“We just help them, be them really” Building positive, included identities: engagement in self advocacy groups by adults with an intellectual disability

Submitted by:
Sian Anderson
B.A. (Hons) Monash University
M.A. University of Melbourne

A thesis submitted in total fulfilment of the requirements for the degree of
Doctor of Philosophy

School of Social Work and Social Policy
Faculty of Health Sciences
La Trobe University
Bundoora, Victoria 3086
Australia

November 2013

Table of Contents

List of Tables and Figures

Abstract

Whilst the policy rhetoric of the Australian Government supports inclusion, the lived experience of many people with intellectual disabilities is very often one of exclusion. The attachment of stigma to the social identity of people with an intellectual disability remains at the heart of the reluctance of the mainstream community to engage with them as individuals or to include them as citizens.

The aim of this research was to examine the experience of engagement in self advocacy groups by adults with an intellectual disability and the impact of self advocacy on their social identities.

Claims are made in the literature about the characteristics of self advocacy and self advocacy groups. Providing opportunities for people to 'speak up', share stories of resilience, and engage with ideas about rights and empowerment are described as some of their key features. The literature also provides commentary on the organisation of groups, with independent or user-led groups being idealised. Whilst the problem of the labelling of people with intellectual disabilities is a part of the literature on self advocacy, there is a limited amount of research which examines the impact of engagement in self advocacy on their social identities. What is also lacking is research which looks at such engagement within different policy contexts.

This was a qualitative study, informed by symbolic interactionism and employed constructivist Grounded Theory methodology. It included participants from groups in the United Kingdom and Australia where approaches to policy and funding support have differed over time. Members of six independent self advocacy groups participated in this research. Two of the groups were in Australia and four in the United Kingdom. Semi-structured interviews were conducted with twenty five individual group members and ten of their support workers.

Analysis of the data led to the development of a Grounded Theory model of the impacts of engagement in self advocacy groups on the social identity of members. The model identifies the key features of the group which produce positive impacts for individuals. The key features of the groups were that they were characterised by collegiality, and that they gave members a strong sense of ownership and control. Through the many and varied activities they offered to members, the self advocacy groups contributed significantly to the members' feeling that they were both more confident and engaged with life. Emerging from these important changes in the lives of the self advocates was the possibility of individuals embracing new, multiple social identities. These were; a self advocate, an expert, a business-like person and an independent person.

Conclusions from the study were that engagement in self advocacy produced positive impacts on the social identity of group members. The groups in the study were 'independent' groups however within those groups, supporters played a crucial role in organising and managing the agenda and activities. The United Kingdom's history of policy support for self advocacy and associated (albeit) limited funding for

groups had clearly impacted positively on both the strength and numbers of groups and this is something which could be replicated in Australia.

Statement of Authorship

I, Sian Anderson, certify that the work contained in this thesis is my own.

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 submitted for the award of any other degree or diploma. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

Professor Christine Bigby (La Trobe University) and Associate Professor Paul Ramcharan (RMIT University) provided supervision for the candidate while completing the thesis.

The study received approval from the La Trobe University Human Ethics Committee No. 11-037.

Signature of candidate:

Date: 27-11-2013

Acknowledgements

There are a number of people who have made an important contribution to this doctoral research and I would like to thank them.

Six self advocacy groups in Australia and the United Kingdom opened their doors to me, enabling me to interview their members and supporters. I was overwhelmed by the warmth of the welcome I received in each and every one, and the generous way in which people offered their time to participate in the research.

Thank you also to Scott Watkin (Mencap and Seeability), Professor Jan Walmsley (Jan Walmsley Associates), Andrew Holman (Inspired Services Publishing), Lauren O’Carroll (Speak Out Council) and Dr Marcus Redley (Cambridge University) for sharing your insights about self advocacy and the intellectual disability policy landscape.

My principal supervisor Professor Christine Bigby, from La Trobe University has been supportive, encouraging and unfailingly enthusiastic throughout the course of my research. Her clear-sightedness, energy, and commitment to the rights and well being of people with an intellectual disability have been at the heart of her supervision, many thanks Chris.

Associate Professor Paul Ramcharan from RMIT University was my co-supervisor in the early stages of this project, providing helpful insights into the history and nature of self advocacy in the United Kingdom.

I would also like to thank Dr Patsie Frawley, and fellow students Gillian Steel, Diane Craig and Michelle Browning for their supportive friendship.

My husband Phil, and sons Matthew and Oliver, your support and enthusiasm for this project have been highly significant in making its completion possible, thank you. Thanks also to my parents who have always been so encouraging and interested.

I gratefully acknowledge the support of the Australian Research Council who provided a scholarship enabling me to undertake my doctoral studies, and the International Association for the Scientific Study of Intellectual Disabilities (IASSID) who awarded me a SINGA Scholarship which supported my attendance as a presenter at the Australasian Society for Intellectual Disability (ASID) 'Research to Practice' Conference in Wellington, New Zealand in November 2012.

Finally, to Denise and Peter – this one's for you.

Chapter 1. Introduction

Whilst the policy rhetoric of the Australian Government supports inclusion, the lived experience of many people with intellectual disabilities is very often one of exclusion. The attachment of stigma to the social identity of people with an intellectual disability remains at the heart of the reluctance of the mainstream community to engage with them as individuals or to include them as citizens. Attempts to address this problem through policy and practice have been broad in range, and outcomes limited, or mixed.

The principles of normalization and its more prescriptive sequent, social role valorization (Wolfensberger et al, 1972) became a prominent ideology in disability services in the 1970's and beyond, placing the onus on people with intellectual disabilities to alter their behaviours, to be 'normal' in order to fit in to the mainstream. Whilst it could be argued that this represented important progress in the recognition of people with intellectual disabilities as individuals, its inherent lack of acknowledgement of the major structural and attitudinal barriers to inclusion did not effectively address the damage attached to their social identities. The movement to close large institutions for people with intellectual disabilities and new ways of thinking about the delivery of disability support emerged around the same time. A recognition that social segregation could not produce a 'good' or 'normal' life (Johnson et al, 2010) combined with shocking revelations about institutional abuse and neglect in many countries, including Australia (Stancliffe, 2006) led to the dismantling of many of the larger scale long-stay institutions and their replacement with smaller ones, such as group homes. Moving into the community has undoubtedly been a positive step towards a better life for many people (Beadle-Brown, Mansell & Kozma, 2007) however, failures to offer adequate support for community engagement and positive relationships have left many socially isolated and excluded. Physical ‘presence’ has not led to social inclusion (Bigby, 2006; MacIntyre, 2008) in the ways in which the advocates of deinstitutionalisation might have wished. Similarly, social integrationist approaches which have focussed on building inclusion through employment have been limited in their success, hampered by a lack of support and creative approaches to promoting disability employment in a range of large and small enterprises (Abberley, 2002). Having the ‘capacity’ to undertake paid work implies equality and recognition as a citizen in such approaches to thinking about inclusion (Johnson et al, 2010). For those unable to participate, for a range of reasons, their social exclusion seems to be sealed. Programmes designed to develop and support relationships between people with intellectual disabilities and between people with intellectual disabilities and others in the community seem to offer great potential in enhancing their social inclusion however these too are often challenged by the imposition of negative categorical identity. Without significant work to change the ways in which people with intellectual disabilities are seen by others as being somehow less ‘socially desirable’ (Gibbons, 1995), such approaches will be of limited success.

Research around the concept of the creation of ‘self authored’ spaces for people with intellectual disabilities offers a new way of thinking about the possibility of addressing their damaged social identities and enhancing their social inclusion.

Milner and Kelly (2009) suggest that within such spaces, people with intellectual disabilities can find community, celebrate their individuality and work together to produce social change. Whilst the self authored space is a segregated space, it seems to mimic those social spaces which exist in the mainstream community; the football club, the community choir, the self-help group, and as such offers great potential for peer relationships, the development of individual and common interests and mutual support. For people with intellectual disabilities, the key self authored space is the self advocacy group. This research examines the impact of engagement in self advocacy groups on the social identities of adults with intellectual disabilities and seeks to understand the ways in which the self authored nature of the groups produces positive change to those identities.

This study focuses on the experiences of individual self advocacy group members in the context of disability policy in both Australia and the United Kingdom which emphasises inclusion and participation. Self advocacy is described in the literature as being about speaking out, having a say and developing particular skills in empowerment (Atkinson, 2002; Barnes & Mercer, 2006; Chappell et al, 2002; Goodley, 2000, 2003, 2005; Goodley et al, 2003; McNally, 2002; Seale & Nind, 2010). Self advocacy groups run by and for adults with intellectual disabilities provide opportunities for individual members to engage with ideas about rights and empowerment and to share and celebrate their personal resilience. Feelings of being ‘powerful and strong’ (Beresford & Carr, 2012) resonate in the narratives of self advocacy offered throughout the literature. Self advocacy groups in the United Kingdom have for several decades enjoyed policy and funding support which has enabled many groups to flourish. The growth of groups in Australia has been much slower and they have struggled for funds in a policy climate which has tended to favour advocacy over self advocacy. There is a lack of research about whether the individual experiences of self advocates are different within different policy contexts or whether the positive outcomes described in much of the literature on self advocacy are dependent on a particular model of funding and policy support.

There is a great deal of commentary in the literature about the different models which provide the organisational framework and set the agenda in self advocacy groups. Claims are made by authors such as Aspis (1997, 2002a, 2002b) and Goodley (2000) about what constitutes an ideal self advocacy group. This 'ideal' is described as being a group which is run and controlled by the self advocates themselves. A distinction is drawn between these 'user led' or independent groups, and 'agency led' groups (Barnes & Mercer, 2003) which are under the auspices of service providers or parent advocacy organisations. Agency-led groups are much derided in the commentary of Aspis, 1997, 2002a, 2002b; Barnes & Mercer, 2003; and Croft & Beresford, 1989. The independent groups, argue Goodley (2000) and Barnes and Mercer (2003), offer individuals opportunities to pursue an agenda which is about autonomy and control, whilst agency groups are more concerned with what they describe as a 'tokenistic' approach which centres on consulting consumer views about services.

Claims are also made in the literature about the potential of engagement in self advocacy to positively change the social identities of people with intellectual disabilities. A study by Beart, Hardy and Buchan (2004) of eight members of a self advocacy group found that their self concept was altered as a result of their participation and was closely tied to individuals' experience of what the authors describe as the 'positive social environment' of the group. This small but important study offered a glimpse of the impact of a self authored environment on social identity. Similarly, Caldwell's (2010) study of thirteen leaders in self advocacy organisations revealed that participation had been personally transformative, with one commenting that they now had 'new way to think about myself'. There are signs throughout these and other accounts of the experiences of self advocates which illustrate the potential of groups to remake identities and to counter some of the negativity and labelling which has entrenched the stigma attached to people with intellectual disabilities and their ongoing social exclusion.

Context of the Study

This PhD project was part of a larger Australian Research Council Linkage Project titled "Self advocacy and inclusion: what can be learned from speaking up?" This was a collaborative research project undertaken with self advocates from the 'Reinforce' self advocacy group in Melbourne. The aim of the study was to examine the significance of self advocacy in building the individual, social and political inclusion of people with an intellectual disability. The chief investigators and their co-researchers have examined the history of self advocacy in Australia and the personal and political experiences of self advocates. This PhD study was one component which examined the impact of self advocacy on the social identity of people with intellectual disabilities.

Research Questions

The aim of the research was to examine the experience of engagement in self advocacy groups by adults with an intellectual disability and the impact of self advocacy on their social identities. The key concepts embedded in the research questions are around claims that ‘independent’ self advocacy groups produce better outcomes for members than service-based groups, that being part of a group leads to change in social identity, and that the different policy contexts of the United Kingdom and Australia may have led to different outcomes for members. The implications of the findings for the way in which self advocacy in Australia is supported and funded in the future was an important aspect of the study. The research questions were;

What are the experiences of self advocates in independent self advocacy groups in Australia and the United Kingdom?

How have these experiences impacted on the social identity of the participants?

How do the experiences of self advocates differ in the different policy contexts of Australia and the United Kingdom?

What are the implications of these understandings for the future funding and policy support of independent self advocacy in Australia?

The unit of analysis for the study was the self advocacy group, with the aim to examine the experiences of individual members and to gather additional insights from their supporters in order to develop an understanding of the ways in which self advocacy groups work to produce positive outcomes for members. The primary source of data for the study was from interviews with participants, supplemented by written material produced by groups, including annual reports, training worksheets and member rule books. Additional interviews were also undertaken with a small number of commentators with significant experience in the fields of intellectual disability policy and the support of self advocacy groups.

Thesis Structure

A critical review of the literature is presented in Chapter 2. It provides critiques of the literature around the problem of the damaged social identities of people with intellectual disabilities and its negative impact on their social inclusion. Also examined are attempts at policy and practice levels to address the problem and consequences of damaged identities. Research and commentary about self advocacy in the literature are also examined. Claims made about the potential of self advocacy to change the lives of individuals and arguments made in favour of particular group models of self advocacy are critiqued. Gaps are found in the literature about the ways in which self advocacy groups work to change the social identities of their members and claims that independent groups are superior to those in services, are not supported by substantial evidence. The need was identified for further research which examines individual experiences of self advocacy within groups and seeks to understand the mechanisms which produce change in people's social identity.

Chapter 3 describes the methodological approach taken in this study. It was a qualitative study, informed by symbolic interactionism (Blumer, 1969) and employed constructivist Grounded Theory methodology (Charmaz, 2000; Morse et al, 2006, 2009). Members of six independent self advocacy groups participated in this research. Two of the groups were in Australia and four in the United Kingdom. Semi-structured interviews were conducted with twenty five individual group members and ten of their support workers. The interviews were recorded with the consent of the participants, transcribed and analysed using NVIVO 9 software.

Chapter 4 provides descriptions of the six self advocacy groups in the study and detailed profiles of two of the self advocate interviewees. These provide important insights into the location, organisation and character of the groups whilst the two vignettes provide examples of the personal stories and impacts of group engagement for two different individuals.

Chapter 5 presents the findings emerging from the data analysis and describes a Grounded Theory model of the impacts of engagement in self advocacy groups on the social identity of members. The model identifies the key features of the group which produce positive impacts for individuals. The key features of the groups were that they were characterised by collegiality and that they gave members a strong sense of ownership and control. Through the many and varied activities they offered to members, the self advocacy groups contributed significantly to the members' feeling that they were both more confident and engaged with life. Emerging from these important changes in the lives of the self advocates was the possibility of individuals embracing new, multiple social identities. These were; a self advocate, an expert, a business-like person and an independent person.

Chapter 6 is a discussion of some of the key themes emerging from the data and focuses on the implications of the findings for the way in which self advocacy groups are organised and controlled and the often complex power relationships between the supporters and members. This chapter examines the impacts of the ways in which groups work to change the social identities of members and assesses them in the light of commentary around the question of a collective identity and the political nature of self advocacy.

Chapter 7 offers some conclusions about the implications of the findings of this study for the future funding and policy support of self advocacy in Australia. Whilst there are a few self advocacy groups in Australia with a long history, it is true to say that there is considerable room for growth in developing more opportunities for people with intellectual disabilities to become engaged in self advocacy. This study sought to compare individual experiences in two different policy contexts and found that those experiences were almost identical with two exceptions. Firstly that the scale and scope of the activities offered by the United Kingdom groups was far larger, and secondly that the United Kingdom groups offered formal opportunities to undertake paid and voluntary work, thus more strongly developing the potential for a business-like identity for group members than for members of the Australian groups. The United Kingdom's history of policy support for self advocacy and associated (albeit) limited funding for groups had clearly impacted positively on both the strength and numbers of groups and this is something which could be replicated in Australia. At the time of writing it seems likely that the limited funds available for self advocacy in the United Kingdom will continue to contract. It is evident that highly positive outcomes can still emerge in a policy climate which is less supportive of independent self advocacy, but that in order to make that opportunity for participation available to more people, support is essential.

Whilst some of the literature on self advocacy, notably Goodley (2000) and Aspis (1997 & 2002a, 2002b) has been critical of the ways in which self advocacy groups have become 'professional', the findings from this study showed that this feature of their organisations contributed strongly to both the enjoyment of members and the security and longevity of groups. The high level of supporter control of group agendas and the ways in which they work with funding bodies does indeed change and challenge the notion of group 'independence'. Further research is needed to investigate whether the positive outcomes produced by the groups in this study are also produced in other models of self advocacy.

A striking feature of the findings of this research was the way in which engagement in self advocacy groups brought about individual change and more positive included identities. The groups lacked a focus on developing a collective disability identity, instead working to build the individual skills and confidence of members. Most of the interviewees did not embrace the label of ‘a person with an intellectual disability’ nor did they wish to wear the badge of the disability activist (Shakespeare, 2006). Self advocacy groups were important places because of the way they made people feel about themselves, and an argument can be made that their positive experiences should be available to all adults with intellectual disabilities.

Chapter 2. A Review of the Literature

Introduction

People with intellectual disabilities remain excluded from mainstream community life, with ‘crude stereotypes’ and the negative perceptions of others about their social identity entrenching their marginalisation (Bogdan & Taylor, 1994; Safilios-Rothschild, 1981). This literature review focuses on issues of damaged or stigmatised identity and its role in the ongoing social exclusion of people with intellectual disabilities. It examines whether attempts to overcome the social exclusion of people with intellectual disabilities have addressed this problem. These include; deinstitutionalisation, building social relationships, strategies which focus on economic participation, access to information and the digital world, and self authored social spaces. Self advocacy groups are amongst the key self authored spaces created by people with intellectual disabilities. They are created by and for people with intellectual disabilities and their potential to have a positive impact on their social identities and challenge their exclusion is examined.

Damaged Social Identities

Having a damaged or stigmatised social identity marginalises individuals and leads to their social exclusion. For those individuals, stigma is manifested in the ways in which they, as negatively labelled people encounter those who promote the label (Dudley, 1997). There is the perception of an ‘undesired difference’ between members of the community and those to whom stigma is attached, which entrenches their social exclusion. This limits community engagement to a point where people are restricted in what Dudley (1997) describes as their ‘mobility’, and are constrained in their social and physical presence. A study by Jahoda and Markova (2004) offers evidence of individuals coping with ‘stigmatizing views’ which limited their social inclusion. The researchers interviewed eighteen individuals with intellectual disabilities who had moved from an institutional environment into community houses and ten moving from the family home into community accommodation, and found that they were highly aware of the negative views of others about their social identity (Jahoda & Markova, 2004). Their sensitivity to the negative impact of their stigmatised identity and determination to reject this imposed view is reflected in other studies, for example; Crocker and Quinn (2000) and Harris (1989), and is a call to service providers to try to understand the views of individuals about the nature of the social experience of disability. Dagnan and Waring’s (2004) study of thirty nine adults with intellectual disabilities found that the interviewees felt that they were ‘different’ from others and that this difference was not positive. This awareness or internalisation of social stigma had a negative impact on their interactions in the social world; the broader community. Focussing on the ‘undesirability’ of the difference between people with damaged identities and others in society both highlights the relationship between negative identity and social exclusion and the extreme nature of the challenge faced by those who have been ‘categorised’ (Tideman, 2005b). Their integrity as human beings is under constant threat (Lemert, 1967).

Social identity theorist Henri Tajfel (1978) defines social identity as “...that *part* of an individual’s self-concept which derives from his knowledge of his membership of a social group...together with the value and emotional significance attached to that membership." (Tajfel, 1978, p.63). Social identity is a 'part' of an individual's self-concept and it is an important one. For individuals with damaged social identities, their membership of a devalued group in society negatively impacts on their sense of self worth and their opportunities for engagement in the broader community (Chase, 1992; Safilios-Rothschild, 1981). The inferior status so pervasively ascribed to people with disabilities has significantly, negatively impacted their self-esteem and confidence to such a degree argues Safilios-Rothschild (1981), that there is an 'internalization' of stigma. This kind of entrenching of damaged identities makes it extremely difficult for individuals to work to change their identities.

Within emancipatory disability frameworks there is an emphasis on highlighting the ways in which the identities of (socially) disabled people are 'fixed' and 'enforced' (Watson, 2002). This is in stark contrast to the depiction of the identities of non-disabled people as individuals 'constantly engaged in negotiating identity' (Ferguson, 2009; Riddell & Watson, 2003). The construct of 'negotiation of identity' presumes levels of freedom, power and agency which simply do not exist in the lives of individuals constrained by experiences of stigma and social exclusion. The notion of negative identities adhering to groups and individuals resonates throughout the literature, highlighting the importance of understanding its impact and strategies to challenge it.

Some commentary, for example Lawler (2008), characterises the question of identity as being about 'identification'. This is problematic and implies a level of agency and self determination which allows people with disabilities to reflect upon and to choose whether to accept and to identify with a form of negative identity or to reject it (Lawler, 2008). Lawler (2008) describes this as the ‘relational’ nature of identity which centres on the notion that to be one thing requires the rejection of another. Mest’s (1988) qualitative study of a small group of people with intellectual disability found that the interviewees had reflected on their damaged identities and refused to use the labels applied to them by others. This is a positive statement towards reclaiming a more positive social identity but represents only a small part of the struggle to alter the stigmatising perceptions of the broader community and their focus on entrenched perspectives of incapacity and dependence. Society has defined, treated and excluded people with disabilities as a group, attributing negative characteristics to their identity and created ‘difficulties’ in their opportunities for participation and inclusion (Bogdan & Taylor, 1994, Finlay & Lyons, 1998; Simons, 1992).

The Socialization of Disability Identities

Robert Scott’s compelling (1969) study of blindness in America ‘The making of blind men: A study of adult socialization’ powerfully demonstrates the ways in which ‘self-concept’ or ‘personal identity’ form the basis of the lived experience of a person with visual impairment. His arguments about the ways in which ‘blind men are made’ are readily transferable to the observable, learned social roles enacted by many people with other forms of ‘difference’ including intellectual disability. Scott (1969) states: “...there is nothing inherent in the condition of blindness that requires a person to be docile, dependent, melancholy or helpless...” (Scott, 1969, p.14) yet this is too often a societal expectation and thus becomes an ingrained aspect of the self-concept of people who are blind (Scott 1969). Scott (1969) observes that the impact of the ‘socialization’ that has created and reinforced blind people’s often negative self-concept has powerfully impacted on the provision of services. The ‘socialization of the blind’ and the promotion of practices which do not enhance self-determination encourage blind people to remain within the agency or support system and not pursue a life in the broader community (Scott, 1969). Some of Scott’s (1969) criticisms of what he regards as the paternalist ‘rehabilitation’ practices of many agencies raise important questions about the ways in which the ‘self concept’ of people with disability develops and can be enhanced by their engagement in the community. His commentary is also revealing about the sustained impact of negative group identity and the ways in which that impacts on all individuals associated with those groups who are forced to manage damaged social identities.

Impacts of a Damaged Identity for People with Intellectual Disabilities

There is a ‘fear of difference’ which is attached to the social identity of people with intellectual disabilities and it is therefore extremely difficult for many of them to engage with the broader community, to overcome prejudice and stigma, and lead full lives of their own design (Goffman, 1961; Hubert, 2000). Having an intellectual disability remains a ‘powerful’ and ‘stigmatised’ social identity (Beart et al, 2005; Zetlin & Turner, 1988). That perception is still, according to Goodley, firmly rooted in a ‘personal tragedy model’ of disability (Goodley 2001) and a belief that people with disabilities are in some way ‘less than human’ (Shakespeare, 1996).

Reviewing studies about self-concept and disability, Harris (1995) argues that people with intellectual disabilities have been consistently categorised by others and by themselves as being part of a ‘devalued’ social group. This has been based on the rigid imposition of medical models of assessment of capacity, specifically Intelligence Quotient (I.Q) measurement instruments. This is an important element in understanding the damaged social identities of people with intellectual disabilities. The unalterable nature of their low I.Q leads others to make a range of assumptions on this ‘fact’ and to categorise them negatively. What Harris (1995) describes as the ‘boundaries’ between disabled and non-disabled people then become fixed. The learning disability label is one which Harris (1995) and Beart (2005) describe as ‘hard to leave’. Beart et al’s (2004) interviews with adults with intellectual disabilities found that they had a deep understanding of the ‘lived experience’ of the label of learning disability in spite of their refusal to embrace this categorisation. That lived experience is very often a negative one and the refusal of individuals such as those in Beart et al’s (2004) study is evidence of this. Further evidence is found in Davies and Jenkins (1997) study of sixty young adults with intellectual disability and in Rapley’s (2004) study which showed individuals describing a high level of awareness of their damaged social identities and the labels attached to them by others. Beart et al (2005) have reviewed research about ‘categorisation’ and labelling of adults finding that there is very often ‘cognitive and emotional’ awareness of their social identity. Whilst the research suggested consistently that people lacked the kind of diagnostic descriptors or understanding of the label ‘learning disability’, they did show a sensitivity to its negative implications and a strong sense that the label was not ‘salient’ to themselves (Beart et al, 2005).

Davies and Jenkins (1997) also ask in their research whether ‘labelled people’ are aware of the ‘public meaning’ or meanings attributed to their label and whether or not they then apply such labels to themselves (Davies & Jenkins, 1997). The researchers asked interviewees to define terms such as ‘learning disability’ and found that whilst the majority struggled to do so, they clearly expressed a desire not to be associated with it. They describe this as ‘categorical identity’ and seek to explore whether and how this might contribute to the formation of ‘self-identity’ (Davies & Jenkins, 1997), further finding in their interviews that ‘categorical identity’ had had a ‘profound’ (negative) impact on their ‘self-identity which had significantly shaped their social relationships’ (Davies & Jenkins, 1997).

The identity development of people with intellectual disability can be ‘complicated’ by what Heller and Harris (2012) describe as an ‘effort to achieve normality’ imposed by others’ rigid medical model assumptions about them. ‘Complicated’ would appear to be an understatement of the problem faced by people who cannot achieve an imposed normalcy. Davies (1997) describes some of the practices of normalization, for example; demanding age-appropriate behaviour, or overly formal attire, as an attack on the personhood of people with intellectual disabilities. Whilst it is wrong to assign negative, categorised identities to individuals, it is also wrong to seek to impose alternatives which continue to perpetuate the notion that all people with disabilities are the same. What is ‘normal’ for the rest of the community is the embracement of a range of social identities; for individuals to have many different identities and for those individuals to exercise some level of self determination about the ways in which these are expressed. For people with intellectual disabilities, their apparent failure to be ‘normal’ is in fact a failure of the remainder of the community to observe the injustice of their damaged identities and the imposed restrictions on their attempts to deal with the stigma attached to them.

Ways of Dealing with Damaged Identity

Tajfel (1978, 1981) asks what choices are open to individuals who find that they are members of marginalised groups and cannot leave those groups, as is the case for people with intellectual disability (Szivos & Griffiths, 1990; Tajfel, 1978, 1981; Turner et al, 1987). As has been suggested by Edgerton (1993) and others, ‘passing’ within the mainstream is one option for members of devalued groups or those who feel that their own social identity is of a lesser value because of their group membership. Edgerton (1993) used participant observation methods to study forty eight individuals with mild intellectual disabilities who had moved into the community from a large institution. His research was begun in 1959, predating policies around normalization and deinstitutionalisation, and focussed on ways in which the participants managed their stigmatised or damaged social identities. Edgerton found that the ‘social adaptation’ of many in his study was greater than their diagnosis may have predicted and that this was a result of their ability to assume a ‘cloak of competence’ enabling them to ‘pass’ in social interactions as a person without an intellectual disability (Edgerton, 1993). The choice to seek to ‘pass’ in the mainstream community is not an option available to all people with an intellectual disability. The nature of the service system requires that individuals must subject themselves to diagnosis and categorisation in order to be eligible to receive assistance with the tasks of daily living. ‘Passing’ may mean that a person may be able to access some of the benefits of community living but lack adequate support and access to social networks of other people with disabilities. Edgerton's (1988) later interviews with his research participants revealed some of the negative features of 'passing' in later life. He found that many were experiencing poor health and had had difficulty accessing mainstream services or basic information about self care and diet. Seeking to 'pass' in the community had produced exclusion from both the mainstream and from disability services and disadvantage which threatened physical and mental health (Edgerton, 1988). Choosing not to identify with a categorical identity may be an option for a person with a damaged social identity but it presents challenges for the individual which may be difficult to overcome.

Rapley's (2004) case studies illustrate the ways in which participants 'carefully' managed their identity as 'disabled' and were aware of what he calls the potential 'toxicity' of that label. Rapley picks up Edgerton's 'cloak' (1993) theme, saying that identities are not necessarily fixed but are 'contestable' and 'situationally constructed' (Rapley, 2004). Thus, the people with intellectual disabilities to whom he spoke demonstrated clear understandings of the 'interactional and social realities' of their lives and were adept at 'passing' in a range of situations (Rapley, 2004). These individuals were limited in their opportunities to test the limits of the 'contestable' nature of their identities, opting to manage or to conceal rather than risk further exclusion.

In Watson's (2002) research with people with physical disabilities, many of the informants chose not to 'identify' as a disabled person and that this is ‘understandable’ given the social status accorded people with disabilities in the dominant social order. For some disability activists, the choice ‘not to identify’ is seen as a rejection of the social model, an ‘internalised oppression’, the fact that many adopt this strategy in their daily lives challenges the notion of common identity (Shakespeare & Watson, 2002). If common identity is not positive, it seems unreasonable to accuse people with disabilities of ‘internalising oppression’. They are dealing with stigma as best they can. How they choose to identify themselves may not be fixed and may alter throughout their lives. Giddens (1991) writing about self-identity in the context of modernity refers to a ‘reflexive project’ “...which consists in the sustaining of coherent, yet continuously revised, biographical narratives...” (Giddens, 1991, p.5). This is an optimistic perspective on the management of ‘spoiled identity’ (Goffman, 1963) and assumes that a ‘reflexive’ project will be available to all. The context of modernity and contemporary society produces the negative features of ‘difference, exclusion and marginalisation’ (Giddens, 1991) which act to constrain both the range and the nature of the identities of people with intellectual disabilities. It is these features which make dealing with the effects of a damaged social identity so challenging.

There is no obvious way for people with intellectual disabilities to challenge their stigmatised their identities and continuing social exclusion. Whilst it seems obvious that no one would want to embrace a damaged social identity, what is less clear is how people with intellectual disabilities can develop or find new ways of building on this rejection of imposed labelling and move towards more positive identities and find more comfortable places to ‘belong’ (Bauman, 1996). ‘Marginalisation’ is too often a fundamental part of the ‘lived experience’ of people with an intellectual disability (Bunning & Horton, 2007) and this must be acknowledged in attempts to overcome social exclusion; “Living with a disabling condition, whether physical, communicative, or intellectual, whether developmental or acquired in type, means that the usual determinants of social inclusion often appear elusive” (Bunning & Horton, 2007, p.9).

Social Inclusion

Many of the attempts to address the problem of the ongoing marginalisation of people with intellectual disabilities have focussed on social inclusion. Social inclusion has been defined in a number of ways in the literature in relation to people with intellectual disabilities. Emerging from some of the thinking around normalization in the 1970’s which focussed on changing the behaviours of individuals so that they would be accepted in ‘normal’ settings and relationships (Brown & Smith, 1992; Wolfensberger, 1975) were ideas and policy about integration (Johnson et al, 2010). This approach acknowledged the stigma attached to the social identity of people with intellectual disability, but placed the onus on them to alter themselves to ‘fit in’, rather than recognising the source of the stigma and seeking to change it. This framework for inclusion acknowledges the harm of segregation, but errs in its failure to understand that people with intellectual disabilities are individuals with different identities and that forcing them to be ‘normal’ risks replacing one kind of institution with another.

Later ideas about social inclusion were strongly influenced by the social model of disability; a discourse which departs from medical, impairment focussed perspectives and instead challenges the social and cultural factors which disable people (Barnes et al, 1999; Barnes & Mercer, 2003; Linton, 1998; Oliver & Barnes, 1998; Rioux & Bach, 1994). The social model moves the focus on the ‘limits on activity’ from the individual, to the ‘outside’ (Thomas, 2007). This approach is markedly different from ‘normalizing’ individuals, and has a focus on changing the disabling practices of the community, challenging and highlighting the ways in which they perpetuate the social exclusion of people with intellectual disabilities.

Other recent approaches to ideas about inclusion focus on individuals living a ‘good life’ (Johnson et al, 2010; Reinders, 2002). A ‘good life’ is difficult to define, but must include the recognition of the rights of people with intellectual disabilities as citizens and opportunities for them to develop relationships of significance. Focussing on the importance of building social relationships, Reinders (2002) argues that a failure to pursue a broader inclusion agenda without the aim of developing positive relationships, will guarantee the continuing social exclusion of individuals. Reinders (2002) shares with Tideman (2005a) the view that the physical integration of individuals has not led to their social inclusion and as such risks their integrity and ability to ‘flourish’ as human beings. The opportunity to develop relationships of significance implies that a framework of individual rights and an acknowledgement of citizenship exists for all in the community. For people with intellectual disabilities, many of whom have only had experience of relationships within or defined by the service system, such ideas about inclusion are a new way of developing and accessing a ‘good life’.

The concept of ‘inclusion’ is, as Seale and Nind (2010) point out, much more ‘ambitious’ than that of ‘integration’ which has formed the basis of policy and service provision in recent decades. They write that the ‘integration’ approach was about ‘allowing in’; – although this was always conditional on ‘fitting in’ and conforming to expectations about socially acceptable, appropriate behaviours (Seale & Nind, 2010, p.10). Inclusion “...carries connotations of rightful and active participation...” (Seale & Nind, 2010, p.10) and also carries with it the idea that in order to achieve access and participation there need to be opportunities for people with intellectual disabilities to make choices, to be able to voice those choices, ‘take control’, ‘take risks’ and ‘take responsibility (Aspis, 1997; Chapman et al, 2012; Seale & Nind, 2010).

Incorporating and validating the perceptions of people with intellectual disabilities in redefining ‘social inclusion’ is necessary argue Abbott & McConkey (2006). This is an acknowledgement that people with intellectual disabilities want to be included in the community ‘on their own terms’ (Ippoliti, Peppey & DePoy, 1994. Efforts to better define and understand ‘inclusion’ have ‘evolved’ from those linked to ‘place’, to where people reside, to those which focus on participation, choice and relationships (Bradley, Agosta & Kimmich, 2001).

Johnson et al (2010) argue that inclusion is a ‘one-way’ journey with people with intellectual disabilities the travellers; they travel into the communities of ‘ordinary life’. There is little opportunity for them to alter the society which excludes them and therefore they are responsible for making sometimes personally risky attempts to be included. In 2005, a British study of three thousand people with intellectual disabilities asked participants to describe their lives. The results revealed that many people were not ‘respected and included’ members of their communities (BMRB et al, 2005) and felt that they lacked ‘control’ over key aspects of their lives including accommodation and employment. The communities of ‘ordinary life’ described by Johnson et al (2010) remain elusive.

Planning for social inclusion.

Strategies to overcome the social exclusion of people with intellectual disabilities require high level policy and planning to support their implementation. Fincher and Iveson (2008) argue that in order to overcome social exclusion there needs to be planning at a public policy level for ‘redistribution’, ‘recognition’ and ‘encounter’, creating ‘social mix’ and safe spaces. The authors suggest that individuals should all be regarded as ‘strangers’ with a range of ‘attachments’ and ‘group-based identities’ which can adapt to a range of social contexts. This focus on diversity, bringing individuals together, and creating frameworks for participation is also discussed by Bates and Davis (2004) and by Putman (2000) who highlight the importance of reciprocity in social inclusion. Increasing opportunities for participation is of course not a guarantee of either greater or more ‘meaningful’ social interaction (Abbott & McConkey, 2006), but may serve to alleviate some of the ‘socially engineered’ exclusion deeply embedded in the isolation of many people with intellectual disabilities (Ramcharan et al, 1997). Writing about social ostracism and isolation, Williams and Carter-Sowell (2009) state that humans ‘rely’ on their interactions with other humans to meet a basic need for ‘belonging’ and ‘recognition’. Approaches which argue for the creation of encounters with the potential to promote the social inclusion of people with intellectual disabilities are important but are limited in their scope because they risk imposing professional ideals of normalcy and an ideal included life on individuals who will have a wide variety of perspectives on what for them, constitutes an included and satisfying life (Renzaglia et al, 2003). Engineered ‘social opportunities’ with measurable indicators, for example; intensity, duration and frequency, are a feature of the lives of many service supported people with an intellectual disability as illustrated in Clement and Bigby (2010). It would be naive and unrealistic to suggest that these can be dispensed with, even in a policy context which promotes self-determination. It is however important that such schemes do not prevent or limit people from making genuine choices, forming and maintaining relationships, engaging as citizens in the community and challenging negative perceptions about their social identity.

Carey’s (2009) argument that inclusion is ‘truly possible’ is immediately qualified with a goal that seems unrealisable in almost all contexts – that it becomes possible ‘only’ if there is a building of capacities within those community contexts “...to ensure that all people feel that they belong and are valued as members” (Carey, 2009, p.228). She argues that there is a strong need for “...an interpersonal and community infrastructure that supports the practices of rights and citizenship...”

(Carey, 2009, p.228). This infrastructure should not be about supporting ‘special rights’ for individuals or groups but offering opportunities for all to exercise their rights and acknowledge the ‘inherently relational nature’ of the exercising of such rights and supporting people in the context of their own life choices. People with disabilities are, as McKnight (2009) asserts, excluded from the ‘power and protection’ gained from inclusion in the life of the community. This highlights the great importance of enabling individuals to seek to meet their own social needs and to define and to value both their encounters and relationships in their own terms.

Deinstitutionalisation and social isolation.

Deinstitutionalisation has long been regarded as an important way in which ‘service dependent people’ could have ‘restored’ to them the right to live in a safe, valued living environment (Bigby, 2005; Cattermole et al, 1990; Forrester-Jones et al, 2002; Gleeson, 1999; Mackenzie & McAlister, 2010; Stancliffe, 2006). The closure of many large institutions for people with intellectual disabilities from the 1970’s onwards must be seen as a positive in promoting the rights and well-being of people with intellectual disabilities. Revelations of systemic abuse and neglect; for example at Aradale in Victoria, Australia (Health Department Victoria, 1991) and more recently at Winterbourne View in the United Kingdom (Flynn, 2012) coincided with changes in thinking about social inclusion. It was not possible for people to live with, or like others in the community if they were physically segregated. However, the belief by that closing institutions and relocating people in the community some kind of ‘magic would be wrought’ (Johnson et al, 2010) has been shown to be flawed.

Whilst arguments abound about the kind of accommodation options available to people with an intellectual disability and about the type and quality of their support and care, there is an obvious question to be asked about the lack of social inclusion of those now living in community settings (Beadle-Brown, Mansell & Kozma, 2007; Department of Families, Housing, Community Services and Indigenous Affairs, 2009; Szivos & Griffiths, 1990). If people with intellectual disabilities lack a visible presence in the communities in which they live and are unable to access and enjoy a range of social, educational, employment and leisure opportunities then perhaps it can be said that that there has been less of a shift in the reality than the ‘policy rhetoric’ might lead us to believe (Bigby, 2006; MacIntyre, 2008). There remains the risk that large-scale institutions have simply been replaced by smaller ones (Bigby & Fyffe, 2007; Beadle-Brown, Mansell & Kozma, 2007). Little is known about the lives of people with intellectual disabilities who live outside the service system with their families at home, and this is reflected in the literature. It seems likely that they too are excluded from much of community life.

Living in the community potentially provides some obvious benefits for people with an intellectual disability; including opportunities to develop skills in community living and self-care, more choice, and far greater opportunities for participation and engagement (Cummins & Lau, 2003; Hall, 2004; Ife, 2010; Stancliffe, 2006). Whilst they are supportive of efforts to enhance social inclusion for people with intellectual disabilities, Harris and Roulstone (2011) argue that “...possibly the only (tenuous) ‘benefit’ of institutionalisation was isolation from oppression, unpleasantness and ridicule by the public” (Harris & Roulstone, 2011, p.24).

Comparing the levels of satisfaction, self-esteem and locus of control of two groups of people with intellectual disabilities, Barlow and Kirby (1991) found that the group who resided in an institution reported similar levels of all of these indicators as members of the second group who resided in community settings. Furthermore, the group of institutional residents reported to the researchers that they were 'more satisfied' with their social life (Barlow & Kirby, 1991). Closing long-stay hospitals and large institutions for people with learning disabilities has failed to 'replace the community' of those institutions leaving people 'without refuge' in an often openly 'hostile' community (Hall, 2005). The results of this study may not be universally generalised, but they are interesting in the context of the challenges which remain for people with intellectual disabilities seeking more independent, included lives in their communities. Evidence from Barlow and Kirby's (1991) study raises questions about a service system failure to acknowledge and support the relationships people have built within institutions and that this had undermined their opportunities to live a 'good life' in the community.

Since deinstitutionalisation, life in the community, particularly for those in group homes often has an institutional feel. Activities are often programmed and outcomes measured, with 'social inclusion' an ambiguous goal. Defining social inclusion in terms of the frequency, duration and intensity of interactions and the relative status of those engaged in the interactions (Blaney & Freud, 1994) is problematic when translated into the daily lives of people with an intellectual disability. Through their study of group homes in community settings in Victoria, Clement and Bigby (2010) provided a number of instructive examples of the way such a definition of inclusion might be enacted. They observed planned, quantified social opportunities which in many instances translated to little more than fulfilling a quota for venturing out of the group home into the community. It was difficult for support staff and for the researchers to determine either what was being measured by staff managing such programs, or to notice attempts to help to create opportunities for genuine engagement in the community (Clement & Bigby, 2010). Whilst the people in this study were living in the broader community, the kinds of activities available to them did little or nothing to address the problem of their damaged social identity or their lack of social inclusion. Having the opportunity to make choices about where and how to live is extremely important. Clarke et al (2005) adopt the term ‘social coherence’ rather than inclusion/exclusion and this seems a useful term, implying that an individual is able or enabled to make choices and to make some sense of their own life in the community context (Clarke et al, 2005). Their study of thirty five people with an intellectual disability living in the community found that many felt that they were living essentially ‘parallel’ lives alongside the social world inhabited and experienced by the ‘mainstream’ community (Clarke et al, 2005). Interviewees consistently described feeling isolated and ‘not valued’ and a strong sense that they were not included in the community and these perspectives are echoed in other studies such as; Robertson et al (2001). Arguing that since institutional closure, people with intellectual disabilities are more ‘isolated’ than before, Rooney (2002) states that greater inclusion will not happen in the absence of ‘creative’ support.

It is risky to ‘prescribe’ a mainstream community existence (Ward, 1988) but without opportunities and support to access a range of relationships and a broad choice of options for community participation, people with an intellectual disability will remain severely limited in their access to some measure of inclusion. These authors argue that policy should embrace more flexible notions of what professionals in the disability sector consider to be ‘normal’ life by listening more closely to what individuals define for themselves as the way in which they would like to ‘lead their own life’ (Clarke et al, 2005). Whilst deinstitutionalisation has been extremely important for people with intellectual disabilities, their continued social exclusion shows that it was not a magic solution.

Social relationships.

Building positive relationships is an important strategy in seeking to challenge the social exclusion of people with intellectual disabilities. As Carnaby (1998) points out, there is sometimes an assumption when the word ‘community’ is used that its use evokes ‘warm, emotive overtones’ producing a welcome for those who have been in the past been segregated (Carnaby, 1998). Whilst those in Forrester-Jones et al’s (2006) study were living in the community, they lacked social networks and crucially felt that they lacked friendships. Some of the long-standing friendships and relationships they had had within the institutions were difficult or impossible to maintain outside it and there was little support to develop new ones. Opportunities to ‘enact or develop’ old or new relationships may be severely limited by a lack of support (Knox & Hickson, 2001) and as a result, loneliness remains a ‘significant problem’ in the lives of many people with a learning disability (Emerson et al, 2005; Holman, 2008; Mason et al, 2013).

Describing the 'apex of social inclusion' as being a "...network of socially integrated, supportive relationships in the community..." Forrester-Jones et al, (2006, p.286) point out some of the difficulties in seeking to achieve this 'apex' for marginalised individuals. The authors interviewed a group of people twelve years after they had been 're-settled' from an institution into community-based accommodation and observed that whilst many had long, stable relationships with other former residents and some with staff, few had social networks or connections outside this group and thus had essentially remained 'segregated' (Forrester-Jones et al, 2006).

Other perspectives on the social inclusion of people with intellectual disabilities highlight the importance of reframing and thus revaluing the kinds of relationships people with intellectual disabilities have with each other and with people without an intellectual disability. Chappell (1994) argues that policies underpinned by normalization have ascribed lesser status to relationships between people with intellectual disabilities, a theme taken up by Carnaby (1998) who argues that it is important to appropriately value roles and relationships between people with intellectual disabilities and understand interdependence as a factor in their relationships (Carnaby, 1998). In fact Ouellette-Kuntz et al (2010) take this further arguing that unless people with and without intellectual disabilities are valued as 'equals' in their interactions with one another then inclusionary strategies will not succeed.

Gibbons (1985) found a 'group concept problem' amongst those people with intellectual disability he interviewed, with many indicating that they found their peers to be less ‘socially desirable’ than people without disabilities. This finding would seem to counter the proposed value of groups such as self advocacy groups whose membership is composed of people with an intellectual disability. It may be that a different problem serves to undermine the development of positive relationships between individuals. McVilly et al’s (2006) study of friendship experiences and aspirations of adults with an intellectual disability, discovered, through interviews with self advocates, that peer relationships between people with intellectual disabilities, even amongst those participating in service supported activities and settings, are generally not well supported by support workers and carers (McVilly et al, 2006). The authors found that many of those interviewed expressed a ‘positive self-identity’ as a person with an intellectual disability and wished to build on this strength to assist in developing their relationships with others (McVilly et al, 2006). The success of the development of social relationships as a strategy to enhance the inclusion of people with intellectual disabilities relies to a significant degree on support from a range of others in the community.

Definitions of social inclusion which focus on economic participation.

