

# Self-Advocacy as a Means to Positive Identities for People with Intellectual Disability: ‘We Just Help Them, Be Them Really’

Sian Anderson and Christine Bigby

*Living with Disability Research Centre, La Trobe University, Bundoora, Vic., Australia*

Accepted for publication 21 September 2015

**Background** Stigma attached to having an intellectual disability has negative implications for the social identities and inclusion of people with intellectual disability.

**Aim** The study explored the effects of membership of independent self-advocacy groups on the social identity of people with intellectual disability.

**Method** Using a constructivist grounded theory methodology, semi-structured interviews were conducted with 25 members of six self-advocacy groups which varied in size, resources, location and policy context: two based in the Australian states of Victoria and Tasmania and four in the UK.

**Results** Collegiality, ownership and control by members characterized groups. They gave members opportunities for paid or voluntary work, skill development and friendship which contributed to their confidence and engagement with life. Possibilities for new more positive identities such as being an expert, a business-like person, a self-advocate and an independent person were opened up. Self-advocacy is an important means of furthering social inclusion of people with intellectual disability.

**Keywords:** intellectual disability, participation, self-advocacy, social identity, social inclusion

## Introduction

Many people with intellectual disability remain socially excluded and economically disadvantaged in western societies such as the UK and Australia (Bigby & Frawley 2010). The range of policies designed to address this problem over at least two decades have had limited success. Normalization (Wolfensberger 1972, 1983), an important force for change in the 1970s and 1980s, represented progress in the recognition of people with intellectual disabilities as individuals. However, its inherent failure to acknowledge the structural and attitudinal barriers to inclusion left the stigma attached to social identities of people with intellectual disability untouched. In parallel with normalization, recognition that segregation could not produce a ‘good’ or ‘normal’ life (Johnson *et al.* 2010) led to deinstitutionalization and the shift to community living, often in small group homes (Bradley *et al.* 1994). However, whilst community living had undoubtedly

been a positive step towards a better life for many people with intellectual disability (Kozma *et al.* 2009), the failure to offer adequate support for community engagement or the development of relationships has more often meant people are physically present rather than socially included in communities (Bigby 2008; MacIntyre 2008). Similarly, social integrationist approaches that sought to build inclusion through employment have had limited success, and the economic participation of people with intellectual disability remains remarkably low (OECD, 2010). This approach to inclusion requires people with intellectual disability to have the ‘capacity’ to undertake paid work (Johnson *et al.* 2010) and seems to seal the exclusionary fate of those unable to participate for a range of reasons. Programmes designed to develop and support relationships between people with intellectual disabilities and others in the community seem to offer greater potential in enhancing social inclusion, but these have remained small in scale (Amado 2014) and are too

often challenged by the imposition of negative categorical identity (Davies & Jenkins 1997).

A fear of difference or stigma continues to be associated with an identity as a person with intellectual disability, which impacts on individuals' self-concept and their social relationships and creates barriers to social inclusion (Goffman 1961; Davies & Jenkins 1997; Dudley 1997; Hubert 2000; Beart 2005; Harris & Roulstone 2011). Without significant work to change the ways in which people with intellectual disabilities are seen by others as somehow less 'socially desirable' (Gibbons 1995), strategies to facilitate social inclusion will be of limited success. The question remains therefore how to overcome this stigmatized identity and the reluctance of the mainstream community to engage with people with intellectual disability as individuals or include them as citizens.

Ideas about the creation of 'self-authored' spaces for people with intellectual disabilities offer a new way of thinking about the possibility of addressing stigmatized social identities and enhancing social inclusion. Milner & 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 one, it seems to mimic spaces in the mainstream community, such as the football club, the community choir or the self-help group, that act as catalysts for inclusion as well as peer relationships, and the development of individual and shared common interests. For people with intellectual disabilities, self-advocacy groups are a key self-authored space.

The dominant narrative about self-advocacy has been about speaking out, having a say and developing skills in empowerment (Goodley 2000, 2003, 2005; Atkinson 2002; Chappell *et al.* 2002; McNally 2002; Goodley *et al.* 2003; Barnes & Mercer 2006; Nind & Seale 2009). They are seen to provide opportunities for members to engage with ideas about rights and empowerment and to share and celebrate their personal resilience. Feelings of being 'powerful and strong' (Beresford 2012) resonate in the narratives of self-advocacy offered throughout the literature. A recent Australian study suggested that self-advocacy had also been a means for social inclusion of long-term members, providing a sense of belonging, social connections and occupation (Frawley & Bigby 2015).

