect what people can do, and to develop equal and supportive relationships that reflect this belief in their capacity. This is evidenced in this study by the clear orientations people have to participation. However, this kind of knowledge needs to be used to shape participatory forums, to enable people with an intellectual disability to gain membership to advisory bodies and to be supported to participate meaningfully in the increasing range of participatory forums that exist at Local, National and International government levels.

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Appendix One Overview of the Disability Advisory Bodies

Council	Level of Government	Membership composition	Reporting arrangements	Date established & Functions
Central	National* Meets quarterly	15 members. People with a personal experience of disability (10), parents (4) and service providers (1) (no required membership categories) 1 Chair; 2 Deputy Chairs (included in membership number)	Federal Minister for Family and Community Services	1996 Government Leadership, Informed Advice, Public awareness and attitudes.
Southern	State Up to six times annually	13 members. People with a disability (10), Parents of children with a disability (3) (this composition is set out in the Terms of Reference) 1 Chair appointed by the Minister (in addition to the membership number)	State Minister for Community Services	2000 Whole of government focus to meeting goals of State Disability Plan; Be a consultative forum; Respond to references from Government on public policy issues affecting lives of people with a disability. [Functions and role set out in Disability legislation]
Northern	State Meets monthly	17 members People with a disability (13) Parent of child with a disability (1) Service provider/advocacy (3) [is provision for 18 members – no required membership categories] 1 Chair, 1 Deputy Chair. Executive of 3 (included in membership number)	Minister for Disability Services	1987/88 Monitor government policy (disabled people and families); Advise on services (effect, relevance and priorities); Advise on role of voluntary organisation; Promote integration and community awareness; Consult and cooperate with the National DAC. [Functions as set out in the legislation that governs this council)
Seascape	Local	11 members appointed by the City Council. Service providers/community	City Council through the Chairperson	1988

	Meets every two months	organisation (4), Individuals with a disability **(4), Individual or Organisational (3). Ex Officio (2) 1 Chair Councillor appointed by Council. (additional to membership number) I Deputy Chair, 1 Secretary appointed by the committee (included in membership number) ** Terms of reference state that there must be 4 individuals but does not state if individuals should be people with a disability		Advise Council on; Implementation of the Disability Action Plan (DAP) and plans and strategies associated with the plan, Development of Council Policies, Strategies and action Plans for groups or aspects of the DAP, Review and evaluation of the DAP, Community disability awareness, Innovative funding to support the DAP.
Hilltown	Local Meets monthly	17 members (11 active at time of study) Person with a disability (6) Carers (5) 1 Chairperson, 1 Convenor (officer from Council) 1 assigned Councillor	Local Council through appointed Councillor via a Community Services Advisory Committee	2001 Advise and support community programs and services on disability issues, Be the community disability focus group, Discuss and plan services and programs, Avenue of advocacy, Increase community awareness about disability, Input into community action plans
Greentown	Local Meetings as needed	15 core members (broader membership of people with a disability via a database of 100 people) People with a disability (15) Facilitated by 1 Council employee and 1 Disability Advocate	Local Council through Councillor representative	2005 To give advice to Local Government, to regional consultancies/reference groups and State Government (via direct representation) about disability issues in the Shire. Implement the DAP. Increase independence of advice given directly by people with a disability

*During this study this Council went into recession to be restructured as a Disability and Carer Council. This table refers to the Council as it was

composed during the study

Appendix Two Central Research Participants

Research Participant (names changed)	Age/Gender	Advisory Body (name changed)	Participation experience
Hannah	43/Female	Southern - State	Self advocacy, reference groups, consultations
Andy	50/Male	Southern - State	Self advocacy, service boards, consultations
Jana	50/Female	Central - National	Self advocacy, reference groups, consultations, self advocacy boards/committees
Karla	40's/Female	Northern - State	Self advocacy, intellectual disability advisory committee, justice advisory committee, self advocacy board
Kieran	40's/Male	Seascape - Local	Self advocacy board, disability service client board
Martin	21/Male	Hilltown - Local	No previous experience
Phillip	50s/Male	Greentown - Local	Self advocacy board, disability service committee, Government department advisory committee
Tyler	20's/Male	Greentown - Local	Self advocacy board, disability service committee
Christine	21/Female	Greentown - Local	Self advocacy committee