Many authors are critical of the ways in which the literature focuses on economic participation, specifically through paid employment as a panacea for social exclusion (Barnes et al, 2002; Goodley & Norouzi, 2005; Hall, 2004 & 2005; Laws & Radford, 1998; Redley & Weinberg, 2007; Ward, 1988). Whilst participation in paid employment may be a desired and achievable outcome for some people with intellectual disabilities, it is certainly not the case for all, and an over-emphasis on this Holy Grail within a capitalist economy insufficiently values some of the other 'relational' and 'convivial' aspects of social inclusion and community participation (Redley & Weinberg, 2007). In fact, Abberley (2002) asks if the social isolation of people with disabilities is an 'inevitable disadvantage' if employment and inclusion remain inextricably linked in the literature and in broader community perceptions about participation and engagement (Abberley, 2002). Placing citizenship and inclusion in terms of 'individual autonomy' in employment and making choices about services (Redley & Weinberg, 2007) seals the social exclusion of many people with learning disabilities.

Laws and Radford's (1998) study of people with intellectual disabilities who were employed found that despite the often poorly paid and menial nature of their work, most expressed high levels of satisfaction with their engagement with the community (Laws & Radford, 1998). The authors reflect that this 'satisfaction' may be a result of their subjects 'low-level expectations', but it also seems to point to the cogency of the accepted link between participation in paid employment and inclusion within our society. Bryson and Mowbray (1991 & 2005), Dowse (1996 & 2009), Ward (1998) and Beland (2007) question whether community building and the 'inclusion of minorities' is achievable in a capitalist framework arguing that the commodification of the individual has fundamentally challenged genuine opportunities for self-determination. This represents a major structural barrier to social inclusion for people with intellectual disabilities.

Levitas (2004) is also critical of the ways in which humans are commodified in what she describes as dichotomous models of society, that is, as having 'insiders', the socially included, and ‘outsiders’, the socially excluded. Those who are excluded are then culturally distinct from the mainstream and seen as less valuable. Levitas (2004) argues that a ‘redistributive discourse’ offers a more useful framework for thinking about the problem of exclusion. Such an approach would focus on the promotion of human rights, the redistribution of wealth to alleviate poverty and a valuing of the range of roles adopted by people in society, including paid and unpaid work and leisure (Levitas, 2004; MacIntyre, 2008). For people with intellectual disabilities managing deeply stigmatised social identities, an approach which acknowledges abilities to engage in a range of social roles beyond that of ‘service user’ (Croft & Beresford, 1989; Simons, 1998) offers positive inclusive potential but seems unachievable without dramatic social reform.

Employment and citizenship.

There is optimism in Christie’s (1999) prediction of a future in which there is less emphasis on people with disabilities as ‘consumers’ and more on their ‘citizenship’ (Christie, 1999). This, he says, will bring about debate over what constitutes a ‘social contribution’, heralding a ‘mutuality’ of rights and responsibilities and bringing about increased social inclusion of marginalised groups (Christie, 1999). Emphasising reciprocity as a defining element in social inclusion, Bates and Davis (2004) argue that people with intellectual disabilities must have “...full and fair access to activities, social roles and relationships directly alongside non-disabled citizens” (Bates & Davis 2004, p.195) but do not explain how this can be brought about. Access to valued roles within society potentially radically alters both the ways in which people with intellectual disabilities are viewed by others and their self-perception and could positively impact their inclusion.

Simons (1998) points to the elements which make up John O'Brien's (1987) framework for 'ordinary life', as a means towards actualising citizenship and inclusion; "...presence, choice, competence, respect, participation..." (Simons, 1998). The promotion of a framework which promotes self-determination and inclusion of course relies on policy settings and resources within the community to provide support and momentum. Other authors including Ward (1988) argue for a community support model to overcome isolation, one in which a variety of occupations, paid and unpaid work, and daytime activity programs are valued (Ward in Towell, 1988).

Social integrationist discourses which focus either solely or heavily on participation in paid employment as the escape route from social exclusion may devalue the role of unpaid work, participation in other activities in the community, as well as some of the problems faced by people with intellectual disabilities who are engaged in paid work, for example, low-pay or poor working conditions (Levitas, 2004; MacIntyre, 2008). Burchadt (2009), in a review of welfare and employment policies regarding people with disabilities, raises concerns about 'educational deficits' in school leavers with disabilities and argues that their lack of relevant employment skills increases their social exclusion (Burchadt, 2009). This would appear to be an even more serious problem for people with intellectual disabilities whose opportunities for participation are already considerably constrained.

Access to information and the digital world.

One strategy for enhancing the inclusion of people with intellectual disabilities has been to improve their access to information and the digital world. This has had mixed success according to evidence found in the literature.

Highlighting the importance of service providers striving to provide accessible information to people with learning difficulties, Townley (1998) cites a study of the usefulness of the ‘Plain Facts’ simple English pamphlets distributed to self advocacy groups in the United Kingdom in 1996, in which respondents reported that they had been able to access information not readily obtainable from other sources through such an audience–specific publication (Ward, 1998). This was a positive outcome. There is no doubt that information is ‘power’ (Ward, 1998), though it is important to be critical about the source and the content of such material and to interrogate its impact on maintaining or challenging the power imbalance in social relations for people with an intellectual disabilities, their carers and service providers.

Aspis (2002b) is scathing in her criticism of attempts by the British Government to implement a policy goal of providing ‘jargon free’, accessible information for people with learning difficulties regarding accommodation and other options. She writes that the basis of what she describes as their failure, is a combination of ‘very low’ expectations of the ability of people with learning difficulties to understand the concepts and themes being presented and a tendency for the use of ‘short-cuts’ (Aspis, 2002b).

> "These things perpetuate the myth of the 'unquestionable' value of simple language and encourage ignorance of the limits to life experience imposed by the practices of institutionalization and other kinds of social exclusion." (Aspis, 2002b, p.179)

Aspis' commentary reinforces the importance of user engagement at both policy and implementation level to avoid practices which may do little or nothing to promote either the greater inclusion or self-determination of people with intellectual disabilities. Without this input, such approaches may serve to reinforce negative perceptions about their social identities and their capacity to engage with the community.

Dowse (2009) raises the concern that if people with an intellectual disability are excluded from the tremendous opportunities for participation represented by technology like the internet with its global scope, there is a risk of actually increasing their social exclusion (Dowse, 2009). It is of course a temptation to overstate the kind of 'participation' which might be occurring through the use of technology. The possibility exists that information technology could increase opportunities for people with disabilities to 'participate' in society but do so at the risk of their greater social isolation (Lee, 2002). Lee (2002) describes computers and related technology as a 'double edged sword' for people with disabilities and shares with Dowse (2009) and Christie (1999) a concern that it will be extremely difficult for many people with learning difficulties to engage with the 'information economy'. Lee's (2002) observations pre-date the massive and still growing popularity of social networking sites on the internet such as ‘Facebook’ and ‘Twitter’ observable nearly a decade later, and it is unclear how the participation in such complex, multi-layered yet intangible activities actually promotes or enhances individual social inclusion. Bunning and Horton (2007) emphasise the vital importance of enabling individuals to ‘perform’ roles which have personal significance and meaning to them, and are not imposed upon them or manufactured (Bunning & Horton, 2007). Accessing technology like social networking sites, looks ‘superficially like participating’ but is in reality an inadequate substitute for face to face engagement and interaction with others in a range of environments (McClimens & Gordon, 2009).

McClimens and Gordon’s (2009) research introduced a group of people with an intellectual disability to the concept and practice of internet blogging. Although the group studied was small, and the research of short duration, its results were interesting. The authors found that the activity of blogging was ‘incidental’ to the participants’ significant enjoyment of their environment (a university campus) and interactions with the researchers and students (McClimens & Gordon, 2009). When the authors write that individuals “...who lack the background characteristics associated with education, youth and wealth are less likely to increase connectivity, sociability, participation or engagement through blogging...”(McClimens & Gordon, 2009, p.28) they highlight a broader difficulty faced by all members of marginalised groups in the community and particularly people with an intellectual disability.

The absence of ‘reciprocity’ in the online blogging activities of the participants in McClimens and Gordon’s study underlined the powerful ways in which social interaction impacts identity formation (McClimens & Gordon, 2008, 2009). Seale and Pockney’s (2002) research on ‘Personal Home pages’ of adults with Down Syndrome found that they could be a positive tool in developing and building friendships between people with and without disabilities. The authors do however raise the issue of who in fact ‘controls’ and ‘owns’ the publication of such pages and the management of the identity projected in such pages, speculating that relatives and carers exercised considerable control over the content, limiting decision-making by the disabled adults themselves (Seale & Pockney, 2002).

Using online technology to attempt to address the social exclusion of people with intellectual disabilities seems to be an inadequate substitute for ‘real’ interactions and relationships (McClimens & Gordon, 2008, 2009). The ways in which staff and carers managed and supported the online activity meant that the social identities of the participants were concealed or massaged which did not contribute positively to the projection or development of their ‘real’ social identities. Being seen by others in a new light in the context of an interaction was the factor which made a positive contribution to the social identity of the participants, not the online activity.

Self authored spaces.

‘Self authored’ spaces where people can ‘reclaim’ and build their identities offer unique opportunities for inclusion. Milner and Kelly (2009) observe that;

> “...we can reasonably anticipate that people with disabilities will find community in other ways that challenge the existing paradigm, perhaps within self-authored segregated spaces and activities that celebrate the culturally distinctive mores of people with disabilities or harness their collective agency.” (Milner & Kelly, 2009, p.59)

The creation of such ‘self authored’ spaces may represent an opportunity for people with intellectual disabilities to challenge their social exclusion and be themselves.

In offering a social geography perspective on the social inclusion/exclusion of people with an intellectual disability Hall (2004, 2005) urges his colleagues to challenge policy and programs which focus solely on participation in the labour market as the major means of overcoming social exclusion, arguing that participation in organisations run by people with disabilities themselves are more likely to create and enhance a feeling of being ‘included’ for participants (Hall, 2004, 2005). These are the kinds of self authored spaces in which people are able to ‘find community’ (Milner & Kelly, 2009). What Hall does not suggest is the possibility of those organisations, such as self advocacy groups offering opportunities to participate through paid or voluntary employment within the inclusive social space they create, a possibility clearly understood by Milner and Kelly (2009).

Castells (2004) also explores the idea of self authored spaces which he calls ‘communal havens’. His work on identity addresses the culturally constructed identities of marginalized people and is useful in considering questions about the potential transformative power of social movements for people with intellectual disabilities (Castells, 2004; Whitehead & Hughey, 2004). He describes what he perceives as the ‘emergence’ in contemporary society of “...powerful resistance identities, which retrench in communal havens...” (Castells, 2004, p.421), arguing that such identities are not ‘limited’ and can be ‘built’ by proactive social movement organisations (Castells, 2004).

Within the self- authored spaces which transform group identity, individuals also rebuild their damaged social identities by writing their own ‘identity scripts’. It is not an accident that Milner and Kelly (2009) and Shah and Priestley (2011) employ the language of writing to describe the potential of new social spaces to build more positive identities. Creatively writing ‘identity scripts’ in ‘self authored’ spaces may offer people with intellectual disabilities exciting opportunities to create and share their individuality.

Self Advocacy and Identity

Arguing in favour of more research into the self concept of self advocates, Harris (1995) states that ‘tentative’ evidence demonstrates that those engaged in self advocacy have a higher ‘self concept’ than those who do not (Harris, 1995). Drawing on research by Finkelstein (1993) and Simons (1992), Harris (1995) argues that when people with intellectual disabilities ‘group together’ they can draw on a collective strength to build more positive self concepts.

Discussing a number of studies which examine the ways in which people view their 'identity' as a person with intellectual disabilities Beart, Hardy and Buchan (2005) argue that there is evidence to challenge an assumption made in some work on self advocacy (Walmsley & Downer, 1997) that self-identification as a person with an intellectual disability is an important first step in enacting self advocacy as part of a self advocacy organisation. In the absence of substantial research it seems likely that this may not be the case and other authors, such as Aspis (1998) have stated that in the case of many service based self advocacy groups, members are more likely to identify as 'service users' before assuming other social identities or labels (Beart et al, 2005; Beart, 2005). Beart et al's (2004) own interviews with self advocates revealed that they did not readily identify with the group because they recognised it as being 'for people with learning difficulties', rather they described the positive impacts their membership had had on their confidence and ability to 'revaluate their past' (Beart et al, 2004). This in turn, the authors argue, led them to new insights about the importance of 'collective action and speaking up' for all people with intellectual disabilities (Beart et al, 2004). Other authors have also recognised the power inherent in the development of a strong identity as 'disabled people', acknowledging the way in which the broader disabled people's movement has achieved this. Goodley (2001) argues that identification with the label 'learning difficulties' has facilitated some collective action via the self advocacy movement. However, the almost overwhelming negative way in which that label continues to be perceived in the broader community has been persistent and not been effectively challenged.

Dudley (1997) describes stigma as being ‘manifested’ in the contact between the ‘labelled’ person and those who ‘promote’ the label. Self advocacy is important in addressing this contact by the ways in which it ‘reconstitutes’ and ‘engages’ with the meanings of labels;

> The self advocacy movement does not simply reconstitute impairment-specific concerns within the wider disabled people's movement but engages with the ways in which the specific meanings of particular labels threaten the very humanity of activists. (Goodley, 2003, p.105)

McClimens (2007) describes the ways in which ‘professionals’ from diverse disciplines in medicine, social science and education have ‘reauthored’ the lived experiences of people with intellectual disabilities, arguing that it is time for groups such as self advocacy organisations to challenge these negative and culturally pervasive accounts by offering ‘resistance’ (McClimens, 2007). He suggests that by ‘resisting’, both ‘self advocates and their allies’ can have a very positive impact on the ways in which the broader population ‘perceives learning disability’ which will enhance their social inclusion (McClimens, 2007). The ways in which ‘resisting’ is enacted is worthy of further investigation.

An interesting perspective on social exclusion and the potential inclusionary impact of ‘self-organising’ groups is offered by Burls and Caan (2004), and it would be appropriate to include user-led, independent self advocacy groups in their definition. These authors argue that ‘self-organising’ groups grow through ‘embracement’ which they define as the process of group members establishing a common identity (Burls & Caan, 2004). Such identities can be of any kind, ranging from being a consumer of a particular health service, a skateboarder, a music lover or a disabled person (Burls & Caan, 2004, this author's examples). It is this 'embracement' which can be a 'driving force' for the group, in which there can be diversity, as well as inclusion in a common group identity (Burls & Caan, 2004). The nature of the group identity is one about which further research needs to be undertaken. For some groups this may be about the embracement of a group identity as people with intellectual disabilities, for others it might be something quite different.

The problem of collective identity and goals competing with those of individuals within self advocacy groups is examined by Carey (2009). She raises an important and interesting issue about the identity-transforming potential of engagement in self advocacy. She is concerned that the self advocacy movement has in her view a tendency to valorize "...the individualism inherent in the liberal understandings of rights and emphasizes the pursuit of individual interests over social obligations." (Carey 2009, p.223). Further, she is concerned that the self advocacy movement, in emphasising the goal of self-determination as the key to a 'valuable' life may risk denigrating or leaving behind those unable to achieve it and therefore may devalue these people (Carey, 2009). The implication here is that it is an inherently negative thing for groups to move away from the embracement of collective identity. Carey (2009) does not offer evidence to support the claim that the self advocacy groups are somehow failing in their 'social obligations' by pursuing goals of individual self determination or that they are 'devaluing' people who may find it difficult to attain.

There are interesting connections to be made here with Dowse's (2009) paper titled " 'Some people are never going to be able to do that': Challenges for people with intellectual disability in the 21st century.". Whilst Dowse (2009) is optimistic about the potential of a globalised, technologically advanced future for people with learning difficulties to enhance their communication, she also acknowledges the risk of people being left behind or left out by either their lack of skills or others' misperceptions of their abilities (Dowse, 2009). To see the same concern being raised about people being 'left out' by the self advocacy movement raises the prospect of a stratified marginalised group in which the stigma attached to the intellectual disability label is further entrenched by notions about a lack of 'competence' from both those within and outside the self advocacy movement (Ali et al, 2012; Carey, 2009; Dowse, 2009). Ideas about a lack of competence have contributed to the social exclusion of people with intellectual disabilities. Within the mainstream community, an 'ideology of stigma' exists in which stereotypes, myths and misperceptions of people with an intellectual disability provide a socially constructed way of (dis)regarding the skills, strengths and rights of 'labelled' people (Dudley, 1997; Goffman, 1963). If indeed what Carey (2009) says is correct, then it would be disturbing to see the self advocacy movement joining in with the reliance on stereotyped views of people with intellectual disabilities and with a pervasive view which links capacity with rights and therefore valorizes only the competent and self-determined (Carey, 2009). To date, this view does not seem to be supported by evidence in the literature.

Sutcliffe and Simons (1993) ask ‘What label, whose label?’ and argue that self definition can be empowering and perhaps this is one of the ways in which self advocacy may be useful in building the social inclusion and transforming the identities of people with intellectual disabilities. Self advocacy emphasises a reframing of identity for the individual; learning ‘to accept who I am’ is an essential part of learning and enacting self advocacy. You need self knowledge in order to ‘put your best foot forward’ in social encounters in the community (Gerber, Reiff & Ginsberg, 1996). In emphasising ‘strengths over deficits’, self advocacy ideally should assist individuals by reducing the stigma associated with negative labels and a ‘characteristic based’ exclusion (Goodley, 2001; Goodley et al, 2002; Harris, 1995; Miller & Keys, 1996). Self advocates and self advocacy organisations ‘celebrate resilience’ through their activities which can be ‘social’ or ‘identity-shifting’ argues Goodley (2001). This kind of ‘celebration’ has the potential to be enormously powerful and significant in the lives of individuals with socially constructed, stigmatised identities (Dudley, 1997; Goffman, 1961; Goodley, 2005; Kenyon, Beail & Jackson, 2013; Rhoades, Browning & Thorin, 1986; Scott, 1969).

Claims made about self advocacy in the literature.

An important way in which people with an intellectual disability might tap into the ‘power and protection’ of community life (McKnight, 1989) and address the problem of a negative social identity, is through engagement with self advocacy. There is little in the literature which clearly links involvement in self advocacy with greater social inclusion for the individual, but if it can be argued that there is great personal value in acts of social engagement, examples of reciprocity and opportunities for social presence, then clearly the empowerment goals of self advocacy have at least the potential to challenge the social exclusion of those individuals involved. Whilst some studies describe self advocates as being, or becoming ‘strong’ as a result of their group engagement (Brennan, Forrest & Taylor, 2012), there is a paucity of evidence about deeper impacts on social identity and roles.

As described in the literature, self advocacy is about speaking up for yourself, it is about having a say, speaking out and developing skills in empowerment, competence and resilience (Atkinson, 2002; Barnes & Mercer, 2006; Brennan, Forrest & Taylor, 2012; Chappell et al, 2002; Dybwad & Bersani, 1986; Goodley, 2000, 2003, 2005; Goodley et al, 2003; McNally, 2002; Miller & Keys, 1996; Nonnemacher & Bambara, 2011; Pennell, 2001; Renzaglia et al, 2003; Rhoades, Browning & Thorin, 1986; Seale & Nind, 2010). Three self advocates writing in Beresford and Carr (2012), say that self advocacy is about “...being powerful and feeling strong”. Self advocacy is ‘useful’ because “...it does not say: 'You are not disabled', which is not true. It does say, “You are able in many ways...” (Bayley, 1993, p.53). Williams and Schoultz (1982) state that there is “...no better way to help a mentally handicapped person become a true citizen than to give him the opportunity for self advocacy” (Williams & Schoultz, 1982). Putting aside the dated language used in their remarks, it is difficult to fail to be enticed by such a promise. Self advocacy “...means advocating on one’s own behalf. It is the root of all social activist movements”; (Hayden & Nelis, 2002, p.221) and ‘empowerment projects’. (Svensson & Tideman, 2007 (trans.)). Involvement in self advocacy offers the chance for people with intellectual disabilities to be seen ‘in a new light’ (Poetz,

2003) and to ‘accentuate the positive’ (Armstrong & Goodley, 2001). Carey (2009) describes self advocacy as being a “...revolutionary concept for people with intellectual disabilities” (Carey, 2009, p.222). Self advocacy is about more than ‘talk’, it is an ‘intent to produce change’ in the lives of individuals (Crawley, 1988). For those involved in self advocacy groups, there is potentially a myriad of benefits which might be recognised as having much in common with self-help groups and political movements. It is possible for self advocacy groups to be both of these in both an episodic and ongoing way through the actions of their individual self advocate members to tackle the problems of their damaged identities and continuing social exclusion (Shakespeare, 1993).

Some authors focus heavily on particular perspectives on the nature of self advocacy groups and this may in fact undermine the perspectives of those actually engaged in the groups. Croft and Beresford (1989) for example, discuss the ways in which self advocacy groups ‘highlight negative relationships’ between welfare services and citizenship. This may be a valid view but there is some doubt that this would be the interpretation shared by the members themselves, nor would it even begin to describe the range of benefits they might derive from participation. Barnes and Oliver’s (1998) description of the transformative ‘potential’ of disabled people’s social movements is useful here in distinguishing between individual and societal goals of groups and their members. These may be limited in scope or hugely ambitious. Ethnographic accounts of self advocacy groups, for example Clement (2003), Goodley (2000) and Williams (2002), reveal complex and evolving groups, some struggling, others dynamic and thriving, composed of a wide range of individuals, some motivated by the personal, some by the political, but all seeking to foster self-determination.

Maguire (1983) argues that groups which have a focus on developing skills in self-reliance in essence provide a ‘new community’ for their members because of the particular ways in which they foster ‘social support and communication’ (Maguire, 1983). Self advocacy groups can provide “...a focus and public recognition of the resilience and resistance themes which emerge from many of the life stories of people with learning difficulties” (Chappell, Goodley & Lawthom, 2002). They provide an important forum for the ‘telling and re-telling’ of such life stories (Mitchell et al, 2006; Spedding et al, 2002). Rhoades, Browning and Thorin (1986) describe the ‘importance’ of self advocacy groups in developing amongst their members a ‘sense’ of empowerment and competence (Rhoades, Browning & Thorin, 1986). The positive outcomes of this enhanced ‘sense’ include, they say, ‘open and persuasive communication’, skills in ‘coping’, opportunities for socialisation and identification with a peer group (Rhoades, Browning & Thorin, 1986). Gilmartin and Slevin’s (2009) study of self advocacy group members in Ireland describes the groups as ‘affirming the person-hood’ of self advocates, offering insights into character, however it is not clear what impacts this has on the social identity of members inside or outside the group. Whittell, Ramcharan, and members of People First Cardiff and The Vale (1998) argue that self advocacy can give individuals more confidence to speak up and importantly, social purpose (Whittell, Ramcharan & members of People First Cardiff and The Vale, 1998). Whilst ‘social purpose’ would seem to be a slippery concept, it certainly conveys a sense that the (self advocate) authors felt more engaged in their communities as a result of their membership. Self advocacy provides opportunities for empowerment, through ‘speaking up and speaking out’ and for becoming the ‘author of your own story’ (Atkinson, 2002). For people who are survivors of the institutional experience to be able to stand up and tell and retell their stories of ‘resilience and resistance’ there are unique opportunities for gaining a sense of empowerment and ‘competence’ (Atkinson, 2002; Rhoades, Browning & Thorin, 1986). Goodley and Ramcharan (2010) refer to these individuals as ‘border crossers’; they have moved from the institutional environment to being participants in the community. The concept of ‘border crossing’ “...captures the idea of an ecological system where there is interplay between the person and the context” (Bunning & Horton, 2007). Until the latter part of the twentieth century, the models of care; ‘incarceration’ and ‘segregation’ (Potts & Fido 1991) practiced in Western countries ‘ensured’ the ‘non-participation’ and thus the non-inclusion of people with intellectual disabilities in the community (Bunning & Horton, 2007). The idea that people can become ‘border crossers’ suggests new levels of participation and that it is somehow possible for individuals to break through the structural and attitudinal barriers which have excluded them.

The activities of self advocates ‘magnify’ the ‘self-help’ aspects of the social model of disability (Oliver, 1996). They offer support to their colleagues and ‘resist’ the assumptions society makes about their deficits in ability and competence and tendency to be ‘inappropriate’ (Goodley 1998, 2002). This represents a challenge to the stigma attaching to members social identity. Whilst some authors, like Clement

(2003) and Aspis (1997) have questioned the ability of some self advocacy groups to organise to achieve even some, let alone all of these activities, there remains throughout the literature on self advocacy an optimism about the potential for individual empowerment which is of itself highly significant.

Enacting self advocacy is an important aspect of progression towards a ‘civil society’, ‘reclaiming’ the rights of all disenfranchised people (Goodley & Ramcharan, 2010). This is a strong statement, positioning self advocacy as a personally transformative and radical act. Carey (2009) describes the dual political and personal nature of the enacting of self advocacy in these terms:

> “The exploration of self and the development of a sense of self-efficacy are important well beyond the realm of formal politics; they are part of developing our humanity. In a dialectical relationship, we enter the political realm with interests but simultaneously become citizens and form interests as we are allowed to participate and make choices. We earn respect and come to see ourselves with a new respect. Because the personal is political and vice versa, political participation is not merely about formal actions such as voting. Rather it includes participation in making a range of everyday choices such as where to live, what kind of work to do, and with whom to spend time.” (Carey, 2009, p.222)

Carey’s point is well made – the act of participation, of engagement, has potentially great power in the life of any individual citizen but for those who have long been marginalised and on many levels, disenfranchised, it can be significant and indeed ‘humanising’ (Carey, 2009). The ‘humanising’ process may offer new and more positive social identities for self advocacy group members.

Positioning self advocacy within a political context, Whitehead and Hughey (2004) argue that people with an intellectual disability should form their own union - ‘a universal bargaining organisation’ in order to gain social power, a position so far removed from the reality of the current Australian context it seems risible. Whitehead and Hughey’s focus on empowerment as a ‘relational phenomena’ (sic) is useful however as it provides an insight into the way in which individuals might, through their relationships, alter their power and status in the community (Whitehead & Hughey, 2004). The self authored space of the self advocacy group seems to have potential to at least begin this process.

Pennell’s (2001) discussion of the self advocacy movement in the United States of America also refers to its potential ability to ‘shift power’ (Pennell, 2001). Self advocacy, as a social movement engages in ‘struggles over meaning’, and attempts to ‘reframe’ inequities in ways which seek to bring about both personal and structural change (Bersani, 1998; Croft & Beresford, 1989; McCarthy, Smith & Zald, 1996). There are more cautiously optimistic views about this in the literature for example; Dudley’s (1997) commentary about the self advocacy movement in the United States of America states that ‘societal myths’ about people with intellectual disabilities have ‘delayed’ the emergence of self advocacy as a social movement (Dudley, 1997). Dudley argues that over time, self advocacy groups and the individuals who are their members, have proven themselves able to transcend the low expectations of those who have ‘labelled’ them (Dudley, 1997). ‘Transcending’ the low expectations of others is important but is surely only a first step towards the achievement of significant social change. Major social change can emerge from modest beginnings and if the self advocacy movement is indeed only in its infancy, its ability to grow and to make an impact needs to be nurtured. If this can be borne out in future research then it would provide powerful evidence to support the ongoing development, through policy and adequate funding, of self advocacy groups in Australia.

What features of self advocacy groups work to change the identity of members?

Caldwell’s (2010) study of leadership development within the self advocacy movement recorded the experiences of thirteen self advocates considered to be leaders (Caldwell, 2010). ‘Leaders’ in this study were those who had held an elected position within their own organisation (Caldwell, 2010). Emerging from the semi-structured interviews Caldwell conducted with his participants were stories of ‘oppression’ and ‘resistance’ which had been the ‘foundation’ upon which leadership skills in self advocacy had been built (Caldwell, 2010).

> “Participation in the self advocacy movement provided personal and collective resistance to disability oppression. The movement provided individuals with confidence and trusting environments to speak up and

> practice self-determination, as well as connections to the disability community.” (Caldwell, 2010, p.1008)

The notion of the ‘trusting environment’ is an important one to explore as it seems to offer a key to understanding why the social context of the self advocacy group may offer unique opportunities for adults with an intellectual disability to challenge the ways in which they see themselves and the way they are regarded by others. Increasing individuals’ confidence and offering them a place to ‘practice’ skills in speaking up were central to the experience of the self advocates in Caldwell’s (2010) study.

Others studies explore the nature of the environment of a self advocacy group. Beart, Hardy and Buchan (2004) used Grounded Theory to consider the impact of membership of a self advocacy group on eight people, all of whom had been engaged with the group for at least six months. A major finding of their study was that the ‘positive social environment’ and the enhanced self confidence of their interviewees was indicative of a changed ‘self concept’ of the participants over the period of their engagement with, and learning about self advocacy (Beart, Hardy & Buchan, 2004). Whilst the group offered a positive and supportive space for members, there were threats from outside. The authors found that there were some ‘emotionally difficult’ components which had arisen for the participants which were focussed around some of the negative reactions they may have received in relation to their group membership (Beart, Hardy & Buchan, 2004). The disapproval of some parents of members was one cited example of a ‘negative reaction’ (Beart, Hardy &

Buchan, 2004). It would be useful to explore through further research into self concept and self advocacy some of the factors external to the group which may or may not support individuals to become or remain engaged in self advocacy. Also, there remains a shortage of research about the ‘meaning’ and ‘significance’ of engagement in self advocacy by people with an intellectual disability themselves (Armstrong & Goodley, 2001; Dybwad & Bersani, 1996).

Models and funding of self advocacy organisations.

Claims are made about the value and efficacy of independent groups compared to other types such as those which are sponsored or that happen within services, yet there is little evidence to substantiate these.

Whilst there are examples of what Goodley (2000, 2005) describes as ‘independent’, ‘autonomous’, or ‘ideal’ model self advocacy groups in Australia (that is those groups whose members operate without some of the conflicts of interest inherent in the ‘service support’ and ‘divisional’ groups), such groups, like ‘Reinforce Inc.’ in Melbourne and ‘Self Advocacy Sydney Inc.’ are rare, and struggle with few members, declining membership and limited funding. There is no national or peak body to which such groups are affiliated. Cooper (1999) and Romeo (1986) writing about the beginnings of self advocacy in Australia in the 1980s, note that ‘People First’, an organisation which has grown and continues to be active in Britain and in the United States of America, had only a fleeting presence but do not speculate about why (Cooper, 1999; Romeo, 1986).

Much self advocacy in Australia happens under the umbrella of what Goodley (2000) describes as the ‘divisional’ model which arises out of organisations created for parents of people with an intellectual disability or the disability service professionals who work with them, for example STAR Inc. in Victoria. Alternatively, self advocacy is ‘located’ in a ‘service system’ model (Goodley, 2000), for example a ‘Client Council’ (Victorian Advocacy League for Individuals with Disability Inc., 2010) or consumer reference group. There are both positive and negative features in each of these models. Whilst the ‘divisional’ model can offer good access to resources to support self advocacy, there exists a risk of a ‘conflict of interests’ between the desires of the organisation and its parent and professional membership and those of the self advocates themselves (Goodley, 2000). There are similar risks attached to the ‘service system’ model but additionally there is a danger that self advocacy groups become ‘token’ – simply another programmed activity on the service provider calendar (Goodley, 2000). Armstrong (2002) takes this idea further arguing that many such groups ‘trap’ people with intellectual disabilities into ‘training to become citizens’. The implication here is that group members will be forever ‘training’ and not putting their knowledge into practice. It would be wrong to argue that there is no value in self advocacy enacted in these models, but there is a level of comfort for policy makers and service providers because their closeness to funding sources and service provision constrains the ability of members to speak out. There is a ‘danger’ in the use of the term ‘user involvement’ ; it sounds as though it ‘challenges welfare paternalism’ but in fact the service users remain service users and are still ‘located’ in the old models of service delivery (Croft & Beresford, 1989). Independent self advocacy groups such as those under the ‘People First’ network umbrella redefine the concept of ‘user’ and can draw attention to ‘negative relationships’ between welfare services and citizenship:

> “Self advocacy groups like People First have highlighted two negative relationships between welfare services and citizenship. First by denying us responsibilities, segregating, stigmatising and lumping us together, they take away rights we associate with being a citizen. Second, they are themselves frequently unaccountable and non-participatory institutions, which are outside our control as citizens. People First has linked the two in its philosophy and strategy. It has sought to challenge the nature of services and seen gaining a greater voice in them as the way to do this.” (Croft & Beresford, 1989, p.15)

Barnes and Mercer (2003) offer this commentary on the difference between what they describe as ‘user-led’ and ‘agency-led’ disability movements:

> “On the one hand, there are user-led movements seeking autonomy, control and power, and on the other hand, there is an agency-led view of consulting with consumers about their preferences, in line with a market economy of welfare approach.” (Barnes & Mercer, 2003, p.39)

Agency-led or service based self advocacy seems to fit comfortably within Wolfensberger’s (1972) view that skills in self advocacy should be ‘learned’ within the ‘shelter’ and ‘protection’ of citizen advocacy (Williams & Schoultz, 1982). This raises the question of at what point, if ever, are people encouraged, even permitted to move outside such paternalistic ‘shelter’ and ‘protection’ and test their skills in self advocacy in a meaningful context? Aspis (1997 & 2002a) is also highly critical of self advocacy in service settings, writing that ‘many’ disability service providers believe that they are ‘promoting’ self advocacy by establishing a self advocacy group (Aspis, 2002a). She describes these groups as places to ask people ‘how they feel’ about particular subjects. They are not about achieving real or long term change and fail to bring about any kind of ‘shift’ in power relations between disabled people and service providers (Aspis, 2002a). Aspis (1997 & 2002a) instead argues that there needs to be a move away from the vested interests inherent in ‘consulting’ people within narrow (organisation-defined) frameworks to enabling and training people with intellectual disabilities to challenge, to strive for change and to have an understanding of ‘how the system works’ (Aspis, 2002a). User groups which fall within Goodley’s (2000) definitions of ‘divisional’ or ‘service-system’ models may risk being ‘sucked into’ tokenistic roles within service and some advocacy groups (Croft & Beresford, 1989). It is of course possible that this is happening, but equally possible that for many people with an intellectual disability, participation in such forms of self advocacy, however muted, may be their first taste of speaking up in any forum and it seems likely that most are, at least initially, unaware of any inherent conflict of interest. The process of ‘gaining a say’ (Croft & Beresford, 1989) is clearly a slow, political process.

It is important to consider the funding of self advocacy groups when considering their potential for taking action which challenges the lack of visibility and damaged identities of people with an intellectual disability in Australian social, cultural, political and economic life. User-led social movements seek autonomy, in contrast with 'agency-led' groups which are about seeking consumer preferences. There is a risk that groups funded to do the latter will remain the only funded self advocacy groups (Barnes, 2003). Bigby and Frawley (2010) observe that the 'independent voice' and the ability to act and to influence on the part self advocates and their organisations is undermined by their limited access to funding and to support from other groups with sometimes conflicting priorities (Bigby & Frawley, 2010). If self advocacy groups wish to challenge old models of welfare paternalism they need to move beyond 'user involvement' to user-led models within which individual group members may seek to tell stories of resilience on their own terms and without fear of negative consequences from their support service providers (Atkinson, 2002; Croft & Beresford, 1989). Len Barton (1993), writing about the United Kingdom policy landscape, argues that an ongoing dilemma for disabled people is that they are seemingly urged by society to pursue their rights as citizens but are not assisted to gain the skills required to pursue those rights.

Supporting self advocacy.

The role of those who support self advocates and self advocacy organisations is a complex one. Goodley's (1997) discussion of the role of the self advocacy support worker argues strongly that it is imperative that they are 'believers' in the social model of disability and understand the ways in which it "...threatens to break-down the dominant oppressive understandings of disability" (Goodley, 1997, p.376). Their focus should be on promoting inclusion (Shakespeare, 2006). The way in which learning disability is understood within the social model is however not clear cut, but self advocacy is created ‘by’ and ‘for’ people with intellectual disabilities and challenges ‘exclusionary’ models of culture promoting those in which oppressive understandings of disability are challenged (Goodley et al, 2003).

Goodley (1997, 2005) argues that in ‘ideal’ self advocacy groups where there is support from ‘believers’ and even in those where these conditions are not met, ‘resilience often exists in spite of disablement’ (Goodley, 2005). There may be conflicts of interest for support workers, particularly those working with agency led or service supported self advocacy groups (Chapman, 2005; Clement, 2003; Williams & Schoultz, 1992). Supporters of self advocacy groups always face a difficult challenge in balancing a role of ‘facilitation’ and control (Collins, 2012; Simons, 1992). Tsuda & Smith (2002) writing about research with self advocacy groups in Japan contend that conflicts between self advocates and supporters, whether open or hidden, often reveal the very complex nature of power and control over who sets and who drives the agenda of the group (Tsuda & Smith, 2002). Whilst ‘self-advocate centred’ groups are consistently described in the literature as being the ideal, they can be very difficult to achieve in practice (Tsuda & Smith, 2002). The role of the supporter appears to be a complex juggling act, balancing multiple agendas and in some groups the outcome can be a balance of power which does not favour the self advocate members.

There is the contention, but no evidence in the literature that the ‘professionalisation’ of self advocacy groups undermines the empowerment or experiences of self advocate members. Armstrong & Goodley (2001) and Blackmore & Hodgkins,

(2012) argue that in groups where the supporters are in control, it is their agendas that are being enacted. They are concerned that in such instances supporters may act in their own interests or even against the interests of members. These commentators believe that the ‘independent’ group model is the ‘ideal’ but do not offer examples of whether greater supporter control or ‘professionalisation’ through close ties with funding agencies has undermined positive outcomes for self advocates.

Caldwell’s (2010) research with self advocates revealed the importance of relationships in self advocacy groups especially those with key ‘support’ workers and group advisors (Caldwell, 2010). Some of these relationships had been ‘trusting’ and ‘long-lasting’ and engaged both parties within and outside the activities of the self advocacy group (Caldwell, 2010), serving to build the confidence of the self advocates and enhance their inclusion. The importance of such relationships is also highlighted by Goodley (2000) and Chapman (2005). Goodley (2000) seeks to remind support workers of the strong networks of resilience building relationships which can develop amongst members of self advocacy organisations and to avoid ‘attaching significance’, or overstating the importance of their intervention (Goodley, 2000). This observation is perhaps too harsh, reflecting as it does an assumption that too many self advocacy advisors overplay their role in facilitation, but it is an important consideration in seeking to understand the complex nature of the role and identity of supporters of self advocacy groups. This kind of assumption may also underplay and undervalue some of the skills of good support workers in building networks and accessing funding for groups.

Perske (1972) describes the ‘dignity’ of risk, arguing that in order for individuals to have the experience of ‘normal’ human development and growth, it is vital that they engage in the ‘risk-taking of ordinary life’ (Perske, 1972; Seale & Nind, 2010). Self advocacy organisation Inclusion International’s (2010) advice to supporters of self advocacy urges them to ‘understand’ that it is ‘okay for self advocates to make mistakes’, to encourage them to learn from them and to move on to make new decisions and have new experiences, to speak up. It is in this context that it seems possible that the self advocacy movement, which seven years ago Buchanan and Walmsley (2006) described as a movement whose ‘time has come’, could enhance the social inclusion of people with intellectual disabilities by rebuilding their damaged social identities and as Bright (2000) says, really change their lives.

The Policy Context of Self Advocacy in Australia and the United Kingdom

Self advocacy in Australia originated in the 1980’s, a little later than in the United Kingdom and the United States of America, and shares a similar broad context of rights based policy with these countries. Available estimates suggest that over 800 groups now operate in the US (Caldwell, 2010; Hayden & Nelis; 2002) and over 1000 in the United Kingdom (Department of Health, 2005), supported by government funding and policy, as well as by local health and community services and universities (Buchanan & Walmsley, 2006; Ledger & Tilley, 2006; McNally, 2002). Rather than the expansion experienced elsewhere, the trajectory of self advocacy in Australia is characterised by decline, government neglect and near fatally low levels of support and resources. Bigby et al (2012) describe the 1980’s until the early 1990’s as being the heyday of self advocacy with ‘strong voices and strong partnerships' providing a context for radical action and engagement. Funding of groups in this period enabled them to connect with professional supporters committed to developing the voices of people with intellectual disabilities (Bigby et al, 2012). Since the mid 1990s, however, neither State nor Federal governments have provided planned support for the ongoing development of self advocacy, nor engaged with it in strategies to foster participation in policy or service development by people with disabilities.

Australia and the United Kingdom are two of one hundred and fifty five signatories to the United Nations Convention on the Rights of Persons with Disabilities (UN, 2006). Australia ratified the convention in 2008, and the United Kingdom in 2009 (UN, 2013), thus accepting their legal obligations to adopt implementing legislation. The UN states that the convention will 'help' people with disabilities because it represents a "...major step toward changing the perception of disability and ensures that societies recognize that all people must be provided with the opportunities to live life to their fullest potential, whatever that may be." (UN, 2006)

The convention has a strong emphasis on participation, access and inclusion across all aspects of life in the community and seeks to detail the rights of people with disabilities and a code for their implementation (UN, 2006). The focus on 'rights' is highly significant emerging from a long history of segregation, marginalisation and paternalism of and towards people with disabilities. The emphasis in Article 8 of the Convention on the need to change perceptions and seek to overcome negative stereotypes of people with disabilities is an indicator that there is still much to be done both in policy and practice to promote and deliver equality and independence (Roulstone & Prideaux, 2012; UN, 2006).

The Council of Australian Governments ‘National Disability Strategy 2010-2020’ endorsed on 13th February 2011, includes a section on advocacy for people with disabilities (Commonwealth Australia, 2011). The Strategy seeks to encompass the needs of people with a range of disabilities through a focus on six broad policy areas: inclusive and accessible communities, rights protection, justice and legislation, economic security, personal and community support, learning and skills, and health and wellbeing (Commonwealth of Australia, 2010). The first year of the ten year plan focussed on identifying ‘areas for future action’ through input from people with disabilities, but in fact political discussion in 2011 and 2012 came to focus on the Government’s plan for a National Disability Insurance Scheme.

Australia.

Self advocacy has grown slowly in Australia. Some of the reasons for this could include the manner in which it has been funded, a failure on the part of policy makers and service providers to understand the positive benefits of engagement in self advocacy for people with intellectual disabilities or public policy reliance on ‘representation by others’, through funded agencies such as the Office of the Public Advocate and the Human Rights and Equal Opportunity Commission. Such reliance may have led to a community sense of complacency about the rights and representation of people with intellectual disabilities.

Under the ‘Guiding Principles’ of Victoria’s ‘State Disability Plan’ 2002-2012 is the important principle of the promotion of self-determination:

> “**The Principle of Dignity and Self-Determination (Choice)** is about respecting and valuing the knowledge, abilities and experiences that people with a disability possess, supporting them to make choices about their lives, and enabling each person to live the life they want to live” (Victorian State Disability Plan, 2002, p.9).

Throughout the thirty two pages of the document there is no mention of self advocacy (or of advocacy). Within a policy document large on rhetoric about ‘enabling’ and ‘empowering’, self advocacy is not identified specifically as a key tool in enhancing opportunities in the community for people with an intellectual disability.

In 2008, the Australian Federal Government made an agreement with State and Territory Governments to implement a ‘National Disability Advocacy Framework’. The framework guidelines describe six ‘broad’ categories of advocacy; individual, citizen, family, self, legal and systemic. Whilst the list does include self advocacy, it seems an awkward fit with the overarching definition of advocacy in the framework;

> “In broad terms, advocacy for people with disability can be defined as speaking, acting or writing with minimal conflict of interest on behalf of the

> interests of a disadvantaged person or group, in order to promote, protect and defend the welfare of and justice for either the person or group by:
>
> Acting in a partisan manner (i.e. being on their side and no one else's);
>
> Being primarily concerned with their fundamental needs;
>
> Remaining loyal and accountable to them in a way which is empathic and vigorous (whilst respecting the rights of others); and
>
> Enduring duty of care at all times." (FAHCSIA, 2008)

This description seems to fit more comfortably with the other models of advocacy described, emphasizing as it does, notions of acting on a person's behalf and 'protecting' and 'defending'. This is not the language of self advocacy, of people speaking up on their own behalf about matters of importance to them.

The list of agencies funded currently through the framework continues to reflect both an emphasis on advocacy by others for people with intellectual disabilities but also the small number of organisations which are involved in self advocacy.

United Kingdom.

In the United Kingdom, significant policy specific to people with an intellectual disability was introduced in 2001; 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (Department of Health, 2001). A revised version was released eight years later; "Valuing People Now: a new three-year strategy for people with learning disabilities" (Department of Health, 2009). The policy has a focus on 'Person Centred Planning', and promotes enhanced 'social inclusion', 'empowerment' and 'equality' and the term 'self-directed' appears repeatedly throughout the document (Department of Health, 2009). The policy clearly recognises the role of self advocacy and its link to citizenship. Chapter 4 of the policy document concerns the citizenship of people with intellectual disabilities and states:

> "...all people with learning disabilities can speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it." (Department of Health, 2009, p.100)

It goes on to say that support should be provided within regions to self advocacy groups and their leaders and that a 'quality tool' (training) will be provided to help increase the effectiveness of self advocacy. The policy also states that there should be more careful scrutiny of the ways in which funding for advocacy is being spent to ensure that it is being used to promote better outcomes for people with learning disabilities (Department of Health, 2009). Buchanan and Walmsley (2006) write that the 'proposition' that all people with intellectual disabilities should have a 'voice' is implicit in the 'Valuing People' (2001) policy document, however they are concerned that an assumption may therefore be erroneously created that self advocacy organisations 'speak up' for and are representative of the views and interests of all people with intellectual disabilities (Buchanan & Walmsley, 2006).

Further they argue that if this is the case, then less time and fewer resources might be available to enable individuals to learn skills and enact self advocacy (Buchanan & Walmsley, 2006). Most recently, the impact of significant budget cuts across the British economy in response to the global financial crisis will test the political will to support independent voices and the disability sector's commitment to the funding of self advocacy in both the short and longer term (NDTI, 2013; Roulstone & Prideaux, 2012).