There are also some indications, in the accounts of self-advocates' experiences, of the potential of groups to positively change the social identities of people with

intellectual disabilities and counter some of the negativity and labelling that entrenches their stigmatized identities and ongoing social exclusion. For example, Beart *et al.* (2004) found that the eight members of the self-advocacy group they investigated experienced an altered self-concept as a result of their participation and experiences of what the authors called the groups' 'positive social environment'. Similarly, Caldwell's (2010) study of thirteen leaders of self-advocacy organizations revealed that participation had been personally transformative, with one person commenting that he now had a 'new way to think about myself'. As Poetz (2003) suggested, in enacting self-advocacy and through engagement with independent self-advocacy organizations, there seems to be the 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'. This study explored this proposition further by investigating the experience of engagement in self-advocacy groups and the impact of membership on the development of the self-identity of people with intellectual disability. The study was part of a larger programme of research funded by an ARC Linkage Grant examining self-advocacy and social inclusion.

## Method

This qualitative study was informed by symbolic interactionism (Blumer 1969) and used constructivist grounded theory methodology (Charmaz 2000; Morse *et al.* 2009). Symbolic interactionism has been used to study difference and disability (Goffman 1961; Söder 1989), providing insight into the powerful and negative ways in which categorization and labelling lead to segregation through a process where 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). The complex ways in which humans respond and the way these acts are defined had important insights to offer this study which sought to focus on the significance of self-advocates' experiences and the possible impact on their social identity.

## Sampling and participants

Purposive and convenience techniques were used to generate a diverse sample of self-advocacy groups and their members and supporters as research participants

(Rodwell 1998; Charmaz 2006). One of the aims was to compare the experiences of self-advocates in the UK and Australia, given the greater prevalence of groups and available support in the UK compared with Australia. Recruitment was managed through mail, email and phone contact with group presidents and supporters. Criterion for inclusion was self-governance, a group was considered independent, if its operations were managed through a committee or board of management made up of members. The final sample comprised two groups in Australia, one in the state of Victoria and one in Tasmania and four in the United Kingdom. As Table 1 shows, the groups varied in size, location and available resources in the form of paid support workers and operational funding.

Twenty-five members of the six independent self-advocacy groups participated and these individuals occupied a range of roles in their groups. Ten of the self-advocate participants were female, with an average age of thirty-five years, and fifteen were male, with an average age of thirty-nine years. They all had good language skills. The study had ethical approval from the Human Ethics Committee at La Trobe University, and consent was gained from all participants.

### Data collection and analysis

The self-advocates participated in semi-structured interviews which were conducted by the first author and lasted for between 40 min and 4 h. The interviews were relaxed and informal, taking place in the offices of each of the groups. The interviewees were asked to talk about the kinds of activities they had been involved in with their group, the highlights of their experiences and to comment on the ways in which self-advocacy groups might have changed and what they might be like in the future. These broad topics provided a framework for a wide ranging conversation about both the lives and experiences of members and the nature of their respective self-advocacy organizations.

The interviews were digitally recorded with the consent of the participants, transcribed and analysed using NVIVO 9 software (QSR International Pty Ltd, Doncaster, Australia). Grounded theory methods were used to code transcripts of the recorded interviews. Coding 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

**Table 1** Characteristics of self-advocacy groups to which participants belonged

<i>Group</i>	<i>Location</i>	<i>Office type</i>	<i>Supporters</i>	<i>Training for members</i>	<i>Social activities for members</i>	<i>Paid employment opportunities</i>	<i>Voluntary employment opportunities</i>
Red Group	Rural town (Aust.)	Colocated 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 (UK)	Self-contained	2 full time, 3 part time	Yes	Yes	No	Yes (with payment for travel and meals)
Green Group	Major city (UK)	Self-contained	1 full time, 2 part time	Yes	Yes	Yes	Yes
Blue Group	Urban centre (UK)	Colocated 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 (UK)	Colocated with advocacy service and health clinic	2 part time	Yes	Yes	No	No

of 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 categorization. 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.