Appendix Three Description of Advisory Bodies

Greentown is a Local Government disability advisory body that was established to address the need for direct representation by people with a disability at a local level. In particular, it was the aim of the worker responsible for this group to move the consultation focus away from disability services to people with a disability. A series of meetings were held to bring people with a disability together with the aim of establishing the group. During these meetings it became apparent that people with disabilities other than intellectual disabilities did not feel represented in previous consultations, as intellectual disability services dominated previous consultative groups. The aim of establishing a new Local Government advisory body was to change this focus and to concentrate on supporting the Local Government inclusion and access plan.

The Local Government worker responsible for developing a consultative forum on disability access and inclusion held a view that the group needed to establish itself rather than have predetermined membership categories and terms of reference. This resulted in a core group 'self selecting' to be members of the disability reference group. There were five people who attended the first meeting and all of these were people with an intellectual disability who were closely connected to the disability services that had dominated previous forums. The worker along with one member developed a range of strategies to bring in the perspective of people with other disabilities including the distribution of a survey

to people who had attended the previous open meetings. This resulted in the development of a database of over thirty people with disabilities who are connected to the group but do not participate on a regular basis. The core group has grown form 5 to 15 and whilst still primarily people with an intellectual disability, does include active members with a range of other disabilities.

Over time this group developed terms of reference[5] and a process for meeting and communicating within the core group, with the broader membership and with external bodies. They developed a formal link with the Local Government by having a Councillor attend meetings and they developed some short term and long-term goals for their work. Their first goal was to let Council know what the issues were for people with a disability in the town. They worked with people from their broader group and a community organisation to develop a video to present to Council about issues like paths, pedestrian crossings, level crossings and community transport. The presenters in the video were core members of the group and some people from their broader membership.

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[5] This process took place as part of the research whereby the researcher developed an Action Research approach with the group. Feedback from the first round of interviews highlighted the need to establish some parameters around the work of the group. The feedback points from the interviews were used as a framework for these.

There are no individual supports provided to individual members of this group. The Local Government worker supports the whole group and works with them to identity how they want to operate. It uses a shared support model along with a focus on procedural support through provision of accessible information and informal decision-making procedures. Members do not have official roles but share roles like chairing meetings. In their first year of operation the group identified that they needed some extra support to be able to do their work, this resulted in some formal training on participating in meetings.

Seascape Disability Advisory Council (SDAC) is a Local Government disability advisory body that has been established for almost twenty years. Members are elected as representatives of organisations or as individual members. There are eleven members; one member is a person with intellectual disability who at the time of writing held the Deputy Chair position.

Over the last twenty years there has been significant changes to how disability is understood and responded to in the community. Over this time Seascape Local Government has also revised the way they organise their work around disability and involvement in disability policy. In 2000 they established a broad Access and Equity Advisory Committee in addition to the existing Disability Advisory Council. The access and equity committee has a broader target group including gender, culture, age and disability and was recommended as part of the Access and Equity Policy and Action Plan. With the establishment of this committee the

SDAC was also revised to have a clearer focus on issues for people with a disability as defined by the Disability Discrimination Act (1992) and as outlined in the Local Governments Disability Action Plan (DAP). The Local Government worker noted "The previous DAC was based on interest, when it was first established the membership was by appointment and were mainly service providers. Historically it was dominated by issues that could be dealt with in other arenas". In 2002 the terms of reference of the DAC were revised and their work aligned with the DAP. The Local Government worker noted this enabled them to focus their work and to address a broader range of issues including some of the more difficult ones set out in the DAP. Essentially this re-structure enabled individuals to become members and required that the work of the SDAC be focused through reporting requirements that were linked to the DAP.