In January 2011, the National Forum of People with Learning Difficulties was commissioned by the Department of Health to produce what is essentially a survival guide for self advocacy groups. Entitled 'Staying Strong: taking self advocacy into the future', this document promotes the positive, inclusive activities of self advocacy groups but warns that in the future groups will need to be aware of a lack of public funding and a need for creativity in generating income to support basic expenses such as rent for meeting facilities, computer and phone access and use (National Forum of People with Learning Difficulties, 2011).

In the years during which Australian self advocacy has languished, a sophisticated network of over 1000 self advocacy groups has developed in England along with a recognised framework of representative decision-making over issues identified by people with intellectual disabilities as being important in terms of their inclusion and life quality. The emergence of Learning Disability Parliaments, in essence a hybrid form of structured self advocacy, were developed as an attempt to make services and politicians hear and incorporate the views and ideas of people with learning disabilities into policy and practice. There are also a number of emergent examples of user-led groups existing through selling their services rather than operating on grant funding (Deardon-Phillips & Fountain, 2005; Goodley, 2005). There is limited research about these newer forms of self advocacy and none which compares them either with independent or service-based groups to examine whether they produce different outcomes for their members.

Conclusion

People with intellectual disabilities remain marginalised in the community by the negative stereotypes and low expectations attached to their social identity (Bogdan & Taylor, 1994; Safilios-Rothschild, 1981). Whilst many strategies have been pursued to enhance their social inclusion, most have had limited or mixed success. Changing the ways in which the broader community thinks about people with intellectual disabilities is crucial to creating opportunities to enhance their engagement and presence and have a ‘good life’. Unless people with and without intellectual disabilities are valued as ‘equals’, then it is unlikely that inclusionary strategies will be successful (Ouellette-Kunz et al, 2010). Self advocacy offers individuals opportunities to have their experiences of being negatively ‘labelled’ heard (Caldwell, 2010) and to celebrate their ‘resistance’ and ‘resilience’ (Atkinson, 2002; Croft & Beresford, 1989). The ways in which self advocacy groups work to provide such opportunities and their impacts on the development of more positive social identities for individuals merits further examination. Criticism is often directed at the ways in which many groups are run, without examining the context in which power and control are being exercised and the extent to which self advocates themselves are experiencing very real positive changes in their social identity as a result of their engagement with the group.

What is also missing from the research on self advocacy is an interrogation of the differences in the experiences of self advocates in the Australian and the United Kingdom contexts. Compared with the United Kingdom, self advocacy in Australia has lacked policy and funding support and remains on a small scale. It would appear that people with intellectual disabilities are ‘missing out’ on opportunities for greater participation and inclusion through the lack of resources provided to support self advocacy in Australia. It is important that research in this area focuses on hearing first hand, the experiences of self advocates in both Australia and in the United Kingdom comparing the similarities and the differences in their stories. Whether and how their experiences have been different in the context of two different policy frameworks will offer insights into which frameworks best support the strength and growth of opportunities for engagement with self advocacy groups.

Chapter 3. Methodology

> "The challenge of social research is to construct powerful and instructive representations of social life that contribute to social theory (the ongoing conversations about social life), and at the same time embrace a breadth or depth of evidence about social life in a systematic way." (Ragin & Amoroso, 2011, p.78)

The aim of this research was to examine the experience of engagement in self advocacy groups by adults with an intellectual disability and the impact of self advocacy on their social identities. Participants in the study were drawn from the membership of self advocacy groups in Australia and the United Kingdom, and the study examined whether and how their experiences differed in the two different policy contexts and the implications of the findings for future support of independent self advocacy organisations.

Research Questions

There were five research questions;

What are the experiences of self advocates in independent self advocacy groups in Australia and the United Kingdom?

How have these experiences impacted on the social identity of the participants?

What are the policy contexts of independent self advocacy in Australia and the United Kingdom?

How do the experiences of self advocates differ in different policy contexts?

What are the implications of these understandings for the future funding and policy support of independent self advocacy in Australia?

Qualitative Research

The theoretical basis of this study was informed by symbolic interactionism and employed constructivist Grounded Theory methodology (Charmaz 2000; Morse et al, 2006, 2009). Symbolic interactionism is concerned with subjective meaning (Crotty, 1998) and "...deals directly with issues such as language, communication, interrelationships and community." (Crotty, 1998, p.12). Blumer (1969) describes symbolic interactionism as theory which sees that; "...human group life is a process in which objects are being created, affirmed, transformed and cast aside." (Blumer, 1969, p.12). The 'self-object' "...emerges from the process of social interaction..." (Blumer, 1969, p.12) and each human being is 'social' in what Blumer describes as a 'profound way' (Blumer, 1969). As Söder (1989) observes, the 'implications' of symbolic interactionism in the study of difference and disability have been examined by theorists like Goffman (1963), who provided insight into the powerful and negative ways in which categorisation and labelling lead to segregation. In this process, the "...characteristic of being disabled is ascribed to the whole person and all his other characteristics become interpreted in light of his disability." (Söder, 1989, p.119). Looking for examples of where social opportunities have been created which facilitate the development of both more positive labelling but also more positive ‘self objects’ (Blumer, 1969; Söder, 1989) was the aim of this study. This is important in the context of evidence which shows that people with an intellectual disability remain marginalised and excluded by negative stereotypes about their social identity (for example Beart, 2005; Dudley, 1997; Harris & Roulstone, 2011) and lack social space in which to develop more positive identities (Hall, 2005; Milner & Kelly, 2009).

The complex ways in which humans respond and act, and the way these acts are defined have important insights to offer this study which seeks to focus on the experiences of self advocates, the significance of these experiences and the possible impact on their social identity. In enacting self advocacy and through engagement with independent self advocacy organisations, there is potential for people with an intellectual disability to develop new skills and take on new roles, to see themselves in different contexts and for others to see them ‘in a new light’ (Poetz, 2003). The taking on of ‘roles’ is of itself a ‘symbolic interaction’ deriving from the ‘symbolic tools’ (Blumer, 1969) such as language which individuals use to create meaning and an understanding of the ways in which the social world is organised. For members of marginalised groups there is potentially great power in identifying social spaces in which positive rather than negative self-object roles can be created and enacted, and for research to seek to find examples of this and to identify the frameworks which may have made it achievable. Self advocacy groups appear to offer such self-authored social spaces.

Qualitative research design emphasises the ‘enhancing’ (Ragin & Amoroso, 2011) of data, using in-depth analysis of individual cases (Ragin & Amoroso, 2011) rather than positivist quantitative methods which may condense data in a way which risks limiting its analysis to a minimum number of variables and neglecting the subtleties and insights which might be gained from looking more closely at the lived experiences of a smaller number of research subjects. In keeping with the aim of this research to examine the experiences of individual self advocates, qualitative research using the lens of symbolic interactionism avoids the risk of ‘condensing’ data and compromising insights into the ways in which the participants understand their social worlds. Understanding the meanings individuals use to interpret social interactions offers a basis for developing a deeper understandings of the ways in which the damaged social identities of people with intellectual disabilities impact on their social inclusion. The symbolic interactionist perspective frames questions about how individuals deal with the meanings of social interactions and how these ‘interpretations’ may determine or change the way they deal with them (Blumer, 1969). This aim of this research is to turn this lens on self advocacy groups and to examine the interpretive approaches of self advocates.

For groups and individuals who lack a ‘voice’ in the community, qualitative research approaches may be able to offer ‘better representations’ of their experiences where these experiences have perhaps in the past been overlooked, disregarded, or ‘misrepresented’ (Ragin & Amoroso, 2011) and in this way seek to be inclusive. The focus of this research was on the life experiences of adults with mild intellectual disability. It was particularly important and appropriate in conducting research *about* their often marginalised life experiences that those experiences were not retold *without* their authentic voices and to seek to fulfil to the greatest extent possible in the context of a doctoral project, the maxim of many disability rights campaigns – 'Nothing about us without us' (Charlton, 1998; Jaeger & Bowman, 2005).

The positive advantages of qualitative approaches over quantitative designs include opportunities for the researcher to "...confront and come up against the constraints of the everyday social world." (Denzin & Lincoln, 2000, p.10). This is important in creating representations of the lived experiences of socially excluded or stigmatized groups like people with intellectual disabilities, and in creating research space in which they may offer and construct their own representations of their experiences. Ragin and Amoroso (2011) describe this kind of research as 'giving voice' and argue that using 'fluid' rather than 'fixed' analytic frames facilitates the hearing of the voices of often marginalised research subjects, offering the researcher newer, richer perspectives and insights (Ragin & Amoroso, 2011). 'Fluid' analytic frames direct the researcher "...where to look and what kinds of factors to look for without forming specific hypotheses about relationships among factors." (Ragin & Amoroso, 2011, p.77). The open research questions in this study were designed to provide the researcher with broad scope in hearing the voices and experiences of the participants avoiding narrow, positivist assumptions about their engagement with self advocacy groups or its impact.

Qualitative methods should produce research which offers new and interesting ways of 'seeing' existing and emerging cultural phenomena (Ragin & Amoroso, 2011).

The commitment of qualitative research to gather rich, emic data provides the basis for the ‘advancement’ of theoretical ideas to describe social phenomena (Denzin & Lincoln, 2000; Ragin & Amoroso, 2011). By gathering in-depth knowledge about the experiences of research participants, qualitative research can ‘elaborate’ and ‘refine’ the concepts which informed the initiation of the research. Not limiting the collection of data to a narrow frame at the beginning of the process of designing the research allows the researcher opportunities to look at emerging patterns and significance from rich, in-depth data (Ragin & Amoroso, 2011).

Grounded Theory.

Symbolic interactionism and Grounded Theory make a ‘powerful package’ (Clarke, 2005, 2006; Morse et al, 2009) because of the ways in which this theory and methodological approach are uniquely placed to ‘give voice’ to disempowered research participants, highlighting both the socially constructed nature of their disempowerment and providing examples of engagement, enrichment and self-determination (Charmaz, 2000; Morse et al, 2009; Ragin & Amoroso, 2011). Blumer (1969) writes that all social interaction is a ‘formative process’ “...that people in interaction are not merely giving expression to such determining factors in forming their respective lines of action but are directing, checking, bending and transforming their lines of action in the light of what they encounter in the actions of others.” (Blumer, 1969, p.53). The fluid nature of the social world is reflected in the Grounded Theory approach to methodology in the context of this research, and its focus on the ‘mutual’ generation of data (Charmaz, 2009) through the interactions of the researcher and research participants will produce resonant and useful insights into the lives of self advocates.

Inductive, constructivist Grounded Theory methods were used to collect and to analyse data gathered in this study. Charmaz (2000) writes that "...constructivist Grounded Theory celebrates first hand knowledge of empirical worlds..." (Charmaz, 2000, p.510) and furthermore it "...assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understandings of subjects' meanings." (Charmaz, 2000, p.510). Constructivist approaches to research are 'emergent' but are not 'atheoretical' (Rodwell, 1998). Theory "...is never selected as a guiding framework for hypothesis testing because no hypotheses are tested in constructivist inquiry." (Rodwell, 1998, p.36). Constructivist Grounded Theory seeks to 'locate' the activities of the research participants in broad social 'structures and discourses' looking for some of the assumptions which lie behind these actions and the ways in which the meanings derived from them reflect dominant social conventions, ideologies or power structures (Mills, Bonner & Francis, 2006; Morse et al, 2009). This approach to 'locating' meanings and actions within a socially constructed context enables a perspective which can highlight the connections between the 'subjective and the social' (Morse et al, 2009). The assumption of 'multiple realities' and a focus on research which examines the experiences of people 'in their natural settings' (Charmaz, 2000, 2006) are key features of this methodological approach. By always seeking the 'multiple perspectives of multiple participants', constructivist Grounded Theory "...can take us deep into the phenomena without isolating it from its social locations. Going deep into the phenomena allows us to gain intimate knowledge of it and to work inductively from this position." (Morse et al, 2009, p.146).

This approach is appropriate to a study of the engagement of people with an intellectual disability in self advocacy because of its focus on 'reflexivity' (Morse et al, 2009). Research using this approach actively 'seeks' "...and (re)represents participants' views and voices as integral to the analysis." (Morse et al, 2009, p.141).

Research Design

Research with people with an intellectual disability.

Shah and Priestley (2011) warn about what they describe as 'ontological drift' in disability research. That is, a danger that in focussing wholly on the first-person accounts of the lives of people with disabilities, there can be a 'de-politicisation' of the research. They argue that if there is a shift away from the underlying assumptions of the social model then there will be a return to a 'study of' approach which does little or nothing to highlight either structural disabling barriers or to inspire social change (Shah & Priestley, 2011). This research produced data which both valued and reflected the voices of individuals whilst acknowledging shared experiences of marginalization (Shah & Priestley, 2011). Self advocacy organisations are uniquely placed in their potential to offer opportunities for individual and shared voices and concerns to be heard.

Frawley's (2008) study of participation by adults in government advisory bodies highlighted an increasing emphasis on inclusive and participatory research with and about the lives of people with an intellectual disability in policy frameworks like *Valuing People* (2001) and *Valuing People Now* (2009). Others describe the importance of hearing the ‘lost voices’ of people with an intellectual disability (Atkinson & Walmsley, 1999) through actively listening to and engaging with the life stories of research participants. Atkinson and Walmsley (1999) state that they are not claiming to ‘recover’ lost voices, rather that they, through their research seek to “...tell a story, make a case, and to present some accounts that might otherwise not be heard.” (Atkinson & Walmsley, 1999, p.215). As these authors point out, it is worthwhile to aim to produce research which moves from a focus on ‘oppression’ to a focus on the experiences of ‘ordinary lives’ (Atkinson & Walmsley, 1999). Manning’s (2009) account of using oral history methods to gather and record the experiences of residents and former residents of Kew Residential Services in Melbourne, reveals some of the challenges inherent in researching with people with an intellectual disability (Manning, 2009). She observes the potential power of merging ‘personal testimony’ with the examination of other relevant evidence such as the examination of documents to produce insights into complex phenomena (Manning, 2009).

Defining independent self advocacy groups.

This research had as its focus, people who have been engaged in self advocacy within *independent* self advocacy organisations and it is important to identify what this term means in this context. There is considerable discussion in the literature on self advocacy which focuses on the variety of models which provide a framework to the way in which organisations operate. The gold standard for a number of authors for example; Bigby and Frawley (2010), Goodley (2000) and Simons (1992), is the ‘independent’ self advocacy group , sometimes also referred to as ‘user-led’ or ‘autonomous’. These groups are contrasted with agency-based, agency-led groups in which opportunities for enacting self advocacy may be far more limited in their scope (Aspis, 2002a; Bigby & Frawley, 2010; Goodley, 2000). The nature of funding to self advocacy groups from government agencies, philanthropic organisations and charity groups means that in some respects they can never be considered to be truly independent. There are examples of self advocacy groups who do generate income to support their own activities but these are rare. Whether it is possible to be the recipient of funding and be ‘independent’ in voice and action is a difficult question to answer. The defining feature deciding a group’s inclusion in this research rested on the question of governance. If a self advocacy group directed its own operations through a committee or board of management which was staffed by members of the self advocacy group, then it was considered ‘independent’ for this study. To use any other definition would have resulted in a tiny pool of potential research participants whose experiences would be important but not reflective of those of the vast majority of people with an intellectual disability involved in self advocacy.

Sampling and Recruitment

The research participants were adults with mild intellectual disability who were members of their respective self advocacy groups. All were members of groups where membership was only available to those with an intellectual disability and all had relatively good language skills. The study was comparative; participants were drawn from self advocacy organisations in Australia and in the United Kingdom. Australian approaches to defining intellectual disability have a focus on the social and the adaptive and move away from a medical model focus on impairment, incapacity and measurement of IQ, which had characterised policy development, support and service provision for many decades. Diagnosis of intellectual disability, then more commonly described as mental retardation, distinguished between borderline, mild, moderate and severe and profound levels of disability or incapacity (Parmenter, 2001). A ‘multidimensional’ focussed definition is now regarded as being more useful in determining need for supports (Australian Institute of Health and Welfare, 1997).

In Victoria, the *Disability Services Act* (2006) defines intellectual disability as “....the concurrent existence of: significant sub-average general intellectual functioning; and significant deficits in adaptive behaviour, each of which became manifest before the age of 18 years.” (Disability Services Act 2006, 16.1). Mencap, a major British charitable and advocacy organisation for people with intellectual disabilities prefers the terminology ‘person with a learning disability’, defining a learning disability as; “...a reduced intellectual ability and difficulty with everyday activities – for example, household tasks, socialising or managing money – which affects someone for their whole life.” (Mencap, 2013). For the purposes of this study, it was assumed that those research participants who identified themselves as members of self advocacy organisations established by and for people with an intellectual disability, met the criteria identified in current international definitions of intellectual disability.

Some of the research participants were members of United Kingdom self advocacy groups so it is important to include a note about terminology. Whilst many current British definitions of intellectual disability share the same focus as those already described (for example; Barnes, 2006; British Institute of Learning Disabilities, 2011; Mencap, 2013) they consistently use the descriptors ‘learning disability’ or ‘learning difficulty’. The descriptor ‘intellectual disability’ is consistently used in the Australian context. These terms were used interchangeably in this research project and where a particular term has been employed in the data gathered in interviews, in material produced by the self advocacy organisations, or in the literature, the choice of term will always reflect that chosen and used by the research participant, author or authors.

Grounded Theory approaches to data gathering involve two discrete forms of sampling processes. Firstly, initial sampling which “...establishes sampling criteria for people, cases, situations, and/or settings...” (Charmaz, 2006, p.100). Theoretical sampling, which follows this relates to ‘conceptual and theoretical development’, it looks at the complexities inherent in the initial sampling and leads to decision making about purposeful sampling of research participants to produce Grounded Theory (Charmaz, 2006). This kind of sampling does not aim for representativeness or generalizability and seeks to avoid collecting ‘unnecessary’ or ‘thin’ data (Charmaz, 2006).

Purposive and convenience techniques were used in this study to generate the initial sample of research participants (Charmaz, 2006; Rodwell, 1998). The researcher had met a number of self advocates and their supporters at meetings and conferences and in several disability service settings over a number of years and was connected to some other groups via social media. These contacts were a useful starting point and led to connections being made with other self advocacy groups who may have had members interested in taking part in this research. An approach was made by letter to the Chairperson or President of four self advocacy organisations within Australia and seven in the United Kingdom. A copy of the letter appears at Appendix 1. The letter explained the nature of the research project being undertaken and invited the addressee and other members of their organisation to participate. Further to this, email or phone contact was made with the offices of each of the groups, usually with the group's supporter or supporters. Due to geographic and time constraints it was necessary to limit the number of organisations represented in this study, but within those organisations there was considerable flexibility and scope for multiple individual respondents to participate in interviews if they expressed a desire to do so. Regular contact with two groups in Australia and six in the United Kingdom was established. This was contact was by phone call, email and with one group 'Skype' was also used. Contact was with group members and with supporters. Two of the United Kingdom groups then ceased their involvement, with one supporter saying that members of the group she worked for did not want to participate having recently been involved in another research project. The other group which withdrew did so as a result of the imminent closure of their group offices due to removal of funding by their local authority and uncertainty about when or if they may be able to re-establish the group. The remaining six groups were sent sample copies of consent forms and an outline of the questions that would be asked in the interviews. See Appendix 2 for a copy of this document.

Interviews were also conducted with supporters of the groups of which the self advocates were members. A total of ten supporters were interviewed across all six groups. Supporters from all groups with the exception of Red Group were part of the initial contact the researcher made with the groups at which time all were asked if they would like to participate in interviews. Additional interviews were conducted with five 'commentators' (named in the acknowledgements) who had knowledge and insights into the policy landscape with respect to self advocacy, as well as three self advocates not currently members of any group but who have had long involvement with self advocacy and the broader disability movement.

Rodwell (1998) warns that whilst convenience sampling is 'accepted and important' as a way of overcoming issues of time or cost for example in an international comparison study like this one, the 'maximum variation goal' should remain in the mind of the researcher (Rodwell, 1998). It was important that in approaching self advocacy organisations that initial contact encouraged the participation of the leaders and office-bearers of such groups and that they in turn were encouraged to promote the inclusion of rank and file group members who may have quite different experiences and stories to tell the researcher and whose voices may usually be unheard. The 'serial nomination' of participants by other research participants has the potential to produce important emergent data categories and add to the richness of the material produced (Rodwell, 1998). In my contact with the supporters, I also encouraged them to invite a diverse range of group members to participate in the interviews. The sample achieved a mixture of gender, age and diversity in the range of roles and activities in which the group members had participated. Ten of the interviewees were female, with an average age of thirty five years, fifteen were male, with an average age of thirty nine years. The age range was twenty one to fifty four years. One of the male interviewees declined to give his age and is therefore excluded from these figures. Table 1 shows the participant details and Table 2 shows details about the six groups in the study. Self advocates, supporters and their groups have been de-identified.

Table 1

Interviewee Characteristics

Group Name	Interviewee	Gender	Age
Red Group	Rita	Female	51
Red Group	Liam	Male	31
Red Group	Daniel	Male	47
Red Group	Anne	Female	23
Magenta Group	Yvonne	Female	38
Magenta Group	Howard	Male	34
Magenta Group	Tony	Male	42
Magenta Group	Laura	Female	26
Magenta Group	George	Male	32
Magenta Group	Sophie	Female	31
Indigo Group	Audrey	Female	48
Indigo Group	Darren	Male	33
Green Group	Trish	Female	47
Green Group	Nick	Male	54
Green Group	John	Male	32
Green Group	Kevin	Male	54
Green Group	Henry	Male	53
Green Group	Frank	Male	49
Blue Group	Nella	Female	25
Blue Group	Ben	Male	? *
Purple Group	William	Male	45
Purple Group	Emma	Female	21
No current group	Celia	Female	43
No current group	Trevor	Male	34
No current group	Oscar	Male	46

? * Interviewee declined to give age.

Table 2

Group Characteristics

Group	Location	Office Type	Supporters	Training for Members	Social Activities for Members	Paid Employment Opportunities	Voluntary Employment Opportunities
Red Group	Rural town (Aust.)	Co-located with advocacy service	2 casual	Yes	No	No	Yes (with payment for travel costs)
Magenta Group	Urban Centre (Aust.)	Self-contained	1 part-time	Yes	Yes	No	Yes
Indigo Group	Rural village (U.K)	Self-contained	1 full time, 3 part-time	Yes	Yes	No	Yes (with payment for travel and meals)
Green Group	Major city (U.K)	Self-contained	1 full-time, 2 part -time	Yes	Yes	Yes	Yes
Blue Group	Urban centre (U.K)	Co-located with advocacy service in high support-needs disability service.	1 full-time, 2 part-time	Yes	Yes	No	Yes (with payment for travel and meals). Gift vouchers sometimes used as 'thank you' for public speaking or meeting attendance.
Purple Group	Rural village (U.K)	Co-located with advocacy service and health clinic.	2 part-time	Yes	Yes	No	No

Data Collection

The research involved the collection of qualitative data through semi-structured interviews with self advocates from six self advocacy organisations, two in Australia and four in the United Kingdom. Supplementary data collection involved the examination of documents such as newsletters and annual reports, websites and social media produced by self advocacy groups which provided important background information for the researcher. Having some prior knowledge of the activities of the groups contributed strongly to the researcher's ability to be able to ask relevant questions and seek clarification from interviewees. Showing a strong interest and desire to find out information about the groups and their members prior to meeting them for the first time was also useful in building rapport and goodwill in the relationship between the researcher and the interviewees.

Conducting interviews with self advocates.

Atkinson (2002) describes participation in research as the opportunity for people with intellectual disabilities to be 'authors' of their own stories and self advocacy as the driver of a desire to do so (Atkinson, 2002). Interviews provided an opportunity to hear and record peoples' experiences of involvement in self advocacy first hand. In a Grounded Theory approach, intensive interviewing allows researchers 'analytic control' over their material (Charmaz, 2000, 2006). "Qualitative interviewing provides an open-ended, in-depth exploration of an aspect of life about which the interviewee has substantial experience, often combined with considerable insight." (Charmaz, 2006, p.28-29). Interviews seek to gain insights into the 'subjective' world view of the interviewee and because of the flexible, open-ended nature of this method it is possible to ‘pursue leads’ which may provide rich or unexpected perspectives or information (Charmaz, 2006). The goal is always to pursue ‘extensive’ and ‘rich’ data with ‘thick description’ (Charmaz, 2000). Rodwell (1998) describes the constructivist research interview as a “...context-embedded conversation with a purpose.” (Rodwell, 1998, p.122). The purpose is for the researcher to ‘hear’ the ways in which the people participating in the research ‘make sense’ of their lives (Ragin & Amoroso, 2011). Grounded Theory interviewing adds a level of purpose beyond other in-depth interviewing as it seeks to remain fluid in approach by continually reviewing and refining the ‘range’ of interview topics in light of the emergent data (Charmaz, 2006).

Charmaz’s (2006) model of conducting interviews includes the following key features; initial open-ended questions, for example; ‘tell me about what happened when...’, ‘could you describe the events that led up to...’ (Charmaz, 2006, p.30). These are followed by intermediate questions, for example; ‘how would you describe the person you are now...’, ‘what has been helpful to you at this time?’ (Charmaz, 2006, p.31). Ending questions follow which should seek to bring the interview to a positive close (Charmaz, 2006). Critical to gaining rich data is the ability of the interviewer to pay close attention to the ‘comfort level’ of the interviewee, to ensure a rhythm to the interview which avoids an ‘abrupt’ ending, to avoid ‘forcing’ the data by trying to pursue lines of questioning which do not reflect the lived experience of the interviewee and by using appropriate language (Charmaz, 2006).

There are important additional issues to consider in research in which the informants are people with an intellectual disability. As with all interviewing, it is essential to seek to establish rapport, ensure that the interviewee is physically comfortable and not feeling under pressure either to participate or to provide particular information to the researcher. However, there is particular need for the interviewer to be sensitive to the use of appropriate and accessible language and to use terminology which is familiar to the participants in the context of their life experiences (Atkinson, 1997, 2002; Booth, 1996; Walmsley, 2004). A ‘flexible’ approach and ‘responsiveness’ to the social context of the research participants is important (Darlington & Scott, 2002). Allowing and encouraging the research participants to use their own choice of words to describe their experiences and to ‘give voice’ to their social context, ideas and agendas is important in generating data which offers new and emancipatory insights into marginalised lives (Atkinson, 1997, 1999, 2002; Atkinson & Williams, 1990; Goodley, 1996, 2000; Ramcharan & Grant, 2001).

It was important that the style and content of the interview questions were appropriate for the research participants and that interviewees felt that their views were both valuable and of interest to the researcher (Lewis & Porter, 2004). Goodley (1996) emphasises the importance of the researcher being ‘sensitive’ and both aware of their own assumptions about the research participants and their power (Goodley, 1996). Whilst Goodley’s (1996) concerns about researcher bias and power are focussed on life history research, they are relevant to this study which seeks to gather ‘stories’ of informants experiences of self advocacy. Grounded Theory approaches also seek to ‘faithfully reproduce the ‘reality’ of research participants

(Goodley, 1996) and therefore great care needed to be taken to avoid the researcher disempowering them by "...imposing their own assumptions, understandings and ambitions upon the stories that emerge." (Goodley, 1996, p.345). Goodley's (1996) conclusion is that research which is inclusive of the voices of people with an intellectual disability is incredibly important particularly because of the contribution it makes to the self advocacy movement (Goodley, 1996). He writes that from "...self-disclosure and reflection self advocates may form a solid base of identity from which they may continue to grow." (Goodley, 1996). The self advocates are uniquely placed as 'Experts', with a capital 'E' as denoted by Knox, Mok and Parmenter (2000), to offer insights into their own lived experiences and have their voices heard.

In some instances, particularly in the case of the United Kingdom based self advocates, opportunities to establish rapport and trust between the researcher and interviewees was limited by lack of prior face-to face contact. The researcher sought to overcome this as much as practically possible via the use of phone, 'Skype' and email contact and through social networking sites like Facebook where some groups had a strong presence. The use of 'supports' (Lewis & Porter, 2004) such as documents produced by the self advocacy organisations, timelines and photographs gathered before I visited each group were extremely useful in developing rapport, prompting conversations, and evoking memories of events for the participants.

Supporters were present at the interviews of eight of the twenty five self advocates interviewed for this research. They were present at the request of the interviewees. Whilst it was not the preference of the researcher to have supporters present in any of the interviews, the choice of the individual self advocate to include them was respected. In each of those interviews, the supporters offered opinions and comment but did so in such a way which seemed to encourage rather than stifle contributions from the self advocate interviewees. It is of course not possible to know what differences there may have been in the commentary offered by the self advocates if the supporters had been absent. The presence of the supporters was helpful in providing some prompts and reminders to the self advocate interviewees about past activities and involvement, but it was possible to replicate this kind of assistance in the other interviews where supporters were not present by using alternative prompts such as printed material including newsletters or posters produced by the group which served to remind people about particular features of their group. Having knowledge of the group and its activities prior to conducting the interview was invaluable in being able to start conversations with the self advocates and their supporters and was helpful in establishing a level of comfort and trust in the interactions necessary to facilitate the interview process.

The interviews were relaxed and informal, taking place in the offices of each of the groups. Many cups of tea, biscuits and cake were shared during the interviews, contributing to a friendly atmosphere with an exchange of information which was more like an informative conversation than an interview. The self advocate interviewees were asked to talk about the kinds of activities they had been involved in with their group, the highlights of those experiences and to provide some commentary on the ways in which self advocacy groups might have changed and what they might be like in the future. These broad topics were covered in each of the interviews and formed a framework for a wide ranging conversation about both the lives and experiences of individual members and the nature of their respective self advocacy organisations. Interviews varied in length from forty minutes to four hours. All of the participants agreed to have their interviews recorded, with many showing interest in the technology used to make the recording – the author's 'iPhone', wanting to be the person responsible for switching it on at the beginning of the interview and off at the end. The participants showed curiosity about the author, asking many questions, and it was helpful that they seemed so relaxed and confident in doing so as this contributed strongly to the establishment of a positive dynamic in the interview process, breaking through the formality of the interviewer/interviewee relationship. The United Kingdom participants were most interested in questions about the length of time it had taken to fly from Melbourne to Britain, the weather in Australia and the famed ferocity of the wildlife. A number were also interested in self advocacy in Australia, asking insightful questions about the number of groups and their funding support.

Interviews with supporters.

Interviews with supporters also took place in the offices of the self advocacy groups. Interviews followed the same format as those with the self advocates. They were semi-structured and supporters were asked about their experience in working with their respective group, positive and negative features of the group and its organisation, personal highlights and their knowledge and understanding of the impacts of group engagement for members. Supporters were also asked to describe what they thought was the future of self advocacy and about their opinion of current policy and funding support. Interviews were recorded with the consent of participants.

Interviews with commentators.

Interviewees were also conducted with five commentators whose views were sought on both the history and current state of self advocacy policy and funding and about the future of self advocacy groups. These interviewees are named with their consent. These commentators were chosen because they have contributed to the literature about self advocacy groups in Australia or the United Kingdom or because they have been long-term supporters of a group or groups. The information and insights they provided made a useful contribution to the development of a context in which to place the experiences of the self advocacy group members. Interviews were recorded with the consent of the participants.

One-shot interviews.

This research had to rely on what Charmaz (2006) describes as ‘one-shot interviews’ (Charmaz, 2006). The challenges which arose in arranging and carrying out the interviews because of geographic spread of the research participants highlighted the importance of gathering as much information about the self advocates and their self advocacy organisations prior to visiting them to conduct the interviews. In most cases it was not possible for the researcher to return to the study site so it was vital that every effort was made to facilitate an effective interview (Charmaz, 2006; Rodwell, 1998). Whilst some minor issues arose, for example a high level of background noise in one interview site which was quickly resolved, interviews proceeded smoothly.

There are implications for data saturation when opportunities for extended or further interviews are limited. Careful preparation and effective interviewing techniques were used to mitigate possible negative impacts on the collected of rich data and to achieve saturation to the greatest extent possible.

Observation.

Not all of the time spent by the researcher in the self advocacy group offices was spent interviewing. Opportunities to chat less formally with members and supporters occurred in all of the groups and this was important in establishing rapport and gaining a broader understanding of the way in which the groups functioned. It was also helpful to observe the nature of the relationships between members and between members and supporters. Two groups invited the researcher to observe activities away from the group offices and these offered further interesting insights into the work those organisations were doing around community education and offering social opportunities for members. No sound recordings were made of conversations in these settings. Reflective notes were made by the researcher at the end of each day with these groups.

Ethical issues.

This research was given ethics approval by the La Trobe University Human Ethics Committee on 21st July 2011. It conforms to the ethics guidelines of the National Health and Medical Research Council (NHMRC) and the code of ethics of the Australian Association of Social Workers (AASW).

The issue of informed consent is complex in any research but especially so when the participants are people with an intellectual disability. Four key principles underpin the AASW's (2002) guidelines for social work research, the first involving consent. It was made clear in all communication with the self advocacy groups that participation in the interviews was completely voluntary and that individuals could choose at any time to discontinue their involvement in the research project.

Interviews were recorded with the knowledge and consent of the research participants. Participants were given as much information about the proposed study, including the use of material gathered in the interviews, as possible. The interviews were transcribed and the transcripts made available to the research participants on request. Recordings and transcripts are being securely stored by the researcher. It was hoped that by providing as much information as possible to the participants in an accessible form, that they were able to comfortably make an informed choice about engaging in the research or withdrawing their consent to participate or use material collected if they later changed their mind. Copies of the consent form and withdrawal of consent form appear as Appendices 2 and 3.

The second principle in the AASW (2002) code of practice concerns ‘harm’. The researcher ensured that she acted in a way which guarded against participants being exposed to physical harm or to psychological harm either through stress, embarrassment or being placed under pressure to speak or to act in ways which they found personally unacceptable (AASW, 2002).

The third principle is the confidentiality of identifiable information. All information about the identity of individual research participants will remain private by the researcher keeping the subjects anonymous in the presentation and discussion of data and safely storing collected data. The self advocacy groups of which the research participants are members will also not be identified by name in the research as this would unavoidably lead to the identification of individuals (Lewis & Porter, 2004).

The fourth and final principle concerns the prevention of deception (AASW, 2002) which states that people participating in research should not be misled by the researcher about the purpose or nature of the project (AASW, 2002). It was particularly important in a study involving people with an intellectual disability that extra care was taken to ensure, to the greatest extent reasonably possible that participants understand the nature and scope of the research and their involvement (AASW, 2002). This was done by providing accessible information to potential interviewees and their support workers and by carefully reading through and discussing the information (in most cases several times) with participants before commencing the interviews and again at the end of the interview process.

Data Analysis

In Grounded Theory approaches to research, analysis of data begins ‘early’ (Charmaz, 2000, 2006). Through coding and through memo-writing, the researcher keeps ‘studying’ the data, building ideas inductively and ‘deepening perceptions’ about the overall research problem (Charmaz, 2000). Charmaz (2000, 2006) argues that the process of initial coding of collected data assists the researcher to “...remain attuned to our subjects’ views of their realities, rather than assume we share the same views and worlds.” (Charmaz, 2000, p.515). Grounded Theory looks for ‘patterns’ in the data, even within single case examples, and through early coding and thoughtful memo-writing this approach was effective in uncovering some of the ‘implicit’, ‘unstated’ and ‘condensed’ meanings in the self advocates’ telling and re-telling of their experiences (Charmaz, 2006). Coding in Grounded Theory begins by using a ‘line-by-line’ approach which seeks to produce emergent categories rather than trying to make the data ‘fit’ what Charmaz (2000, 2006) describes as ‘preconceived or standardised codes’ (Charmaz, 2000). By carefully examining the data in this way ‘sensitizing concepts’, for example ‘who is exercising power in the group?’ emerged which offered insights into the experiences being described and contributed to a refining and development of analysis and emergent theory (Charmaz, 2000). Whilst this piece of research did not engage with people with an intellectual disability as co-researchers (Bigby & Frawley, 2010; Bjornsdottir & Svensdottir, 2008; Chapman, 2005), it did seek to try to ‘give voice’ to them, and it was important that in coding data that care was taken to represent the meanings held by the participants to the greatest extent possible.

Memo writing.

Memo writing is a feature of Grounded Theory methods and was an important feature of the research process in this project as it helped to refine the early analysis and identify emerging themes which could then be explored in later interviews. Charmaz (2000, 2006) describes memo-writing in Grounded Theory research as being an opportunity for the researcher to 'conceptualize' the data in a narrative form. The concepts emerging from memo writing were then useful in building codes in analysis. Charmaz (2006) describes memo-writing an 'intermediate step' between the coding of data and the process of drafting and completing the analysis of the data. Memo-writing prompted the researcher to analyse the ideas about coding the collected data, 'capturing' the emerging 'comparisons and connections' and clarifying approaches needed to gather useful data (Charmaz, 2006). Memos provided a record of the analytic process in Grounded Theory research and served as useful prompts to understanding areas of weaknesses in coding, categories or approaches in gathering rich data (Charmaz, 2006).

Four examples of memo writing are provided below:

> Memo.18th August 2011. Showing everyone we can run an office. Red Group
>
> I am very struck by the talk today about 'running an office'. All of the group members are strongly focussed on 'doing things right' – and this seems to be defined by the appearance of the office surroundings, the dress and conduct of the members and a strict adherence to rules. And they have rules for

everything! Although there was a lot of talk about having fun and enjoying themselves, the self advocate always came back to the importance of the rule book and making sure that everyone knows and understands its content. The identity of this group and its members are bound up in ideas about being business- like in the way they go about things.

Memo. 23rd September 2011. We're not sure about the future. Purple Group.

I had a long conversation with William this afternoon. He says that the group is 'bone dry for money' and may have to close or maybe join up with another in the area. Life would be 'pretty bloody boring' without the group he said. Talking to the support worker later, she agreed. Things were looking grim and she felt that she had few options left to find even a small grant to keep things going.

Memo. 7th October 2011. Having the last laugh. Green Group.

Henry's story about his former day centre manager stood out as an example of complete triumph – as he was telling me, he was laughing so hard that tears were running down his cheeks. He explained that he had worked for many years in a sheltered employment setting within a local day service. The same man had been manager all of that time and Henry had approached him on a number of occasions about support to look for work. The manager had said dismissively to Henry – 'you'll never get a job'. Henry is currently working for the self advocacy group, doing office work and loving every minute of it. He recently saw his old centre manager/supervisor and they'd had a conversation during which Henry had proudly told him that he had a job. The centre manager seemed 'surprised' according to Henry and then revealed that the day centre had recently shut and that he had been made redundant. The absolute glee with which Henry told me this was palpable. He said 'I think that's what you call having the last laugh'! For Henry, being a worker, having a paid job and the responsibility and trust which are implicit in his holding of that role is clearly incredibly important to him. He had told the story many times before and said he would like to tell everyone 'in the world, even in Australia'!

Memo. 11th October 2011. Being acknowledged. Blue Group.

Two of the self advocates I interviewed today talked at length about the importance of being recognised and acknowledged for themselves and also because of the work they have done in talking to school groups. For one, a veteran of many years of giving talks to lots of different schools in the area, his long involvement meant that children had met him multiple times over the years as he visited to address their class in primary school and then years later in secondary school 'They remember me' he said proudly 'and they remember that I tell them that I'm a human being, just the same as them, although I know a lot more about some things than they do'. Nella, who is less experienced in talking to school groups has already had an experience

> which has delighted her. She told me that she was recognised by a couple of girls who'd been in a group at a school she'd visited. They were in Tesco's [supermarket] at the same time and had come up to her at said 'Hi', and 'how you been?' This friendliness had clearly moved Nella, she was beaming as she told me about what had happened.

Coding.

Interviews were recorded and then transcribed, with the transcripts then loaded into NVIVO 9. Coding began early and was undertaken on a line by line basis in three stages, beginning with initial, descriptive categories and developing these into significant focussed categories following the constructivist Grounded Theory approach of Charmaz (Charmaz, 2006). Initial coding stayed 'close to the data' (Charmaz, 2006), carefully looking at the observations of the research participants and beginning the process of defining the key themes and threads and producing 'In Vivo' codes. The second stage involved focussed coding. The codes in this stage were more 'directed' and 'selective' (Charmaz, 2006), moving away from line by line analysis to look at larger chunks of data and deciding which of the initial codes will be most useful in building the next level of categorisation. Theoretical coding was the third stage of analysis and over time allowed the researcher to develop a Grounded Theory model of the ways in which self advocacy groups work to build more positive social identities for people with intellectual disabilities.

Figure 1 and *Figure 2* illustrate the process of coding the data collected in this study. The examples used are of the development of the codes 'Business-like identity' and

‘An Expert’, and show how initial and then focussed codes were used to refine categories to produce elements of the Grounded Theory model presented in Chapter 5. Findings.

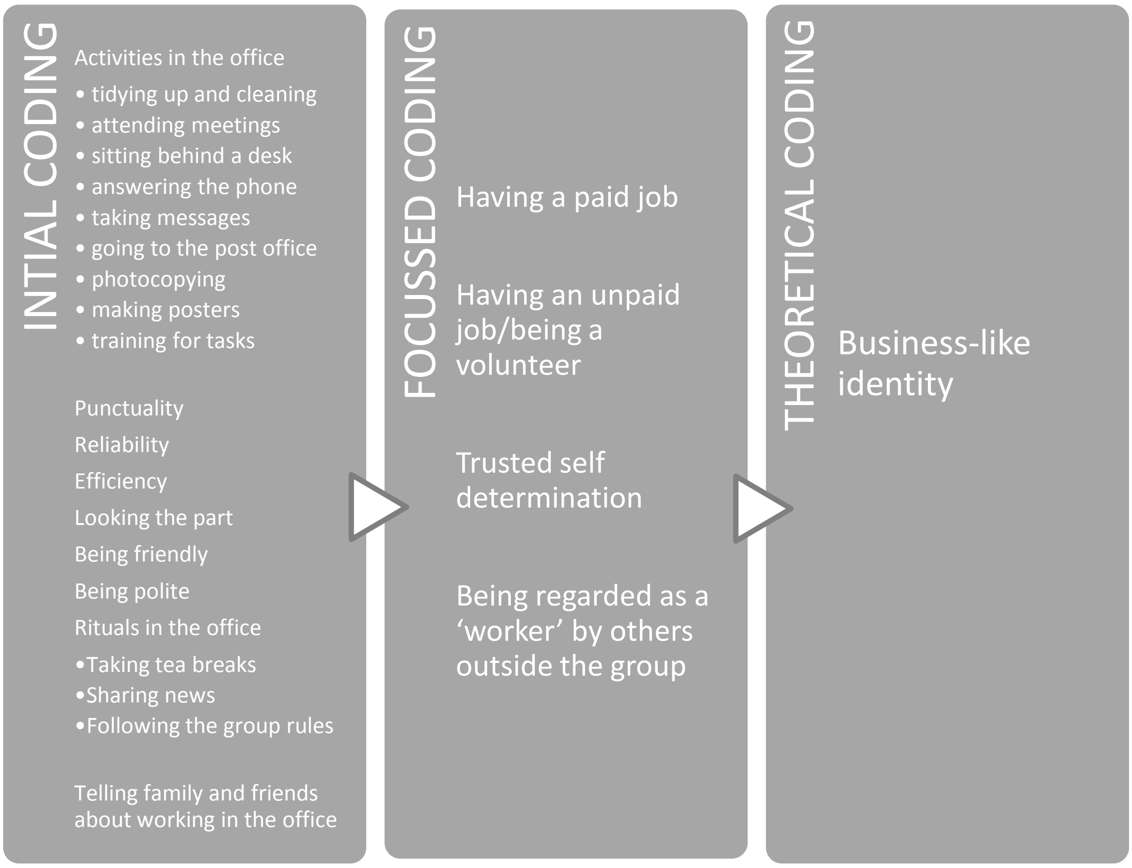

Figure 1. The process of coding data to develop the theoretical code 'business-like identity'.

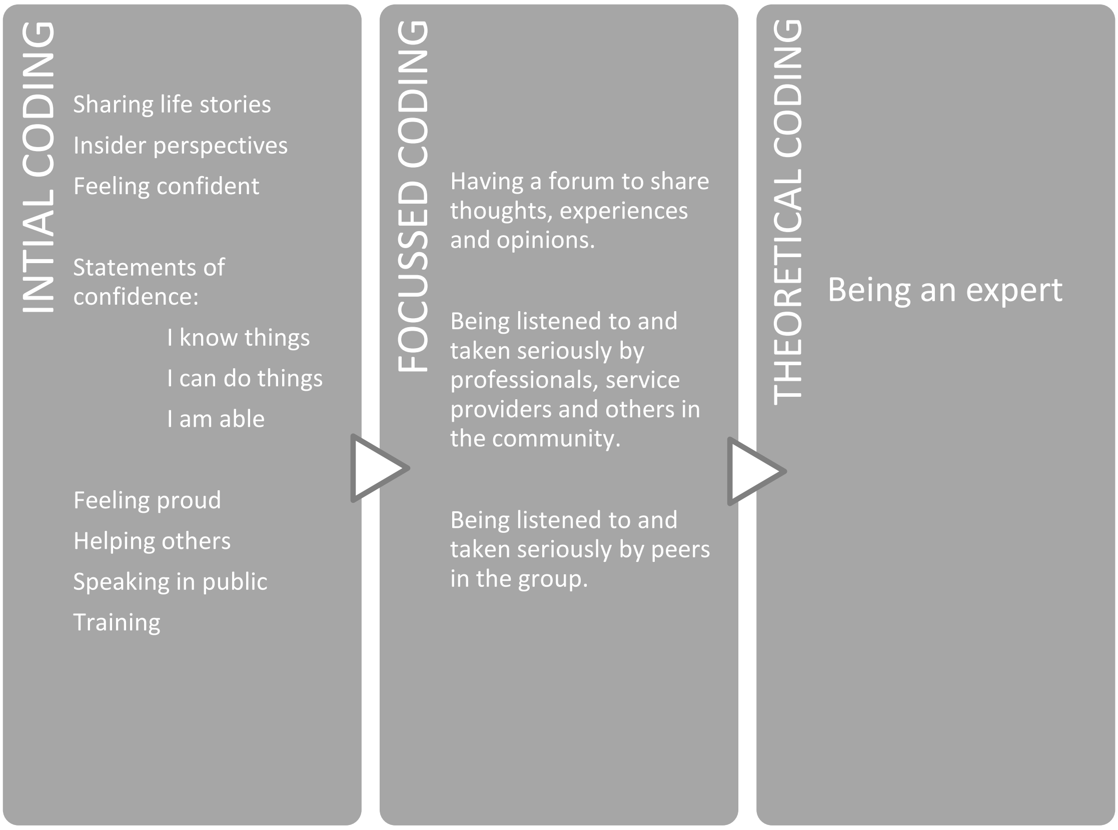

Figure 2. The process of coding data to develop the theoretical code 'an expert'.