In presenting the findings, the names of the participants and self-advocacy groups have been changed to preserve anonymity. Where quotes are used, the interviewee is identified by name and a two letter code distinguishes each group (e.g. BG).

### Limitations

This piece of research was essentially exploratory in nature. Whilst rich data were sought and collected, it was from a small sample of participants all of whom were relatively able and articulate and whose experiences may not be echoed in those self-advocates with moderate or severe intellectual disabilities. Whilst the study did include both female and male self-advocates, data were not analysed in ways which may uncover any possible differences in impacts according to gender.

### Findings

There was remarkable similarity in the experiences of the self-advocate participants despite differences in the location, size and resources of the groups of which they were members. The UK groups were larger and longer established than the Australian groups and offered their members a broader range of opportunities for engagement. An historical lack of policy or funding for support for self-advocacy groups had served to restrict the growth of the Australian groups; however, the experiences and impacts described by the participants equalled those of group members in the UK. Their experiences were strongly characterized by change both in respect of their opportunities to participate in a range of activities and to create new positive self-identities. Figure 1 summarizes the

findings diagrammatically, and they are illustrated in the following sections using key quotes from participants. This study does not explore the actions of support workers or the nature of their support that contributed to self-advocates' experiences, as these are the topic of a companion paper.

## Key Features of Self-Advocacy Groups

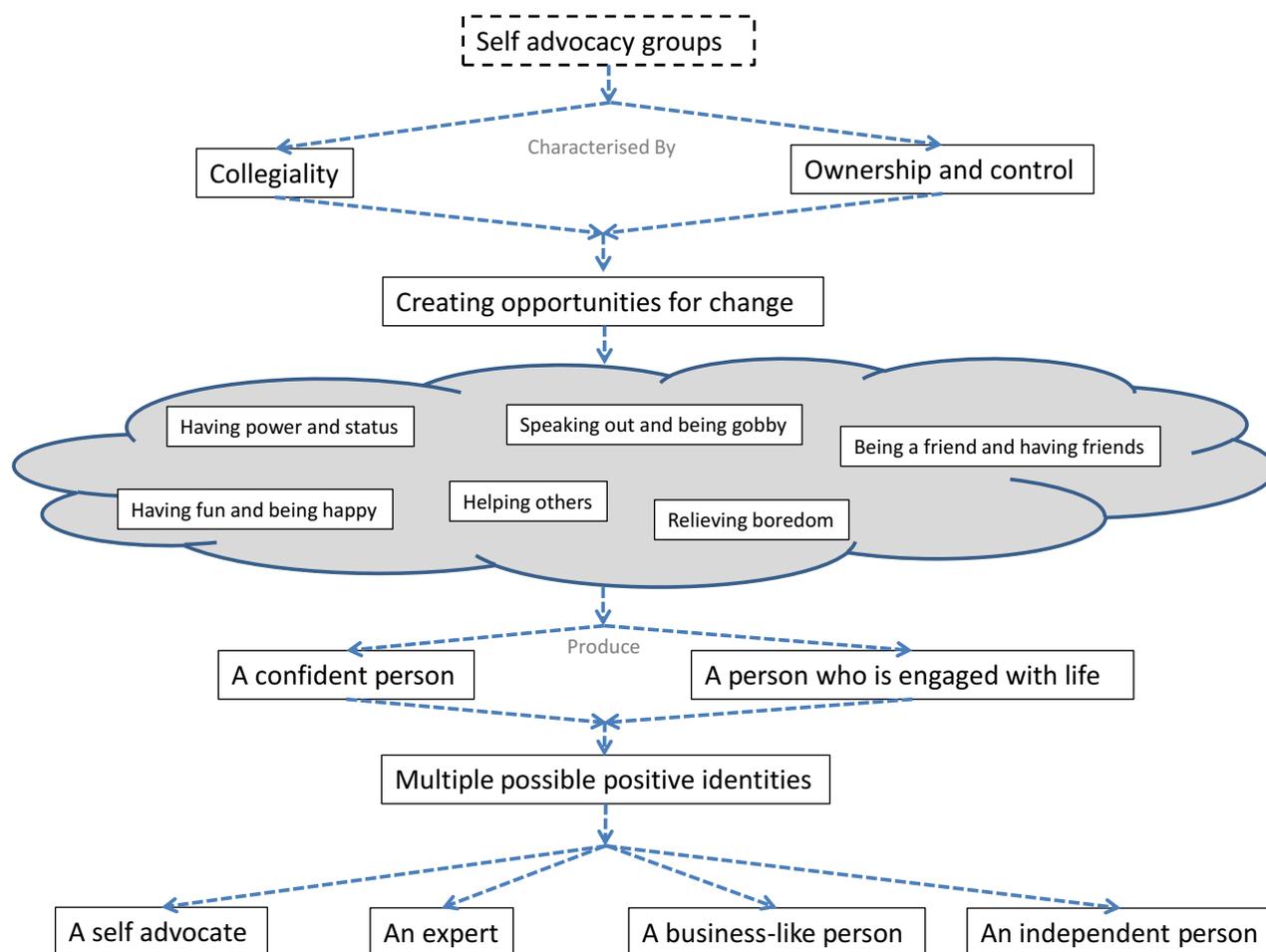
Collegiality and a sense of ownership and control featured strongly in the way all the groups were described by self-advocates. As William a member of Purple group said, 'We all share it and it's just our group...a friendly group, we can decide what we want to do and we all just treat each other the right way'.