The SDAC has the same status as other advisory committees within the Local Government area. They report formally to the Local Government via their Chair who is a Local Government Councillor. They hold formal meetings every two months and the minutes of these are public documents.

A worker who has a broad community development and social planning role provides support to the SDAC. People with disabilities on SDAC do not have access to individual support workers, however if they require specific and specialist support (eg sign language interpreters or attendant carers) these can be arranged. The members of this body noted that they all support each other.

The member with an intellectual disability saying that he learnt how to participate from watching another member, saying that if he gets stuck he asks anyone there for help. This group uses a collegiate approach to support with a strong focus on procedural support through accessible information and meeting procedures that are based on the needs of the group. It also uses shared support where the one worker provides administrative, policy and practical support to the whole group.

The SDAC is characterised by having a formal structure but operating in a more informal way to achieve its outcomes. Meetings are structured with formal decision making procedures, however there is an informal approach to them where people enjoy a meal together as they meet and bring a range of issues to the discussions based on their personal experiences.

Hilltown disability advisory body is a Local Government disability advisory group that has been established for just over five years. They have seventeen members but not all are active. They have an appointed chairperson and a Local Government councillor who has some contact and connection with the group. Hilltown disability advisory group comprises members with a personal experience of disability along with parents, carers and some service providers. A government employee who has a broad disability community development role, which includes managing three of these groups across the region, provides support to the group and facilitates their meetings and activities.

The group does not work from a specific plan however they do refer to broader State and Local Government disability, access and inclusion policies for some direction and identification of their goals. Local issues brought to the group by the group members, Councillors or the Local Government disability/community development worker set their agenda. They focus mainly on community awareness raising and issues of access and inclusion within the local community. They aim to increase access and participation in the community for people with a disability by raising issues with the Local Government. They also have a stated role to receive, share and distribute relevant information within the community and services in the area.

None of the current members have support workers. The Local Government disability/community worker provides support to the group for developing the agenda, making information and the meeting procedure accessible to everyone in the group and connecting the group to information, issues and other participatory forums at a regional and State level. This worker also provides general and specific support to the members at the meetings and supports them with their planning. The person with an intellectual disability does not have a specific support worker; they use the worker and/or other members of the group for support during a meeting. They do not receive any support between meetings or in preparation for meetings. This group has a very strong focus on procedural support through its use of Plain English for agendas and minutes and the

informal approach to the meetings. There is also a strong collegiate support model where members of this group noted that they support each other in the meetings.

Hilltown disability advisory body is semi-formal in its approach to its work; they have formal agendas and minutes and have formal representatives on a regional disability advisory council and a regional community health advisory group. Their meetings are conversational with decisions made and actions noted based on a consensus model rather than formal meeting procedures. Members of this group noted that there is a social aspect to the group; they sometimes have lunch together as part of the meeting and always share information on member's health, recent activities and other issues making the meetings and the agenda connected to people's own experiences.

Northern disability advisory council (NDAC)was established in 1988 under State legislation. It's terms of reference, membership composition and reporting arrangements are outlined in this legislation. Its broad aims are to advise the State Minister for Disability on disability policy, to monitor government policy that affects the lives of people with disabilities, carers and families, to promote community awareness and to advise on disability service provision in the State. It has seventeen members; thirteen are people with a disability. There is one member with an intellectual disability; this council has always had members with

a range of disabilities including intellectual disability, sensory disabilities, physical disability and psychiatric disability. There are also service provider members.

This disability advisory council is a formal body that complies with the State Government requirements for advisory bodies. Members are appointed for set terms and must adhere to the roles and responsibilities as outlined in their terms of reference. It also provides advice on the affects of National Government policy at the State level. Members are paid sitting fees and out of pocket expenses for attending advisory council meetings.