The process of analysis was lengthy and the steps described above were what Charmaz (2006) describes as being part of an 'interactive process' which involved defining, refining and redefining codes and categories in some cases many times over. This process was important in trying to better understand the interviewees' views and actions from their perspective (Charmaz, 2006) to the greatest extent possible. The results of the analysis are found in Chapter 4. Findings.

Saturation.

The question of saturation in Grounded Theory is complex. Grounded Theorists are in Charmaz's (2006) model, looking for 'theoretical saturation' to occur, at which point they stop collecting data. Analytic categories "...are 'saturated' when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories." (Charmaz, 2006, p.113). 'Saturation' as it is defined here differs from other definitions in qualitative research which focus on 'repetition' or 'redundancy' (Ragin & Amoroso, 2011). It is important to strive for 'theoretical sufficiency' (Charmaz, 2006) by not forcing collected data into 'preconceived' categories and to be open to building interpretative understandings from a sufficiently representative research sample (Charmaz, 2006; Ragin & Amoroso, 2011). Based on information from the groups' supporters, the participants in this study were 'sufficiently representative' of their groups to enable the development of emergent theory based on their experiences. Underpinning the study was a commitment to obtaining as many different perspectives on individual experiences of engagement with self advocacy as possible give the constraints of time and geography.

Trustworthiness.

Trustworthiness in a qualitative study is achieved by the application of evaluative criteria which seek to establish credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). One of the ways in which Lincoln & Guba (1985) suggest that credibility in the research can contribute to its trustworthiness is through the use of well established research methods. The Grounded Theory methods employed in this study have been successfully used in comparable research in the field of intellectual disability and in self advocacy (for example; Beart, Hardy & Buchan, 2004; Knox, Mok & Parmenter, 2000). The development of an 'early familiarity' (Shenton, 2004) with the culture and organisations of each of the groups was important in establishing a relationship of trust between the researcher and potential participants before any data was collected. Rich, thick descriptions emerged from the data collection facilitated by the established of a strong rapport with interviewees and the use of iterative questioning informed by prior knowledge of the group context. Use of memo writing (Charmaz, 2000, 2006) contributed to a process of 'reflective commentary' which Lincoln and Guba (1985) argue is an important element in establishing credibility. Member checking was limited due to the geographic constraints of the study, but the researcher remained in contact with some of the members and supporters of each of the groups by phone or email, providing some feedback about the progress of the research. All interviewees were offered a copy of the sound recording made of their interview or the transcript. Debriefing was provided by the supervisors of the research and was important in providing a 'sounding board' for the researcher to test her ideas (Shenton, 2004).

Descriptions of the groups with which individual interviewees were engaged provides background data important in allowing transferability (Lincoln & Guba, 1985; Shenton, 2004) and these appear in Chapter 4. Research Participants. Interviews with commentators who each had long involvement with self advocacy provided a variety of nuanced perspectives which contributed valuable contextual information to the study.

Dependability was established through the provision of detailed description of research methods employed, enabling the study to be repeated (Lincoln & Guba, 1985; Shenton, 2004) or an inquiry audit to be undertaken (Miles & Huberman, 1994).

Confirmability was established through triangulation, with the researcher and supervisors jointly examining and discussing interview transcripts and critically reflecting on the development of a Grounded Theory model. Methodological triangulation occurred through the use of multiple data sources; interviews, field notes from observation, memo writing and examination of documents developed by the self advocacy groups. Site triangulation was achieved by using multiple sites in both urban and rural locations in both Australia and in the United Kingdom.

Limitations of This Study

This piece of research was essentially exploratory in nature (Finestone & Kahn in Polansky, 1975). Whilst rich data was sought and collected, it was from a small sample, and recruiting equal numbers of groups from Australia and the United

Kingdom was not possible. Using Grounded Theory approaches to both data collection and analysis produced material which is representative of the life experiences of the individual participants but may not be generaliseable to the experiences of all in the peer population. It is hoped that through listening ‘with openness to feeling and experience’ (Charmaz, 2000), insights were gained in this study which highlight positive impacts on the social identity of adults with intellectual disability through their engagement in self advocacy and membership of independent self advocacy organisations. Possible implications for policy support and funding for independent self advocacy organisations also emerged from the data collected for this research. These are discussed in Chapter 6. Discussion.

Summary

The research has employed Grounded Theory techniques in gathering and analysing data. This qualitative methodological approach was chosen as a means of ‘giving voice’ to the research participants (Ragin & Amoroso, 2011). Data collection methods included semi-structured interviews, observation and memo writing and produced rich data, enabling the development of a model of the way in which self advocacy groups work to build more positive social identities for people with intellectual disabilities. The findings of the research and the model are described in Chapter 5. Findings.

Chapter 4. Research Participants

This chapter provides descriptions of the six self advocacy groups included in this study. The names and locations of the groups have been de-identified.

Four of the groups were in the United Kingdom and two in Australia. Common to all groups was leadership by a committee of management with self advocate office bearers and members. All of the groups had their own offices although these varied tremendously in size, from a suite of rooms with office space and meeting rooms at one extreme, to a single office with only enough room to accommodate one desk, at the other. Three of the groups shared their accommodation with an advocacy service, one was located in a city-based office building with other community organisations as co-tenants, one had offices located within an 'Independent Living Centre' and one within a special needs disability support service. All of the groups had paid supporters.

Red Group (Australia).

Red Group is based in a large country town and occupies a small office within the larger offices of an advocacy organisation. The offices are in an old house which has been converted, with space for minibus and car parking at the front as well as a wheelchair ramp. The building is in a side street leading off the town's main shopping strip and is close to the railway station and bus stop. Workers from the co-located advocacy organisation provide casual support to the group by identifying and writing funding submissions, assisting in the delivery of training programmes for members and facilitating some networking activities with other self advocacy groups in the region. Five members of the group regularly staff the office of the group on a voluntary basis for two days per week, answering phone calls and writing emails. One of these members is very interested in social media and has set up and manages the group Facebook page. Red Group holds monthly ‘speaking up’ meetings which are attended by up to forty members and these meetings regularly feature individual members making speeches about their life experiences, as well as visits from guest speakers who are usually service providers. Additional to these large meetings, there are meetings of smaller groups, described by the members as the ‘a’ group of experienced and long-standing members, and the ‘b’ group made up of newer members. Red Group has on paper, two committees of management as there are elected self advocate leaders of both the ‘a’ and ‘b’ groups, however it is the ‘a’ group management committee which makes the significant decisions in relation to the organisation’s activities. The rules of Red Group are very important to its members and a significant amount of group activity is focussed on developing, revising and reinforcing group rules. Other activities of the group include a peer-led sexuality education programme which involves a small number of members. The group receives government funding which covers the rental coats of office space and equipment and the wages of two casual support workers. It has undertaken a small amount of fundraising but does not generate income from any of its activities.

Interviewees from Red Group: Rita, Liam, Daniel, Anne (self advocates), Liz and Ruth (supporters).

Magenta Group (Australia).

Magenta Group is based in a regional town centre and is one branch of a large self advocacy organisation. The group operates independently of the other two branches, having its own elected management committee and office bearers. The office bearers also represent the group at meetings of the larger organisation and the position of 'President' of the larger group is open to members of any of the three branches. This is an elected position and has only once been held by a member of Magenta Group. Magenta Group employs a supporter who divides her time between co-ordinating the activities of the group and providing advocacy services. The organisation is funded primarily to provide advocacy services, so that self advocacy activities are supported by short term project monies generated through submission writing, sponsorship or a small amount of fundraising. The group holds monthly meetings for its seventy members and offers opportunities to participate in special projects which have a focus on personal growth and development. Funding specifically targeted at improving women's health has generated a number of projects aimed at enhancing the well being and inclusion of younger women with intellectual disabilities. A highlight for members is the Magenta Group's annual conference which provides an opportunity for members to meet with self advocates from the other two branches of the organisation and to participate in a wide range of activities which could include workshops on topics as diverse as discrimination and bullying, to responsible pet ownership. Members of the management committee have a strong interest in social media and use social media sites such as Facebook to communicate with self advocates spread across their region.

Interviewees from Magenta Group: Yvonne, Howard, Tony, Laura, George, Sophie (self advocates), Jenny (supporter).

Indigo Group (United Kingdom).

Indigo Group is based in a small rural community. Its offices, which include administrative space and a large meeting room, are co-located with a range of disability advocacy organisations. The group is supported by a small team of support workers which includes a business co-ordinator and an advisor/director. The group has an active management committee of elected self advocate members which meets regularly, and one hundred and ten active members. A ‘speaking up’ group meets monthly and the group additionally runs special topic forums and consultations for and with its members on subjects like hate crime and independent living. Indigo Group has recently begun a young person’s group offering social activities as well as opportunities for ‘speaking up’. The group employs a number of people with learning disabilities who are also group members, in a variety of roles, including administration and the production of resources such as multimedia presentations and posters. Funding for the group is mostly project based and comes from local government. Additional income is generated through the sale of training resources and courses in collaboration with three other self advocacy organisations. Indigo Group also promotes itself in the local community through brochures offering a range of other services which may generate funds for the group; working on service brochures and documents to make them jargon free and ‘easy read’, offering advice about recruitment of people with learning difficulties, workshop facilitation and user-led service audits.

Interviewees from Indigo Group; Audrey, Darren (self advocates), Charlotte and Simone (supporters).

Green Group (United Kingdom).

Green Group is based in a major city. It has its office in a multi-storeyed office building which is co-tenanted by a range of non-government organisations, including several advocacy services for people with physical disabilities. The group has one hundred and forty members, about half of whom participate regularly in activities and meetings. Green Group has a number of small, connected rooms in the building for administrative purposes as well as a meeting room. The group employs a director, several supporters as well as six self advocates who work as trainers on community education sessions or doing administrative tasks in the office. Other members volunteer their time to work for the organisation and are also considered to be staff. Green Group has a committee of management composed of elected self advocate group members. Monthly meetings of the group are held at the office where members are encouraged to raise issues of concern about the group and about wider issues in the community. One person (usually an office bearer) is then selected to take the issues raised to a regular consultative meeting with local government service coordination staff. A young person's group meets on a weekly basis and there are separate groups for women, men and members of a particular ethnic group which meet regularly, usually for social activities away from the office. The group also offers its members a wide range of training opportunities; to learn to become trainers for the community education programme, as well as to participate in courses with an emphasis on building independent living skills and healthy relationships. Green Group is actively involved in campaigning against cuts to disability support payments and seeks to lobby the local authority about issues concerning housing and health for people with learning disabilities. The group became a registered charity seven years ago and relies on project funding to pay its expenses.

Interviewees from Green Group: Trish, Nick, John, Kevin, Henry, Frank (self advocates), Harriet (supporter).

Blue Group (United Kingdom).

Blue Group has its offices in a centre housing a special-needs day service for adults with severe and profound learning disabilities. The centre is located in an industrial estate on the outskirts of a large regional town. Additionally, the group operates programmes from a community centre in a residential area located close by, as well as facilitating ‘speaking up’ groups within several local day services for people with learning disabilities. The group employs three staff, including a development manager who combines management of the group’s activities with some advocacy work. Blue Group has ninety members. The group has a committee of elected office bearers and a small number of members who participate as speakers in community education sessions for schools and for public sector employees such as nurses and police officers. Members of the group participate in regular ‘having a say’ meetings with a few also attending local authority consultations and regional conferences with other self advocacy groups. A significant amount of the group’s activity is around training, with programmes offered about healthy relationships, living safely in the community and dealing with bullying and hate crime. Some of these programmes are accredited and recognised and as such require considerable time commitment on the part of the facilitators and participants, for example, a ‘Healthy Relationships’ programme may run for a half day per week over eight weeks, or a ‘Hate Crime Summer School’ conducted over a week. Blue Group is a registered charity and receives some recurrent funding from the local authority as well as some project funding from other sources.

Interviewees from Blue Group: Ben, Nella (self advocates), Claudia and Janet (supporters).

Purple Group (United Kingdom).

Purple Group is based in a large town and has its offices in a community facility housing a range of advocacy and support organisations. The group has one large office space with both desks for administrative tasks and a conference table in the middle for meetings. The group employs two part time supporters, one of whom works the remainder of the week for one of the co-located advocacy services for adults with learning disabilities. Purple Group has an elected committee of management and a current membership of fifty four of whom about twenty regularly attend meetings and activities organised by the group. Fortnightly ‘speaking out loud’ meetings are held with members’ participation in these sessions dependent on their completion of a training programme which focuses on a knowledge of rights and responsibilities. A calendar of monthly social activities is published in the group newsletter and includes day trips, pub meals, tenpin bowling and a Christmas party.

Members of the committee of management participate in consultations with the local authority and are active in lobbying for better public transport, writing letters and signing petitions. Purple Group receives a small annual grant from the local authority which covers the salaries of the two part-time staff. Other funds are sourced from sponsors and from project funding from lottery funds and philanthropic trusts. At the time members of Purple Group were interviewed for this project, negotiations were being undertaken to join the group with another in the region due to uncertainty about the future funding of the respective groups. It seemed likely that the amalgamation of the groups would result in the loss of the Purple Group name.

Interviewees from Purple Group: William, Emma (self advocates), Marion and Julia (supporters).

Summary

All of the six groups in the study were independent groups with committees of management composed of self advocate group members. All operated from their own office space and employed supporters. Groups varied in their size and the kinds of activities they offered members.

Twenty five self advocates were interviewed for this study, each with a different life story and varied engagement in their respective groups. The two profiles below are of Emma and William who were both members of the Purple Group and offer an insight into their background and experiences. These individuals were chosen as they provide examples of the broad range of life experience, age and interests of members in self advocacy groups. Individuals have been de-identified.

Emma, self advocate member, Purple Group.

Emma is twenty six years old. She lives with her parents and two younger siblings in a small rural village approximately 20km from the town where Purple Group has its offices. Emma attends a day service two days per week. She is friendly and outgoing and says that she ‘loves to chat’. Emma joined Purple Group after a social worker at the local authority recommended the organisation to her mother. As Emma described it, she was bored, wanted to get out of the house and find new things to do. She has been a member of Purple Group for three years and has been involved in a range of social activities including meals out and bowling nights as well as being a volunteer in the office on Wednesday afternoons where sending emails and answering the phone are her two favourite activities. A keen baker, Emma brings in homemade cakes to share with members and supporters at meetings. Emma also attends the fortnightly ‘Speaking Up Loud’ meeting and will be attending the committee training programme which begins in October. Emma would like to use the work experience she has gained from working in Purple Group’s office to get a job outside the group. She has been to one job interview so far but was not successful, describing the experience as ‘fair to middling’, but is optimistic that there will be other opportunities in the future. Emma is extremely positive about her engagement in the Purple Group’s activities and says that the only change she would like made to the group is an increase in the number of members closer to her age. Emma described herself as being ‘much more chatty and confident’ since she joined the group.

William, self advocate member, Purple Group.

William is forty four years old. He lives with three other men of similar age in supported accommodation in the outer suburbs of the large town where Purple Group has its office. William describes himself as being a ‘bit of an orphan’ as his mother died when he was a young child and he has not had contact with his father for many years. William spent a number of years in foster care, and then lived in a large long-stay hospital for approximately fifteen years. He has since lived in a number of supported accommodation placements, many of which he described as being ‘not much fun’. He says that the men he currently lives with are the ‘best blokes I’ve ever met’, but would like to move to a flat to live on his own. He has spoken to his case worker about this and feels encouraged by the positive reaction he had to his request. William first became involved in Purple Group about nine years ago and is an active member, participating in a wide range of activities. He attends the fortnightly ‘Speaking Up Loud’ group, although he says that ‘by now everybody’s sick of my voice’ and is currently a member of the management committee. In the past he has held the position of treasurer but says that he didn’t really enjoy it as ‘I’m no good about money’. William attends the weekly meeting of the men’s group and their regular social activities including the monthly ‘darts and pints’ evening at a local pub. William says that he feels more self confident since he joined the group and that he feels ‘very at home’ in the office, enjoying the company of the ‘superfriendly' members and supporters. He described the group as being 'our place', where 'bullies and such are not allowed'.

Chapter 5. Findings

Overview

Change was the key theme which emerged from the data. Self advocacy groups created opportunities for change to occur in the lives of their members and opened up the possibility of multiple, positive social identities for people with intellectual disabilities. The self advocates had a strong sense that they were more confident, more engaged and socially included people as a result of their involvement with their respective groups. This chapter presents an analysis of the findings and a model of the way self advocacy groups impact on the social identity of members.

In presenting these findings, interviewees are referred to by pseudonyms and labelled as a self advocate member or a supporter. Group names have also been changed. Quotes from self advocates and supporters are from transcripts of recorded interviews. Where '...' is used it indicates a pause in the speech of the interviewee.

Figure 3 is a model of the impact of self advocacy groups on the social identity of people with an intellectual disability. The groups had two key features; **collegiality** and **ownership and control** by members. **Collegiality** represented the strong positive regard members held for each other, and that the groups' offices and activities were friendly and accessible. Self advocacy groups were places where members felt a strong sense of ownership and control. Self advocates described their groups as 'belonging' to members.

The two key features of **collegiality** and **ownership and control** provide the context in which the activities of the groups take place. Members experienced some or all of the following opportunities within their organisations; **speaking out and being 'gobby', having power and status, having fun and being happy, helping others, relieving boredom** and **being a friend and having friends.** These opportunities were not offered in a sequenced or hierarchical way. They were created through the diverse activities of the groups. Whilst not all of the self advocates in the study had experience of all of the opportunities described, each one had experience of at least four of the six, and this lead to two positive outcomes which were described by all of the self advocates. These were; **being confident** and **engaging with life** and these important changes led to the development of one or more positive social identities by the group members. These were; **an expert, a business-like person, an independent person** and **a self advocate**.

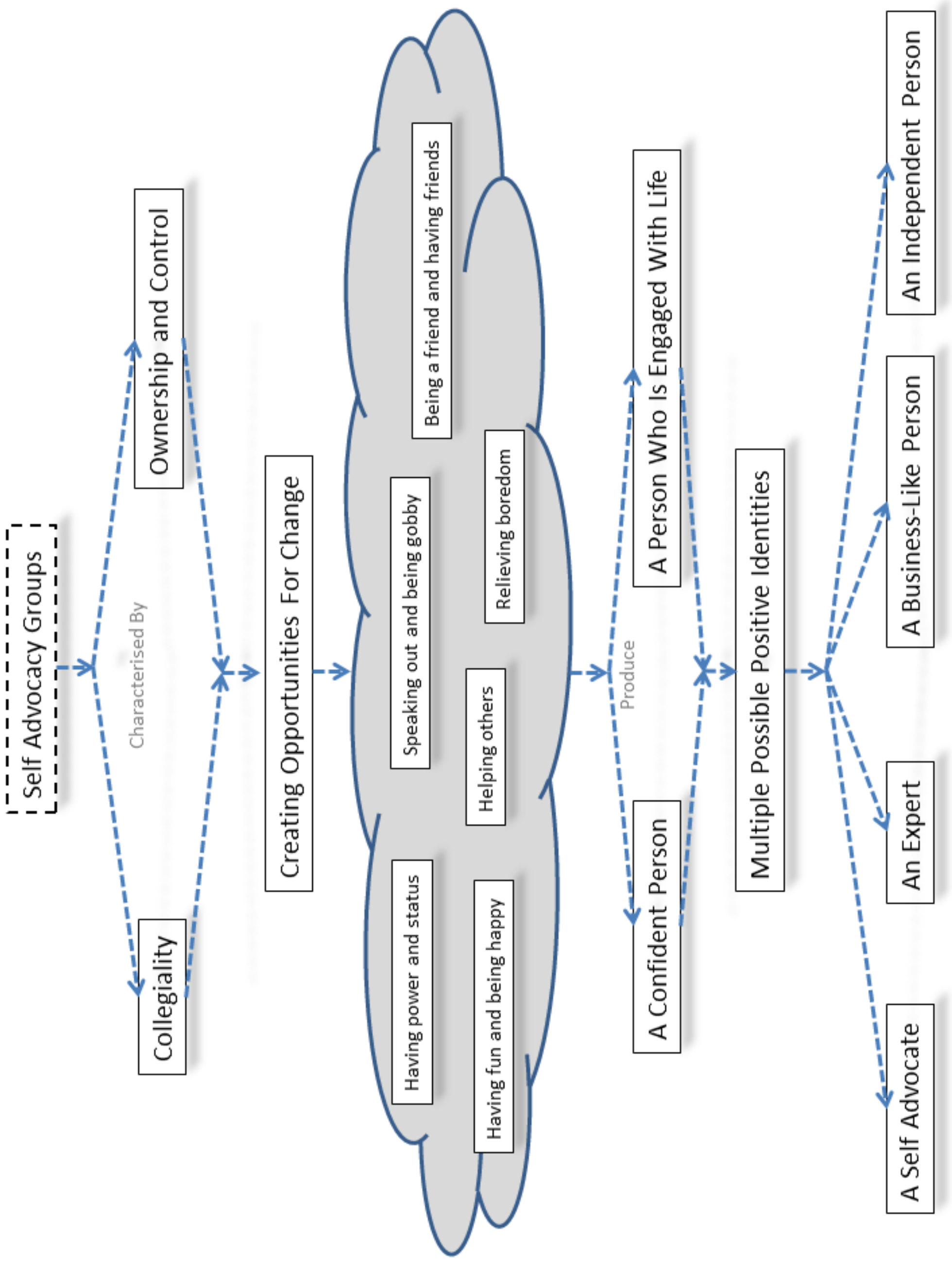

Figure 3. A model of the impact of self advocacy groups on the social identity of people with an intellectual disability.

Collegiality

Members held each other in positive regard and the group offices and activities were friendly, socially accessible places. Being spoken to in a respectful manner contributed strongly to Emma's experience of the collegiality of her group;

> Nobody calls me a mong here. They know my name, they use it properly. I like it. (Emma, self advocate member, Purple Group)

Many talked about the positive and respectful way in which they were treated by their fellow group members and about the ways in which they felt that their opinions and feelings were heard and respected.

> I think people listen to what I've got to say. I do think they take note. (Kevin, self advocate member, Green Group)

> People are listening...listening quiet, no interrupting when I have something to say. (Nella, self advocate member, Blue Group)

Within the group, there was a strong sense of mutual respect and that this respect was the basis of all interactions;

> I'd talk about things, but then I'd sit back a bit... and listen to what others had to say. (Yvonne, self advocate member, Magenta Group)

> We’ve all got a say, don’t speak, no, don’t speak when everyone’s talking, only one person speaking at a time. (Daniel, self advocate member, Red Group)

Relationships between members and supporters.

Members felt that they were held in equal, positive mutual regard and crucially also by paid supporters.

> We just muck in together, know what I mean? All us members, like me, [names three other group members], the support workers, them too. We just do all the work together. They don’t get too big...you know, fancy themselves, just work together doing things round here. (Emma, self advocate member, Purple Group)

Daniel from Red Group described feelings of being valued by the supporters of his group. The collegial atmosphere began with the warm greeting he received when he arrived at the offices of the organisation;

> Like, the staff now come to the door and be nice to you at the door. (Daniel, self advocate member, Red Group)

Liam also commented that he had noticed the positive and friendly way group members and paid staff interacted with one another;

> We all get along really well. They listen to what we think about things and we all listen to what they've got to say, their ideas and stuff. It's really good when that happens. (Liam, self advocate member, Red Group)

The respectful way in which supporters interacted with the self advocate group members led to the development of some strong positive relationships between them. Some of the members described their group's supporters as being like 'teachers' and 'mentors', valuing the knowledge, skill and support they provided;

> The staff they help us to learn about how to ask for the things, to say what we think about things. (William, self advocate member, Purple Group)

> She [Jenny] has supported me to do leadership training and go to heaps of conferences and such and she gave me an awesome reference! (Yvonne, self advocate member, Magenta Group)

These kind of positive relationships help to build the collegial character of the group, making it a place where mutual respect underpinned activities and interactions.

The self advocacy group also provided a place like no other in the lives of some of the self advocates. Daniel described it as a place where support staff are not always physically present or their presence is less felt, freeing people, perhaps for the first time to be heard and taken seriously by their peers. Supporters in this instance showed respect for members desire to be alone or to talk privately amongst themselves;

> You see before, the staff didn’t leave the room and now they’re leaving the room and we can all say what we think of them and things like that, things we need to say, sometimes for a long time. (Daniel, self advocate member, Red Group)

It was clear that the supporters played a crucial role in creating the collegial nature of the self advocacy organisations and that they used a variety of strategies including welcoming members on arrival at meetings and activities, and sharing meals, to achieve this. Marion, supporter for Purple Group detailed some of the strategies used in the group to make people feel valued and comfortable;

> It’s an important part of my job, I think. To make sure that everyone here can get involved and have a say about what we do. Little things around this place make a big difference as well. We make each other cups of tea, me and the other casual support staff and the members – we do it for each other. We bring in cakes to share and see there... there’s a photo board where we all put pictures of us, photos of pets and such or just things we like in magazines and things...just to share with everyone, like in an office. It’s just like your average office that people would work in. See through there...comfy bean bags and chairs, people can hang out if they want too. We all share the same loo too – didn’t plan that though, [laughs] it’s the only one on this floor! I want it all to feel like it’s a good place to be. The group should be friendly and welcoming for everyone who walks in the door. Even visitors - hope you felt welcome too. (Marion, supporter, Purple Group)

The respectful relationships fostered by supporters and members contributed strongly to the friendly atmosphere of the group's offices and was evident in encounters observed between self advocates and supporters at other venues and on the phone.

> If I have to ring and say something like...I can't come to Speaking Out Group today 'cos I'm not feeling well or something, they are so nice to me on the phone if I ring up, they say hope you get better soon! (Nella, self advocate member, Blue Group)

> The supporters are top people, they are, the staff, the ones we got working in here. They are always funny and have good manners to me, you know, friendly and making jokes up, to everyone really, we all get on very well I think. (Trish, self advocate member, Green Group)

A safe place.

The respectful and friendly atmosphere of the group was also characterised by members as being a 'safe' place for speaking frankly and openly about their lives.

> No-one is going to judge me here, say nasty things when I tell them what I want to say. (Ben, self advocate member, Blue Group)

> It makes me feel better about it all...I tell all the friends here at [Red Group] about having a crap day or whatever they listen to me until I finish talking. It's good. (Anne, self advocate member, Red Group)

Trish valued the opportunity to tell stories about her life both formally at group meetings and in a less formal way at the social events organised by the group;

> It’s a big relief to talk to the people here. Just to say, this is me and this is my life...had quite a few ups and downs but it’s not too bad. Not too bad really. They understand, they listen and that’s such a nice thing for me. Sitting down here, having a cup of tea...you can have a laugh about it all can’t you? Life can be a little bit better... feels better in here...know what I mean? (Trish, self advocate member, Green Group)

Some of the sharing of life experiences contributed to members feelings of being bonded to the group and to one another. Group members felt that they were ‘in it together’, working and co-operating with one another, with Kevin of Green Group describing a sense of the group ‘growing’;

> The good things I’ve got out of self advocacy are, watching it, watching us growing you know. We work together. I’ve seen it for a long time. (Kevin, self advocate member, Green Group)

Darren of Indigo Group also spoke about the growth and development of his group;

> We’ve grown a lot from the early days when we just had a few people. We get bigger and stronger all the time...we...all the members do things together and share all sorts of stuff, working together, it’s really good. (Darren, self advocate member, Indigo Group)

Choosing to take part.

The voluntary nature of participation in the groups was an important factor in their collegial character. The choice to become a member and the level of participation in the activities of the groups was at the discretion of individual self advocates;

> Some weeks I do things here every day, like go to meetings and stuff. I have a break sometimes and just do a couple of like social things, stuff like the quiz night maybe. (William, self advocate member, Purple Group)
>
> One good thing is it’s up to us, you know to choose. If I feel like it I can go to the men’s group, but mostly I just like coming in to the office to do my work, have a little chat and then I go back home on the bus or I can get a lift sometimes. Mostly I like being in the office every Tuesday. (Nick, self advocate member, Green Group)

Indigo Group had a large membership list and this was a mixture of active and less active members with engagement in the group ranging broadly from a core group who participated in activities on at least a bi-weekly basis to members who only received the group newsletter. Supporters emphasised the voluntary nature of participation and sought to offer a wide range of activities to ‘tempt’ people to engage with their group, welcoming them when they did connect. This was also the case for Purple Group with supporter Marion commenting;

> We like our members to feel that they have lots of choices about what they would like to do with the group. Everything is relaxed, friendly and we make things as easy to access as we possibly can. People dip in and out of being involved... apart from a core little group who do everything on offer. Whenever someone reappears after a while they get a huge welcome from all the members and me of course. (Marion, supporter, Purple Group)

The collegial atmosphere of the groups was underpinned by the respectful relationships between self advocate members and between members and staff and made both the offices of the group and the activities of the group comfortable and desirable places for the members to be.

Ownership and Control

Members had a strong sense of ownership and control of their groups.

> This is our group you know? It’s just for us and we can run it for ourselves. It’s so great this group, it’s our very own. It is our group this one. (William, self advocate member, Purple Group)

> This is our own group, for us, just for us to do things... and I love it! I do love it! (Nella, self advocate member, Blue Group)

Members of other groups also described having a sense of ownership and control;

> This is our very own group, all people round here who want to be a part of it. (John, self advocate member, Green Group)

> I'm proud to say I've been a member here for many years...at least ten...or more... and it's a good place, we run it our way, it's our own group, not many people can say that they've got a place that's just for them and they're in charge and stuff, you know of stuff what happens. (Howard, self advocate member, Magenta Group)

> We all like the way we can run the group for ourselves, for us...to do what we want and I like it a lot. (Ben, self advocate member, Blue Group)

Members gained a sense of ownership and control through the existence and activities of a committee of management, with all positions occupied by elected self advocates. Having elected office bearers with titles such as President and Chairperson made a powerful statement about who was setting the agenda in the organisation. Even in groups where there were clear examples of the supporters making many of the major decisions about the activities and direction of the group, the self advocates members still felt strongly that it was the members' committee that was 'in charge'.

Emma and William, members of Purple Group talked about the important role of the committee of management in their organisation;

> We have a committee right and we all choose which ones, who's the ones that's going to be on it and then they come up with the ideas for what our group's going to do. We give them some ideas too...just in case theirs are really rubbish! [laughs] (Emma, self advocate member, Purple Group)

> The committee...that's what's in charge of it all. I've been Vice President but not anymore. We all got a say about how we run it...the committee's in charge in the end though for our group. (William, self advocate member, Purple Group)

Tony of Magenta Group spoke with pride about the group's sign on the door of the building which houses the group's offices, reflecting not only his strong sense of ownership of the group but also the strong statement it makes about the members' strength and skills to control their own community based organisation;

> I love coming in here, even if it's only for a quick visit. This is our own group we're in charge of it...I do think we are in charge. It says [Magenta Group] on the sign, did you see when you come in it says it on the sign at the bottom of the stairs. That's us. (Tony, self advocate member, Magenta Group)

A sense of ownership and control, described by self advocates as; having 'our place' or 'our group' was a powerful statement of capacity and competence;

> We can do it. We show everyone that we can run meetings, we can run the office, keep our place going. (Daniel, self advocate member, Red Group)

> It's important that we keep this group going. We can show people that people with some difficulties...learning disabled, with sometimes some problems and such, they can have their own group, be in charge of it all. This is what we are trying to do. Get a message across. Say this is our group and it is! (Trish, self advocate member, Green Group)

The role of supporters in developing members' sense of ownership and control.

Whilst the self advocate group members felt a strong sense of ownership and control within and about their respective groups, the role of the supporters in developing this sense was clearly important. Supporters in all of the groups worked in ways which promoted feelings of ownership and control whilst at the same time pursuing agendas which sought to limit the potential threats of a lack of policy support and funding to the groups' activities and longevity.

> Yes it is their group. The members' own group but I honestly think that groups such as this one and I know a few others locally too...they need support staff with their finger on the pulse to keep some income going, otherwise we can't continue...we are struggling now, really, with the cuts...we'll have to move to a cheaper office. I just don't think our members

> can handle that sort of stuff on their own ...but together ...we can sort something out. (Marion, supporter, Purple Group)

Speaking about the establishment of Indigo Group, Janet, its long term supporter described her understanding of the importance of ‘ownership and control’ underpinning all of the activities of the group;

> It soon became clear though that what people really wanted was self advocacy, peer support and speaking out and a group that they ran and controlled. (Janet, supporter, Indigo Group)

Supporters were engaged in a great deal of activity concerning the day to day needs of the group for funding, for meeting spaces and for planning. This work was carried out in ways which did not detract from members’ sense of ownership and control, rather it provided the scaffolding for the work of the committee of management and for members engaged in other activities of the group. This was recognised by the self advocates as these examples show;

> [Marion] does the boring bits really. She’s quite good at it, at being a supporter. She talks to all those people at [local authority] when our money comes up for...when the budget runs out and we need more to keep it all going. (William, self advocate member, Purple Group)

> We leave it all to the workers here in the office, they know who they’ve got to ask when we need it...I’ve got my other things to do really. I think I’m

> better for speaking up meetings and such, for running the place with the others, the people on the members' committee, I wouldn't have a clue what to do about the other things [Supporter] does. (Kevin, self advocate member, Green Group)

It was clear that the issue of funding preoccupied the minds of many of the supporters interviewed for this project and that for the United Kingdom groups in particular, being able to secure a relatively stable funding stream had been the result of many years of intense lobbying and relationship building with local authorities.

> You have to spend a long time to get the statutory sector to trust you and realise you are not just there to make their life difficult, we want to work together. It's been a long time, you know I say it's me, it's not just me, it's about the stability of the organisation. They didn't give us an uplift but they didn't cut us, most of the other groups did have something shaved off and some others just disappeared altogether. Some self advocacy groups have gone [names two other regional self advocacy groups] disappeared overnight and elsewhere about five groups went and disappeared. (Janet, supporter, Blue Group)

Even groups which currently had funding, worried about future funding, and often found that their activities were limited by small one-off grants or project-based monies. This insecurity threatened some of the positive opportunities currently offered to members.

> There won’t be much if any core money in future I don’t think, we need to be creative and try and apply for bits and pieces where we can, lottery fund, trusts, things like that. I think the funding situation will start to limit what we can do, I worry about having to say to people that we can’t employ them anymore, I think that will really be a big negative in their lives, because realistically they won’t get paid work anywhere else. (Harriet, supporter, Green Group)

> Money is really tight here. (Claudia, supporter Blue Group)

Charlotte and Simone, supporters of Indigo Group, described the importance of ‘being political’ and ‘strategic’ in their relationships and partnerships with local authority bureaucrats and with organisations such as philanthropic trusts;

> It’s been political on my part...they have to keep funding us. (Simone, supporter, Indigo Group)

The two Australian groups seemed to be struggling too, with limited resources and few options for future funding and with their supporters largely relying on applications for grants delivering short term and small sums for particular projects. For Jenny, supporter of Magenta Group, this compromised both the range and quality of the kinds of activities the group offered its members and restricted the number of members who could participate;

> The lack of funding is the other thing you know, trying to get groups together, outside of the monthly self advocacy group, meetings is, yes, is really difficult. The [State Government] Minister has said that she sees the value in it yes, she sees it as important but it’s tough economic times and everybody has to...you know the same old spin... in the short term anyway they are not going to provide us with any more funds, they just don't see the importance in it, certainly not the self advocacy aspect of it. (Jenny, supporter, Magenta Group)

The Red Group supporters adopted a relaxed attitude to a funding situation which was concerning to some of the self advocate committee of management members. At the time of the interview, the small annual grant to the group was due to run out in twelve weeks time and no contingency plans were in place to secure more funding. The self advocates themselves were planning to make representations to the head of Disability Services and seemed confident that the situation would be resolved;

> Liam: We will talk to him to [Senior Disability Services bureaucrat] and he will give us more money.
>
> Daniel: Yeah, probably. (Liam & Daniel, self advocate members, Red Group)

Whilst Red Group were supported by a local advocacy service, they were largely reliant on a central self advocacy resourcing service for advice and assistance in organising funds and that did not appear to be happening in a timely way or in a way which secured the longevity of a relatively new group. They did however have a clear idea that the group and its future were ‘owned’ by its members.

> This is our group, all of us here. If we get some money...funds from the government, we can keep having our meetings here and maybe go on a few trips one day too. We will decide... all of us together. (Anne, self advocate member, Red Group)

Interviews with the supporters revealed positive attitudes about self advocacy. Those connected with the United Kingdom groups shared a belief in the necessity of remaining closely connected to the apparatus of government, suggesting that becoming embedded in the fabric of the local authority at all levels ensured some ongoing funding, however limited.

> Got to keep at them all the time, make sure they don’t forget about all the good things that happen here. (Harriet, supporter, Green Group)

The lack of opportunities to become involved at political and strategic levels has frustrated the supporters of the Australian groups and severely limited the kinds of opportunities they can offer their members. It represents an ongoing threat to the survival of groups;

> I don't know about the future. It's a real concern, it's a concern because we are forced to do more with less, the State Government is in such a mess. I

> think without the resources to be able to develop training and quality things...you know quite often we develop things and they're great, we deliver them fantastically but without a shiny manual and the resources to be able to support it adequately you know it’s always not as good as it should be. (Jenny, supporter, Magenta Group)

Whilst supporters worked to secure funding and a voice for the groups which employed them, they also worked closely with members to develop relationships which built and maintained members’ feelings of ownership and control. Members described the supporters as being helpful in organising the supply of resources to the group;

> They supply and loan all the computers and things. That’s actually their role, to support the group in that way, so, yeah, they are a huge support. (Liam, self advocate member, Red Group)

> We do things ourselves but it’s a lot done by [supporter] she gets us all the stuff we need for the office, money for tea and coffee and such. We don’t have to worry about any of that kind of thing, it’s all done thank goodness... I don’t know what to do about that! [laughs]. (William, self advocate member, Purple Group)

> [Supporter] sorts out the taxi vouchers and such. She knows what we need to have there for each of the meetings we have. (Emma, self advocate member, Purple Group)

There was also evidence of the sometimes fragile nature of the relationship between supporters and members. Members of Magenta Group and Green Group talked about their frustration at the turnover of supporters of their group throughout the many years of their membership.

> I reckon I've seen about, oh, if I had to recollect I reckon I would have seen about five, ten, maybe different supports come and go. (Howard, self advocate member, Magenta Group)

> Sometimes it's hard to get to know them, know what they're going to be like, and then just when you do, they leave, just gone. It's hard, I like to get to know people a bit, to trust them, you know? (Kevin, self advocate member, Green Group)

Members recalled a particular past supporter who had epitomised what they thought was the essential set of skills and attributes for effective support.

> Howard: To put things you need to know in a simpler, well, to be able to explain within simple terms, for those that don't quite understand, you know, and I mean everybody's got different ways of understanding, but to be able to explain it in a way that they can cope with understanding it and that.

> Tony: Yes, I think [past supporter] went out of her way, to enable everyone so they could actually understand things that were actually said.

> Yvonne: She was always easy to get hold of too. (Howard, Tony & Yvonne, self advocate members, Magenta Group)

Amongst the supporters, there was an acknowledgement that a lot of time was needed to establish strong relationships with the self advocate members and that stability was an important element in the group. Whilst they had a key role in fostering respectful relationships, their work in developing the sense members had of ownership and control was important to ensure the longevity, and in some cases survival of the groups.

> I've got to keep the money flowing for the members...so they can do the things they'd like to do. Ultimately it is their self advocacy group but me and [support worker], if we don't do our job then things will slip and we'll be in a situation where nobody's going to be able to be a part of this anymore...sometimes I've just got to be the one in control, you know, make a few decisions about things, different issues that come up...as long as the committee still feels like they can make a decision or two, then I think we can keep going along. (Marion, supporter, Purple Group)

Some of the self advocates reflected on the need for supporters to manage the issue of control cautiously;

> So everyone gets a chance to speak up and run things in the group...that's what the staff do, they should do that always I think. (Trevor, self advocate)

> They make things run like clockwork, the people in the office at [Indigo Group]. It runs like clockwork and then we can get on with doing all the things...like the leisure things and the speaking up group we have every week. (Darren, self advocate member, Indigo Group)

> At the end of the day...you know...it is our group you know, but its them, the staff that runs it...they run it for us...we decide what to do but its them, you know what runs all the things, day to day. (Emma, self advocate member, Purple Group)

Supporters were important in facilitating the sense of ownership and control experienced by members. They worked to ensure that the nuts and bolts of the group’s organisation, including funding, office space and other practicalities were in place, and they did so in ways which did not undermine or take away control of things which were important to the self advocates. As Emma commented;

> [Supporter] is pretty good. She gets the things we need...you know money for the biscuits for meetings and paper, computer and such. I think she pays all the bills when they come in...I don’t know how to do that, maybe other people do but I don’t know...anyway, she does all the little jobs around here...keeps it all going. The committee, that’s with me too when I’m in the office, we decide what the things will be...like the things we’ll do, have a pub night or we did a big one, a meeting about bullying the other day. (Emma, self advocate member, Purple Group)

Summary

Having a sense of **ownership and control** was a key feature of the descriptions of their groups by the self advocates in this study and it exists in each of the six groups. In combination with the other key characteristic of the groups, **collegiality**, clear examples are offered of the unique social environment of the self advocacy group.

> The group is a great place you know. We all share it and it's just our group...a friendly group, we can decide what we want to do and we all just treat each other the right way. (William, self advocate, Purple Group)

Creating Opportunities for Change

Participation in self advocacy groups offered members a change in lifestyle with opportunities to try new and interesting activities on a frequent and regular basis and to participate in training programmes and develop new skills and relationships.

The chance to try different and interesting things and to have a place or places to go was clearly a major drawcard for many self-advocates;

> At [Green Group] we do a lot of things here. (Trish, self advocate member, Green Group)

> We've got our own committee, management committee, a women's group that meet every Wednesday and we do a lot of activities. (Trish, self advocate member, Green Group)

> I love going to all the meetings and public speaking too. (Rita, self advocate member, Red Group)

> We meet people. We have beer out as well. I've had some fantastic experiences. (Frank, self advocate member, Green Group)

> I go to conferences, meetings... (Ben, self advocate member, Blue Group)

> We have guest speakers. Yes, like, I think on one occasion we had a sergeant, wasn’t it, from the police force. (Tony, self advocate member, Magenta Group)

> We always start our speaking up group having a news round saying what people have done and sometimes we have things such as consultations that the council has sent us to go through and read through with them or sometimes we have more informal meetings where we don't have anything planned. (Audrey, self advocate member, Indigo Group)

All of the self advocacy groups involved their members in programmes which had a focus on training for citizenship and personal growth. Programmes offered across all six groups included; skills around developing friendships and relationships, practising safer sex, personal grooming, interview skills, cookery, pet ownership, travel training and community safety. These were in addition to programmes specifically described as being about self advocacy, speaking up, and rights.

For some self advocates, participation in local training, workshops and conferences were highlights.

> Oh different types of workshops, some of them are like fun, leisurely ones, but there's a lot that help give you information on how to like access different services, or about rights, or it might be like, I did a healthy cooking one once. And even like social skills and things and meet, to get to meet different people. We take our meetings to the pub sometimes! (Sophie, self advocate member, Magenta Group)
>
> Sometimes we have a speaker coming, like next week we have someone from the ambulance service coming out if my memory serves me correctly...we've got them coming out talking about what they do and how they can help people with a learning disability and that. (Darren, self advocate member, Indigo Group)

In his interview, Henry described the enjoyment and benefit he had derived from participating in training programmes offered by his group and the change he had noticed in his confidence;

> Author: you've been involved in some training here?
>
> Henry: Yes. For me to be more independent and more confident. That's training the staff at [Green Group] did for me, they did it for me here. The training has been fun. (Henry, self advocate member, Green Group)

Blue Group was unique in the way in which it regarded training as being a progressive process, with members participating in programmes for fixed periods after which they 'moved on' to other activities, often outside the group. Within the group, limits on the participation of self advocates in training programmes were enforced. Members participated in structured, accredited programmes over a number of weeks or months and were then 'moved on' to other programmes within the group or encouraged to attend alternative activities outside the self advocacy group.

> We like to give as many people an opportunity...to be in some training about being a self advocate... and then try out some other activities. A few people have become really good at giving training sessions so they stay on...and we support them...and support other people to get into doing that too. (Claudia, supporter, Blue Group)

Support staff provided numerous examples in their work of programmes and activities designed to develop self-confidence and broaden and enrich the experiences of group members.

> It's been really about how to encourage people to speak up and also self empowerment but recently...it's one of the projects that we have been doing its getting people to be more confident to be out and about. (Simone, supporter, Indigo Group)

> It's really nice for people that they've got the role within [Blue Group] of delivering a session. (Claudia, supporter, Blue Group)

> At the moment we are actually doing 'Healthy Relationships', because people really need to know and understand themselves as well. We also deliver training to police, nurses, public housing workers, public sector. (Claudia, supporter, Blue Group)

> We do a summer school every year and this year we did a great play about anti-bullying which we showed in about five different places which was brilliant, so we've done quite creative things, we've tried to find creative ways of working with different groups. (Janet, supporter, Blue Group)

> We just finished a relationships training program with the guys – a lot of them would like to have girlfriends. (Harriet, supporter, Green Group)

> We look for every opportunity to give people a voice. (Jenny, supporter, Magenta Group)

For some of the self advocates, there was a stark contrast in their activities and associated enjoyment of life since they joined their respective groups. They had noticed a positive change.