### Collegiality

Members held each other in positive regard, and groups' offices were friendly and socially accessible places. Emma from Purple group commented, that, 'nobody calls me a mong here. They know my name, they use it properly. I like it', illustrating the positive and mutually respectful way that members treated each other. Many of the self-advocates echoed this sentiment and talked about the way their opinions and feelings were heard and respected in the group. For example, Kevin from Green group said, 'I think people listen to what I've got to say. I do think they take note'. Nella from Blue group said, 'people are listening...listening quiet, no interrupting when I have something to say'. Reflecting the respect members accorded one another, Yvonne from Magenta group said, 'I'd talk about things, but then I'd sit back a bit... and listen to what others had to say'.

As these comments from Ben and Anne illustrate, members felt their self-advocacy groups were 'safe' places 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, BG) and 'I tell all the friends here about having a crap day or whatever, they listen to me until I finish talking. It's good' (Anne, BG).

Being able to share life experiences contributed to members' feelings of belonging to the group and forming bonds to the extent that they were 'in it together', working cooperatively. For example, Kevin of Green group described the group as 'growing' saying, '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'. The voluntary nature of participation, choice about becoming a



**Figure 1** A model of the impact of self-advocacy groups on the social identity of people with an intellectual disability.

member and level of participation in activities, was an important factor in creating a sense of collegiality. As Nick from Green group said, for example,

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.

Self-advocacy groups had provided a place like no other in the lives of some of the self-advocates. Daniel from Red group, for example, described it as a place where support staff were not always physically present or their presence was less imposing, which perhaps for the first time freed people to be heard and taken seriously by their peers. He said,

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.

Although at times it was important as Daniel suggested that support workers left members alone, their presence also helped to strengthen the overall sense of collegiality.

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, PG)

Some of the members described their group's supporters as being like 'teachers' and 'mentors',

valuing the knowledge, skill and support they provided. For example, William from Purple group said, 'The staff they help us to learn about how to ask for the things, to say what we think about things', and Yvonne from Magenta group, 'she [supporter] has supported me to do leadership training and go to heaps of conferences and such and she gave me an awesome reference!'

### A sense of ownership and control

All the self-advocates had a strong sense of ownership and control of their group. For example, William from Purple group said, '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', and Nella from Blue group echoed this sentiment when she said, 'This is our own group, for us, just for us to do things... and I love it! I do love it!'

Members gained a sense of ownership and control through committees of management, comprised of elected positions occupied by self-advocates. Elected office-bearers with titles such as President or Chairperson made powerful statements about who set the groups' agenda. Even in groups where there were clear indications that supporters made many of the major decisions, the self-advocate members still felt strongly that the members' committee was 'in charge'.

### Creating Opportunities for Change

Participation in self-advocacy groups offered members a chance to change their lifestyle through opportunities to try new and interesting activities, to participate in training programmes and develop new skills and relationships. All the groups involved their members in programmes that focussed on training for citizenship and personal growth which included things such as, skills for developing friendships or intimate 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. Participation in workshops or conference of this nature was a highlight of self-advocacy for some members, such as Sophie from Magenta group who said,

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 access different services,

or about rights... We take our meetings to the pub sometimes!