Northern disability advisory council has a range of policy areas that it advises on and members are assigned to participate in these policy portfolio groups in addition to the broader work of the council. These portfolios link the NDAC to whole of government policies, opportunities to comment on specific disability or community policy and the network of State Government disability advisory councils. The NDAC secretariat staff coordinate these policy portfolios and bring together NDAC members to lead and participate in their work. The advisory council has a strategic plan that guides their work and sets out a framework to enable the council to participate in a set agenda as well as responding to emerging issues.

The NDAC secretariat staff of six provides policy related support to the council as outlined above. The secretariat has a Director, administration office and three

policy/research/project officers. There is also a designated support role called the logistical support specialist. Individual members' support needs are considered by council and provisions made for people to have access to the supports they need; this can include individual attendant care, sign language interpreters and for the member with an intellectual disability a support worker who works with the member at the meetings and provides support outside meetings to enable the member to prepare for meetings and participate in portfolio work. This council relies primarily on an individual model of support where they identify member's needs and resources are allocated to support their participation. The strong secretariat support also suggests a shared model of support, in particular in relation to supporting the members' understanding of the issues and development of responses to policy issues.

The council has formal operating procedures with meetings managed by the Chair. This position also has responsibility for liaising with the secretariat and with government officials including government ministers. Other members are often involved in these meetings and forums. The Chair creates the participatory environment at the meetings whilst also adhering to formal meeting procedures. In this way the Chair also provides participation support to the members using their knowledge of the person to provide opportunities for them to engage in the meeting and the broader work of the council.

Southern disability advisory body (SDAC) is a State Government disability

advisory council originally set up as an initiative of the Minister responsible for

disability services, following the lead from other States. Since its inception it has

developed a formal role in providing advice on whole of government policy as it

affects the lives of people with a disability. The terms of reference, membership

composition and reporting requirements are outlined in State disability legislation.

These new terms of reference outline that personal experience of disability is the

key selection criteria with positions also available to parents of children with a

disability. There are no service provider positions and members are appointed as

individuals, not representatives of disability services, advocacy organisations or

other organisations.

The agenda of this council is to support the implementation of and to monitor the

State Government disability policy. It also aims to act as a consultative forum on

disability issues and is required to respond to direct requests from government

for advice on disability or broader government policy that affects the lives of

people with a disability.

SDAC is a formal body that adheres to State Government requirements of

government advisory bodies. Members are appointed for set terms and are

remunerated for their work through sitting fees. Individual members can have

access to resources to support their participation; these have been used to

provide sign language interpreters, attendant carers, note takers and individual

support workers for members with an intellectual disability. Collegiate support is discouraged to ensure that members are seen as individuals with responsibilities for their own participation. The Chair is responsible for setting the agenda in consultation with the other members and is primarily responsible for enabling participation by all members at the meetings. There is recognition by the Chair that for some members participating in the council is about learning skills and getting paid to do a specific job, therefore acknowledging that whilst its primary role is high level policy advice it also has a role to build the capacity of individual members.

SDAC uses an individual model of support and pays some attention to procedural support; however the secretariat acknowledged that this is highly dependent on the Chair and that documents are rarely fully accessible or in Plain English. There is a small secretariat staff that is limited to administrative support and some policy related support. The advisory council is managed by this secretariat which is in a State Government department.

Central disability advisory body (CDAC) is a National advisory body[6]. It was established in 1996 to provide information and advice to the Federal disability minister. It has members with a range of disabilities, carers and representatives of non-government disability services and peak bodies.

CDAC enables people with a disability to have input into National disability policy and to provide comments on other government initiatives relating to disability. It works from the National disability policy and from a policy that outlines State and Federal disability policy responsibilities. CDAC receives advice on national disability policy issues from a network of State advisory councils, which are required to liase with the National council as stipulated in their terms of reference and legislation.

It is a formal government advisory body that is managed through a Federal Government department secretariat. Individuals are able to access individual support to participate in the council, they are also paid sitting fees and travel and accommodation costs. This council relies on an individual model of support which has included provision of note takers, attendant carers and individual support workers for people with an intellectual disability.