> Life is great now. It was so boring before...never did that much really. I do like to be busy ...being quite busy like I am. (Emma, self advocate member, Purple Group)

Ben described spending more than thirty years assembling toys in a day centre before the centre closed and he joined Blue Group. He now regularly attends

‘Speaking Up’ meetings, gives presentations to local schools and other groups and participates in training programmes facilitated by the group’s support staff.

> It makes me happy. I feel more confident I think I am. I can go to different places. It makes me so happy. (Ben, self advocate member, Blue Group)

Henry (Green Group) had also had the experience of significant change occurring in his life since joining the group;

> I used to go to a day centre. I didn't like it there. Woodwork and maxi packs and things, boring... I've moved on since the day centre. Done things I never would have done before, that’s right. (Henry, self advocate member, Green Group)

The range and type of activities serve to create opportunities for enjoyment and positive social interactions which are for some members unmatched by previous experiences or other aspects of their lives.

> We do stuff...stuff we never tried before, never had the chance really where I was before. Coming here to [Green Group], I get a good surprise every time, with something different to do! (Kevin, self advocate member, Green Group)

Supporters noticed changes in self advocates’ skills as a result of having new life experiences through their engagement with Magenta Group;

> I think that the... seeing people's skills develop...the development of individuals, has been extraordinary. And our conference, while it is a small conference, it really gives people the opportunity to leave their services because many of them are supported by services and they do not have much of a life outside of a service. (Jenny, supporter, Magenta Group)

Janet noted that building skills in having confidence to ‘speak out’ can take a long time even within supportive groups;

> For lot of people in the group, they are not used to speaking up I don't think, they just haven't for most of their lives and for the last couple of years we've been doing these having a say groups with them and I think they are still at the stage where they are still not quite sure if it’s ok. (Janet, supporter, Blue Group)

Twenty of the twenty five self advocates had been members of self advocacy groups for more than ten years and clearly articulated a process of developing new skills and learning to ‘speak out’. The strong sense that many of the self advocates had of a new confidence built through their years of engagement with their groups led to them describing new and enhanced feelings of happiness and satisfaction. Change was a theme which recurred in the self advocates’ commentary;

> It’s changed my life a lot. Sticking up for my rights, you can speak out.
>
> Author: and how has that made you feel?

> Good, good about my life. (Darren, self advocate member, Indigo Group)

> [Before I joined Green Group] I was basically miserable and I was shy. I enjoy everything more now. (Henry, self advocate member, Green Group)

> Totally, I think it's probably totally changed everyone's life actually. Like before yeah, like I wouldn't even travel anywhere and now I just jump on the bus and go to [city] and that's all through self advocacy ... it's huge, just huge, huge changes in my life. (Liam, self advocate member, Red Group)

Groups created opportunities for change for their members through the diverse range of activities and experiences they offered, enabling people to live more interesting and socially engaged lives.

Speaking out and being gobby.

Opportunities for speaking out and being gobby came from activities based around training about rights and citizenship and scheduled 'speaking up' or 'speaking out' sessions which occurred in all of the groups. Whilst the term 'speaking out' was used by many of the interviewees, the phrase 'being gobby' was used by Celia (self advocate) and beautifully encapsulates the sense of speaking up strongly on one's own behalf, being courageous and bold.

> I used to be quiet and now I'm gobby. (Celia, self advocate)

These speaking up sessions or meetings provided opportunities for people to give voice to opinions, feelings and concerns;

> We have to have self advocacy, I mean, people have a voice but self advocacy is what helps them to use it. (Janet, supporter, Blue Group)

All of the organisations offered regular meetings at which ‘speaking up’ was the main or sole item on the agenda. The language used at these meetings and in the members’ descriptions was derived from the training programmes about self advocacy;

> That’s what we do at our self advocacy meeting. Sticking up for my rights, you can speak out. (Daniel, self advocate member, Red Group)

> I can speak out at the meeting...say about my rights...it’s my rights not to have bullying by other people. I have to stand up and speak out. (William, self advocate members, Purple Group)

> Self advocacy is a good thing for us. People with learning disabilities need to have a way to speak up. (Trish, self advocate member Green Group)

Outside formal meetings, members felt they could speak out about issues and concerns with supporters and fellow self advocates and do so with confidence;

> When I come in here, if I come in and I’ve got something I want to say, I just can. I come in and here in the office I can speak up about the things on my

> mind today. People listen and then they'll say well done, well said. (Daniel, self advocate member, Red Group)

Self advocates developed an understanding of the concept of 'rights' and of the language of 'speaking out' through the training provided by their groups and by practising their skills at specifically created opportunities;

> I learned how to sort of like speak up and say what I think and not take the crap basically. (Celia, self advocate)

> I have learned what to say to ask about...to stand up for what is my rights. I have to speak up for my rights so the people know that I can stand up for myself...that's it really. (Anne, self advocate member, Red Group)

Giving members the language of 'speaking up' and an opportunity to practice using that language was a key feature of meetings;

> When we have our meetings here together we can practice to say it, to say I can speak up for myself and then I speak up in the proper way. (William, self advocate member, Purple Group)

> Basically it like teaches you how to speak up for your own rights and you're taught to speak up for yourself. (Sophie, self advocate member, Magenta Group)

Using the opportunities created by their respective groups, members found that the experience of ‘speaking up’ or ‘speaking out’ contributed significantly to their feelings of self efficacy.

> When people are speaking up, you know when we have our speaking up meetings...we have them every Thursday usually, they feel good, feel much better about it all I think. I do, I like it when I’ve been speaking up with the other ones here listening too. I feel better and stronger about everything. (Emma, self advocate member, Purple Group)

The concept of ‘rights’ shared by most of the interviewees centred on an understanding that this corresponded with being treated ‘well’.

> My rights, I can speak up about here...speak up about things, so those people they don’t have respect...they know don’t they? It’s my rights, they have to treat me better don’t they? (Anne, self advocate member, Red Group)

> I would like people to treat me nicely, treat me well, like other people who don’t have learning disabilities or such...or other problems. That’s my rights, I have to speak up for my rights. (Trish, self advocate member, Green Group)

Interviewees focussed strongly on speaking out about being denied choice;

> ...we weren’t even allowed to pick our own menus, choose what to eat. I used to hate weetbix [cereal] for breakfast, for years and years. Now I spoke up and said to my house supervisor, I said, I want cornflakes instead and she said that’s ok, you can! See I hate weetbix. (Rita, self advocate member, Red Group)

> I want to do the things I like doing in my free time. Like, I’m really into scrapbooking and if I want to do that, I can choose. It’s better than being told what to do all the time. I can make my own choices and say what I think about things...about what I want to do. (Anne, self advocate member, Red Group)

Identifying oneself as being a ‘brave’ and ‘courageous’ person, a ‘gobby’ person who speaks up about matters of significance recurred in the members descriptions of themselves.

Trish described having intense feelings of powerlessness and of being disregarded prior to her engagement with Green Group, saying that her decade of involvement had given her ‘courage’ to speak out about choices and decisions about her own life;

> It's given me a lot of courage to speak up, to say what I want. I could never have done it a couple of years ago, I would have been too scared to. (Trish, self advocate member, Green Group)

The theme of practicing the newly gained skills of ‘speaking out and being gobby’ recurred in other interviews too;

> My highlight has been that I can speak up for myself now whereas before I couldn’t. (Rita, self advocate member, Red Group)

> I used to be afraid of saying what I think about things and such but now I can be confident. (William, self advocate member, Purple Group)

> I can do different kinds of stuff I couldn’t do before. I can speak up for myself much more better than I could before and do many more things I couldn’t do before...talking on the phone, talk to new people and I can say sometimes what I think about things. (Emma, self advocate member, Purple Group)

> You couldn’t guess really now, [Audrey] can tell you this too, but before I wouldn’t say boo to a goose! (Darren, self advocate member, Indigo Group)

One self-advocate talked about members of his group overcoming fear in their relationships with some of their support staff, which had led to people being able to speak out about often long-standing issues and concerns;

> We used to have a bit of trouble with the staff and they wouldn’t want to leave the room. You see people were afraid, they didn’t want to say anything because the staff didn’t want to leave the room. But people got more

> confident. They knew what they wanted to say so when the staff did leave the room they could talk about those things. Things they had been wanting to talk about for years and years. They were too afraid. It was good to see. (Daniel, self advocate member, Red Group)

Group members were speaking out with confidence both to each other, in meetings based at the self-advocacy group offices, and outside it to staff who provide services to support daily living;

> Now everyone is feeling more confident to say things face to face. (Daniel, self advocate member, Red Group)

One self advocate, describing the early years of his group's history observed that once people had tasted the experience of 'speaking out' it became something they wanted to keep doing;

> It felt good to hear people speaking up for themselves...never had tried it before and when they did they didn't want to...you know, to stop saying what they think about things. (Kevin, self advocate member, Green Group)

There were some examples in the data of where groups had worked to increase members' skills as well as their opportunities for speaking out and being gobby through training around elections and voting and encouraging members to become registered voters. The promotion of people's identity as 'voters' was important as it created a sense of empowerment and inclusion. It also had the potential to impact on the opinions of members of the community who may be reluctant to acknowledge the rights and citizenship of people with intellectual disability. William clearly relished the opportunity;

> I never thought I'd be able to vote, it's great. I get fired up you know, it's good I can tell the buggers what I think, you know what I mean? (William, self advocate member, Purple Group)

Jenny, Supporter of the Magenta Group spoke of her excitement about a number of group members enrolling to vote for the first time;

> When we had our conference, I said, well who's the politician who thinks the same as you around that? And they said 'well I don't vote' and I said 'why don't you vote?' - 'mum says I wouldn't be able to vote, mum and dad took me off the electoral roll, they made it so I didn't have to vote' and I said 'do you want to vote'? You don't have to know about everything to vote. Then we had the electoral commission come and talk to people about voting...so from that conference we had fourteen people who actually got their electoral status changed and now vote. (Jenny, supporter, Magenta Group)

Other opportunities for speaking out and being gobby were provided through the involvement of groups in activities which either overtly or more subtly were working towards changing perceptions and raising awareness of people with an intellectual disability in the broader community. The existence of the organisation, an office with a sign on the door, challenged the way in which some people in the community consider the social identity of people with intellectual disabilities.

> Our office is here...in this old building...it's here in the middle of all of the town, of [name of town] and I think we're gonna be here...here for a long time...people can see that we're here, I like seeing them walking past the window and having a little...sometimes they can have a little look...see us working...working in the office, doing jobs and things like that. (William, self advocate member, Purple Group)

Self advocates were involved in campaigning in a number of different ways, all ways which offered examples of people speaking up. Members of the Green and Magenta Groups were engaged in overt political campaigning, participating in protest marches, politically themed morning teas and barbeques and signing petitions and this impacted on their perception of themselves as people who have a say and their groups as being strong and visible in the community.

> People are very worried about cuts and local issues, like lack of housing. We have been on a march in [city] – you have seen the video and our banners and things. (Trish, self advocate member, Green Group)

> The National Disability Insurance Scheme, that we've been doing, is having some input, we had a morning tea to let people know about that one.
> (Sophie, self advocate member, Magenta Group)

Magenta Group had also campaigned strongly and successfully for the restoration of a local bus service and this had invigorated the group's supporter Jenny's interest in them taking on other issues. She acknowledged that the 'constant lobbying' required to even achieve small changes on key issues affecting members, was a huge drain on the resources of the group.

> It's hard work, getting everyone revved up, knowing it might not do anything at all, not achieve anything, that's frustrating. It is worth trying though, I do believe that. (Jenny, supporter, Magenta Group)

Speaking out sometimes took the form of involvement in awareness-raising or community education programmes about intellectual disability. This kind of activity also afforded the self advocates opportunities to be 'experts' about their own lives, to be 'teachers' about that experience and to enjoy the associated benefits of being listened to and held in some regard.

> I like talking to the people...I do a good job when I tell them the things on paper...I have a practice with [supporter] ...then I can tell people all about it...what learning disabled is about. I think those people...those that hear me talk...talk about the things, they like it...it's really quite...really interesting they say. (Nick, self advocate member, Green Group)

The self advocates offer views in such programmes which support and reinforce ideas about the social model of disability and challenge negative stereotypes about people with intellectual disabilities.

> We like to say, I’m a person, just the same as you. Lots of people are surprised when I say things like that. (Ben, self advocate member, Blue Group)

> They still think we’re like little children. I’m a person, a real person, that’s the kind of thing I say to people. Some of them agree, I don’t care about the ones that can’t see...I don’t know what to say about those ones. (Trish, self advocate member, Green Group)

> I have done school visits for thirteen years now and I like it so much. (Ben, self advocate member, Blue Group)

A number of the older interviewees had been involved in past campaigns around institutional closures and this experience had contributed strongly to their commitment to keeping their self advocacy group running. They had a strong sense both of the significance of engagement in self advocacy in their own personal histories but also a strong desire to see opportunities to ‘speak up’ continue to grow.

> I moved out of [institution] into the community and self advocacy followed me and its stayed with me in the community! As you can see its now got members here in [Green Group]. Don't ask me the numbers ‘cos I'm not good at numbers... but we are going from strength to strength. I found people speaking out for us and I wanted to give people a chance to speak out for themselves. (Kevin, self advocate member, Green Group)

The self advocates also saw themselves as campaigners and agents for change through their involvement in community education and awareness-raising training sessions and workshops. ‘Speaking out and being gobby’ happened both within the groups and in the wider community.

Having power and status.

All of the groups had committees of management with self advocate office bearers and the interviewees offered some interesting insights into the status attached to these roles. It was clear that many of the interviewees saw such positions as ‘president’, ‘secretary’, ‘members rep.’ and ‘chairperson’ as being highly desirable and most expressed aspirations to hold, gain, or in some cases, re-gain such roles in the group.

Nick, a member of the Green Group talked about his desire to re-gain the office of president at the organisation’s next elections:

> Nick: Yeah. I am going to try again
>
> Author: And who is the chair now, is it somebody you know?
>
> Nick: Yes, she's in the ladies meeting, the ladies group for [Green Group].
>
> Author: And how long is she going to be chair for, do you know?

> Nick: No. Not for long! [laughs]. (Nick, self advocate member, Green Group)

Rita shared Nick's ambition within her self advocacy group;

> In the long run, when [Liam] retires, I'd like to have a go at president. (Rita, self advocate member, Red Group)

Within Red Group, there was a clear hierarchy; with a 'main' and 'second' or 'b' stream and members were clear about their role within it;

> I am second in charge of the 'b' group in the advocacy group so I go to all the meetings and things like that. It's good. (Rita, self advocate member, Red Group)

Members from the 'second' group could only attend meetings of the 'main' group with permission from the president and vice president of the 'main' group. Having two groups expanded the number of leadership roles potentially available to members, increasing their opportunities to have power and status in Red Group.

Howard, a founding member of the Magenta Group, described himself and his fellow members' committee personnel as being 'the elite bunch'. Howard has during his time with Magenta Group, occupied each of the office bearer positions in the organisation and now watches, with some frustration, the efforts of others in the same roles.

> I don't know how many roles I've played, but I've played them all, right from president, vice president, and treasurer, whatever... well for instance say [Laura], like she's only just started, not got it so far and she's just learning it, and it will seem hard for a little while but gradually she'll pick up. (Howard, self advocate member, Magenta Group)

There were other examples too of people's pride in being an office bearer in their self advocacy groups;

> I'm the campaigning officer for [Green Group], doing campaigns. It is important to do a good job on it. (Trish, self advocate member, Green Group)

> I've done so many things in my role as president. (Yvonne self advocate member, Magenta Group)

> I'm going to be real good at it...being the president for just the one year I think it is...yes it will be good. (Laura, self advocate member, Magenta Group)

The actual power of people in the office bearer positions to make decisions and set the direction of the committee and the group was in some cases quite limited. The supporters had a key role to play in all of the groups and it was difficult to determine to what extent their support spilled over into directing the work of the committees of management. What was clear however was that the self advocates themselves felt empowered in their roles on the committee.

Speaking about his time as president of Green Group, Nick was quite explicit in describing the way the committee of management meetings were run.

> [Harriet] puts it on the paper...puts it on a sheet of paper for me what to say. That's the agenda of the meeting. I'm in charge of the meeting, I tell people you be quiet if they go on talking and talking. (Nick, self advocate member, Green Group)

Nick was 'in charge' in spite of the fact that he did not appear to be in control of the topics being discussed at the meeting and the words he spoke were from a script provided by the group's support worker, Harriet. Harriet provided support in ways which did not detract from Nick's experience of having status and power within the group.

It was clear that from the self advocates' perspective, supporters who worked in ways which facilitated feelings of being in charge and in control exerted positive power in the group.

> Howard: The key to being a good support is having plenty of patience, plenty of understanding, and...
>
> Yvonne: Plenty of knowledge.
>
> Howard: Yep, a lot of knowledge about everything. (Howard and Yvonne, self advocate members, Magenta Group)

Within the Indigo, Blue, Red and Purple Groups, there were opportunities for members to participate in meetings and committees outside their organisations. These meetings were attended by the members with supporters and in the case of the United Kingdom groups were convened by local authorities. Some of the self advocates described their experiences at these meetings, which were often about policy matters, as being ‘hard to follow’ Ben, (Blue Group) and Audrey (Indigo Group);

> Well, it was really hard to understand, we only stayed for half an hour or an hour because it was really difficult. (Audrey, self advocacy, Indigo Group)

Simone (supporter, Indigo Group), identified the problem as the ‘formality’ of the meetings and the tendency of the learning disability professionals and bureaucrats to ‘talk shop’ during meetings. Nevertheless, she describes the presence of members of Indigo Group at such meetings and consultations as being an important element in enabling self advocates to ‘hear and spread the news’ about what is going on locally. This is of course dependent on people’s ability to engage with the activities of such groups at a level which makes this possible.

Janet (Supporter, Blue Group) highlighted the closeness of the group’s relationship with their local authority, crediting its relatively secure funding to the positive nature of this relationship. She also acknowledged that the way in which it seeks the views of self advocates is flawed.

> They have tried very hard to include people in things like strategic planning. I don't think they've been successful because I think that's just, it's just ingrained in people that that has to be high-powered...and we've talked about maybe people not having to sit there for three hours and listen to all this, just come in for the bits that are important to them really, so to find other ways, but I don't think sitting around at board meeting table is very good at all really. (Janet, supporter, Blue Group)

In contrast with the kind of embedded relationship described by members and staff of Indigo and Blue Groups, Jenny, Supporter of the Magenta Group, described her frustration at not being able to get what she sees as the ‘consumer perspective’ and representation from members of the group onto relevant committees and policy review forums;

> It’s our aim to have as many people as possible on boards and on committees, because we are not their voice, we just facilitate them having a voice, so trying to make sure as many people as possible have the opportunity to sit on boards and have input and in their own communities the better. (Jenny, supporter, Magenta Group)

These opportunities are very limited in Magenta Group’s region and as a consequence, she was concerned that the group does not have a strong voice in the disability sector and that the members were frustrated by this;

> I can imagine how the people themselves, the self advocates feel about constantly having to bang their head against the wall and constantly say we want to be heard. (Jenny, supporter, Magenta Group)

However, this was not a view expressed by any of the self advocates in the group; rather they spoke positively about the social aspects of the community campaigns and consultations in which they had participated.

> We just pitch in where we can you know. It's not like them bad old days for most of us and we do get a chance to come here and say our piece. We've been into some demonstrations and such, made posters and stuff, it's all been good fun. (Howard, self advocate member, Magenta Group)

> We had a morning tea, sitting out in the cold but it was fun and another one was a car wash we did for people. (George, self advocate member, Magenta Group)

What was clear from the interviews was that the self advocates who were office bearers within their groups were very often also called upon to represent, not their group, but more broadly the views of people with intellectual disabilities. The inherent difficulty in this task for self advocates, with or without support was not fully addressed. Despite the frustrations of attempting to engage with processes and discussions which might not have been clear, it was evident that the way in which the office bearer roles of some self advocates extended into outside forums enhanced the enjoyment and feelings of being valued and taken seriously of those participants.

> I go to lots of different meetings, we travel by taxi and there’s a good lunch, usually there is. (Audrey, self advocate member, Indigo Group)

The aspirations of group members to hold onto or attain office bearer positions was underpinned with knowledge that there were benefits attached to this status and that whilst the external committee meetings and consultations may often have been tedious or sometimes incomprehensible, the perceived benefit of engaging in a different activity was valued by the participants.

Having fun and being happy.

A number of the self advocates talked about feelings of happiness and enjoyment derived from their engagement with their self advocacy group;

> It's good fun. (John, self advocate member, Green Group)

> It’s really good and I like going along. (William, self advocate member, Purple Group)

> Oh, I do enjoy [Magenta Group]. It is so much fun, we have a good time here. (Laura, self advocate member, Magenta Group)

> All in all we have good fun. (Audrey, self advocate member, Indigo Group)

> It’s great fun being here. (Nick, self advocate member, Green Group)

There was fun to be had in the setting of the groups' offices or when activities and celebrations took place at community venues;

> We go to a pub and have a meal or if it's like, a special birthday like a 50th or such then we'll have a party, yes, yes. Having fun together for a birthday or whatever, it's good fun I think. (Ben, self advocate member, Blue Group)

> I have had so much fun over the years with all the things I've done with [Purple Group]. Going out together is great, at Christmas time is the best... we have a disco and a big, big lunch, so good! Whatever we are doing all of us together it is good fun, lot of laughs...yes... especially with me and [member]. (Emma, self advocate member, Purple Group)

Members felt happy and had fun when they were participating in the activities organised by their group, either in or outside the group offices and it was clear that the opportunities provided by the group for members to socialise with one another and enjoy each other's company were a highlight for many.

> Just all spending time together having fun, that's my best part of all this, this place. (Anne, self advocate member, Red Group)

> Because we all are getting on together, having fun and such in the office, on the days I am here I have a good time and I have fun, really do, yes. (William, self advocate member, Purple Group)

Helping others.

Many of the interviewees saw their self advocacy group as a place for mutual aid. They felt that the combination of training and experience gained within the group enabled them to ‘help’ people – especially those new to the group.

> I enjoy that, you know, helping out the other ones here. (Emma, self advocate member, Purple Group)

> We help people to speak up for their own rights and help them to choose for themselves what they want to do...we try to help people as best we can. (Trish, self advocate member, Green Group)

> And I help people. If they have problems they come and talk to me and that. (Rita, self advocate member, Red Group)

Helping other people to learn to speak out was particularly important;

> Self advocacy is really important. It really helps people. I can speak up for myself but other people can’t. (Trevor, self advocate)

> I know that self advocacy is standing up for your rights you know like helping people and stuff like that but when I first came here I wouldn't have a clue. Now I help people, I can do that. (Frank, self advocate member, Green Group)

> I really do help people now...with speaking out and stuff, saying you can do it! I know all the things they need to know just from being here and learning all about it. (Nick, self advocate member, Green Group)

Claudia, a supporter of Blue Group described her excitement at seeing a long-standing group member who had often appeared withdrawn and reluctant to engage with other members ‘reach out’ and offer assistance to others in a self advocacy training course;

> And I don't know whether she's thinking then actually I'm a long-standing member here now but she's just started supporting other people. I don't want to say, 'why are you helping?’ just to say 'ooh that's wonderful'. (Claudia, supporter, Blue Group)

One self advocate who had many years of experience speaking about learning disabilities to groups in schools described his role as a mentor, teaching and supporting a new member to become his co-presenter;

> I am going to more schools with her, yes... she's a quiet girl. I am going to help [Nella] like it! (Ben, self advocate member, Blue Group)

This opportunity to share knowledge and support is clearly valued by Ben.

The sense of efficacy self advocates gained from seizing opportunities to ‘help’ rather than be ‘helped’ was strongly reflected in the language used by Oscar in describing a conference for which he was an organiser and speaker;

> I had to make sure that a group from that area would take part. I thought it would be very helpful for them and I just decided that I wanted to have people to be involved with it too. I want to be helpful, it’s useful to people. (Oscar, self advocate)

Oscar had a clear idea of what he ‘wanted’ to have happen and that it would be ‘helpful’ to others.

This confidence and a belief that others will benefit from knowledge gained through experience was shared by Howard (Magenta Group) and Darren (Indigo Group);

> There’s only one theory for me, is that I do what I do, what I do best, working with the people with disabilities and making sure that they get their rights. (Howard, self advocate member, Magenta Group)

> We did a workshop with a group of people who we thought would need help to get out, just to be more like... just like myself... just be more confident in going out and trying new things and meeting new people. It helped them a lot, it really, really did. (Darren, self advocate member, Indigo Group)

The opportunity to help others featured strongly in self advocates' description of the features they most enjoyed about their participation in their respective groups.

Relieving boredom.

Participation in the activities of the group was an important means of relieving boredom.

> There's always something going on here. Outside, at home, there's nothing to do. It's really, really boring. (Frank, self advocate member, Green Group)

> Lots to do, all days of the week, I can choose and it's not boring like going to most of the other places you get to go to. (Emma, self advocate member, Purple Group)

The issue of the monotony of daily life for many people with intellectual disabilities was raised by a number of the self advocacy supporters interviewed for this study.

> For some people I think it's just a big relief to be doing something different with their time. A lot of people with learning disabilities really have nothing much to do with their time. Coming here is interesting, there is someone to talk to, have a cup of tea, a chat. (Simone, supporter, Green Group)

> They want to have fun, see friends. (Marion, supporter, Purple Group)

> But there's lots of our members that don't want to be part of long meetings, much as they all want to come along and have their say and influence the council policy, they also want us to help them just to have a more varied life. (Charlotte, supporter, Indigo Group)

> We try to get people more socially included, making decisions and having fun. (Simone, supporter, Indigo Group)

The chance to try different and interesting things and to have a place or places to go which were outside the usual routine and to be ‘busy’ was clearly a major drawcard for many self-advocates;

> At [Green Group] we do a lot of things here. (Trish, self advocate member, Green Group)

> We meet people, we have beer out as well. I've had some fantastic experiences. (Frank, self advocate member, Green Group)

Being busy and having something interesting to do was very important for Rita and were key factors in relieving boredom;

> It’s good. I’m very busy, probably the only time I’m home is Saturday or Sunday. Unless something comes up, I’m out, busy. I don’t like being home, I’d rather be out. It’s boring at home, just doing cleaning, vacuum the

> floor again and watching TV and stuff like that. (Rita, self advocate member, Red Group)

Being a friend and having friends.

Self advocacy groups were places where people had friends and formed friendships. The majority of the interviewees had had many years of involvement with their respective self advocacy groups and therefore had long-standing relationships with fellow members and group supporters.

> Sophie: A lot of our friends come from here.
>
> Yvonne: Yes, yes. (Sophie and Yvonne, self advocate members, Magenta Group)

> I have made good friends. (William, self advocate member, Purple Group)

> That's the best thing. Making new friends. Make more friends. (Henry, self advocate member, Green Group)

> I come to meetings with my friend, with [Rita]. (Anne, self advocate member, Red Group)

> The men's group is friendly, just friends. (Nick, self advocate member, Green Group)

> I have friends here. (Ben, self advocate member, Blue Group)

> It makes me happy. I feel more confident I think I am. I can go to different places. It makes me so happy. I have friends. (Kevin, self advocate member, Green Group)

Friendships formed and maintained within the group were important to these self advocates and added to their enjoyment of activities in the group.

Some of the interviewees attended meetings and activities at the group offices on every week day, spending many hours with other members and supporters.

Claudia (Supporter, Blue Group) commented;

> People get to know each other quite well. (Claudia, supporter, Blue Group).

> I am friends with lots of the other people who come here. (Liam, self advocate member, Red Group)

At the same time, there are no examples in the data of self advocates speaking negatively about fellow members. Whilst there was small amount of commentary about rivalry for leadership positions, most of it was good humoured. None of the interviewees described having social contact with fellow members outside the activities of the group.

> I like spending time with my friends here. [Member] and me, we’ve been friends together for years and years since we first started. I don’t really be in

> touch with anyone when I’m not here at [Purple Group] but I am here all the time, on some days and we catch up then, you know, say how you been going and that. (William, self advocate member, Purple Group)

Friendships were made and sustained through the regular contact of members, particularly those engaged regularly in the office based activities of their groups.

> I just know when I come in here...there’s always someone, a friend to talk to. (Howard, self advocate member, Magenta Group)

> I see her [member] here all the time. I’d say by now she’s my best friend and I met her through speaking up loud group and we still go there. I make sure I keep a seat for her, she sometimes is late when her bus turns up late. [Member] likes me minding her bag for her when she has to go out for a minute too. (Emma, self advocate member, Purple Group)

These friendships were important to members, enhancing their enjoyment of group activities;

> I do love it at [Red Group]. It’s always so good when Anne comes as well...we can chat at the end, we are enjoying it all together. (Rita, self advocate member, Red Group)

> I’ve found it quite easy to make friends with the other people here. They are some good people, friendly people and I like to be their friend as well. It’s a

> good group to do things with... very good when the people are your friends as well. You often have a good time when it's with your friends. (Nick, self advocate member, Green Group)

The Impact of Providing Opportunities for Change – Being More Confident and Engaged With Life

The findings from this study offer substantial evidence which shows that for the self advocate interviewees, the important outcome of their engagement with the many and varied opportunities offered by their groups was a change which moved them closer to the possibility of embracing multiple positive social identities. All of the groups offered members opportunities to participate in some or all of the following; speaking out and being gobby, having power and status, helping others, relieving boredom, being a friend or having friends and having fun and being happy. The result of having these opportunities for change produced members who had become **confident** and were **engaged with life.**

Henry and John, who are members of Green Group, talked about their increased self-confidence:

> I've become like, more relaxed, more friendly with people they taught me get out of my shell...go and do things with people, learn to do new things. (Henry, self advocate member, Green Group)

> It helps me to speak up for myself, like it makes me speak up for myself and makes me feel more confident. (John, self advocate member, Green Group)

William too felt greater self confidence;

> I have much more confidence with myself and now I can...being able to do things. (William, self advocate member, Purple Group)

A feeling that involvement in the activities of their respective self advocacy organisations has positively impacted on their perceptions of their own social confidence, was common amongst members of other groups as well;

> Then I had to go out and do my speech. Speak in front of all the people, it was great. I felt so confident to do that. (Rita, self advocate member, Red Group)

> Well, before, I was, oh, I didn't know how to communicate very well, with others, and I didn't know how, I couldn't interact properly, with others and that, but with being in both, being involved with [Magenta Group] it's helped me, it helped me interact, with others. I've found out a lot more about things. I think I've made it with being more confident within myself. (Tony, self advocate member, Magenta Group)

> Before I joined [Indigo Group] I was really drawn into myself, I didn't really do much or go out anywhere ... I've really found that it's been really useful. (Darren, self advocate members, Indigo Group)

Increased feelings of confidence led people to feel able to speak their minds, express preferences and make choices;

> I used to be upset because I used to be too afraid to speak up and I found out that whatever you say to the staff, people will be talking about you and what you've been doing all the time. I'm better with it all...with being confident nowadays. (Rita, self advocate member, Red Group)

> I think lots of things have changed, but one... basically because we learned to speak up and not keep things, and we know we can have a choice. (Sophie, self advocate member, Magenta Group)

> Everything's improved; I've got a lot of confidence. (Liam, self advocate member, Red Group)

Interviewees were **engaged with life** through the many activities offered by their self advocacy groups and through the links that had been created, by or with the assistance of supporters to activities offered by other groups in the community. Darren (Indigo Group) offered an excellent example of this. Through a connection made to a local theatre company, he fulfilled a long-held desire to participate in amateur dramatics but was also 'busier', had made social connections, and felt more included in his local community.

> I talk to the people I know from the drama group...I see them sometimes when I'm out at the library. I'm quite busy these days...I've got this group

> [Indigo Group], drama group and a few other things too, gets me out and about the place which is what I like. (Darren, self advocate member, Indigo Group)

The Green Group organised social occasions away from the group offices and disability services, for example regular snooker nights at a local pub which members enthusiastically embraced;

> I get out and about more now. Couple of nights a week I'm at the pub, for snooker and hot dogs one of those and then I go with a couple of the others from here just to chat, not just them though we chat with other people in the place...sometimes we do...I like to be busy to be out and about. It makes things interesting, good. I record the soaps anyway. I can watch it later on see? (Nick, self advocate member, Green Group)

> There's ladies against the men bowling nights coming up. I think we're going to win! (Kevin, self advocate member, Green Group)

Emma described her experience of engaging with life through the activities of her self advocacy group and its spill over into activities outside the group as 'getting stuck in'.

Members of Red Group talked about how much 'fuller' their lives were since they joined the group;

> My life is full up now...visit friends more...I might go to see my brother at some stage...I am out of my unit a lot these days...stuff to do and it’s better like that...I’m meeting new people all over the place I didn’t know before. Done a good course too...enjoyed that. (Liam, self advocate member, Red Group)

> Sitting at home...I spent lot of time watching tv and just nothing really much, just tv and stuff. I go out much more now...shopping and I’m going to start going to craft group...its Friday afternoons I think or there might be one on another day...do more scrapbooking and stuff and coming here...Mondays and sometimes Tuesdays...I’m busy doing things now. (Anne, self advocate member, Red Group)

The opportunities for change offered by the self advocacy groups had produced highly positive outcomes for their members enabling them to be more confident people who were leading significantly more engaged and enjoyable lives.

Multiple Positive Identities

Group members spoke about the social identity of people with intellectual disabilities through their descriptions of the ways in which their organisations engaged with other groups in the community. Through community education programmes the self advocates emphasised a shared identity with members of their group but also a desire for an acknowledgement of their shared humanity with all members of the broader community;

> Yes because, if you've a learning disability people don't want to accept you. I've experienced that myself, I've got a learning disability, I've been fighting all my life for awareness and for other people, speaking up on their behalf 'cos we're the invisible people, we're the silent minority and that's wrong. In my eyes that's bloody wrong. Don’t matter if you've got a disability or not, we're all human beings anyway. (Trish, self advocate member, Green Group)

> We say I’m a person I’m just a human being too, just like you. (Darren, self advocate member, Indigo Group)

Collective strength did not necessarily spring from a notion that the self advocates were bonded by their shared disability, rather that in sharing their experiences and gaining confidence in the collegial environment of the group, individuals were more confident about being themselves.

> Accept me as I am, that’s what I say, otherwise...well I don’t care really what they say. I am going to stay being who I am really. (Trish, self advocate member, Green Group)

> I’m now a self advocate, I can speak up. Everyone at [Purple Group] has got the learning disabilities or some problems... but who cares I say. They are mostly good blokes here and we can get along just fine. (William, self advocate member, Purple Group)

William and many of the other interviewees identified themselves as self advocates but did not place this identity in the context of a disability movement. It seemed that this, like the other newer, more positive identities was personal, and that whilst it may have been shared by other group members, it was not indicative of either a level of comfort or acceptance of it being an all-encompassing intellectual disability identity.

Four key positive social identities were described by the self advocates (refer *Figure 3*); a self advocate, an expert, a business-like person and an independent person.

The opportunities offered by the self advocacy groups in this study for members to assume any or all of these positive social identities makes them incredibly important in the lives of people with intellectual disabilities. The findings showed that all of the group members had assumed the identity of 'self advocate'. Additionally, through the activities and opportunities offered by their groups, some had also assumed the identities of 'an expert', 'a business-like person' and 'an independent person'.

A self advocate.

Self advocacy groups have an important role to play in building a sense of empowerment and competence in their members. Trish, from Green Group has assumed the identity of self advocate, defined by her as a person who can;

> Just stand up and be counted, that's how I feel. I really can do that. (Trish, self advocate member, Green Group)

Daniel saw himself and the other members of his group as self advocates characterised by their skills and confidence in 'speaking out';

> We are all just people. People speaking out for their rights. (Daniel, self advocate member, Red Group)

When the group members talk about being able to 'speak out' they are expressing a strong, bold social identity which challenges the core of notions about passivity and incapacity on the part of people with intellectual disability. Assuming the identity of 'self advocate' makes a strong statement of individuality, strength, particular knowledge and a willingness to use it.

An expert.

Self advocate interviewees were involved in programmes which featured them as 'experts' about their own lives. Indigo, Green, Blue and Purple Groups were all very active in providing information sessions or training to others in the community. Groups participating in these programmes included; primary and secondary school students and service providers, for example; doctors, nurses, medical reception staff and the police. The structured programmes were facilitated by self advocates with their group supporters.

> I do all the psychologists, nurses, doctors, and the police. (Henry, self advocate member, Green Group, describing his involvement in a learning disability awareness community training programme)

Without exception, these programmes had a focus on promoting the personhood and equality of people with learning disabilities and whilst they encouraged an understanding of ‘difference’, their major and sometimes conflicting point was to emphasise ‘sameness’.

> I help with the police training too... we talk to some of the police about us, about learning difficulty and being people the same as you and me. (Nella, self advocate member, Blue Group)

> We say we have a learning disability but all equal at the end of the day. (Henry, self advocate member, Green Group)

The power of having the self advocates speak to people about their own life experiences was understood quite clearly by the support workers, as was the potential risk of exposing them to negative reactions by participants;

> Sometimes I think oh my god, they're going to be made fun of and all this and actually, I was looking at some evaluation forms last week and a young person in school writes down something like, you've done a very brave thing putting yourself out there...and it is, isn't it if you think about it? (Claudia, supporter, Blue Group)

For one of the presenters of these school sessions, her involvement in them had, in spite of its recent nature had a significant positive impact;

> I go along with Ben but he's been doing it for ages and ages so I just let him do all the talking (laughs). Maybe soon I will [do more of the talking], but I'm nervous. I like meeting all the kids and sometimes after if I see them in the street a couple have said 'hi [Nella]!' to me which was so great, I couldn't believe it. (Nella, self advocate member, Blue Group.)

Nella's obvious pleasure at being acknowledged in the street was an affirmation she had been unused to experiencing, and was an example of the kind of outcome which for Blue Group's supporters justified some of the risk-taking of the self advocates involved.

Trish, from Green Group described a recent experience of presenting an 'awareness raising' session for a group of nurses which she felt had received a less than positive reaction. She reflected that the session had been a 'waste of time' because she had not had a positive response from participants;

> I don't think I can really put my finger on what was wrong with them but I felt it was a waste of my time (laughs). They are stuck in their own ways about learning disability that's what I think. (Trish, self advocate member, Green Group)

She did however also comment that the opportunity to speak to people outside the self advocacy group was one which she valued highly as the audiences were usually receptive and listened well;

> Just to have people have their ears open and listen to me say this is my life and this is how I want to run my life. (Trish, self advocate member, Green Group)

Other self advocates were highly positive about their experiences of being an expert, addressing groups of service providers and in running disability awareness training in schools;

> It's basically training public service people like doctors, nurses, police and that, just to make them more aware of how to communicate and to treat people with a learning disability a lot better. I think they always enjoy it and I enjoy it a lot too! (Darren, self advocate member, Indigo Group)

An acknowledgment that the audience think that what he has to say is 'important' is essential to Henry's enjoyment of delivering training sessions. He is at that moment an expert, whose unique understanding of learning disability is being conveyed to an audience of service providers who in the past in Henry's experience have disregarded or ignored his views.

> They enjoy my speech. My training, they enjoy it. They reckon it's important. (Henry, self advocate member, Green Group)

The opportunity to ‘tell the story’ of your own life was clearly also very important to some of the other self advocates;

> I like to tell them a story, about each part of my life, like housing, work, and leisure, things to do when away from work, travelling, all those usual, everyday things you know, what people, most people do. (Oscar, self advocate)
>
> I find the staff and the children are so friendly. I tell them about my life ... about what it was like being a child...about having disability when I was a child going to school. (Ben, self advocate member, Blue Group)

Janet, Supporter with Blue Group was ambitious about her hopes for attitudinal change as a result of self advocates from the group running training sessions for service providers;

> I think the work we do in [Blue Group] around public education is incredibly important because that's going to be the springboard from which a lot of integration and inclusion can happen. With the nursing students it’s great because we've contributed to the workforce becoming more enlightened I would say. (Janet, supporter, Blue Group)
>
> Awareness training is really important. You can do it in the community. It is cheap to run and is very important. (Trevor, self advocate)

A number of groups were involved in activities other than training which were designed to try and change attitudes and perceptions about people with intellectual disabilities in the broader community. At the time of interview, Green Group members were working on a major history project, chronicling the history of a large institution for people with intellectual disabilities which had been home in the past to many group members. They were also researching the history of their group. Members had been conducting interviews, visiting the city archives and the old long-stay hospital site, gathering photos and artefacts for a public exhibition at the city museum.

> We are doing a bit of research on the old hospital you know, like what the life was like, how the patients were treated and all that, so we're doing that project at the moment. We went to the archives, in a place, its somewhere in [city], by the museum, the place there, they took us upstairs, and they showed us the old... like where they keep all the important files and stuff. It was very interesting. (John, self advocate member, Green Group.)

When the exhibition was held six months later, it attracted wide media coverage and Green Group were prominent as ‘researchers’ and ‘curators’ of the exhibition. They had become experts about their own history.

Indigo Group members had been involved in a research project with a local university and Darren described the positive feelings he experienced in having social contact with students at the conclusion of the project. Having refreshments on campus with them was to him a potent indicator of a level of affirmation he had not often experienced. He was acknowledged both as a contributor to the student project and as a member of the community;

> There is the project we did with the university students, we went over to the university when they did their presentation and it was really good, they mentioned us right at the beginning and pointed to us which was really good and afterwards they took us into one of the canteens there and bought us coffee and muffins. (Darren, self advocate member, Indigo Group)

Blue Group had been involved in a project which was developed to both enhance the self confidence of members and change perceptions about the identity of people with learning disabilities. Through the use of photographs of individual members, combined with a few lines of verse in each of the member's own words, striking posters were created which highlighted the individual personalities of each person depicted. These made a strong and positive statement about valuing difference.

> I am proud of that picture. Lots of people have seen it and they say it's a good one of me and they like my poem all about going out, it makes me proud and we did that at [Blue Group]. It shows people we can be smiling and a bit funny and proud. (Ben, self advocate member, Blue Group)

The posters had been on display in several community settings and Ben commented that a number of people had said how 'handsome' he looked in his photo and that his poem had ‘made them laugh’. He expressed pride about this positive acknowledgment and was keen to share a copy of the poster with the author.

> I am proud when people see me and remember I know what I’m talking about when I visit their school or wherever. (Ben, self advocate member, Blue Group)

> I know about learning difficulties...you know being a person who has learning difficulties, I can tell people all about it, what’s what and ...what’s it’s like, so when I finish giving my speech, I do think they know that I am a good person to tell them all about that. [Supporter] says I am really good at doing the speech. (William, self advocate member, Purple Group)

Affirmation of particular life knowledge and an ability to share it effectively were important in developing the identity of ‘expert’.

A business-like person.

The self advocates placed great value on the business-like or worker identity they derived from their participation in the group. Members derived enjoyment and meaning from the work orientated or business-like processes of the group and its rules, infrastructure and activities whether they worked in a paid or voluntary capacity for their group.

Red Group were notable in their focus on business-like processes which they called ‘the rules’, regularly meeting to discuss the group rules and publishing updates to members' handbooks. An ability to follow the rules to the letter and have a thorough knowledge of accepted processes was regarded as an important component of the positive identity of the self advocate members of this group;

> We all know how to have a meeting. (Daniel, self advocate member, Red Group)
>
> Liam: Yeah we have a handbook that we actually run through, we've got a copy in there [the office].
>
> Daniel: it says in the handbook you've got to contact the person if you're not coming to the meeting.
>
> Liam: That's the [Red Group] handbook and what it is, is basically just the rules and stuff like that, what we go by.
>
> Daniel: What the rules say are what we do. (Liam and Daniel, self advocate members, Red Group)

Self advocates from other groups offered examples of their enjoyment of participating in committees and attending other meetings;

> The meetings are really good. And we've got our management committee group, we meet twice a month to discuss what's going on with the funding and such, and if there's an issue we need to speak about. (Trish, self advocate member, Green Group)

> Usually a self advocacy group meeting and where we’ve got like two and a half hours... it just goes so quickly! (Yvonne, self advocate member, Magenta Group)

Self advocates seemed comfortable with using the language of committees and management jargon; talking about ‘members execs’ (Tony and Yvonne, Magenta Group), ‘trustees and directors’ (Sophie, Magenta Group, Henry and Nick, Green Group), ‘best practice and think tank’ (Liam and Rita, Red Group), ‘action events’ (Darren, Indigo Group) and ‘organisational structure, finances and admin’ (Audrey, Indigo Group). Liam from the Red Group described how the committee of management had in collaboration with a support organisation, undertaken a ‘SWOT’ analysis;

> We have done a SWOT plan which basically looks at our strengths, weaknesses, opportunities and any threats. (Liam, self advocate member, Red Group).

Audrey from the Indigo Group talked about the importance for members of carrying and keeping an appointment diary to ensure the smooth running of scheduled meetings. This was an important factor in affirming her business-like identity; she had commitments in relation to the group and her contribution was acknowledged. The need to have a diary was a sign of her busyness and status.

A number of the self advocates discussed the importance of group members being punctual and dressing smartly for their attendance at the offices of the organisation and when they are participating in meetings;

> Be on time, dress smart, be punctual. (Henry, self advocate member, Green Group)

> I always wear my best shirt for coming in to the office. It's very important. (Ben, self advocate member, Blue Group)

> I like looking very smart when I come in here. It's important to look smart, see here...shiny shoes and all, just like a hard worker. (William, self advocate member, Purple Group)

> We all be on time and official when we're coming to the office. It's great to be here. (Daniel, self advocate member)

Maintaining particular standards of conduct was seen as important in demonstrating that the group was running 'properly'.

> We've got to prove ourselves, can we run an office properly, see? (Daniel, self advocate member, Red Group)

> It's sort of like work, you have to ring in if you're sick, if you don't ring in when you're sick you get in trouble. (Anne, self advocate member, Red Group)

Darren praised the committee of management and support staff for making sure that;

> [Indigo] Group runs like clockwork. (Darren, self advocate member, Indigo Group)

Many of the self advocates clearly enjoyed the tasks they undertook in the office.

> I work every Thursday. I love that. I answer the phone. You do get some funny people. Yes! They are nice people [laughs]. I just say, can I pass you on to somebody else? [laughs] (Trish, self advocate member, Green Group)

> I comes in here Wednesday morning I am answering the phone, and checking the post...it's really good. (Nick, self advocate member, Green Group)

> I work in the office, to help out with opening the post and answering the phone. I really like being in the office, it makes me so happy and sometimes we laugh - all the people who work in the office have cups of tea together when we are working, it's really good. (Emma, self advocate member, Purple Group)

The Green Group offered both paid and voluntary work in the organisation's office and this was clearly a valued part of the identity of the self advocates interviewed. There were a limited number of positions available for which people were paid due to funding constraints and both the paid and voluntary positions were offered subject to the external constraints of the welfare benefits system.

> We employ six on a paid basis, for two or three hours a week only, because of the rules about benefits they can’t do more paid work than that. The volunteers can also only be here a small number of hours depending on their benefits. I’m glad we’ve got the money to employ a few people though, it seems to work well, they enjoy it. (Harriet, supporter Green Group)

The self advocates in this group spoke with great pride and satisfaction about the process of ‘getting a job’, and ‘having a job’;

> All of a sudden there was a job going for here like, so I went and I put an application in for my job and I went for an interview as normal and they offered me the job of course! And I’ve worked here now, with [Green Group], seven and a half years. (Frank, self advocate member, Green Group)

> I've done this job thirteen years. It was voluntary in the beginning but now it's a paid job, part time. (Henry, self advocate member, Green Group)

Frank described a meeting with a former teacher from his early school days and the pride he felt in being able to say to him that he had a job and that he worked at Green Group;

> I told him I've been working down in [city], like, and he was surprised and he said; '[Frank], I am surprised that you've got a job'. (Frank, self advocate member, Green Group)

Having the identity of a ‘business-like person’ was clearly very important to the self advocates. The small number of hours attached to the paid positions held by Green Group members did not diminish their pleasure at having a job; it was a job, and that was of crucial importance to the self advocates feeling that they had a business-like identity.

Many of the attributes of the business-like role being described were those of a white collar worker.

> Working in the office is important isn’t it? Sitting at the desk and answering the phone, I like that... and stapling up the copies...the copies of the notes, other stuff for people. I make sure it’s all tidy in here, no rubbish lying around and all the paper in a stack under the table in case we need it.
> (Daniel, self advocate member, Red Group)

> Making some of the photocopies and putting the pens in the right place, they are some of the jobs what’s good to do. I can answer the phone too...sometimes I do if no one else is here which I like to do. (Nick, self advocate member, Green Group)

> Now I come in the office and I got a role to do, work to do and that makes me feel better. (John, self advocate member, Green Group)

Underpinning this is an insight into what it means to be a ‘worker’, that to be a success in the context of the organisation’s office environment implies a level of efficacy and reliability;

> They rely on me, they trust me as well because all you got to do is ask me and I go away and do it. (Kevin, self advocate member, Green Group)

> I go to the post office you see like when we run out of stamps and we want more stamps and my boss says [Frank] will go down the post office and get more stamps so I go down there right away to the post office, get some stamps. I been here seven and a half years ...they rely on me, they trust me as well because all you got to do is ask me and I go away and do it. They know I can do it. (Frank, self advocate member, Green Group)

Frank felt he was ‘trusted’ by both the other group members and by the support staff to do his job well.

The members of the committee of management of Red Group were paid a small per diem on each of the two days that the organisation’s office opens during the week. Daniel described this as being paid in order to ensure that everything in the office was ‘running right’, explaining that;

> See, they won’t give you money for no reason. (Daniel, self advocate member, Red Group)

These members were not officially employed by their organisation and whilst they did not speak about the activities in the office as being ‘work’, many of the tasks they described were similar to those undertaken by members who were formally employed. Members in Red Group derived the same kind of ‘business-like’ identity from their activities in the office as did members of other groups who had ‘jobs’.

Jenny, who is the Supporter of Magenta Group, spoke about her strong desire to be able to pay the self advocates in the organisation who undertake work for the group, particularly running community awareness-raising and other training programmes. The group has been unable to secure funding to pay to employ any self advocates;

> To be able to pay people to, you know, to do things, is what we would really, really like to do. If they go and come with us to deliver a workshop and it’s just, you know, we can make sure that their expenses are covered, but you know, to be able to pay them an award wage would be just fabulous, and that’s our philosophy, but it just is impossible. (Jenny, supporter, Magenta Group)

Currently, an arrangement is in place to cover out-of-pocket expenses for members. Blue Group similarly does not offer its members ‘a job’, but reimburses expenses and offers shopping vouchers or trips to conferences to members who give talks or presentations to outside groups. This was, according to Claudia, because of a lack of funds;

> It would be wonderful to be able to pay everybody but then if we were doing that then we wouldn't be able to do as much work with people out there. (Claudia, supporter, Blue Group)

To have a ‘job’, whether voluntary or paid was regarded by the self advocates as highly significant in providing tangible evidence that things had changed and improved and that they were now occupying valued roles.

For the self advocates who worked in the offices of their respective groups, either in a paid or voluntary capacity, the time spent in the office was time in which they were ‘trusted’ to manage their tasks and were supported rather than rigidly supervised to complete those tasks in a timely manner. Henry (Green Group) and Ben (Blue Group) had both had many years of experience in a factory setting in which there was no flexibility or autonomy, and both described the stark contrast between the rigid, unchanging and ‘boring’ environment of that workplace and the more interesting environment of the self advocacy group where they were respected and trusted to act as workers. The groups created valued, ‘business-like’ roles for their members and in doing so produced highly positive impacts on the social identity of those members.

An independent person.

A number of the self advocates described their greater independence since becoming members of their groups and how an increased confidence and skill in articulating choices had brought about significant change.

Frank had recently moved out of his mother's house and into a flat. He was enjoying the experience as well as what he saw as the opportunity to prove that he really could manage on his own;

> I talked to my social worker and said can you find me a flat and he found me a flat. It's the first time I've been living on my own, and I've got my own independence now. I go out when I want to. I can watch television or do what I want to. I don't go out drinking or stuff like that I just like stopping at home. I wish my mother and my sister could talk to me and see I can cope on my own like. I like being independent. (Frank, self advocate members, Green Group)

Kevin who is also a member of Green Group was enjoying having a place of his own;

> I've been enjoying being out in the community, having my own front door key, what I'd never had before... (Kevin, self advocate member, Green Group)

For others, independence was defined in terms of the opportunity and confidence to travel around their community and even further afield;

> Like before yeah, like I wouldn't even travel anywhere and now I just jump on the bus and go to [city] and that's all through self advocacy. I go to [city]

> quite a bit. I think I should actually move to [city], I spend more time there than I do at home! (Liam, self advocate member, Red Group)

> I'm much busier my mum says! I like to get out of the house more and talk to people. I can do different kinds of stuff I couldn't do before. I can speak up for myself much more better than I could before and do many more things I couldn't do before... talking on the phone , talk to new people and I can say sometimes what I think about things. (Emma, self advocate member, Purple Group)

> I go out when I want to, I stop in when I want to and I can use the buses or sometimes I go on a taxi to go some places I like to go. I go by myself if I feel like it. (William, self advocate member, Purple Group)

Janet, supporter of the Blue Group described an unintended but positive impact of recent funding cuts in her group's area which had impacted heavily on the travel budget of many learning disability support services. People who in the past had been driven door-to-door to a range of activities, including self advocacy group meetings, were now engaged in travel training or were already travelling independently and enjoying new freedom and feelings of independence.

> One of our committee members, when she first came to meetings, we would go and pick her up from home, like a twenty mile round trip and we had to look at our travel and say well actually we are spending an awful lot of money on transport and she's got a bus pass, so what I'm saying is why not

> use it, now she's great, she enjoys it. So it's little things like that, suddenly you say to people, you know, you can do that on your own and people realise they can. (Janet, supporter, Blue Group)

Members of Magenta Group spoke about their independence in making choices about services they received in the community, notably choosing doctors and disability support workers;

> I’ve picked a doctor that I can go to by myself now. He’s alright, you know. (George, self advocate member, Magenta Group)

> Like with our support workers and that, we might have just stuck with having bad ones for ages, but now we know we don’t have to put up with that sort of thing. We have a say, in our, like how our lives are run, and what services we get. (Sophie, self advocate member, Magenta Group)

> I think lots of things have changed, but one, basically because we learned to speak up and not keep things, and we know we can have a choice about who our supports are. (Sophie, self advocate member, Magenta Group)

Within Indigo Group, supporters had scaffolded greater independence for members seeking to participate in a range of groups other than the self advocacy group. These were groups catering to special interests and were not specific to people with intellectual disabilities. Supporters sought out groups which matched the interests of individual group members and were ‘open’ to participation by people with intellectual disabilities. Some examples included members who had been linked into a local knitting group and a camera club. Darren described his very positive and ongoing engagement with a local theatre group, fulfilling a long-held desire to be involved after attending some of their performances.

> They made me feel really welcomed and that, I said I'd like to join but how would you feel about having someone with a learning disability? They said how's your reading? And I said good, and they said well as long as that's ok, ‘cos we do play readings and that see, they said as long as that's ok you can come and join us. It’s so much fun. I help with the lights, backstage and things. (Darren, self advocate member, Indigo Group)

There were many positive examples of where self advocacy groups had enhanced individual member’s independence by promoting and developing confidence in decision making, mobility through travel, and inclusion through participation in a range of social groups. This had largely occurred through supporters working closely with individual self advocates.

Summary

Emerging from the data is a positive picture. The groups are important and unusual social environments which are characterised by collegiality and a strong sense of ownership and control. From the perspectives of the self advocates, engagement with their respective groups brings about positive change in their self-confidence and a belief in their own abilities to experience different activities, assist others and to use new and established skills. The opportunity to assume a range of positive social identities; as a self advocate, an expert, a business-like person and an independent person, is for many interviewees a new and exciting one not replicated in their life experience prior to joining their group. Change was occurring also in the kinds of social space occupied by the self advocates as they explored and engaged in a range of activities both within their groups and in the broader community, raising their visibility and independence.

Darren summed up the purpose of his self advocacy group as a conduit for people discovering and developing their own identities;

> We just help them, be them really. (Darren, self advocate member, Indigo Group)

Chapter 6. Discussion

> We like to say, I'm a person, just the same as you. Lots of people are surprised when I say things like that. (Ben, self advocate member, Blue Group)

The aim of the research was to examine the experience of engagement in self advocacy groups by adults with an intellectual disability and the impact of self advocacy on their social identities.

A Grounded Theory model was developed which shows the impact of self advocacy groups on the social identity of people with an intellectual disability. A diagram of the model is found in Chapter 5. Findings and clearly shows that the kinds of change produced by individual engagement in self advocacy groups were facilitated by the organisational structure of the group, the nature of its activities and the relationships within the group. Groups were characterised by their collegiality and a sense of ownership and control by members. The 'trusting environments' described by Caldwell (2010) were here, creating opportunities for members to use their new found confidence to practice and build on their skills as workers, and as key contributors to the purposeful activity of the group. Participation in some or all of the many activities offered by groups contributed to members feeling that they were more confident and engaged with life and these significant changes led to them embracing newer, more positive social identities. Those identities were; an expert, a business-like person, an independent person and a self advocate. The kind of self advocacy being enacted here was about as Crawley (1988) writes, ‘more than just talk’, it was an opportunity to create and enact very real change in individual lives.

The findings were about change. This change was about a positive personal transformation which interviewees described as a product of their membership of their respective self advocacy group and an involvement in its activities. The self advocates were asked to describe themselves and their lives before joining the group and to compare that with their feelings now. They talked about a transformation, and the findings showed that assuming the identity of self advocate as a result of group membership and participating in ‘speaking up’ training was clearly an important element in this.

Included in the findings are numerous examples of what Goodley (2000, 2005) hails as resilience ‘existing in spite of disablement’ in the context of a ‘disabling community’. Many of the participants in this study demonstrated that they had considerable personal resources to cope well with some of the more difficult challenges they faced in living in a community which resisted their inclusion. The ‘elusive quality of resilience’ Goodley (2005) described was not difficult to find within these groups. Self advocacy groups were, as he describes developing, articulating and focussing on resilience. The findings show many examples of self advocacy groups and their members ‘reworking’ social identities and roles. Goodley (2005) may be right to be sceptical about any perceived colonisation of self advocacy by policy makers, but this study shows that what he calls the ‘lived reality’ of engagement in self advocacy offered members a great deal.

Self advocacy has, particularly in the United Kingdom context, become part of the learning disability policy landscape and there has been an inevitable depoliticisation of its activities as a result, but it would appear that the kinds of self advocacy being enacted here were not without potency. The findings demonstrated that great social power lies within the multi-faceted ways in which the self advocacy groups worked to develop the self confidence of members and include them in a wide range of new and engaging experiences.

Developing Self Confidence and Skills

All of the self advocates interviewed described themselves as being more confident people, some explicitly using that terminology, others able to articulate a definite change in their ability to 'speak up' about particular issues, to tackle tasks or situations which had daunted them in the past. They characterised themselves as being less passive, shy or fearful since their engagement with the group. Darren of Indigo Group commented that as a new member of the group a number of years ago he wouldn't have 'said boo to a goose'. He now feels confident and is outspoken and sociable. These findings reflect those in Beart, Hardy and Buchan's (2004) study of eight self advocacy group members which found that participation had positively impacted on the 'self-concept' of the individuals and that this was clearly indicated by their increased self confidence.

The focus of groups on training and developing the skills and confidence of self advocates served to create opportunities for significantly altering the marginalised lives of people with intellectual disabilities. As Carey (2009) argues, the act of participation, of engagement, has potentially great power in the life of any individual citizen but for those who have long been marginalised and on many levels, disenfranchised, it can be significant and indeed ‘humanising’. For the self advocates, ‘feeling’ that they are self advocates and that they are strong and able to speak out, highlighted everything that was different and more positive in their life. The findings offer many examples of participants who said that they felt a greater sense of personal efficacy. This accords with the description of self advocacy organisations given by Brennan, Forrest & Taylor in Beresford & Carr (2012) as being places where people ‘feel stronger’ and more able to make choices and act with independence within the group and to a lesser extent, outside it.

Different Kinds of Groups with Similar Outcomes

Blue and Magenta Groups could be described as growth and education groups as their focus was on developing and strengthening skills, particularly towards independent living (Shulman, 2009). These groups had committees of management which contributed ideas about future direction, activities and engagement but it was clear that it was the supporters who drove the agenda of the group. The findings showed that the activities of these groups were very much focussed on the development of the personal and interpersonal skills of the members with a strong emphasis on healthy relationships, dealing with bullying, identifying feelings, personal grooming and practical skills such as cooking. Members’ engagement with the broader community through disability awareness programmes had a very personal focus, urging people to consider the members’ individuality rather than their intellectual disability. Office bearers in the group did have some status attached to their roles, but little actual power. There was also status attached to the community education presenter roles in the group and to the consultative roles connected to the local authority. These were important because selection for these roles seemed to allow the members chosen to engage with the group in a way which was not time-limited. It was the group's supporters, not the members who selected people and trained people for these significant roles and it was a strong reflection of the nature of the power relations within the group that this occurred.

The Green, Purple and Indigo Groups had a stronger focus on 'social action' and as such could be categorised as being task and action groups. These groups combined training for members about 'speaking up' as well as training in a range of personal and independent living skills with social activism and engagement in research, history projects and developing connections with disability activists within and outside the area of intellectual disability. Green and Indigo Groups employed self advocates within their office who worked closely with the groups' supporters. Purple Group had volunteer staff members drawn from its membership. Whilst all these groups had a committee of management with self advocate members and paid positions within their offices, there still existed an unequal power relationship between the self advocates and the supporters which echoed that in the Blue and Magenta Groups. The skill and professional connections of the supporters all of the groups except Red Group, played a key role in ensuring the funding stability for these groups and in developing the opportunities for members to be able to gain paid or voluntary work with the group. There were no examples of resentment of the level of management of the direction of activities by the supporters amongst the self advocates interviewed for this study, rather a sense of appreciation for what they have done and continue to do.

The findings showed that members from groups in the United Kingdom and Australia experienced the same positive outcomes in spite of the differences in the policy contexts in which they were positioned. The United Kingdom groups appeared to be better resourced than the Australian groups and were therefore able to offer a larger number and a greater range of activities for members. There was however no difference in the type or level of impact individuals described. All of the groups produced highly positive outcomes for their members. All of the interviewees were asked specifically to describe positive and negative experiences which had formed a part of the engagement with their respective group. With the exception of a few, mostly joking remarks about unhappiness at not being selected for office bearer positions, participants were overwhelming positive about being a part of their group and the activities on offer. There was no sense that this reporting of positive experiences was a result of an eagerness to please, to say the ‘right’ or ‘expected’ thing particularly in the presence of supporters. The context in which the remarks were made and the confident strong voices of the participants gave weight to their stories.

New Identities

Being an expert.

Many of the self advocate interviewees talked about being ‘experts’ about their own lives and used this expertise in powerful ways; sharing experiences with other group members, talking to community groups or participating in research. The idea that a person with an intellectual disability could be an ‘expert’ was an important shift in their social identity. For many this major shift came from a position of a lifetime of experience as a service user, a client or a patient of services, treatment or rehabilitation. It is not difficult to see that the impact of being regarded by others as having important knowledge would produce a massive shift in the self confidence and esteem of these self advocates. The notion of members as ‘experts’ existed in all of the groups but was particularly strong in the groups which delivered programmes to community groups; Green, Indigo, Purple and Blue Groups. The Red and Magenta Groups lacked this external training focus but members still shared life stories with one another and the respectful ways in which they were heard was important in building a sense of each individual being the ‘expert’ about their own life. Speaking to community groups afforded self advocates opportunities to tell people about their lives; ‘what life with learning disabilities is like’ (Trish & Nick, Green Group). This was a personally powerful experience for those involved, heightened by some of the audiences present to hear them speak; nurses, doctors, social workers, psychologists and police officers. These were all professionals with whom members had dealt. but never on their own terms, and the sense of satisfaction members felt at being able to be the ‘expert’ present was palpable. The message about personhood featured strongly across all of the groups in their presentations to adult professionals and to children in schools – ‘see me as a person just like you’. Whilst the school sessions I observed were at times confronting and uncomfortable with a minority of students in each of the groups either unresponsive, or laughing and disrespectful, the self advocate presenters either did not observe this negativity or chose to ignore it. Self advocates like Ben were elated at the end of the sessions, filled with enthusiasm, positive and happy. Ben said that he ‘loves’ going to schools and speaking and that the children enjoy hearing him speak. He felt affirmed as a person, and as an expert about his own life, and that had had a powerful, positive impact on his sense of self.

Being listened to as an expert by others who are experts in their field, and importantly have significant power as service providers offered self advocates tangible evidence of a change in their social identity beyond the group. Commentators including; Atkinson (2002), Chappell et al (2002), Booth (1996), Browning, Spedding et al (2002) and Mitchell et al (2006) all describe the positive impact of members telling their own stories of resilience and survival. This is occurring in other arenas too. Maestri-Banks’ (2013) description of the ways in which the perspectives of people with learning disabilities have been incorporated into nurse education at Liverpool John Moores University provides an excellent example of how the work of self advocacy group members might have spill over effects in the community. When members are supported to do this outside their groups the impacts can be on both a personal and a community-wide level. Changing the way service providers regard people with an intellectual disability can enhance their social inclusion, making key features of society such as the health system, more accessible and responsive in meeting their individual needs.

The importance of a 'business-like' identity.

Many of the interviewees gave examples of deriving what I have called a 'business-like' or worker identity from their involvement in their respective self advocacy organisations. The enormous pleasure and satisfaction gained from participating in the 'business' of the self advocacy office seemed to stand out as being a highlight for many whether they did so on a paid or voluntary basis. Whilst only two of the groups offered members regular paid employment, most of the others offered some payment, either in money, vouchers, snacks and meals, or subsidised event attendance in exchange for delivering training programmes. All of the groups, with the exception of Blue Group offered members voluntary work opportunities based around the administrative tasks of the organisation's office. The trusted self determination implicit in the assigning of tasks in the office context was important to the self advocates in many ways. It signified the positive regard in which they were held by both the group's support staff and by fellow members. The tasks, such as answering the phone, passing on messages, buying tins of coffee and stamps were all examples of 'work' of the kind the self advocates recognised, and their participation in these tasks gave them the identity of 'worker'; an identity many had been told, (or had understood) that they could never attain. The office-based nature of the tasks marked them as white collar jobs perhaps mimicking the work environments of some of the disability professionals with whom many of the self advocates would have had prolonged contact – all from the other side of the desk.

The experience of having a defined, business-like role was clearly something enjoyed by members of other self advocacy groups not included in this study such as this example written and posted online by a member of Newport People First on January 21st 2013;

> I am a volunteer for peoples [sic] first I come to work every Monday I come in make tea coffee do letters answer the phone and do the hovering [sic], I work eleven till one. (Newport People First, 2013*)*

Members of the Magenta and Red Groups derived a ‘business like’ identity from their engagement with the apparatus of the committee of management but this identity was not strongly expressed as they did not have paid or voluntary employment in the organisation. There was however a very strong sense of ownership and connection in these groups, of being engaged in a shared enterprise and this emerged through members describing themselves as being more confident people but also as people who help others.

Groups’ activities and meetings were carefully, even meticulously planned and those I observed ran in ways which enhanced the enjoyment of participants, and maximised both the number of self advocates who could participate and the range of ways in which they could participate. Supporters played a key role in producing this outcome. The findings were very different from those uncovered in Clement’s (2003) ethnographic account of ‘People First Anytown’ in which the author was critical of the ‘inefficient’ and ‘unproductive’ way the organisation’s office and particularly meetings were run. The findings of this study showed that self advocates were happy and comfortable with the way in which the activities and offices of their organisations were administered. The business-like identity assumed by members emerged from the business-like environment and organisation of the group and this was, in the case of five of the groups, a reflection of the high quality support they received. It appeared that the creation of a business-like environment was not dependent on either supporters alone, or even supporters and self advocates as colleagues, as is evidenced by the highly organised Red Group which operated effectively almost completely without support. Within this, and all of the other groups, there was a strong desire expressed by individual members to engage with the group as a ‘worker’ and to contribute to the smooth running of processes and activities. Clement (2003) speculated that in the case of the group he studied that greater efficiency in its operation may in turn lead to “...greater access to power and control for members.” (Clement, 2003). This would certainly seem to be true for the groups in this study. Quality support which empowered members to take on business-like roles created opportunities for people to contribute to the overall running of the group and to engage in acts of trusted self determination which were personally empowering. This was a good outcome for both the individuals and the group.

The findings showed that Green Group offered its members the most opportunities to develop a ‘business-like’ identity. Encouraged to spend time in the group’s office, office-bearers and ordinary members engaged in voluntary and paid work in what they clearly considered to be their own space. Whilst more formal work related activity was going on, the social aspects of an office were enjoyed by members as well, with people making cups of tea and chatting. The office setting of this group reflected a high level of trusted self determination. The contrast for members between this work environment and the sheltered employment setting from which many of the self advocate members had come was clearly articulated by the interviewees. The trust and respect inherent in the way in which tasks were given to members by the supporter offered great opportunities for people to feel strongly that they were regarded in a more positive way than they had ever been before.

The findings showed that self advocates enjoyed and valued the paid and voluntary work they undertook for their respective organisations, they clearly understood its significance in enhancing their engagement with life and developing their self confidence. Two of the interviewees demonstrated a broader effect, speaking about the impact on their identity beyond the group to people or institutions which in the past had denied the possibility of them ever achieving a business like identity. Whilst many authors, including; Abberley (2002), Redley & Weinberg (2007), Hall, (2004 & 2005), Laws & Radford (1998) and Ward (1988), are critical of the kind of social integrationist discourse which focuses on economic participation, specifically through paid employment as a panacea for social exclusion, the findings in this study point to the great sense of confidence and satisfaction individual self advocates derived from their adoption of a business-like identity. The findings show that these members had a clear understanding of the high social value placed on work and being a worker within the broader community and eagerly embraced its inclusive implications. The self advocates placed great emphasis on the ‘work’ aspect of their engagement with the group with many describing it as a personal highlight.

Being an independent person.

Some of the self advocates interviewed embraced the social identity of an ‘independent person’. For Frank and Kevin of Green Group, having their own front door keys, their own flats, was evidence that they were living as more independent people. They felt pride and pleasure at their ability to live with confidence in a new setting with limited support and to be able to make choices about daily living and activities such as choosing what to watch on television and whether to invite friends or family around for a meal.

The opportunity to be able to make a choice or a decision was significant in making people feel that they had a measure of independence not experienced before. Many of the self advocates had lived, or still lived in highly controlled environments with little if any chance for self determination. Opportunities to express opinions and preferences in the context of the self advocacy group had led, for some, to opportunities outside the group, to live in new environments or to become involved in activities in the wider community. For Rita of Red Group, being able to choose what to have for breakfast contributed to her sense of self as a confident person able to take control of an aspect of her life. Rita’s ‘independence’ may seem limited and modest in many contexts, but for her, having the ability to change something, to be a person who was doing something different and of her own choosing after many years of frustration and unhappiness was highly significant. Her identity had been altered in a positive way.

Engagement in the self advocacy groups contributed to people developing the identity of an independent person by supporting participation in activities in the broader community. Greater personal confidence led to people feeling more comfortable about being out and about in the community, able to travel and to participate in a greater range of activities and be in social spaces like pubs and cafes. The opportunity to be ‘out and about’ and to be able to be anywhere but at home and to access places and activities easily accessed by other community members, contributed strongly to people feeling that they were more independent people. The examples of independence in the findings are significant in the context of the highly constrained lives many of the self advocates had led.

Being a self advocate.

All of the interviewees had developed identities as self advocates, a social identity they had developed through their membership of their respective groups but significantly through the training provided by those groups. Training had focussed on learning the language of individual rights and of advocacy – speaking up for the rights of other group members. Goodley et al (2003) are critical of the notion that self advocacy is something that ‘needs to be taught’ to people with learning difficulties, arguing that to do so does ‘a disservice’ to the resilience of members. The self advocates in this study however relished the self advocacy training provided by their groups and regarded it as an opportunity to practice and to hone statements of strength and to be ready to deliver them to the community outside the group. For the self advocates, the self advocacy group offered a safe place to take such risks and to build skills in articulating opinions and choices which drew on, rather than detracted from individual resilience.

The identity of ‘self advocate’ encompassed both speaking up for oneself but also acting in ways which supported and enabled peers to understand their rights and to deal with the negative consequences of a disabling society, including exclusion and bullying. Members spoke as much about ‘helping’ as they did about ‘speaking out’ in describing what they understood to be ‘self advocacy’. It is this insight which reveals a great deal about the potential that membership of such groups has to change the lived experience of people with intellectual disabilities. It was extremely important for people to see themselves as being people able to stand up for themselves. Seeing themselves as capable and skilled in bringing about change in the lives of their peers radically altered their social identity. Having the identity of ‘self advocate’ meant that they were someone who was joining what Marcus Redley described as the ‘common human experience of the struggle for self efficacy’ (M.Redley, personal communication, October 13, 2011). The neutral or sometimes negative identity attached to a person who is a client, patient or service user is underpinned by an assumption that they are passive recipients – of advice, of treatment, of therapy or control. The findings show that self advocates are people who ‘help’ themselves and others and were actively engaged in issues which mattered to them in their lives.

Creating Opportunities for Social Engagement

The nature of the relationships and interactions occurring in all of the groups in this study provide vivid illustrations of Blumer's (1969) characterisation of the 'profoundly social' human being emerging from social interaction. For adults with an intellectual disability, the way they are treated and regarded within self advocacy groups can be seen as nothing short of revolutionary because it contrasts so dramatically with the kinds of relationships and interactions they experience when they engage with service providers or the broader community. People have for so long been seen as 'passive', as people "...who always need to have things done *for* them." (Simons, 1998, p.7). The findings showed that within self advocacy groups, members had the opportunity to do things for themselves and for others, and this dramatically changed the nature of their relationships and interactions as well as their self concept.

Groups of many different kinds including sporting clubs and special interest organisations are accessible to most in the community. Collegiality and a sense that members are in control are common features of these types of organisations. Such groups are not generally accessible to people with an intellectual disability and it has been difficult for them to find a way to enjoy the benefits that are associated with membership (Cummins & Lau, 2003; Walsh-Allen, 2010). These findings suggest that self advocacy groups therefore are extremely important because they offer people with intellectual disabilities many of the benefits others in the community gain from their membership of social and other community groups. The choice of the word 'engagement' in the title of this thesis is important because it represents an individual’s connection to a group which is stronger and more significant than ‘participation’, ‘attendance’ or ‘involvement’. None of these other words hint at the transformative potential of ‘engagement’ with self advocacy so strongly highlighted by the experiences of the twenty five individuals interviewed for this study.

Group members valued one another, and the high status they ascribed to relationships within their groups belies the concern raised by Chappell (1994) that policies underpinned by normalization have acted to lessen the status of relationships between people with intellectual disabilities. Members had a clear sense of ‘interdependence’, reframing it as an opportunity to ‘help’ and support others (Carnaby, 1998). In fact, the ‘group concept problem’ raised by Gibbons (1985) did not exist in the six groups in this study. Members were enjoying, developing and valuing friendships and other relationships with peers with intellectual disabilities and certainly not finding their peers ‘less socially desirable’ than people without disabilities as Gibbons (1985) found in his research.

A key factor in contributing to the change identified in this study was the ‘positive social environment’ of the self advocacy group, similar to that described by Beart, Hardy and Buchan (2004). However, this study showed that the environments of the six groups were far more nuanced than Beart, Hardy and Buchan’s (2004) description would suggest. It demonstrated the multi-levelled way in the ways in which self advocacy groups worked to shape and build the confidence and the enhanced social identity of their group members. The inclusive nature of the group was important, and although it was clear in some of them that there were strict rules about members' behaviour, especially during formal meetings, all were welcome to engage with the groups' varied activities. In spite of the observed power of the supporters in determining the agenda of the group, the self advocates themselves did not seem to feel concerned or resentful about this. The self advocates in this study had a strong sense that theirs was an organisation in which all people were valued for their participation separately from any specific contribution they made. Whilst positions on the committee or specific roles in the office were seen as desirable by most group members, the engagement of *all* members was important. The kinds of relationships fostered in the group between members and between members and staff were built on mutual respect and illustrate the kind reciprocity Amado (1993) describes as being an important 'bridge' in developing friendships. The findings showed that members held their peers in the group in high regard and embraced opportunities to support and to assist them in ways which enhanced their own and others experience of group engagement.

Self Advocates and the Social Model of Disability

The collegiality and sense of power and control within the groups created a framework to launch new activities and skill building which in turn led to newer, more positive social identities. The findings show that individuals were encouraged in the groups to look beyond medical model descriptors of themselves and to embrace a different view. The activities of self advocates within their groups 'magnify' the 'self-help' aspects of the social model of disability (Chappell, 2002; Oliver, 1996) which include; self empowerment and advocating for change, particularly change to services, as well as sharing of experiences as labelled people.

These are not the activities of individuals in isolation - the self advocacy *group* is the catalyst for much of this activity and they challenge the community to look at members with an intellectual disability in a different way, just as they are being challenged to see themselves in a different way. Self advocacy groups invite their members to say more than ‘accept me for who I am’ rather, ‘accept me for the many things I am and can be.’

Moving Away from Collective Identity

Findings from this study offer many examples of the ways in which self advocacy groups worked to build and develop more positive social identities for their members. There are as Shah and Priestley (2011) argue, very few opportunities for people with intellectual disabilities to write their own ‘identity scripts’. Evidence from this study suggests that this rare opportunity does exist within self advocacy groups.

Whilst some commentators on self advocacy have focussed on the potential of such organisations to build a more positive ‘intellectual disability identity’ (Goodley, 2005; Milner & Kelly, 2009), this is couched in terms of a more positive *collective* identity. This idea seems to build on a reclaiming of negative labels and stereotypes and a working together, adopting an awareness raising focus which simultaneously seeks to strengthen the ties of individuals to their group identity and change the way outsiders perceive its members. Although there was some activity which focused on disability identity in some of the groups in this study, there was generally a far greater focus on *individual* social identity. This was multi-stranded and allowed the group members to be someone else in addition to being a ‘person with an intellectual disability’. This was highly significant for some of the self advocates, particularly those with experience of institutional living where their disability identity in many senses defined them. In the self advocacy groups in this study, self advocates embraced the opportunities created within their groups to write and rewrite their own ‘identity scripts’ (Shah & Priestley, 2011) which focussed strongly on self determination and individuality.

Self advocacy groups provided opportunities to take on a range of roles which mimicked those provided by the social institutions so readily accessible by people without intellectual disabilities within the broader community. For most adults, there are opportunities to be partners, parents, workers, colleagues, friends, neighbours or team members. Opportunities to inhabit multiple social identities are rarely accessible to people with an intellectual disability whose diagnosis appears to run deeper than any other in terms of social exclusion and negative perceptions. The writing of ‘identity scripts’ of the kind described by Shah and Priestley (2011) occurring in self advocacy groups was of a powerful and highly personal nature. It had implications which stretched beyond the personal into an impact on the collective identity of members, and changed the way they perceived themselves as people with an intellectual disability.

The strong focus of groups on capacity rather than incapacity worked to change the social identity of members within the group. The findings included numerous examples of groups identifying and developing particular individual skills and talents and finding ways to use those in activities of the group. Interviewees spoke about the many things they ‘could do’ and ‘could do well’, with many stating that they were ‘very good’ at doing tasks which ranged from public speaking to tidying the office. Supporters played a key role in both promoting individuality and in finding opportunities to use sometimes niche talents, such as an ability to do impersonations or an encyclopaedic knowledge of pop music. Key messages about capacity were the foundation of all of the internal training in the groups and featured strongly in the community information and training sessions which some of the groups provided.

The community training activities of Green, Blue and Indigo Group were examples of where self advocates were involved in highlighting their shared identity as members of society; as workers, as volunteers, shoppers, public transport users and as ‘a person too’ (Indigo Group) rather than as a person with an intellectual disability. As facilitators of these programmes, the self advocates were not representative of a particular group, they could not be neatly categorised, they were there as themselves with multi-faceted social identities, interacting with others in the broad social landscape outside their group.

Tajfel (1978 & 1981) and Turner’s (1987) work on identity described an individual’s social identity as being ‘derived’ from their membership of a particular social group. They suggest that when a person is a member of a stigmatised group then, it is clearly difficult for them to have a positive social identity which may in turn lead to their social exclusion. Self advocacy, enacted in the user led groups observed in this study seemed to tackle this challenge head on, providing opportunities for individuals to change the focus from their intellectual disability onto other aspects of their identity, daring themselves and others to engage with them as an individual, with individual traits, skills and strengths. This created the setting in which the personality of individual members could ‘unfreeze’ (Söder, 1989) and a significant opportunity for a positive change in self concept and potential for enhanced interaction and participation with others.

There has always been a tension in self advocacy groups between ‘affirming’ individual identity and efforts towards collective goals (Buchanan & Walmsley, 2006; Carey, 2009). In almost all of the groups in this study this tension was not problematised by the members or supporters, rather the collective goals of the group were woven into the personal development activities of the group. The groups did offer a forum, sometimes a ‘public’ one as Chappell et al (2002) and Clifford (2013) describe, for telling stories of resilience and this was an important part of the efforts of all of the groups towards changing the perception of people outside the group towards people inside it. This could be seen as a strategy to build a more positive collective identity but was always secondary to the work going on within the group to affirm the positive individual social identity of members.

Border-crossers?

The expression of the self advocates’ new identities was to a great extent still confined to their activities within their self advocacy groups. Whilst there were examples of where these newer more positive identities were spilling over into the lives of self advocates in the broader community, these were small in scale and number. This suggests that the literature may overstate the outcomes of members' participation in terms of its impact on their identity as 'participants in society'. The 'border-crossers' described by Bunning and Horton (2007) are in most cases still at the checkpoint. The findings show that they were, as these authors describe, 'breaking out' of the roles so often ascribed to them and assuming more positive social identities, but this was happening largely within the group setting and activities. The self advocacy groups did provide a part of what Borland and Ramcharan (1997) describe as a 'facilitative mechanism' necessary to develop included identities, but the discriminatory outside world continues to act as a limiting factor to inclusion beyond the group.

The impact of the activities of the groups in this study is important and significant. The findings show that the self advocacy groups were building a necessary first step in the process of developing and strengthening greater social and political awareness and engagement on the part of adults with intellectual disabilities. Having the opportunity to write one's own 'identity script' and embracing the changes associated with this may in fact be an essential step towards confident engagement and participation with the community outside the group. 'Participation' is a slippery concept, and in spite of policy which supports inclusion there is much to be done to make true 'border crossing' a reality for more group members.

Jan Walmsley (personal communication, September 28, 2011) observed that over the course of her many years of involvement with self advocacy groups that 'moving on' was a difficult issue for both the individual members and their groups to deal with. For individuals who had had the experience of being leaders and office bearers in the group, there really were no places for them to 'move on' to. For others in the group, a small number of members maintaining their leadership positions for many years meant that there was no opportunity for others to have the experience and develop the skills for those roles. In some groups, this had created a kind of tiered membership where a small number of people were having enhanced experiences and opportunities. (J.Walmsley, personal communication, September 28, 2011). Some of the groups in this study were seeking to prevent this from happening by restricting the length of time individuals held particular positions but Blue Group was an exception, taking the idea of limiting people's participation to a different level. This limiting of individual participation by imposing time limits, cast as a process of 'moving through' training, development and personal growth changes, imprints strongly on the nature of the self advocacy group. Whilst this group did provide training to community organisations, training which a few supporter-selected self advocates presented, a major part of the group's efforts and energy were focussed on life skill training where the supporters were the 'experts'. The issue of the difficulty of 'moving on' for self advocates raises further questions about the claim that they are 'border-crossers' (Borland & Ramcharan, 1997; Bunning & Horton, 2007). The findings showed that supporters understood the limited opportunities for self advocates to engage with other groups in the community and particularly to further develop their business-like identities. Supporters were actively seeking to develop programmes within the groups and links with community organisations to attempt to improve this situation.

A Community for People with Intellectual Disabilities

The self advocacy groups in this study were indeed offering a ‘community’ to their members but it was a community which was not just about disability. The respectful ways in which the organisations sought to bolster the self confidence, self esteem and practical skills of their members worked in a subtle but sophisticated manner to change the nature of the way in which members live and engage inside and outside the group. They scaffold people’s enhanced social inclusion and broaden their sense of self beyond that of being a person with an intellectual disability. The findings showed that the inclusive character of the groups focussed on their collegial nature and not on disability. Gill (1997) highlights what could be a potential risk in forming a ‘disability community’ such as a self advocacy group, questioning if there is a danger that it could be seen as a ‘capitulation to the forces of exclusion’ (Gill, 1997). She argues that the risk is worthwhile because within those communities there are opportunities for ‘growth processes’ which contribute to the affirmation of the ‘disability experience’, enabling individuals to claim an important and positive part of their social identities (Gill, 1997). The findings illustrate that ‘disability communities’ can ‘affirm’ individuals but do not as Gill (1997) suggests necessarily work to highlight the ‘disability’ part of their social identity. The self advocacy groups were not denying the intellectual disability of members but rather than focussing on it, were developing other aspects of the individual and finding ways to build and develop inclusionary experiences.

As Janet (supporter, Blue Group) described, there is a conundrum at the heart of the self advocacy movement for people with learning disabilities – that in order to join and be a member of the group, a person has to identify themselves as a person with a learning disability. This can be problematic as Shakespeare (2006) describes it, as it 'builds an identity around oppression' leading "...the minority group into taking up a victim position." (Shakespeare, 2006). The minority group may seek to engage in activities which highlight their 'difference', which works to develop a shared identity, bind the group members to their group and develop positive self-regard in the individual members (Shakespeare, 2006; Tajfel, 1978, 1981). There was ample evidence of these processes at work across all of the self advocacy organisations in this study. They did however seek to do more by focussing much of their effort on developing identities which expanded their members' individual identities beyond that of being people with intellectual disabilities.

Identity as a person with an intellectual disability was acknowledged but not central to the social identity of the participants in this study. They did not, as Finlay and Lyons (1998) describe 'identify strongly' with an ascribed label or embrace the kind of strong 'disabled identity' at the core of the collective action focus of the broader 'disability movement' (Dowse, 2001). This movement has not been inclusive Dowse (2001) argues because of the way in which it has worked to promote a 'disabled identity' has left people with learning disabilities out by failing to acknowledge that it may be difficult for them to achieve. Participants in this study did not acknowledge or express frustration with this perceived failure of the disability movement. They did not express a feeling of being 'left out' of the broader disability movement. Nor did they adopt the 'assimilation' approach described by Szivos and Griffiths (1990) where individuals in stigmatised or disadvantaged groups seek to ‘pass into the mainstream’. What emerged from the findings was a modulated version of ‘consciousness raising’ which seeks to build a positive social identity based both on difference (Szivos & Griffiths, 1990) and on shared humanity.

Subtle Radicalism? Working to Erode Negative Community Perceptions About People With Intellectual Disabilities

The findings show that the move towards more positive, included identities was being produced without overtly radical roots. There was instead evidence of a more subtle emerging political agenda which worked to alter, albeit slowly, the deeply held perceptions of many in the community about people with intellectual disabilities. Whilst much of the activity in groups like the Blue and Magenta Groups seemed to look inwards, to focus on the skill and personal development of individual members, there was a strong sense that this was being undertaken with an important purpose. The personal development agendas of these groups sought to prepare people to live happier and more included lives in a society which does indeed disable them through negativity and low, or no expectations of their capacity. This is indeed ‘radical meaning-making’ (Goodley, 2005) but perhaps lacked the kind of urgency and overt character that authors like Goodley (2005) and Aspis (1997 & 2002a) might wish for. Characterising idealised groups as working within a ‘rubric of sovereignty’, which promotes identification as a member of a disempowered group, Clifford (2013) argues that commentators will be ‘dissatisfied’ with what they find when they observe self advocacy organisations. However, like Clifford (2013), this author found that a closer look revealed that the self advocates in all six groups reframed empowerment in a highly personal way and in so doing offered "...an engaging and highly dynamic vision of political action." (Clifford, 2013, p.5).

The social model of disability (Barnes et al, 1999; Barnes & Mercer, 2003; Linton, 1998; Oliver & Barnes; 1998, Rioux & Bach, 1994) underpinned the activities of the self advocacy groups in this study. Some groups made that explicit, for example, Harriet, Green Group Supporter stated that her group 'believes' in the social model. Supporters of some of the other groups shared this understanding too, but what was most interesting was the way in which this was translated into the day to day activities of the group. A 'belief' in the social model seems to imply that activism might be focussed on the ways in which the social context of the self advocates 'disables' them. Indeed Shakespeare and Watson (2002) are highly critical of the way in which they say that the social model has become the 'litmus test' of disability politics for disability groups. The groups in this study did work to try to challenge the manifestations of disability models which are deficit focussed but they did so in a highly personal way which at first glance does not look radical at all.

Shakespeare's (2006) commentary on the impact of the social model on disability identity offers a scathing critique of the way in which an 'ethnic or cultural' conception of disability risks a separatist approach on the part of disability activists, 'denying' the impacts of impairment and reinforcing a divide between disabled and non-disabled people. The emergence of the social model over a medical model is important, but for the self advocates in this study, the disability activism in which they were engaged took them beyond negative social identities ascribed by the broader community, embracing multiple (more) positive and included identities. These newer identities, which emerged from their engagement in self advocacy groups were highly individual and demonstrated that many people with an intellectual disability were not interested in wearing *either* the ‘label or the badge’ (Shakespeare, 2006), but in being recognised as themselves.

It is these more positive identities which can potently subvert and change broader community perceptions of what lies beneath negative labels. This kind of outcome does not fit comfortably within social movement or disability activism descriptors of self advocacy but should not be regarded as inferior as it was highly valued by the self advocates themselves.

In essence, all of the groups in this study could be described as ‘neat and consensual’ (Goodley, 2005), but their activities and impacts must not be lightly dismissed and need to be considered in the context of the ways in which their organisations produced such empowering outcomes. Goodley (2005) and some other commentators may argue that the closeness to the policy and service apparatus of some self advocacy groups is out of step with some of the ‘complex and radical’ work of others. The findings show that the six groups in this study juggled the political and personal goals of their members but always favoured activities which focussed on personal agendas around engagement and inclusion.

'Professional' Groups

The findings showed that outcomes of group engagement for the individual self advocates were hugely positive and were enabled by the way the groups were organised. Most of the groups were 'professional' in the way that they operated. 'Professional' can be defined as well organised, supported and resourced and this was a positive rather than a negative feature of groups. The negative connotations of 'professional' described by Blackmore and Hodgkins (2012) imply a lack of radicalism, of spontaneous action, but these kind of attributes may not suit the members of self advocacy organisations. There are as Armstrong and Goodley (2001) describe, 'submerged dangers' in relationships between professionals and members of self advocacy groups, but emerging from the inherent complexity was a picture of organisations being run for the benefit of members and in ways which maximised potential for individuals to become more confident and engaged with life. Indeed it was the high level of organisation, of predictability, of planning by supporters which characterised all of the groups with the exception of the Red Group and these were features prized by the members. The findings showed the self advocacy groups were 'professional' but in ways which worked to build more positive social identities for members rather than work against their 'liberation' (Aspis, 1997).

The findings of this study showed that supporters viewed their relationships with self advocates as a partnership in empowerment. Gilmartin & Slevin (2009) drawing on Jackson (2009) observe that an "...inevitable consequence of achieving empowerment for a person with an intellectual disability is professional disempowerment" (p.154). Implicit in this assessment is the risk that supporters, as professionals working with self advocates may not be willing to act against their own interests. Whilst there was some evidence of supporters working to limit participation in group activities, there was overwhelming evidence which showed supporters working both with, and for members to achieve positive outcomes for individuals and for the group. From the members' point of view, the active engagement and scaffolding work of supporters enhanced their view of them as 'professionals', valuing their particular and complementary skill sets.