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[6] Note that in 2007 this advisory body was re-structured as an advisory body on Carers and Disability with two streams and two Deputy Chairs.

Appendix Four Consent Form

CONSENT FORM

I …………………………………………………………..(write your name here) have read the project information form , and any questions I have had have been answered. I agree to participate in the study, and know that I can withdraw at any time. I agree that the information I give can be used in a thesis the findings of which can be presented at conferences and published in journals on the condition that I am not mentioned by name.

Name of participant:

Signature: Date

Name of researcher :

Patsie Frawley

Signature: Date

Name of student supervisor:

Dr Christine Bigby

Professor Judith Brett

Appendix Five Information Form

Project Information

Title of Project

Making it real ,making it meaningful. The participatory experiences of people with

an intellectual disability on advisory councils in Australia.

Who to contact about this study

Researcher

Patsie Frawley, PhD Student LaTrobe University Bundoora

Ph (61 3) 52563120

Supervisors

Dr Chris Bigby, School of Social Work and Social Policy

Ph (61 3) 94791016

Dr Judith Brett, School of Social Sciences and Humanities

Ph(61 3) 94791287

What this study is about

This study aims to find out about the way people with an intellectual disability

participate in government disability advisory councils. This is important because

people with an intellectual disability are being asked to work on these councils for

government and organisations and there is not very much information available

about what it is like and how these groups support participation. Participation on

these councils is one way people with an intellectual disability can have a say in policy that effects their lives, so it is important that their experiences are listened to and used to improve the way people can participate.

You have been identified because you are on the New Zealand Disability Advisory Council and your name was on their website. You are invited to be a part of this study.

What will be happening?

You will be invited to talk to the researcher, Patsie Frawley about your experiences on the New Zealand Disability Advisory Council. Patsie will tape these talks and write notes about the things you tell her. You will be asked to do this 3 or 4 times, each interview will be between one and two hours. You can choose where the interviews take place. The researcher, Patsie Frawley will arrange this with you. The things you talk about will be reported in Patsie's Phd thesis and might be used in the future for other publications and conference presentations, but your name or anything else that could identify you will not be used. Patsie will also come to some of your meetings where she will be looking at how the groups work. The Chair of your council will get a letter to explain this and the whole council will get a chance to say whether they agree to have Patsie at the meetings.

How the information will be kept

During the research all of the information will be kept in a locked filing cabinet and on a computer that only Patsie can use. You can get copies of the notes and tapes that Patsie makes when she talks to you and before they are used Patsie will go over them with you. She will also show you where and how they are used in her thesis (her final report). At the end of the study the notes and tapes will be kept for five years.

What being a part of the study will mean for you

Participating in this study will give you a chance to think and talk about the experiences you have had on the …..Disability Advisory Council. Your ideas and information will be put together with other peoples to get a better idea about how people with an intellectual disability can participate on these groups and how the organisations that ask people to participate can make sure meaningful participation is happening. This could then be used to develop the way these groups work to include people with an intellectual disability. You can say how, when, where and how often you want to talk to Patsie and tell her how you want the information about you written so people won't know it is about you. Anytime during the study you can decide not to keep going. Patsie will find out what supports you need to have the talks and will help with these, for example paying for transport or interpreters. You should not be disadvantaged in any way by being involved in this study.

What to do if you have questions or complaints

You can contact Patsie, Chris or Judith on the phone numbers at the top of this page if you have any questions about this study. If you have any complaints or questions that these people cannot answer you can contact the Secretary of the FHEC, Natalie Humphries by phone on (61 3) 94793573 or

n.Humphries@latrobe.edu.au

If you agree to be involved fill out the following part of the form, sign it and return it to Patsie Frawley, P.O Box 785.Ocean Grove, Victoria Australia. 3226

Appendix Six Information Form (words and pictures)

What we will be doing.

Talking about you and the things you do.

[Martin] TELL ME ABOUT YOURSELF

Material on this page has been removed due to copyright.