Examples from this study show that engagement with self advocacy groups is considered by members to be positively life changing. This seems counter to Simone Aspis's (1997) damning critique of the 'state' of self advocacy in which she argues that being engaged with self advocacy cannot be a 'liberating' experience "...where its process and contents are being managed by the same people who have the power to oppress those who have been labelled as having learning difficulties." (p.652). It is undeniable that policy makers, those who fund self advocacy and the supporters who work closely with self advocates have such power, but it must also be acknowledged that without the influence of such political structures and powerful individuals, none of the groups in this study would be likely either to have developed or to have survived. Whilst they had the 'power to oppress', this was not expressed. Findings from this study show that expert support of groups did involve the use of power and control but that it could be enacted in such a way that the members did in fact enjoy the 'liberation' of having a sense of ownership and control of their group and the many positive outcomes which flow from that. Aspis's (1997) criticism that such individuals control the ‘process and content’ of self advocacy may indeed be valid, however it must be considered in the context of the lived experience of the overwhelming majority of self advocates. ‘Liberation’ must be considered as a relative concept. For individuals who have lived highly marginalised lives and lived with the implications of negative labelling, the opportunities for personal growth and change offered by self advocacy groups are unparalleled. This is not to suggest that people with an intellectual disability should in any sense ‘settle’ or be content with the current situation, rather that it might be regarded as progress towards inclusion. Aspis (1997) seems to miss the subtleties of self advocacy suggested by authors such as Butera and Levine (2009) who focus on the ways in which the activities of the group work over the longer term in an ‘innovative’ way to change perceptions about themselves and to bring about a shift in the way others see them.

The findings revealed the complex relationship between the support workers and the self advocate members in setting the agenda for the group. It was clear that the work of the supporters had made significant contributions to developing the strength of the groups, the wide range of activities they are engaged in and in ensuring their future existence through management of an income stream. In fact, the Red Group stood out as an example of a group which lacked support and whose survival was threatened as a direct result.

The issue of the power of the supporter is clearly an important one but in the context of this study, it is important to note than even in the groups which to an outsider looked to be the antithesis of an ‘independent’ self advocacy group, self advocates themselves described being able to ‘speak up’ and ‘having more confidence’ and these were highly desirable outcomes (Buchanan & Walmsley, 2006). The members of these groups still felt that the self advocate office bearers had power and actively sought either to attain or retain such positions. Nick (Green Group) described his role as president, presiding over management committee meetings, as ‘reading a script provided by the supporter’ but it would be a mistake to disregard the great sense of self-efficacy Nick felt about being the one chosen by his peers to read that meeting agenda. He was being supported in a role which made him feel self confident and efficacious and this was important.

There can be a lack of openness about who is controlling the direction of self advocacy groups. Walmsley (personal communication, September 28, 2011) spoke of the importance of ‘good people’ providing ‘honest and direct’ advice and support to groups. From the organisational perspective it would seem that ‘good people’ made a huge difference to self advocacy groups for a range of reasons. In this study, all of the groups, with the exception of Red Group had strong, ‘direct’ supporters. Blue, Indigo and Purple Groups had clearly benefitted greatly from the very close relationship their supporters had forged with their funding bodies. Green Group also had very strong support but had maintained a more distant relationship from the local authority system by seeking funding through other sources and whilst this had meant that the group managed on very short term grants, they seemed freer to pursue their own agenda and were more politically active than the other groups. The Magenta Group benefitted from what Walmsley (personal communication, September 28, 2011) called ‘honest and direct’ advice from its supporter but she expressed frustration that she had been unsuccessful in creating closer connections with government disability bureaucracies and felt strongly that this jeopardised the future viability of the group.

When Walmsley (personal communication, September 28, 2011) speaks about a lack of openness in discussions and commentaries about who is in control of the agenda in self advocacy groups it is crucial to consider the perspectives of the self advocates themselves. The findings offered numerous examples in which self advocates described having feelings of being trusted and respected in the group, of having personal power and status and this was common across all groups. It was as much a feature in all of the five groups where supporters seemed to drive the agenda of the group, as it was in Red Group which lacked support. Scaffolding the collegiality and members' sense of ownership and control was at the heart of effective support of self advocacy groups and self advocates. The findings offered many examples illustrating the positive outcomes which are produced when this is done really well.

There is a risk inherent in rejecting the kinds of models of self advocacy seen here. Whilst it is true to say that the groups fell far short of idealised user-led organisations, it seems unlikely that rejection of these would see them replaced with something closer to the imagined exemplar. The groups themselves are not truly 'independent' but it would be a grave mistake to ignore the positive outcomes they produce for their members.

Some of the groups in this study could be regarded as what Blackmore and Hodgkins' (2012) call 'pseudo-government agencies'. Their closeness to the bureaucracies which fund them may have limited their opportunities to speak out about issues directly affecting their members, and the lack of member control of the agenda and group activities mimicked that found in many service agencies. However, even where this was the case, the character and context of each of the groups was such that outcomes for members far exceeded the policy and practice goals of many government agencies. The user-led framework which guided the activities of self advocacy groups set them apart from other organisations within the service system and in the broader community for people with an intellectual disability. The framing of all of the activities of the groups in the context of their collegiality and the sense of ownership and control by members radically altered their character and their impact on participants. The self advocates were not passive recipients of a service, they were engaged at levels which operated to enhance skills and confidence, shaping their social identities.

There is, as Buchanan and Walmsley (2006) state, a kind of inevitability about the power imbalance between the self advocates and the supporters where a level of 'sophisticated skill' is necessary to achieve the outcomes of budget and resource management needed to keep groups alive (Buchanan & Walmsley, 2006). The way in which supporters acted to develop the collegiality of the groups and to build members' sense of ownership and control indicated sensitivity to the importance of providing a careful balance of actions which facilitated the scaffolding of members' experiences without undermining or overtly intruding in self advocates' opportunities to express newly developed social identities. Supporters acted in ways which did not threaten the character of a ‘self advocacy group’ avoiding the risk that for the members at least, the groups began to look like more mainstream service model groups or even day centre programmes. The modus operandi of supporters had to be a complex act of mediated power, working at times in the background on securing the nuts and bolts of the group’s funding resources and at other times more directly, supporting members, developing their skills and sometimes as described in Green Group ‘writing the script’ to enable self advocates to act in personally powerful ways. This appeared to be happening in all of the groups with the exception of Red Group, and members acknowledged the role of supporters in doing what William from Purple Group described as the ‘boring’ practical tasks which ensured the smooth running of offices and activities.

Managing the ‘inherent tension’ (Chapman, 2005) in self advocacy between individuals gaining greater confidence through speaking out and the group campaigning as one voice, is difficult, but there is further tension where the power of the self advocates to operate as the managers of their own organisations is restricted by their supporters. The findings showed that the self advocates did not problematise the close management of their engagement in this group, rather they praised the support workers for their facilitation of opportunities to participate. Self advocates framed the power relationship in the group between themselves and their supporters as being positive and empowering.

Limiting and controlling participation.

Common to both the Blue and Magenta Groups was that some limits on participation were imposed by the group's supporters. These went beyond the rules governing the election of office bearers and the limits on how long and how many times any individual can hold a particular position. Instead, these were limits placed on participation in activities such as training programmes. For example, in Blue Group, formal, accredited training is provided to members by staff and upon completion of a number of modules, people were encouraged to 'move on' to create opportunities for others to participate. Janet (Supporter, Blue Group) described people as 'hanging on to People First', 'nobody wants to move on'. This statement sits awkwardly in the context of an 'independent' self advocacy organisation. The support staff rationalised this movement of some members through the organisation as being necessary to open up opportunities for participation to others in the community but it seems incongruous for an organisation seeking to promote independence and personal choice to be making decisions about who can be a self advocate and who cannot and to recast commitment and attachment to their group as 'hanging on'. The Blue Group supporters acknowledged that there was little, particularly in the area of employment, for people to move on to after they have completed the training programmes offered by the self advocacy group.

On the surface, some of what was happening in Blue Group looks like the kind of self advocacy Aspis (2002a) dismisses as 'service supported' and as such not about campaigning or learning to challenge and move power structures. From the perspective of the members interviewed about this study, their engagement had been about those things but in quite a subtle and personal way with the most significant impacts being in their own sense of a more positive, confident self-identification rather than in overtly challenging community views of a shared learning disability identity.

Within the findings, this action to limit participation and choices about participation was the only example of the kind of restrictive ‘management’ of self advocacy processes and content described by Aspis (1997), but it existed in the context of a group described by members as having the same characteristics as others in this study. Feelings of ownership and control and of collegiality existed in spite of the supporters actions to limit participation and offer tightly regulated skill development opportunities.

Power, control and location.

The kind of tensions evident in examples of growth and education groups like the Blue and Magenta Groups, and the task and action groups such as the Green, Purple and Indigo Groups, between the mechanisms of an ‘independent’ self advocacy group; its elected committee, and the support workers, are writ large in the findings. The key to making what looked like an uneven balance of power acceptable to the self advocate members was in the way in which the relationships between them were managed. Feelings of collegiality which emerged strongly in the data between the self advocates were also evident in the relationships between the supporters and the members. There was a strong sense that the group ‘belonged’ to all who worked for it and were associated with it, and a level of respect and regard which created a highly positive atmosphere within the organisations' offices. Within the office environment of the Indigo, Purple and Green Groups, supporters and self advocates shared space and there was a relaxed and friendly atmosphere. There was a strong sense in all of the organisations of busyness and purposeful activity. All of these groups employed self advocate members in either a paid or voluntary capacity and this contributed strongly to the strong sense members had that they occupied roles in which there was trusted self determination. Trusted self determination within the context of the office environment was highly significant as the self advocate staff understood that they had a particular task or tasks to achieve and that they must be done in a particular way and at particular times. Fulfilling others' expectations of their ability to achieve these goals was a source of great personal pride for many interviewees.

The physical location of the office of Blue Group within a high support needs specialist disability service had a strong impact on the way the group operated. It was not possible even to access the front entrance of the building without being 'let in' by the reception staff. There was no sense that this was a place for members to drop in and have a cup of tea or an informal chat as was the case in all of the other groups visited, rather that the group's office was a small part of a larger disability service. On the surface it might seem that a formalised office setting may restrain a sense of ownership or collegiality amongst group members and could serve to reinforce the notion that it is the supporters who direct and control the activities of the group. The findings showed that in spite of the formal setting of the group, it was clear that the supporters and the members had developed highly positive and mutually respectful relationships and that this kind of positive regard contributed strongly to the kinds of outcomes described by the self advocates. Members of Blue Group spoke about their group in the same terms as members of all of the other groups; the group ‘is our group’, ‘it is a friendly place’. The offices of the other five groups were quite different from that of Blue Group. These offices were all in buildings housing the offices of advocacy groups representing the interests of a range of disability and health interests. It was relatively easy to access these buildings and the ability of members and visitors to come and go freely helped to create an impression of friendliness and openness.

The self advocacy group offices were clearly important in creating a strong group identity. The sign on the door and the presence of the organisation in the community made a strong statement both to those in and outside the group. For the United Kingdom groups in particular, their continued existence and presence was a sign of resilience and strength in a harsh economic climate which has seen significant funding cuts and even the forced closure of some self advocacy organisations. The office very much ‘belonged’ to its members. This strong positive feeling was not replicated in the way individuals felt about places they had lived, worked or trained in the past. All of the organisations in this study described themselves as being run ‘by and for’ people with intellectual disabilities and there was a strong sense that in sharing the ‘ownership’ of the organisation with fellow members, there was a commitment to making the group, both as an idea and as a physical location, a place which was built on respectful relationships and mutual regard.

Relationships with government.

The supporters of the Blue and Indigo Groups displayed an acute awareness of the ways in which their close ties to the bodies which fund them had enabled them to grow and to expand both their membership and the range of activities in which they were involved. In fact this closeness had developed into a symbiotic relationship with these self advocacy groups becoming inextricability woven into the consultative fabric of their respective local authorities. The Blue Group was positively regarded by the local government authority because, states Janet (supporter Blue Group), of its 'longevity ' and 'stability' as a result of her management and leadership over many years and this had created a relationship where its future funding support was almost guaranteed. She offered the evidence that Blue Group did not receive a funding cut in a recent round of swingeing cuts by the local authority which saw several other local advocacy and self advocacy groups lose all their funding, stating that the group has worked to make itself 'almost indispensible'.

This relationship was of a kind which would concern commentators like Aspis (1997 & 2002a) and Goodley (2000); characterised as it was by having the self advocate group members embedded in the framework of consultation in exchange for the secure funding of their group. When 'independent' self advocacy groups look so much like the derided 'divisional' or 'service-system' models (Goodley, 2000), how can any kind of shift come about in the balance of power between self advocates and service providers or the broader community? The answer for many of the groups in this study was that their supporters acknowledged the tension in their relationship with their funding bodies and promoted and supported the co-opting of a few members onto many committees, consultations and forums whilst at the same time turning the focus of the group largely inward, to develop the individual skills and knowledge of the self advocates, building their self confidence and esteem to a level which had maximum personal impact. Any shift in power relations may occur subtly and over time but the aims of these groups was largely to enhance people's confidence to 'speak up' within the smaller frame of their group and in a few cases, outside it, within their families and other service providers. Supporters and members did as Goodley et al (2003) describe offer 'complex and sophisticated understandings' about self advocacy which was reflected in their relationships within the group and with outside organisations.

The close relationship between the local authority and the Blue Group, particularly its supporters was a complex one. On one hand the 'independence' of the group and its ability to campaign and be openly critical about policy and service provision risked being severely compromised, on the other, the group had secure funding and could provide opportunities for participation for a large number of people with learning disabilities. The role of the support workers for groups like Blue Group was clearly a crucial one but when they exercise this level of control, then an 'independent' self advocacy group started to look a lot like a service based or service supported group.

The findings showed that the participation of self advocate group members in local authority consultations and committees seemed at best to be problematic. Whilst their inclusion may make a statement about attempts by bureaucracies and service providers to be more socially inclusive, the reality of participating may be that the experience was not always a rewarding or meaningful one. Audrey (self advocate) and Simone (supporter) of Indigo Group commented that the ‘formality’ of the kinds of meetings to which group members were invited made them difficult to follow and frustrating. However, Audrey clearly gained positively from her attendance. Being included was important to her identity as an expert about a life lived with a learning disability, and the opportunity to attend was an enjoyable outing which she looked forward to. Other self advocates like Trevor, Oscar and Celia shared this experience of being part of high level consultations. Oscar described being part of a Department of Health consultation and the opportunity he and others present had there to raise issues of importance to them. They were, as he described it, able to ‘make a fuss’ about the issues which really mattered to them to an audience perhaps unused to such a direct approach and in doing so offered examples of how self confidence gained through engagement with self advocacy groups had led to the development of more positive social identities. Participation in the forum was for Oscar, evidence that he was engaged with life and as a delegate he was confidently assuming a business-like identity, a self advocate identity and the identity of an expert.

Marcus Redley (personal communication, October 13, 2011) noted that in his experience, opportunities to engage in inclusive consultations and forums were in reality only available to a few individuals and that bureaucracies had through the formal structures they had created produced a ‘learning disabled elite’ (M.Redley, personal communication, October 13, 2011). Whilst Redley’s observation may be correct, it was clear that for those who did participate there was positive status attached to their involvement and for the group as a whole, involvement equalled inclusion in the planning and policy making processes of government and therefore priority for funding and support.

The Policy Context of Self Advocacy Groups

The policy climate surrounding self advocacy is important. Rhetoric is useful in guiding change and embedding the ideas which support self advocacy, but it is funding which is crucial to the development and support of groups. Goodley (2003) observes that the "...life of a self-advocacy group is constantly under threat." and this reflection was echoed by all of the supporters and some of the self advocate interviewees. Feeling uncertain about future funding and being preoccupied with such concerns were experiences shared by all of the groups.

The strength and stability of the six groups in this study varied significantly. At the time interviews were conducted, Blue and Indigo Groups had relatively secure funding, Green and Magenta Groups slightly less secure but ongoing funding. Red and Purple Groups had small grants which in both cases seemed unlikely to be renewed. In fact, at the time of writing, Red Group had managed to secure additional ongoing funding but Purple Group had been 'defunded' and had closed its doors.

One of the research questions of this study asked whether the outcomes of engagement in a self advocacy group differed in the different policy contexts of Australia and the United Kingdom. As has been noted in early sections of this thesis, policy support for self advocacy in the United Kingdom has for many decades strongly influenced both the way groups are funded and their level of embeddedness in the consultative structures of government. The lack of support in Australia has conversely limited the growth of independent groups, instead overseeing the growth of service supported or 'divisional' self advocacy (Goodley, 2000) and its role in representing the community of people with intellectual disabilities.

The Australian Federal Government's 'National Disability Advocacy Program' (FAHCSIA, 2008) recognises self advocacy as a model of advocacy but at the time of writing only two of the sixty two organisations funded by the program were self advocacy groups. This may of course be the result of a number of factors but it is a clear reflection of prevailing culture within the disability sector of people speaking *for* people with disabilities rather than a focus on developing skills and confidence to enable people to do more speaking up for themselves. Some Australian self advocacy groups receive funding from relevant State Government bodies, for example in Victoria, the Office for Disability's 'Disability Advocacy Program' currently funds several organisations as well as a leadership development programme for people with disabilities (Department of Human Services, 2013). Material published by this department is positive about the benefits to people with intellectual disabilities of engaging with self advocacy, stating; "Self-advocacy plays a significant role in enabling people with a disability to develop the skills to ensure that their rights and interests are respected and realised." (Department of Human Services, 2013). This statement seems to particularly support the training and personal development agendas of the groups in this study.

Whilst it may have been expected that the different policy contexts of the United Kingdom and Australian groups might have produced different outcomes for members, the findings show that in terms of the impact on their social identities, there was no difference. Self advocates across all six groups described their groups in the same way with the key characteristics of collegiality and a sense of ownership and control by members. All of the groups offered their members an opportunity to participate in a range of interesting activities although the choices were greater in number and range in the British groups. Members across all of the groups described the same changes in their levels of personal confidence and in their greatly increased engagement with life and that they had adopted one or more positive social identities as a result of their engagement with the group. The outcomes across the two policy contexts were the same. What differed was that the self advocacy groups in the United Kingdom appeared to have been more mature in their development. They had over many years built complex relationships within and outside the group, established extensive training programmes for their members and developed a wide range of special interest groups within their organisations; there were simply more, and more varied opportunities for people to participate.

The ‘Valuing People’ (2001) policy emerged at a time when there were many ‘independent’ self advocacy groups in the United Kingdom. Goodley (2005) expresses concern that the policy agenda of this document has led to more ‘business-like’ structuring of groups which may or may not mesh with the goals of self advocates and their organisations. The findings show that the United Kingdom groups were indeed highly ‘business-like’ and worked closely with policy makers in their local areas. Some of their activities did embrace a service-oriented model of self advocacy but if the alternative is, as Goodley (2005) speculates, no government funding for self advocacy groups, it seems better to value and acknowledge some of the strengths of the 'business-like' groups and encourage people with intellectual disabilities to actively engage with them.

An uncertain future.

The findings showed that whilst members and supporters in all six groups expressed some concern about future funding, it was the Australian groups that seemed the most concerned, with supporters worrying that policy support for advocacy rather than self advocacy risked the small amount of funding they currently had. At the time of writing, an important piece of legislation appears set to change the disability policy landscape in Australia. The passage through parliament of the National Disability Insurance (NDIS) Scheme Act 2013 marks an important shift in disability policy in Australia. The Act came in to force on 1st July 2013 with the launch of the National Disability Insurance Agency (NDIA) at six sites around the country. The legislation for a national scheme, includes access criteria, age requirements and sets out how a person with disability works with NDIA to draw up individual plans within what is defined as 'reasonable and necessary support' (NDIA, 2013). A grant scheme entitled 'The Practical Design Fund' has been designed to support people with disabilities, their families and carers and service providers to 'transition' to the new arrangements (NDIA, 2013). One Tasmanian self advocacy group has already accessed funding under this scheme and whilst it is short term and project based money rather than recurrent funding, it may offer other self advocacy organisations the opportunity to undertake projects or develop resources.

Whilst the overarching aim of the National Disability Insurance Scheme is to 'support a better life' for all people with disabilities, it is unclear how engagement with self advocacy will fit within an implementation framework which has as its centrepiece individualised funding. It may for example be possible for an individual to identify in their plan that they would like funds to go towards their membership fee for a particular self advocacy group, but there are some problems which could arise under such an arrangement. If individualised funding results in the end of, or cuts to direct self advocacy group funding then this threatens the ongoing survival of such groups. Many people with intellectual disabilities are not members of self advocacy groups and may not know of their existence. If individualised funding becomes the only method of funding groups, then individual engagement will rely heavily on service providers' knowledge of local groups and initiative in linking people with intellectual disabilities into their activities. As the implementation of the NDIS across all regions of Australia proceeds, the fate of funding to self advocacy groups will be interesting to observe. What is clear is that without strong policy and funding support, the future growth of independent self advocacy in Australia seems likely to be severely constrained.

Conclusion

By developing and promoting self confidence and engagement with life, self advocacy groups change the individual social identity of their members. This is a significant change which the findings showed had a significant positive impact on the lives of members. The self-perception of individuals with and without disabilities is constructed on the ways in which others define and respond to them, and is dependent on social context. Self advocacy groups emphasise the individuality and humanity of their members and whilst this may to some commentators seem like a risky ‘compromise’ (Oliver & Barnes, 2012) because it could be seem in some ways as a capitulation to the disabling culture outside the group, this is not supported by the findings of this study. The self advocates interviewees were all getting ‘stuck in’ to their lives through the agency of their groups and this change was encouraging evidence that for some people at least, the rhetoric of social inclusion is bearing fruit. Changing individual identity has the potential to begin to erode negative perceptions strongly held in the community about labelled people. Building a more positive collective identity is clearly important in shaping societal attitudes to people with intellectual disabilities and whilst the findings show that groups placed the development of individual identities at the centre of their activities, this will over time have an impact outside the group. Change outside the group seems likely to happen slowly and will be difficult to measure.

Findings from this study support the view that self advocacy ‘can be a pathway to empowerment’ (Miller & Keys, 1996) and offers many examples which support that view. The ‘transformative’ potential (Miller & Keys, 1996) of self advocacy is not possible to quantify, but the findings show that individual impacts are significant. How that potential can be harnessed to greater enhance the social inclusion of people with intellectual disabilities is an important question. It seems likely that creating opportunities for individuals to change the way they perceive themselves will have spill over effects in changing the way they are perceived in the broader community and that that will lead, over time to a breaking down of some of the negativity and stigma surrounding the intellectual disability identity. Self advocacy groups have a vital role to play in facilitating this important process. They and their members are ‘social innovators’ (Butera and Levine, 2009 drawing on Moscovici (1976)).

Chapter 7. Conclusion

> Now I really get stuck in. You know what I mean? I do this and that...go places... busy all the time. It’s so interesting doing new things and I like meeting people. Mum says I’m a really big talker now [laughs]. I’ve tried different cafes... different shops and stuff ...and I can ask people to help me if I need it...I’m really getting stuck in and enjoying everything! (Emma, self advocate member, Purple Group)

Self advocacy has been described as a way for people with intellectual disabilities to gain access to the ‘power and protection’ of community life (McKnight, 1989). This is a bold and optimistic claim about the potential of self advocacy to radically alter long-held negative perceptions in the community about people with intellectual disabilities and to contribute to the development of a more inclusive society. This study found that whilst engagement in self advocacy groups makes a dramatic positive difference in the lives of individuals it is making modest gains in improving ‘access’ to the broader community and all it has to offer.

The findings of this study support the notion that engagement in self advocacy groups enhances the individual skills, happiness and confidence of members, but the acts of ‘self advocacy’ – literally speaking up for oneself, remain almost completely confined to the group. The inroads made by self advocates into barriers to their social inclusion are significant but still modest. This is not a criticism, rather an observation that change outside the group is difficult to achieve in the context of deeply entrenched negative labelling of people with intellectual disabilities in the broader community. The work of members inside self advocacy groups to develop multiple positive social identities for themselves and for their peers is incredibly important and these acts are indeed radical and political. Their impacts on the broader community may be slow to take effect, and changes in attitudes and efforts to be more inclusive on the part of group outsiders difficult to test or measure, but this is important work towards a time when people can truly be regarded as 'border-crossers' (Bunning & Horton, 2007). As Borland and Ramcharan (1997) observe, the kind of 'inclusionary socialisation' which goes on in self advocacy groups is an important stage in drawing out the 'embedded identities' of members and creating the settings for greater social inclusion.

Self advocacy groups in Australia and the United Kingdom currently exist in a variety of different forms with some operating as independent groups, whilst many others are service based. Some of the literature has focussed on the relative merits of different models of self advocacy (Armstrong, 2002; Barnes & Oliver, 2003; Croft & Beresford, 1989; Goodley, 2000) however this was not an aim of this research which looked only at members' experiences in 'independent groups'. These were defined as groups which had elected committees of management. Whilst all six groups in the study met this qualification, the findings showed that the role of the committee and of other members in the group in managing and setting the agenda for the groups' activities was fairly limited. Supporters made many of the significant decisions about the groups, particularly the financial ones. This was not problematised by the self advocate interviewees, rather their commentary highlighted an important feature of the way supporters worked in the group which was that they made members *feel* a sense of ownership and control of their group. The value of this kind of support, dismissed by some commentators as being counter to the empowerment goals of self advocacy and mimicking the ‘tokenistic’ service based groups (Aspis, 1997; Croft & Beresford, 1989) needs to be reconsidered.

The findings of this study showed that group members greatly valued the ways in which their supporters worked, understanding clearly the manner in which they sought to build and maintain the background administration of the organisation and promoted the skills and confidence of members. Some of the interviewees explicitly articulated an appreciation for the ways in which supporters undertook some of what they saw as the less desirable, boring or confusing aspects of running the organisation, preferring to focus instead on their engagement with other office activities, training programmes or social activities. There was no evidence of the risk Armstrong and Goodley (2001) suggest; that some group support workers will act in their own interests rather than those of members. Whilst some commentators see the ‘professionalisation’ (Armstrong & Goodley, 2001; Blackmore & Hodgkins, 2012) of self advocacy groups as posing just such a risk, it is important to listen closely to the insider perspective of the self advocates themselves. Goodley (2003) is correct when he writes that self advocacy is always under threat, and it is also the case that self advocacy *groups* are under threat. Some of the derided ‘professionalisation’ of self advocacy organisations by their supporters and funders is in fact what has allowed them to continue and in many cases flourish. The example of Red Group offers a clear insight into the precarious nature of a group with little effective ‘professional’ support or structure, whilst the demise of the Purple Group since its members were interviewed for this study, shows that even with strong support internally, a lack of close relationships and networks with funding bodies can lead to group closure. What has emerged strongly from the findings is the need for members and supporters to develop strong relationships and be supportive of each other in the different roles they play in the group. When supporters work to give members a sense of ownership and of power and control, they are creating a backdrop for members to practice self advocacy.

Goodley’s commentary on his own (2000) study of self advocacy observes correctly that much of the past literature “...has been concerned with generalizations, organizational typologies and the role of advisors.” (Goodley, 2000). This literature has however made an important contribution to our understanding of self advocacy and Goodley’s study adds to this through the use of life stories which he describes as ‘narratives of resilience’ (Goodley, 2000). Characterising self advocacy as the public recognition of the resilience of people with learning difficulties (Goodley, 2000), he draws on the experiences of those he describes as ‘top self advocates’ to show the personal and political nature of self advocacy. Findings of this study show that the personal and political do emerge as features of self advocacy groups but that from the perspectives of the self advocates, the political outcomes of their activities are secondary to the personal change they experience as a result of their participation. Being able, perhaps for the first time in their lives, to get ‘stuck in’ to life resonates more with individuals than the wider agenda to alter to the way people in the broader community perceive adults with an intellectual disability. Change occurs in the community through the way people get ‘stuck in’, as greater engagement results in greater visibility and an increased number of planned and spontaneous social interactions, however this is not a guarantee of inclusion. What emerges from the findings is that people feel socially included within the positive and collegial nature of their self advocacy groups and that all of the activities of those groups build their esteem and confidence and lead to the development of positive identities. The potential of this to enhance inclusion outside the group seems great, but remains untested.

Social identity theorists like Tajfel (1978, 1981) and Turner (1982, 1987) argue that it is difficult for people to whom negative social identities are attached to reclaim and develop more positive ones. This study has investigated the experience of engagement in independent self advocacy groups by adults with an intellectual disability. The findings show that group members resisted wearing as Shakespeare (2006) describes the ‘badge’ of activist, or the ‘label’ of a person with an intellectual disability, and that this occurred in spite of their clearly articulated sense of ownership of the group and strong feelings of collegiality towards the other members and supporters. By rejecting the ‘label’ with all of its stigmatising connotations and the ‘badge’, with its collective identification and activist imperative, the findings of this study showed that self advocates had found an important space in which to build their own individual, more positive and included social identities.

The development of a Grounded Theory model (refer *Figure 3*) of the way in which this occurs offers new insight into the important potential of engagement in self advocacy groups for people with intellectual disabilities. Through the lens of symbolic interactionism, the researcher sought to gain insights into the meanings and significance attributed by the self advocates themselves about their interactions with the group (Blumer, 1969). Within this model, the generative nature of the ‘independent’ self advocacy group is clear. Such groups are generative because they offer new ways of talking and thinking about people with intellectual disabilities, challenging past understandings and opening up what Gergen (1999) describes as ‘new possibilities for action’. Despite their focus on the personal, on individual identity development, self advocacy groups are working to alter community perceptions of their members and whilst this work may sometimes lack radical urgency, it is important in challenging long-held negative and disabling beliefs.

The findings of this research showed that the notion of ‘independence’ sprang from the key elements of group structure; collegiality and a sense of ownership and control by members. The findings also clearly showed that supporters played an important role in creating those features of all of the groups. Some of the literature has criticised groups which are not ‘independent’ (Aspis, 1997 & 2002a, 2002b; Goodley, 2000), and it would be useful to investigate through future research whether the service-based groups such authors deride are also capable of producing some of the highly positive outcomes for members seen in this study. It seems possible that it is not the power structures which differ between independent and service-based groups, rather that they are framed in different ways and it would be useful to be able to interrogate the difference that members experience of having a *sense* that they own and control the group makes to their identity.

The future of many self advocacy groups seems uncertain in a climate of severe budgetary restraint, although others, through their professionalisation have developed a model of operation which has enabled them to access project funding and develop their level of engagement with local authorities to a degree which makes their future reasonably assured. Self advocacy groups in the United Kingdom have operated in a supportive policy climate until relatively recently. The policy documents; Valuing People (2001) and Valuing People Now (2009) stated their support for people with learning disabilities ‘as citizens’ and were explicit about support for self advocacy groups. The future commitment of the United Kingdom’s Coalition government to the principles of both policy documents is at present unclear although it seems likely that the implementation teams established across all regions in the United Kingdom will be defunded during 2013 (NDTI, 2013). Whilst participation is sometimes restricted to those Marcus Redley (personal communication, October 13, 2011) described as ‘the usual suspects’, all of the United Kingdom groups in this study were seeking to broaden the impact of their activities and inclusion of their members by participation in forums, training and consultations, boosting their engagement with the community and creating important opportunities to influence policy and practice in the intellectual disability field.

In Australia, self advocacy is still the poor relation of advocacy, a product of policy which favours models of people without disabilities speaking on behalf of those with disabilities, over those which support people to speak up for themselves. Advocacy is important, but this study shows that self advocacy and self advocacy groups are important too. The great potential of self advocacy groups to produce positive outcomes for adults with intellectual disabilities shows the importance of providing support at both policy and funding levels to ensure that they not only survive but thrive. The election of a conservative Coalition government in Australia in September 2013 marks the beginning of what is likely to be a period of budgetary constraint in the community sector. The new government is committed to the early stage implementation of the National Disability Insurance Scheme but it is currently unclear whether it will be supportive of self advocacy groups or programmes. Matching the policy rhetoric about inclusion for people with an intellectual disability requires creative approaches to enabling them to live fuller, more included lives.

Darren from Indigo Group made this remark in his interview when asked to describe what members gained from engagement with his self advocacy group; “We just help them, be them”. His beautifully understated way of describing significant personal transformation seems to sum up some of the many quiet achievements of self advocacy groups. The chance to ‘be yourself’ and to embrace more positive, included social identities is not often available to people with intellectual disabilities. Self advocacy groups are uniquely placed to offer people just such an important opportunity.

Appendices

Appendix 1. Letter to Self Advocacy Group Presidents and Chairpersons

School of Social Work
and Social Policy
Faculty of Health Sciences
June 2011

Dear President/Chairperson,

I am a student from La Trobe University in Melbourne, Australia and I am doing a research project which is about comparing the experiences of people who have been involved in self advocacy groups over the years and in different parts of Australia and in England and Wales.

I would like to interview people like yourself who have had some involvement in self advocacy, to find out about your experiences as a group member and what you think the future of self advocacy will be like.

I hope that you would be willing to have me come and visit [group name] and interview you and other group members who might be interested in talking about their experiences too. Some of the questions I would like to ask are on the next page of this letter.

If you would like to contact me to ask any questions my email is s7anderson@students.latrobe.edu.au or you can call me on Skype where my user name is siananderson2011. If you would like to contact my university supervisor, her name is Professor Christine Bigby and her email is c.bigby@latrobe.edu.au .

Hope to hear from you soon.

Best wishes, Sian

These are some of the questions I would like to ask you and other members of your self advocacy group;

How did you first become involved in your self advocacy group/organisation?

How long have you been involved?

What are some of the activities you have been involved in as a member of your self advocacy group?

Over the time you have been a member of the group have the kind of activities you have been involved in changed? If so, what are some of the activities the group used to do but doesn't anymore?

How has being involved in your self advocacy group changed things for you?

What are some of the good things and the bad things about being a member of your self advocacy group?

Appendix 2. Interviewee Information and Consent Form

School of Social Work
and Social Policy
Faculty of Health Sciences

Participant Information Sheet

Building positive, included identities: The experience of engagement in self advocacy groups by adults with an intellectual disability.

This study is about self advocacy in Australia and in the United Kingdom and is funded by the Australian Research Council. It is a study which will try to find out about what it has been like to be a member of a self advocacy organization. It will look at how important self advocacy has been in getting people with an intellectual disability included in society and in the politics about disability.

You have already received general information about the project and an invitation to participate and have said that you would like to be involved in the project. The reason why you were invited to be involved is because you have been a member of self advocacy group in Australia or in the United Kingdom.

The researcher – Sian Anderson is a student at La Trobe University in Victoria, Australia and is undertaking this research for her doctoral thesis.

I will be interviewing people who have been involved in self advocacy about their experiences of being a self advocate, as well as talking to some other people who are involved in making policy about self advocacy or who have supported self advocacy organisations over the years.

I would like to interview you about your involvement in your self advocacy group. I am very interested in hearing about: your memories of activities and events you have been involved in, meetings you have been to and time you have spent on self advocacy activities. I would also like to hear about what you think the future of self advocacy groups will be like. You may enjoy talking about the things you have done in the past but may also feel sad remembering some things. You can talk for a short time or for as long as you like. If you do feel upset when you are being interviewed, the researcher will help you find a support worker or someone who knows you well who can support you.

The interviews will take place at the office or meeting place of your self advocacy group.

I would like to tape record the interview with you and will write down the things you say. I will not use your name when I do this so that the things you say will stay private. You do have the option of using your name if it is important to you. All of the information I collect will be stored safely in a locked room at La Trobe University.

I will use your interview and the information from other people in the study to write about people's experiences of being involved in self advocacy in Australia and the United Kingdom. I will use the information I collect to write my thesis and other academic papers. I am happy to give you a copy of these in the future if you would like to have them.

My supervisor at La Trobe is collecting information for a larger ARC project about self advocacy and for an archive about the history of self advocacy and some of the information I collect will be stored with the information she collects. None of this material will include your name of other personal information.

You have the right to stop being involved in this project if you choose and, if you do this you can say that the information you provided cannot be used. You can do this anytime during the interview or up to four weeks after you have talked to the researcher. If you do this you will fill in a form called "Withdrawal of Consent Form" and need to contact the researcher by email or telephone that you wish to withdraw your consent for your data to be used in this research project.

All the information will be stored for 5 years in a locked room at La Trobe University.

I hope you will enjoy talking about your experiences in self advocacy.

You should think about whether you want to be involved in this research. There will not be any problems if you decide you do not want to participate.

If you have questions regarding this project you should contact me, Sian Anderson, School of Social Work and Social Policy, La Trobe University, my email is s7anderson@students.latrobe.edu.au or my supervisor, who is: Professor Christine Bigby, of the School of Social Work and Social Policy, La Trobe University, email c.bigby@latrobe.edu.au . If you have any complaints or queries that I am not able to answer to your satisfaction, you may contact the Secretary, Human Ethics Committee, Research and Graduate Studies Office, La Trobe University, Victoria, 3086, phone: 03 9479 1443, e-mail: humanethics@latrobe.edu.au

School of Social Work
and Social Policy
Faculty of Health Sciences

Consent Form

Building positive, included identities: The experience of engagement in self advocacy by adults with an intellectual disability.

Sian Anderson, PhD Student, La Trobe University, Melbourne, Australia

Professor Christine Bigby, La Trobe University, Melbourne, Australia

"I ……. ….. …………………..(the participant) have read (or, where appropriate, have had read to me) and understood the **participant information sheet and consent form**, and any questions I have asked have been answered to my satisfaction. I agree to participate in the project, realising that I may physically withdraw from the study at any time and may request that no data arising from my participation are used, up to four weeks following the completion of my participation in the research. I agree that research data provided by me or with my permission during the project may be presented at conferences and published in journals.

I do not want my name or any other identifying information used.

☐ **Yes** ☐ **No**

I agree to be identified if this is relevant in any material that is published or presented.

☐ **Yes** ☐ **No**

Signature______________________________________Date_________

Name of Researcher

____

Signature_____________________________________Date_________

Name of Witness _________________________________

Signature_____________________________________Date________

Appendix 3. Withdrawal of Consent Form

(Participant's copy/Researcher's copy)

School of Social Work
and Social Policy
Faculty of Health Sciences

Withdrawal of Consent Form

Building positive, included identities: The experience of engagement in self advocacy groups by adults with an intellectual disability.

Sian Anderson (PhD Student), La Trobe University, Melbourne, Australia and

Professor Christine Bigby (Principal Supervisor), La Trobe University, Melbourne, Australia

"I ……. ….. ………………….. (the participant) withdraw my consent to participate in the research project."

Signature___________________________________Date__________

Witness signature ___________________________________

Date____________________

Please return to Sian Anderson. Email:

s7anderson@students.latrobe.edu.au

Bibliography

AASW. (2002). Code of ethics (2nd Edition.). Canberra: Australian Association of Social Workers.

Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap and Society, 2*(1), 5- 19.

Abberley, P. (2002). Work, disability and European social theory. In Barnes, C., Oliver, M., & Barton, L. (Eds.). *Disability Studies Today* (pp. 121-138). Cambridge: Polity Press.

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*(3), 275-287.

Abrams, D., & Hogg, M. (Eds.). (1990). *Social identity theory. Constructive and critical advances*. London: Harvester Wheatsheaf.

AIHW. (1997). The definition and prevalence of intellectual disability in Australia. Canberra: Australian Institute of Health and Welfare.

Albrecht, G., Seelman, K., & Bury, M. (Eds.). (2001). *Handbook of disability studies*. California: Sage Publications.

Ali, A., Hassiotis, A., Strydom, A. & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities, 33*(6), 2122-2140.

Armstrong, D. (2002). The politics of self-advocacy and people with learning difficulties. *Policy and Politics, 30*(3), 333-345.

Armstrong, D., & Goodley, D. (2001). *Self-advocacy, civil rights and the social model of disability. Final report to the ESRC. Research Grant R000237697*: University of Sheffield & University of Leeds.

Aspis, S. (1997). Self-advocacy for people with learning difficulties: Does it have a future? *Disability and Society, 12*(4), 647-654.

Aspis, S. (2002a). Self-advocacy: vested interests and misunderstandings. *British Journal of Learning Disabilities, 30*(1), 3-7.

Aspis, S. (2002b). What they don't tell disabled people with learning difficulties. In Corker, M. & French, S. (Eds.). *Disability discourse* (pp. 173- 182). Buckingham: Open University Press.

Atkinson, D. (2002). Self advocacy and research. In Gray, B. & Jackson, R. (Eds.). *Advocacy and disability* (pp. 120-149). London: Jessica Kingsley.

Atkinson, D., Jackson, M., & Walmsley, J. (1997). *Forgotten lives. Exploring the history of learning disability*. Kidderminster: BILD Publishers.

Atkinson, D., & Walmsley, J. (1999). Using autobiographical approaches with people with learning difficulties. *Disability and Society, 14*(2), 203-216.

Atkinson, D., & Williams, F. (Eds.). (1990). *'Know me as I am' : an anthology of prose, poetry and art by people with learning difficulties*. Kent: Hodder & Stoughton in Association with the Open University and MENCAP.

Barlow, J., & Kirby, N. (1991). Residential satisfaction of persons with an intellectual disability living in an institution or in the community. *Journal of Intellectual and Developmental Disability, 17*(1), 7-23.

Barnes, C., & Mercer, G. (Eds.). (1996). *Exploring the divide: Illness and disability*. Leeds: The Disability Press.

Barnes, C., & Mercer, G. (Eds.). (1997). *Doing disability research*. Leeds: The Disability Press.

Barnes, C., & Mercer, G. (2003). *Disability*. Cambridge: Polity.

Barnes, C., & Mercer, G. (Eds.). (2004). *Disability policy and practice: Applying the social model*. Leeds: The Disability Press.

Barnes, C., & Mercer, G. (2006). *Independent futures. Creating user-led disability services in a disabling society*. Bristol: The Policy Press.

Barnes, C., Mercer, G., & Shakespeare, T. (1999). *Exploring disability. A sociological introduction.* Cambridge: Polity Press in association with Blackwell Publishers.

Barnes, C., Oliver, M., & Barton, L. (Eds.). (2002). *Disability studies today*. Cambridge: Polity Press.

Barton, L. (1993). The struggle for citizenship: The case of disabled people. *Disability, Handicap and Society, 8*(3), 235-248.

Bates, P., & Davis, F. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability and Society, 19*(3), 195-207.

Bathmaker, A-M., & Harnett, P. (2010). Introduction. In Bathmaker, A-M. & Harnett, P. (Eds.). *Exploring learning, identity & power through life history narrative research* (pp. 1-10). London: Routledge.

Bauman, Z. (1996). From pilgrim to tourist - or a short history of identity. In Hall, S. & du Gay, P. (Eds.). *Questions of cultural identity* (pp. 18-36). London: SAGE.

Bayley, M. (1997). *What price friendship? Encouraging the relationships of people with learning difficulties*. Minehead: Hexagon Publishing.

Beadle-Brown, J., Mansell, J., & Kozma, A. (2007). Deinstitutionalization in intellectual disabilities. *Current Opinion in Psychiatry, 20*(5), 437-442.

Beart, S. (2005). 'I won't think of meself as learning disability. But I have': social identity and self-advocacy. *British Journal of Learning Disabilities, 33*(3), 128-131.

Beart, S., Hardy, G., & Buchan, L. (2004). Changing selves: a Grounded Theory account of belonging to a self-advocacy group for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*(2), 91-100.

Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities, 18*(1), 47-56.

Beland, D. (2007). The social exclusion discourse: ideas and policy change. *Policy and Politics, 35*(1), 123-139.

Beresford, P. (2012). The theory and philosophy behind user involvement. In Beresford, P. & Carr, S. (Eds.). *Social care, service users and user involvement* (pp. 21-37). London: Jessica Kingsley.

Bigby, C. (2007). The challenge of implementing state disability policy to achieve second generation rights for people with disabilities. *Just Policy, 43*, 68-75.

Bigby, C. (2005). The impact of policy tensions and organizational demands on the process of moving out of an institution. In Johnson, K. & Traustadóttir, R. (Eds.). *Deinstitutionalization and people with intellectual disabilities. In and out of institutions* (pp. 117-129). London: Jessica Kingsley.

Bigby, C., & Frawley, P. (2010). Reflections on doing inclusive research in the

"Making life good in the community" study. *Journal of Intellectual and Developmental Disability, 35*(2), 53-61.

Bigby, C., & Frawley, P. (2010). *Social work practice and intellectual disability.* Basingstoke: Palgrave Macmillan.

Bigby, C., Frawley, P., Ramcharan, P. & Reinforce Self Advocacy History Group. (2012). Understanding the development of self advocacy in Victoria, Australia: the early years. IASSID conference presentation.

Bigby, C., & Fyffe, C. (2007). *Housing and support for people with intellectual disability and high, complex or changing needs.* Paper presented at the Second Annual Roundtable on Intellectual Disability Policy. Bundoora: La Trobe University.

Bigby, C., Fyffe, C., & Mansell, J. (2006). *From ideology to reality: Current issues in implementation of intellectual disability policy.* Paper presented at the Roundtable on Intellectual Disability Policy. Bundoora: La Trobe University.

Bjornsdottir, K., & Svensdottir, S. (2008). Gambling for capital: learning disability, inclusive research and collaborative life histories. *British Journal of Learning Disabilities, 36*, 263-270.

Blackmore, T., & Hodgkins, S. L. (2012). Discourses of disabled peoples' organisations: Foucault, Bourdieu and future perspectives. In Goodley, D., Hughes, B. & Davis, L. (Eds.). *Disability and social theory. New developments and directions* (pp. 70-87). Basingstoke: Palgrave Macmillan.

Blaney, B & Freud, E. (1994). Trying to play together: competing paradigms to inclusion through recreation and leisure. In Bradley, V., Ashbaugh, J. & Blaney, B. (Eds.). *Creating individual supports for people with* *developmental disabilities: A mandate for change at many levels* (pp. 237-253). Baltimore: Paul H. Brookes Publishing.

Blumer, H. (1969). *Symbolic interactionism. Perspective and method*. Englewood Cliffs: Prentice-Hall Inc.

BMRB, Lancaster University & Central England People First. (2005). *English national survey of adults with learning disabilities 2003-4.* London: The Health and Social Care Information Centre.

Bogdan, R., & Taylor, S. (1976). The judged, not the judges. An insider's view of mental retardation. *American Psychologist, 31*(1), 47-52.

Bogdan, R., & Taylor, S. (1994). *The social meaning of mental retardation* (Reissue of "Inside Out" edition.). New York: Teachers College Press.

Booth, T. (1996). Sounds of still voices: issues in the use of narrative methods with people who have learning difficulties. In Barton, L. (Ed.). *Disability and society: emerging issues and insights* (pp. 237-255). London: Longman.

Booth, T., & Simons, K. (1989). Whose terms? *Community Care, 5th October*, 19-22.

Borland, J., & Ramcharan, P. (1997). Empowerment in informal settings. The themes. In Ramcharan, P., Roberts, G., Grant, G. & Borland, J. (Eds.). *Empowerment in everyday life. Learning disability*. (pp. 88-100) London: Jessica Kingsley Publishers Ltd.

Bradley, V., Agosta, J., & Kimmich, M. (2001). Social and community participation. How to enhance supports for people with mild cognitive limitations. In Tymchuk, A., Lakin, K. & Luckasson, R. (Eds.). *The forgotten generation. The status and challenges of adults with mild cognitive limitations.* (pp. 169-

189). Baltimore: Paul H Brookes.

Bradley, V., Ashbaugh, J., & Blaney, B. (Eds.). (1994). *Creating individual supports for people with developmental disabilities. A mandate for change at many levels.* Baltimore: Paul H. Brookes Publishing.

Brennan, M., Forrest, V., & Taylor, J. (2012). Involving people with learning difficulties in self-advocacy. In Beresford, P. & Carr, S. (Eds.). *Social care, service users and user involvement* (pp. 243-264). London: Jessica Kingsley Publishers.

Bright, A. (2000). Towards a better future for the self-advocacy movement. *Community Living, April/May*, 13-14.

Brown, A. (1992). *Groupwork* (3rd edition.). Aldershot: Arena.

Brown, H., & Smith, H. (Eds.). (1992). *Normalisation. A reader for the nineties.* Tavistock/Routledge, London.

Brown, I., & Brown, R. (2003). *Quality of life and disability. An approach for community practitioners.* London: Jessica Kingsley.

Brown, S. (2007). Intergroup processes: social identity theory. In Langdridge, D. & Taylor, S. (Eds.). *Critical readings in social psychology* (pp. 133-163). Maidenhead: Open University Press.

Browning, P., Thorin, E., & Rhoades, C. (1984). A national profile of self help/self-advocacy groups of people with mental retardation. *Mental Retardation, 22*(5), 226-230.

Bryson, L., & Mowbray, M. (1981). Community: the spray-on solution. *Australian Journal of Social Issues, 16*(4), 255-267.

Bryson, L., & Mowbray, M. (2005). More spray on solution: Community, social capital and evidence based policy. *Australian Journal of Social Issues, 40*(1), 91-106.

Buchanan, I., & Walmsley, J. (2006). Self- advocacy in historical perspective. *British Journal of Learning Disabilities, 34*(3), 133-138.

Bunning, K., & Horton, S. (2007). "Border crossing" a route to inclusion. A shared cause with people with a learning disability? *Aphasiology, 21*(1), 9-22.

Burchadt, T. (2009). Disability, capability and social exclusion. In Millar, J. (Ed.). *Understanding Social Security: Issues for Policy and Practice* (2nd ed., pp. 145-162). Bristol: The Policy Press.

Burls, A., & Caan, W. (2004). Social exclusion and *embracement*: a helpful concept? *Primary Health Care Research and Development, 5*, 191-192.

Butera, F., Levine, J., & Vernet, J.-P. (2009). Influence without credit : How successful minorities respond to social cryptomnesia. In Butera, F. & Levine, J. (Eds.). *Coping with minority status. Responses to exclusion and inclusion*. New York: Cambridge University Press.

Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research, 54*(11), 1004-1014.

Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities, 49*(5), 315-326.

Caldwell, J., Arnold, K. K., & Rizzolo, M. K. (2012). *Envisioning the future: Allies in self-advocacy report*. Chicago: Institute on Disability and Human Development, University of Illinois.

Campbell, J. & Oliver, M. (1996). *Disability politics: Understanding our past,* *changing our future*. London: Routledge.

Carey, A. (2009). *On the margins of citizenship. Intellectual disability and civil rights in twentieth-century America*. Philadelphia: Temple University Press.

Carnaby, S. (1998). Reflections on social integration for people with intellectual disability: does interdependence have a role? *Journal of Intellectual and Developmental Disability, 23*(3), 219-228.

Castells, M. (2004). *The power of identity* (Second ed. Vol. 2). Oxford: Blackwell.

Cattermole, M., Jahoda, A., & Markova, I. (1990). Quality of life for people with learning difficulties moving to community homes. *Disability, Handicap and Society, 5*(2), 137-152.

Chapman, M., Bannister, S., Davies, J., Fleming, S., Graham, C., Mcmaster, A., Seddon, A., Wheldon, A. & Whittell, A. (2012). Speaking up about advocacy: findings from a partnership research project. *British Journal of Learning Disabilities, 40*, 71-80.

Chapman, R. (2005). *The role of the self-advocacy support-worker in UK People First groups. Developing Inclusive Research.* Unpublished thesis. Open University.

Chappell, A. (1994). A question of friendship: community care and the relationships of people with learning difficulties. *Disability and Society, 9*(4), 419-434.

Chappell, A. (2000). Still out in the cold: people with learning difficulties and the social model of disability. In Shakespeare, T. (Ed.). *The disability reader* (pp. 211-220). London: Continuum International Publishing Group Ltd.

Chappell, A., Goodley, D., & Lawthom, R. (2002). Making connections: the relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities, 29*(2), 45-50.

Charlton, J. (1998). *Nothing about us without us. Disability oppression and empowerment*. Berkeley: University of California Press.

Charmaz, K. (2000). Grounded theory: objectivist and constructivist methods. In Denzin, N. & Lincoln, Y. (Eds.). *Handbook of qualitative research* (Second Edition ed., pp. 509-536). Thousand Oaks: Sage Publications Inc.

Charmaz, K. (2006). *Constructing grounded theory. A practical guide through qualitative analysis.* London: SAGE Publications Ltd.

Chase, J. (1992). The self and collective action: dilemmatic identities. In Breakwell, G. (Ed.), *Social psychology of identity and the self concept* (pp. 101-128). London: Surrey University Press.

Christie, I., with Mensah-Coker, G. (1999). *An inclusive future? Disability, social change and opportunities for greater inclusion by 2010*. London: Demos.

Clarke, C., Lhussier, M., Minto, C., Gibb, C., & Perini, T. (2005). Paradoxes, locations and the need for social coherence: a qualitative study of living with a learning disability. *Disability and Society, 20*(4), 405-419.

Clement, T. (2003). *An ethnography of People First Anytown: A description, analysis, and interpretation of an organisational culture.* Unpublished thesis. Open University.

Clement, T., & Bigby, C. (2010). *Group homes for people with intellectual disabilities*. London: Jessica Kingsley.

Clifford, S. (2013). A narrative inquiry of a self-advocacy meeting: rethinking empowerment from sovereignty to spontaneity. *Disability Studies Quarterly, 33*(3), 1-15. Accessed on 5th July 2013.

Cocks, E., & Duffy, G. (1993). *The nature and purposes of advocacy for people with disabilities*. Canberra: Commonwealth Department of Health, Housing, Local Government and Community Services.

Collins, S. (2012). *An exploratory study of advisors to self-advocacy groups.* Unpublished thesis. University of Illinois, Chicago.

Commonwealth of Australia. (2009). *Research of the models of advocacy funded under the National Disability Advocacy Program*. Canberra.

Commonwealth of Australia. (2011). *National Disability Strategy 2010-2020. An initiative of the Council of Australian Governments*. Canberra.

Cooper, M. (1999). The Australian disability rights movement lives. *Disability and Society, 14*(2), 217-226.

Crawley, B. (1988). *The growing voice. A survey of self-advocacy groups in adult training centres and hospitals in Great Britain.* London: Values into Action.

Cresswell, J. (2009). *Research design. Qualitative, quantitative, and mixed methods approaches* (Third Edition). London: Sage Publications.

Crocker, J., & Quinn, D. (2000). Social stigma and the self : meaning, situations and self-esteem. In (Eds.) Heatherton, T., Klede, R., Hebl, R., & .Hull, J. *The Social Psychology and Stigma* (pp. 153-183). New York: Guildford Press.

Croft, S., & Beresford, P. (1989). User-involvement, citizenship and social policy. *Critical Social Policy, 9*(5), 5-18.

Crotty, M. (1998). *The foundations of social research. Meaning and perspective in the research process*. St Leonards: Allen and Unwin.

Cummins, R., & Lau, A. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability.

Journal of Applied Research in Intellectual Disabilities, 16, 145-157.

Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: testing a social–cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy, 11*(4), 247-254.

Darlington, Y., & Scott, D. (2002). *Qualitative research in practice. Stories from the field*. Crows Nest: Allen & Unwin.

Davies, C. (1998). Constructing other selves: (in)competences and the category of learning difficulties. In Jenkins, R. (Ed.). *Questions of competence. Culture, classification and intellectual disability* (pp. 102-124). Cambridge: Cambridge University Press.

Davies, C., & Jenkins, R. (1997). 'She has different fits to me': how people with learning difficulties see themselves. *Disability and Society, 12*, 95-109.

Davis, L. (Ed.). (1997). *The disability studies reader*. New York: Routledge.

Deardon-Phillips, C., & Fountain, R. (2005). Real power? An examination of the involvement of people with learning difficulties in strategic service development in Cambridgeshire. *British Journal of Learning Disabilities, 33*(4), 200-204.

Della Porta, D., & Diani, M. (2000). *Social movements. An introduction*. Oxford: Blackwell.

Dempsey, I., & Nankervis, K. (2006). *Community disability services: an evidence-based approach to services*. Sydney: UNSW Press.

Department of Families, Housing, Community Services and Indigenous Affairs. (2008). *National Disability Advocacy Program*. Accessed on 14th March 2013. www.fahcsia.gov.au/our-responsibilities/disability-and-carers

Department of Health. (2005). *The Government's annual report on learning disability*. London: Department of Health.

Department of Health. (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities*. London: Department of Health.

Department of Health. (2001). *Valuing People: A new strategy for learning disability for the 21st century*. London: Department of Health.

Department of Health, Housing, Community Services and Indigenous Affairs. (2009). *National Disability Strategy - community consultations and submissions report 2009*. Canberra: Department of Health, Housing, Community Services and Indigenous Affairs.

Department of Human Services - Disability Services. (2002). *Victorian State Disability Plan 2002-2012*. www.dhs.vic.gov.au/for-individuals/disability Accessed 21st October 2010.

Department of Human Services – Office for Disability. (2013) *Disability Advocacy Program.* www.dhs.vic.gov.au/ /for-service-providers/disability/protecting-rights/disability-advocacy Accessed 20th March 2013.

Dingham, H. (1968). A plea for social research in mental retardation. *American Journal of Mental Deficiency, 73*(1), 2-4.

Ditchman, N., Werner, S., Kosyluk, K., Jones, N., Elg, B. & Corrigan, P. (2013). Stigma and intellectual disability: Potential application of mental illness research. *Rehabilitation Psychology, 58*(2), 206-216.

Dowse, L. (2001). Contesting practices, challenging codes: self advocacy, disability politics and the social model. *Disability and Society, 16*(1), 123-141.

Dowse, L. (2009). 'Some people are never going to be able to do that.' Challenges for people with intellectual disability in the 21st century. *Disability and Society, 24*(5), 571-584.

Dudley, J. (1983). *Living with stigma: The plight of people who we label mentally retarded*. Springfield: Charles C Thomas.

Dudley, J. (1997). *Confronting the stigma in their lives. Helping people with a mental retardation label*. Springfield: Charles C Thomas Publisher Ltd.

Dybwad, G., & Bersani, H. (Eds.). (1996). *New voices. Self-advocacy by people with disabilities*. Cambridge, MA: Brookline Books.

Edgerton, R. (1988). Aging in the community – a matter of choice. *American Journal of Mental Retardation. 92*(4), 331-335.

Edgerton, R. (1993). *The cloak of competence* (Revised and updated edition). Berkeley: University of California Press.

Emerson, E., Malam, S., Davies, I. & Spencer, K. (2005) *Adults with learning difficulties in England 2003/4.* London: Health and Social Care Information Centre.

Felce, D. (1996). Quality of support for ordinary living. In Mansell, J. & Ericsson, K. (Eds.). Deinstitutionalization and community living (pp. 117-134). London: Chapman & Hall.

Ferguson, H. (2009). *Self-identity and everyday life*. Abingdon: Routledge.

Fincher, R., & Iveson, K. (2008). *Planning and diversity in the city. Redistribution, recognition and encounter*. Basingstoke: Palgrave Macmillan.

Finestone, S., & Kahn, A. (1975). The design of research. In Polansky, N. (Ed.). *Social work research: methods for the helping professions* (pp. 61-64). Chicago: University of Chicago Press.

Finlay, M., & Lyons, E. (1998). Social identity and people with learning difficulties: implications for self-advocacy groups. *Disability and Society, 13*(1), 37-51.

Flynn, M. (2012) *Winterbourne View. A serious case review.* Bristol: South Gloucestershire Safeguarding Adults Board, South Gloucester Council.

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M. & Beecham, J. (2002). The quality of life of people 12 years after resettlement from long stay hospitals: users' views on their living environment, daily activities and future aspirations. *Disability and Society, 17*(7), 741-758.

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Hallam, A., Knapp, M. & Wooff, D. (2006). The social networks of people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 19*(4), 285-295.

Frawley, P. (2008). *Participation in government disability advisory bodies: An intellectual disability perspective.* Unpublished thesis. La Trobe University.

Frawley, P., Bigby, C., & Forsyth, H. (2006). Why are conferences "sometimes about us, without us"? *Journal of Intellectual and Developmental Disability, 31*(4), 249-251.

Freire, P. (1970). *Pedagogy of the oppressed* (Ramos, M., Trans.). New York: Herder and Herder.

Frey, L., & Bernstein, S. (1973). *Explorations in group work: essays in theory and practice*. New York: Milford House.

Fyson, R., & Cromby, J. (2012). Human rights and intellectual disabilities in an era of 'choice'. *Journal of Intellectual Disability Research, 56*(12).

Gerber, P., Reiff, H., & Ginsberg, R. (1996). Reframing the learning disabilities experience. *Journal of Learning Disabilities, 29*(1), 98-101.

Gergen, K. (1999). *An invitation to social construction.* London: SAGE Publications.

Gibbons, F. (1985). Stigma perception: social comparisons among mentally retarded persons. *American Journal of Mental Deficiency, 90*(1), 98-106.

Giddens, A. (1991). *Modernity and self-identity. Self and society in the late modern age*. Stanford: Stanford University Press.

Gill, C. (1997). Four types of integration in disability identity development. *Journal of Vocational Rehabilitation, 9,* 39-46.

Gillman, M., Heyman, B., & Swain, J. (2000). What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability and Society, 15*(3), 389- 409.

Gilmartin, A., & Slevin, E. (2009). Being a member of a self-advocacy group: experiences of intellectually disabled people. *British Journal of Learning Disabilities, 38,* 152-159.

Gleeson, B. (1999). *Geographies of disability*. London: Routledge.

Goffman, E. (1961). *Asylums: essays on the social situation of mental patients and other inmates*. London: Penguin Books.

Goodley, D. (1996). Tales of hidden lives: a critical examination of life history research with people who have learning difficulties. *Disability and Society, 11*(3), 333-348.

Goodley, D. (1997). Locating self-advocacy in models of disability: understanding disability in the support of self-advocates with learning difficulties. *Disability and Society, 12*(3), 367-379.

Goodley, D. (1999). Disability research and the "researcher template": reflections on grounded subjectivity in ethnographic research. *Qualitative Inquiry, 5*(24), 24-46.

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties.* Maidenhead: Open University Press.

Goodley, D. (2001). 'Learning difficulties', the social model of disability and impairment: challenging epistemologies. *Disability and Society, 16*(2), 207-231.

Goodley, D. (2003). Against a politics of victimisation: disability culture and self-advocates with learning difficulties. In Riddell, S. & Watson, N. (Eds.). *Disability, culture and identity* (pp. 105-131). Harlow: Pearson Education.

Goodley D. (2004). De/constructing 'learning difficulties' in educational contexts: The life story of Gerry O'Toole. In Barnes, C. &. Mercer, G. (Eds) *Disability policy and practice: applying the social model* (pp. 175-190). Leeds: The Disability Press.

Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities, 9* (4), 333-343.

Goodley, D. (2011). *Disability studies. An interdisciplinary introduction.* London: SAGE Publications.

Goodley, D., Armstrong, D., Sutherland, K., & Laurie, L. (2003). Self-advocacy, "learning difficulties", and the social model of disability. *Mental Retardation, 41*(3), 149-160.

Goodley, D., Lawthom, R., Clough, P., & Moore, M. (2004). *Researching life stories. Method, theory and analyses in a biographical age*. London: Routledge Falmer.

Goodley, D., & Norouzi, G. (2005). Enabling futures for people with learning difficulties? Exploring employment realities behind the policy rhetoric. In Roulstone, A. & Barnes, C. (Eds.). *Working futures? Disabled people, policy and social inclusion* (pp. 219-231). Bristol: The Policy Press.

Goodley, D., & Ramcharan, P. (2010). Advocacy, campaigning and people with learning difficulties. In Goward, P., Grant, G., Ramcharan, P. & Richardson, M. (Eds.). *Learning disability. A life cycle approach to Valuing People.* Second Edition. (pp. 87-100): Open University Press.

Goodley, D., & Rapley, M. (2002). Changing the subject: postmodernity and people with 'learning difficulties'. In Corker, M. & Shakespeare, T. (Eds.). *Disability/postmodernity: embodying disability theory* (pp. 127-141). London: Continuum.

Goodley, D., & Van Hove, G. (Eds.). (2005). *Another disability studies reader? People with learning difficulties and a disabling world.* Antwerp: Garant Publishers.

Gove, W. (Ed.). (1980). *The labelling of deviance. Evaluating a perspective* (2nd Edition.). Beverly Hills: Sage Publications.

Gray, B., & Ridden, G. (1999). *Lifemaps of people with learning difficulties*. London: Jessica Kingsley.

Hagner, D., & Helms, D. (1994). Qualitative methods in rehabilitation research. *Rehabilitation Counselling Bulletin, 37,* 290-303.

Hall, E. (2004). Social geographies of learning disability: narratives of exclusion and inclusion. *Area, 36*(3), 298-306.

Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health and Place, 11*(2), 107-115.

Harris, G. (1989). Concepts of individual, self, and person in description and analysis. *American Anthropologist, 91*(3), 599-612.

Harris, J., & Roulstone, A. (2011). *Disability, policy and professional practice*. London: SAGE Publications.

Harris, P. (1995). Who am I? Concepts of disability and their implications for people with learning difficulties. *Disability and Society, 10*(3), 341-352.

Hayden, M., & Nelis, T. (2002). Self-advocacy. In Schalock, R., Baker, P. & Croser, M. (Eds.). *Embarking on a new century: mental retardation at the end of the 20th century* (pp. 221-233). Washington: American Association on Mental Retardation.

Health Department Victoria. (1991). The investigative task force's findings on the Aradale Psychiatric Hospital and Residential Institution. Melbourne: Health Department Victoria.

Heller, T., & Harris, S. (2012) *Disability through the life course.* Los Angeles: SAGE.

Henderson, R., & Pochin, M. (2001). *A right result? Advocacy, justice and empowerment.* Bristol: The Policy Press.

Hogg, M., & Abrams, D. (1988). *Social identifications. A social psychology of intergroup relations and group processes*. London: Routledge.

Holman, A. (2006). In conversation. Robert Martin. *British Journal of Learning Disabilities, 34*(3), 131-132.

Holman, A. (2008). The loneliness of being someone with learning disabilities. *Community Living, 22*, 12-13.

Holmes, A. (1995). Self-advocacy in learning disabilities. *British Journal of Learning Disability Nursing, 4*(8), 448-550.

Hreinsdottir, E., Stefansdottir, G., Lewthwaite, A., Ledger, S., & Shufflebotham, L. (2006). Is my story so different from yours? Comparing life stories, experiences of institutionalization and self-advocacy in England and Iceland. *British Journal of Learning Disabilities, 34*(3), 157-166.

Hubert, J. (2000). The social, individual and moral consequences of physical exclusion in long-stay institutions. In Hubert, J. (Ed.). *Madness, disability and social exclusion. The archaeology and anthropology of 'difference'.* London: Routledge.

Hutton, S., Park, P., Park, R., & Rider, K. (2010). Rights, respect and tokenism: challenges in self-advocacy. *Journal on Developmental Disabilities, 16*(1), 109-113.

Ife, J. (2010). *Human rights from below. Achieving rights through community development*. Melbourne: Cambridge University Press.

Inclusion International. (2010). *Linking local voices to global change*. www.inclusion-international.org/self-advocacy Accessed 8th November 2010.

Ippoliti, C., Peppey, B., & Depoy, E. (1994). Promoting self-determination for persons with developmental disabilities. *Disability and Society, 9*, 453-460.

Jahoda, A., & Markova, I. (2004). Coping with social stigma: people with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research, 48* (8), 719-729.

Jaeger, P., & Bowman, C. (2005). *Understanding disability. Inclusion, diversity and civil rights*. Westport: Praeger Publishers.

Kaplan, H., & Liu, X. (2000). Social movements as collective coping with spoiled personal identities: intimations from a panel study of changes in the life course between adolescence and adulthood. In Stryker, S., Owens, T. & White, R. (Eds.), *Self, identity, and social movements* (pp. 215-238). Minneapolis: University of Minnesota Press.

Kenyon, E., Beail, N., & Jackson, T. (2013). Learning disability: experience of diagnosis. *British Journal of Learning Disabilities.* DOI: 10.1111/bld.12054

Knox, M., & Hickson, F. (2001). The meanings of close friendship: the views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 14*(3), 276-291.

Knox, M., Mok, M., & Parmenter, T. (2000). Working with the experts: collaborative research with people with an intellectual disability. *Disability and Society, 15*(1), 49-61.

Labonte, R. (2004). Social inclusion/exclusion: dancing the dialectic. *Health Promotion International, 25*(2), 115-121.

Langness, L., & Levine, H. (Eds.). (1986). *Culture and retardation. Life histories of mildly mentally retarded persons in American society.* Dordrecht: D. Riedel Publishing Company.

Lawler, S. (2002). *Identity. Sociological perspectives.* Cambridge: Polity.

Laws, G., & Radford, J. (1998). Place, identity and disability. In Kearns, R. & Gesler, W. (Eds.). *Putting health into place. Landscape, identity, and well-being* (pp. 77-101). Syracuse: Syracuse University Press.

Ledger, S., & Tilley, L. (2006). The history of self-advocacy for people with learning difficulties: international comparisons. *British Journal of Learning*

Disabilities, 34(3), 129-130.

Lee, P. (2002) Shooting for the moon – disability politics at the millennium. In Barnes, C., Oliver, M., & Barton, L. (Eds.). *Disability studies today*. (pp. 139-161). Cambridge: Polity Press.

Lemert, E. (1967). *Human deviance, social problems, and social control*. Englewood Cliffs: Prentice-Hall Inc.

Levitas, R. (1998). *The inclusive society? Social exclusion and New Labour.* Basingstoke: Macmillan.

Levitas, R. (2004). Let's hear it for Humpty: social exclusion, the third way and cultural capital. *Cultural Trends, 13*(2), 41-56.

Lewis, A., & Porter, J. (2004). Interviewing children and young people with learning disabilities: guidelines for researchers and multi-professional practice. *British Journal of Learning Disabilities, 32*, 191-197.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Newbury Park: Sage Publications.

Linton, S. (1998). *Claiming disability. Knowledge and identity*. New York: New York University Press.

Mackenzie, F., & McAlister, H. (2010). The roots of biomedical diagnosis. In Goward, P., Grant, G., Ramcharan, P. & Richardson, M. (Eds.). *Learning disability. A life cycle approach.* Second edition. (pp. 33-45): Open University Press.

Maestri-Banks, A. (2013). Learning disability, education and empowerment: learning from individuals who live with a learning disability. *Health and Social Care Education, 2(1),* 21-24.

Maguire, L. (1983). *Understanding social networks.* London: SAGE Publications.

Manning, C. (2009). 'My memory's back!' Inclusive learning disability research using ethics, oral history and digital storytelling. *British Journal of Learning Disabilities, 38*(3), 160-167.

Mason, P., Timms, K., Hayburn, T., & Watters, C. (2013). How do people described as having a learning disability make sense of friendship? *Journal of Applied Research in Intellectual Disabilities, 26*, 108-118.

McCarthy, J., Smith, J., & Zald, M. (1996). Accessing public, media, electoral and governmental agendas. In McAdam, D., McCarthy, J. & Zald, M. (Eds.). *Comparative perspectives on social movements* (pp. 291-311). Cambridge: Cambridge University Press.

McClimens, A. (2005). From vagabonds to Victorian values: the social construction of a disability identity. In Grant, G., Goward, P., Ramcharan, P. & Richardson, M. (Eds.). *Learning disability: a life cycle approach to valuing people* (pp. 28-46). London: Open University/McGraw Hill.

McClimens, A. (2007). Language, labels and diagnosis: an idiot's guide to learning disability. *Journal of Intellectual Disabilities, 11*(3), 257- 266.

McClimens, A., & Gordon, F. (2008). Presentation of self in e-veryday life: how people labelled with intellectual disability manage identity as they engage the blogosphere. *Sociological Research Online, 13(4)* (1).

McClimens, A., & Gordon, F. (2009). People with intellectual disabilities as bloggers. What's social capital got to do with it anyway? *Journal of Intellectual Disabilities, 13*(1), 19-30.

McClimens, A., & Hyde, M. (2012). Intellectual disability, consumerism and identity: to have and have not? *Journal of Intellectual Disabilities, 16*, 135-144.

McConkey, R. (2007). Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of Intellectual Disability Research*, *51*(3), 207-217.

McDermott, F. (2002). *Inside group work*. Crows Nest: Allen and Unwin.

McDonald, K., Kidney, C., & Patka, M. (2012). 'You need to let your voice be heard' research participants views on research. *Journal of Intellectual Disability Research, Online edition* (1st February).

McNally, S. (2002). A survey of self-advocacy groups for people with learning disabilities in an English region. *Journal of Intellectual Disabilities, 6*(2), 185-199.

McVilly, K., Stancliffe, R., Parmenter, T., & Burton-Smith, R. (2006). Self-advocates have the last say on friendship. *Disability and Society, 21*(7), 693-708.

Meininger, H. (2006). Narrating, writing, reading: life story work as an aid to (self) advocacy. *British Journal of Learning Disabilities, 34*, 181-188.

Mencap. (2013). www.mencap.org.uk Accessed 5th January 2013.

Mest, G. (1988). With a little help from their friends: use of social support systems by persons with retardation. *Journal of Social Issues, 44*(1), 117-125.

Miles, M., & Huberman, A. M. (1994). *Qualitative data analysis. An expanded sourcebook* (Second edition.). Thousand Oaks: SAGE Publications.

Miller, A., & Keys, C. (1996). Awareness, action, and collaboration: how the self-advocacy movement is empowering for persons with developmental disabilities. *Mental Retardation, 34*(5), 312-319.

Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods, 5*(1), 3.

Milner, P., & Kelly, B. (2009). Community participation and inclusion: people with disabilities defining their place. *Disability and Society, 24*(1), 47-62.

Mitchell, D., Traustadóttir, R., Chapman, R., Townson, L., Ingham, N. & Ledger, S. (Eds.). (2006). *Exploring experiences of advocacy by people with learning disabilities. Testimonies of resistance.* London: Jessica Kingsley.

Morris, J. (1991). *Pride against prejudice. Transforming attitudes to disability*. Philadelphia: New Society Publishers.

Morse, J., Stern, P., Corbin, J., Bowers, B., Charmaz, K., & Clarke, A. (2009). *Developing grounded theory. The second generation*. Walnut Creek: Left Coast Press Inc.

Moscovici, S., Mucchi-Faina, A., & Maass, A. (Eds.). (1994). *Minority influence*. Chicago: Nelson-Hall Publishers.

Mowbray, M. (2004). The new communitarianism : Building great communities or Brigadoonery? *Just Policy* (32), 11-20.

National Disability Insurance Scheme. (2013) http://www.ndis.gov.au/about-us Accessed 19th November 2013.

Nario-Redmond, M., Noel, J., & Fern, E. (2012). Redefining disability, re-imagining the self: disability identification predicts self-esteem and strategic responses to stigma. *Self and Identity, 11*(1), 1-21.

NDTI National Development Team for Inclusion. (2013) *Valuing People- what now?* www.ndti.org.uk/publications/ndti-publications Accessed 25th April

2013.

National Health and Medical Research Council. (2011) *Human research ethics.* http://www.nhmrc.gov.au/health-ethics/human-research-ethics Accessed 4th March 2011.

National Forum of People with Learning Difficulties. (2011). Staying strong. Taking self advocacy into the future: National Forum of People with Learning Difficulties. Cambridge: Voice Ability.

Newport People First. www.facebook.com/pages/Newport-People-First/ Accessed 21st January 2013.

Newell, C. (1996). The disability rights movement in Australia: a note from the trenches. *Disability and Society, 11*(3), 429-432.

Nind, M., & Seale, J. (2009). Concepts of access for people with learning difficulties: towards a shared understanding. *Disability and Society, 24*(3), 273-287.

Nonnemacher, S., & Bambara, L. (2011). ‘‘I'm supposed to be in charge’’: self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities, 49*(5), 327-340.

Oakes, P., Haslam, S., & Turner, J. (1994). *Stereotyping and social reality*. Oxford: Blackwell.

Oliver, M. (1992). Changing the social relations of research production. *Disability, Handicap and Society, 7*(2), 101-114.

Oliver, M. (1996). *Understanding disability: from theory to practice*. Basingstoke: Palgrave.

Oliver, M., & Barnes, C. (1998). *Disabled people and social policy: from exclusion* *to inclusion*. Harlow: Addison Wesley Longman.

Oliver, M., & Barnes, C. (2012). *The new politics of disablement.* Basingstoke: Palgrave Macmillan.

Olney, M., & Kim, A. (2001). Beyond adjustment: integration of cognitive disability into identity. *Disability and Society, 16*(4), 563-583.

Ouellette-Kuntz, H., Burge, P., Brown, H., & Arsenault, E. (2010). Public attitudes towards people with intellectual disabilities as measured by the concept of social difference. *Journal of Applied Research in Intellectual Disabilities, 23,* 132-142.

Owens, J. (2009). The influence of 'access' on social exclusion and social connectedness for people with disabilities. In Taket, A., Crisp, B., Nevill, A., Lamaro, G., Graham, M. & Barter-Godfrey, S. (Eds.). *Theorising social exclusion* (pp. 78-86). Abingdon: Routledge.

Parmenter, T., Cummins, R., Shaddock, A., & Stancliffe, R. (1994). The view from Australia: Australian legislation, service delivery and quality of life. In Goode, D. (Ed.). *Quality of life for persons with disabilities. International perspectives and issues* (pp. 75-102). Cambridge, MA: Brookline Books.

Pennell, R. (2001). Self-determination and self-advocacy: shifting the power. *Journal of Disability Policy Studies, 11*(4), 223-227.

Percy-Smith, J. (2000). Introduction: the contours of social exclusion. In Percy-Smith, J. (Ed.). *Policy responses to social exclusion. Towards inclusion?* (pp. 1-22). Berkshire: Open University Press.

Perske, R. (1972). The dignity of risk. In Wolfensberger, W., Nirje, B., Olansky, S., Perske, R. & Roos, P. (Eds.). *The principles of normalization in human* *services*. Toronto: National Institute on Mental Retardation through Leonard Crainford.

Phillipson, C., Allan, G., & Morgan, D. (Eds.). (2004). *Social networks and social exclusion. Sociological and policy perspectives.* Aldershot: Ashgate.

Pierson, J. (2002). *Tackling social exclusion*. London: Routledge.

Poetz, C. (2003). Reflections on 30 years of involvement in self-advocacy. *Journal of Intellectual and Developmental Disability, 28*(1), 84-86.

Pyles, L. (2009). *Progressive community organizing. A critical approach for a globalizing world*. New York: Routledge.

Race, D. (2007). *Intellectual disability. Social approaches*. Maidenhead: Open University Press.

Ramcharan, P. & Borland, J. (1997). Empowerment in informal settings. The themes. In *Empowerment in everyday life. Learning disability.* (pp. 88-100). London: Jessica Kingsley.

Ramcharan, P., Roberts, G., Grant, G., & Borland, J. (1997). Citizenship, empowerment and everyday life. Ideal and illusion in the new millennium. In Ramcharan, P., Roberts, G. Grant, G. & Borland, J. (Eds). *Empowerment in everyday life. Learning disability.* (pp. 241-258). London: Jessica Kingsley.

Ramcharan, P., & Grant, G. (2001). Views and experiences of people with intellectual disabilities. (1) The user perspective. *Journal of Applied Research in Intellectual Disabilities, 14*, 348-363.

Rapley, M. (2004). *The social construction of intellectual disability*. Cambridge: Cambridge University Press.

Rapley, M., Kiernan, P., & Antaki, C. (1998). Invisible to themselves or negotiating identity? The interactional management of 'being intellectually disabled'. *Disability and Society, 13*(5), 807-827.

Redley, M. (2009). Understanding the social exclusion and stalled welfare of citizens with learning disabilities. *Disability and Society, 24*(4), 489-501.

Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment. *Sociology of Health and Illness, 29*(5), 767-786.

Reinders, J. (2002). The good life for citizens with intellectual disability. *Journal of Intellectual Disability Research, 46*(1), 1-5.

Renzaglia, A., Karvonen, M., Drasgow, E., & Stoxen, C. (2003). Promoting a lifetime of inclusion. *Focus on Autism and Other Developmental Disabilities, 18*(3), 140-149.

Rhoades, C., Browning, P., & Thorin, E. (1986). Self-advocacy movement: a promising peer-support system for people with mental disabilities. *Rehabilitation Literature, 47*(1-2), 2-7.

Riddell, S., Baron, S., & Wilson, A. (2001). *The learning society and people with learning difficulties*. Bristol: The Policy Press.

Rioux, M., & Bach, M. (Eds.). (1994). *Disability is not measles*. North York, Ontario: L'Institut Roeher Institute.

Robinson, W. P. (Ed.). (1996). *Social groups and identities. Developing the legacy of Henri Tajfel*. Oxford: Butterworth Heinemann.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S. & Hallam, A. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation, 39,* 201-14.

Rodwell, M. (1998). *Social work constructivist research*. New York: Garland Publishing Inc/Taylor Francis.

Romeo, L. (1986). The wheels of self advocacy in Australia. In Dybwad, G., & Bersani, H. (Eds.). *New voices. Self-advocacy by people with disabilities* (pp. 140-170). Cambridge, MA: Brookline Books.

Rooney, S. (2002). Social inclusion and people with profound and multiple disabilities. In Race, D. (Ed.), *Learning disability - a social approach* (pp. 184- 197). London: Routledge.

Rosenberg, M. (1979). *Conceiving the self*. New York: Basic Books.

Roulstone, A., & Barnes, C. (Eds.). (2005). *Working futures? Disabled people, policy and social inclusion.* Bristol: The Policy Press.

Roulstone, A., & Prideaux, S. (2012). *Understanding disability policy*. Bristol: The Policy Press.

Safilios-Rothschild, C. (1981). Disabled persons' self-definitions and their implications for rehabilitation. In Brechin, A., Liddiard, P. & Swain, J. (Eds.). *Handicap in a social world* (pp. 5-13). Kent: The Open University.

Sands, D., & Wehmeyer, M. (Eds.). (1996). *Self-determination across the life span. independence and choice for people with disabilities*. Baltimore: Paul H Brookes Publishing.

Scott, R. (1969). *The making of blind men. A study of adult socialization*. New York: Russell Sage Foundation.

Seale, J. (2007). Strategies for supporting the online publishing activities of adults with learning difficulties. *Disability and Society*, *22*(2), 173-186.

Seale, J., & Pockney, R. (2002). The use of the personal home page by adults with

Down's syndrome as a tool for managing identity and friendship. *British Journal of Learning Disabilities, 30*(4), 142-148.

Self Advocacy Resource Unit (SARU). http://www.saru.net.au/ Accessed 30th October 2012.

Shah, S., & Priestley, M. (2011). *Disability and social change. Private lives and public policies*. Bristol: The Policy Press.

Shakespeare, T. (1993). Disabled people's self-organisation: a new social movement? *Disability, Handicap and Society, 8*(3), 249- 264.

Shakespeare, T. (1996). Disability, identity, difference. In Barnes, C. & Mercer, G. (Eds.). *Exploring the divide: illness and disability* (pp. 94-113). Leeds: The Disability Press.

Shakespeare, T. (1996). Power and prejudice: issues of gender, sexuality and disability. In Barton, L. (Ed.). *Disability and society: emerging issues and insights* (pp. 191-214). London: Longman.

Shakespeare, T. (Ed.). (1998). *The disability reader. Social science perspectives.* London: Cassell.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Taylor and Francis Routledge.

Shakespeare, T., & Watson, N. (2002). The social model of disability: an outdated ideology? *Research in Social Science and Disability, 2*, 9-28.

Shapiro, J. (1993). *No pity. People with disabilities forging a new civil rights movement*. New York: Times Books.

Shenton, A. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information. 22*, 62-75.

Shevellar, L., Pacey, S., & Collins, P. (Eds.). (2005). *On being the change we want to see. A collection of writings from CRUcial Times and CRU's occasional papers* (Vol. 3). Brisbane: CRU Publications.

Shulman, L. (2009). *The skills of helping individuals, families, groups, and communities* (Sixth ed.). Belmont: Brooks/Cole.

Siebers, T. (2006). Disability studies and the future of identity politics. In Alcoff, L., Hames-Garcia, M., Mohanty, S. & Moya, P. (Eds.). *Identity politics reconsidered* (pp. 10-30). New York: Palgrave Macmillan.

Simons, K. (1992). *'Sticking up for yourself' . Self-advocacy and people with learning difficulties*. York: Joseph Rowntree Foundation.

Simons, K. (1998). *Home, work and inclusion. The social policy implications of supported living and employment for people with learning disabilities*. York: Joseph Rowntree Foundation.

Sinason, V. (1992). *Mental handicap and the human condition. New approaches from the Tavistock*. London: Free Association Books.

Smith, G. (Ed.). (1999). *Goffman and social organization. Studies in a sociological legacy*. London: Routledge.

Söder, M. (1989). Disability as a social construct: the labelling approach revisited. *European Journal of Special Needs Education, 4*(2), 117-129.

Souza, A. with Ramcharan, P. (1997) Everything you ever wanted to know about Down’s syndrome but never bothered to ask. In Ramcharan, P., Roberts, G., Grant, G. & Borland, J. (Eds.). *Empowerment in everyday life. Learning disability*. (pp. 3-14) London: Jessica Kingsley Publishers Ltd.

Spedding, F., Harkness, E., Townson, L., Docherty, A., McNulty, N., & Chapman,

R. (2002). The role of self-advocacy. Stories from a self-advocacy group through the experiences of its members. In Gray, B. & Jackson, R. (Eds.). *Advocacy and learning disability* (pp. 137-151). London: Jessica Kingsley.

Stainton, T. (2005). Empowerment and the architecture of rights based social policy. *Journal of Intellectual Disabilities, 9*, 289-298.

Stalker, K. (1997). Choices and voices: a case study of a self-advocacy group. *Health Soc Care Community, 5,* 246-254.

Stammers, N. (2009). *Human rights and social movements*. London: Pluto Press.

Stancliffe, R. (2006). Services: availability, issues and models. In Dempsey, I. & Nankervis, K. (Eds.). *Community disability services. An evidence-based approach to practice* (pp. 272-295). Sydney: UNSW Press.

Stroman, D. (2003). *The disability rights movement*. Maryland: University Press of America.

Sutcliffe, J., & Simons, K. (1993). *Self advocacy and adults with learning difficulties. Contexts and debates*. Leicester: National Institute of Adult Continuing Education.

Sutherland, A. (1981). *Disabled we stand*. London: Souvenir Press.

Svensson, O., & Tideman, M. (2007). Motvärn, motståndsidentitet och empowerment bland personer med intellektuella funktionshinder. *Socialmedicinsk tidskrift (Journal of Social Medicine), 84*(3), 193-203.

Swain, J., French, S., Barnes, C., & Thomas, C. (Eds.). (2004). *Disabling barriers - enabling environments* (Second ed.). London: SAGE Publications.

Szivos, S., & Griffiths, E. (1990). Group processes involved in coming to terms with a mentally retarded identity. *Mental Retardation, 28*(6), 333-341.

Tajfel, H. (Ed.). (1978). *Differentiation between social groups. Studies in the social psychology of intergroup relations*. London: Academic Press Inc.

Tajfel, H. (1981). *Human groups and social categories*. Cambridge: Cambridge University Press.

Tajfel, H. (2010). Interindividual behaviour and intergroup behaviour. In Postmes, T. & Branscombe, N. (Eds.). *Rediscovering social identity* (pp. 97-117). New York: Psychology Press.

Thomas, C. (2007). *Sociologies of disability and illness: contested ideas in disability studies and medical sociology*. New York: Palgrave Macmillan.

Tideman, M. (2005a). Conquering life. The experiences of the first integrated generation. In Johnson, K. & Traustadóttir, R. (Eds.). *Deinstitutionalization and people with intellectual disabilities. In and out of institutions* (pp. 211-221). London: Jessica Kingsley.

Tideman, M. (2005b). A relational perspective on disability: an illustration from the school system. In Gustavsson, A., Sandvin, J., Traustadóttir, R., & Tössebro, J. (Eds.). *Resistance, reflection and change: Nordic disability research* (pp. 219-232). Lund: Studentlitteratur.

Titchkosky, T. (2003). *Disability, self, and society*. Toronto: University of Toronto Press.

Traustadóttir, R. (2006). Learning about self-advocacy from life history: a case study from the United States. *British Journal of Learning Disabilities, 34*, 175-180.

Tregaskis, C. (2002). Social model theory: the story so far... *Disability and Society, 17*(4), 457- 470.

Tsuda, E., & Smith, J. (2004). Defining and organizing self-advocate centred groups:

implications of survey research on self-advocacy groups in Japan. *Disability and Society*, *19*(6), 627-646.

Turner, J. (1982). Towards a cognitive redefinition of the social group. In Tajfel, H. (Ed.). *Social identity and intergroup relations* (pp. 15-41). Cambridge: Cambridge University Press.

Turner, J., Hogg, M., Reicher, S., & Wetherell, M. (Eds.). (1987). *Rediscovering the social group. A self-categorization theory*. Oxford: Basil Blackwell.

United Nations. (2006). *Convention on the rights of persons with disabilities*. www.un.org/disabilities/convention/conventionfull.shtml Accessed on 13th May 2013.

United Nations. (2013). *United Nations treaty collection*. www.un.org/treaties Accessed on 13th May 2013.

Valios, N. (2008). Supporting self-advocacy. *Community Care, Jan 31*(1707), 34-35.

Victorian Advocacy League for Individuals with Disability Inc. (2010). www.valid.org.au Accessed on 30th October 2010.

Walmsley, J. (2004). Involving users with learning difficulties in health improvement: lessons from inclusive learning disability research. *Nursing Inquiry*, *11*(1), 54-64.

Walmsley, J., & Downer, J. (1997). Shouting the loudest. Self advocacy, power and diversity. In Ramcharan, P., Roberts, G., Grant, G. & Borland, J. (Eds.). *Empowerment in everyday life. Learning disability* (pp. 35-48). London: Jessica Kingsley.

Walsh-Allen, M. (2010). Integration or segregation? The same or different recreation and leisure facilities for people with learning disability. *Critical Social*

Thinking: Policy and Practice, 2, 93-107.

Ward, L. (1988). Developing opportunities for an ordinary community life. In Towell, D. (Ed.). *An ordinary life in practice. Developing comprehensive community-based services for people with learning disabilities.* London: King Edward's Hospital Fund for London.

Ward, L. (Ed.). (1998). *Innovations in advocacy and empowerment for people with intellectual disabilities*. Chorley: Lisieux Hall Publications.

Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability. *Disability and Society*, *17*(5), 509-527.

Whittell, B., Ramcharan, P., & Members of People First Cardiff and The Vale. (1998). In Ward, L. (Ed.). (1998). *Innovations in advocacy and empowerment for people with intellectual disabilities*. (pp. 39-58). Chorley: Lisieux Hall Publications.

Whitehead, T., & Hughey, J. (2004). *Exploring self advocacy from a social power perspective*. New York: Nova Science Publishers.

Williams, K., & Carter-Sowell, A. (2009). Marginalization through social ostracism: effects of being ignored and excluded. In Butera, F., & Levine, J. (Eds.). *Coping with minority status. Responses to exclusion and inclusion* (pp. 104-122). New York: Cambridge University Press.

Williams, P., & Schoultz, B. (1982). *We can speak for ourselves. Self advocacy by mentally handicapped people*. London: Souvenir Press (Educational and Academic) Ltd.

Williams, V. (2002). *Being researchers with the label of learning difficulty, An* *analysis of talk in a project carried out by a self-advocacy research group.* Unpublished thesis. Open University.

Wolfensberger, W. (1975). *The origin and nature of our institutional models*. New York: Human Policy Press.

Wolfensberger, W. (2002). Social role valorization and, or versus "empowerment". *Mental Retardation, 40*(3), 252-258.

Wright Mills, C. (1959). *The sociological imagination*. New York: Penguin Books.

Zetlin, A., & Turner, J. (1988). Salient domains in the self-conception of adults with mental retardation. *Mental Retardation, 26*(4), 219-222.

Zola, I. (1993). Self, identity and the naming question: reflections on the language of disability. *Social Science and Medicine, 36*(2), 167-173.