Appendix Seven Advisory Body Information and Consent Form

LA TROBE
UNIVERSITY

Consent form for Advisory Councils

As Chair of the …………………………………………, I have discussed this research study at the full meeting of (date) ………………………………………… The Project Summary for Advisory Councils was read/distributed (please indicate by circling appropriate response) to all members present and a motion to agree to involvement in the study was passed. This motion is minuted in Council minutes of …………........................

Name of participant (your name and role on Council in block letters):

Signature: Date

Name of researcher (block letters):

Patsie Frawley

Signature: Date

Name of student supervisor (block letters):

Dr Christine Bigby
Dr Judith Brett

Appendix Eight Interview Framework

Background to Interviews (Booth & Booth, 1998)

"Life review' is a narrative method used where people are invited to reflect on and appraise their past experience from their standpoint in the here and now (Birren &Deutchman, 1991; Magee, 1988).

They recommend the se of an *aide memoire* to provide a framework for the interviews and as a checklist for marking off material covered and pinpointing topics for discussion and information to be collected in subsequent interviews These also outline some direct questions; however the rest of the interview is a free ranging conversation. The interviewer's prompting and questioning is driven by storyline determined by informant. Interviews are not intended to produce factually accurate or verifiable accounts of lives. People re-construct their past in light of their present sense of who they are: "Memories constitute one of the building blocks of identity and the meanings people give to their own past are intimately bound up with the image they choose to present to others" (p.17)

Interview schedule/framework

1. Introductions and clarification of the purpose of the study, assessing the person's strengths and limitations as informants (build up a picture of them)

2. Evaluative aspects of narrative – fill out the details, exploration of feelings, reflection on experiences

3. Member checking

Interview One

Restate purpose of study and scope – Further assess persons strengths and limitations as an informant (partially done in briefing meeting as a group)

Life review:

Building Picture of person. Tell me about yourself (general) – age, where you live, what you do with yourself, what you are interested in

Exploration of experiences Let's talk about you and what you have done throughout your life (person history); family, school, work, social life, advocacy. How do you see yourself and what you do? How would you describe yourself ? What's important to you and how do you go about doing those things that are important to you?

Filling out the details How did you start to get involved in councils and committees (representation history); when did it start? How did it start? Who was involved in getting you into it? What things have you done in the past and what do you do now?

Evaluative aspects – exploration of feelings about experiences. Why have you got involved in councils/committees? What do you get out of it? How do you feel about what you are doing? What have some of the highlights been for you in your life/work?

Member Checking 1

Before interview two present a summary of interview one to the participant. The summary will be developed from the detailed transcript of the interview

Interview Two

Life Review - Specifics about participatory experiences

<u>Exploration of experiences .</u> Tell me about the things you do with the

……council/committee.

<u>Evaluative – reflection on experiences.</u> Thinking about the work you are now

doing on the ……/Council/committee

Member Checking 2

Read through the narrative written from the combined interviews

Subsequent interviews

Filling in details if needed

Appendix Nine Secondary Respondent Interview Schedule

1. Restate purpose of the study and scope. Further assess person's strengths and limitations as an informant.

2. Review of the person in the place….

    a) Building the picture of the person. Tell me about yourself and your current role in the DAC. (background, how they came to this role, other relevant experiences, why they are doing this work/role)

    b) Tell me about your involvement with ….and what you know about them/how you see them. How would you describe…….

    c) Filling out the details Can you give an overview of what….has done as a member of the DAC, since you have both been involved. What kind of role have they played? How do you work with them? What supports do they get? What has the organisation given them to enable them to participate?

    d) Exploration of experiences. Can you talk about what this has been like for you/the group/the organisation. Describe how it all works. Can you discuss any examples of how it works, what …..has done as a member of the DAC

    e) Evaluative aspects. What does the group get out of …… involvement? Is …an effective member of the DAC? How do you and others feel about this persons involvement? What have some of the highlights been? What would you do differently? What are the most important things to supporting …..to participate?