The training about rights and citizenship and scheduled 'speaking up' sessions which occurred in all the groups contributed to participants' feelings of increased self-efficacy, as Emma from Purple group explained,

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.

Speaking up sometimes extended to involvement in community education programmes about intellectual disability which afforded self-advocates' opportunities to be 'experts' about their own lives. Participation in awareness raising sessions of this nature enabled self-advocates to be 'teachers' and to enjoy the associated benefits of being listened to and held in some regard. They also gave self-advocates the chance to challenge negative stereotypes about people with intellectual disabilities. Participants said for example,

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, GG)

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, BG)

Self-advocates talked about the status associated with being on management committees and the highly desirable positions of 'president', 'secretary', 'members rep' and 'chairperson'. Many expressed aspirations to hold or regain such roles, seeing them as powerful, whether or not this was actually the case in practice. For example, as president of Green group, Nick had felt he was 'in charge' even though he may not have decided the topics being discussed and the words he spoke were from a script provided by the group's support worker.

Talking about the committee of management meetings, he said,

[Supporter]...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.

Self-advocates talked about the feelings of happiness and enjoyment they derived from involvement with their self-advocacy group: 'It's good fun' (John, GG) and 'It's really good and I like going along' (William, PG). Many also saw their group as a place for mutual aid, whereby the training and experience they gained enabled them to help other people – especially those new to the group. Emma from Purple group said, 'I enjoy that, you know, helping out the other ones here' and Trish from Green 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'.

For many self-advocates, participation in the groups' activities was an important means of relieving boredom as Frank from Green group observed, 'There's always something going on here. Outside, at home, there's nothing to do. It's really, really boring'. And as Nick, also from Green group said, self-advocacy groups were also places where people had friends and formed friendships, '...the men's group is friendly, just friends'.

### Positive Self-Identities

The opportunities groups offered to members to participate in some or all of; speaking out sessions, holding positions of power and status, helping others, relieving boredom, being a friend or having friends and having fun, provided the catalyst for self-advocates to become more confident and engaged with life.

As their belief in their own abilities increased, a range of new and more positive social identities had opened up for them, different and more exciting ones unimagined in their previous life experiences. These new identities involved occupying different kinds of social space, both within their group and in the broader community which raised their visibility and changed their public image. Four new more positive identities assumed by self-advocates as a consequence of their membership of groups were identified, being a self-advocate, an expert, a business-like person and an independent person. Not all participants took on all of these identities, but all assumed at least one with a

clear line of association to their membership of the group.

### Being a self-advocate

For all the participants, self-advocacy groups had played an important role in building a sense of empowerment and competence, and an identity as a self-advocate. In talking about being able to 'speak out', they expressed a strong, bold social identity that challenged the core of notions about passivity and incapacity on the part of people with intellectual disability. For example, Trish from Green group defined a self-advocate as a person who can 'just stand up and be counted, that's how I feel. I really can do that'. Daniel saw himself and the other members of Red group as self-advocates characterized by their skills and confidence in 'speaking out'. 'We are all just people. People speaking out for their rights'.

The identity of self-advocate encompassed not only speaking up for oneself but also helping, acting in ways that supported and enabled peers to understand their rights and to deal with the negative consequences of a disabling society such as exclusion and bullying. Participants' understanding of 'self-advocacy' revealed much about the potential of groups to change the lived experience of people with intellectual disabilities, seeing themselves as capable and skilled in bringing about change not only in their own lives but that of their peers.

### Being an expert

Involvement in community education and awareness programmes gave self-advocates the chance to be seen and to see themselves as 'experts' about intellectual disability. This was a powerful experience for people such as Henry who enjoyed delivering training sessions. He also found it affirming that during those moments, his unique understanding of intellectual disability was conveyed to an audience that often included professionals such as nurses, doctors, social workers, psychologists or police officers, who may in the past have disregarded or ignored his views. He said, 'they enjoy my speech. My training, they enjoy it. They reckon it's important'. For the first time in such sessions, self-advocates met with professionals on their own terms, and the sense of satisfaction they felt at being able to be the 'expert' present was palpable. Being seen as having important knowledge produced for some self-advocates a massive shift in their own self-

confidence, and being listened to as an expert by others who were also experts in their fields, and who had significant power, offered self-advocates tangible evidence of a change in their social identity beyond the group.

Sharing the story of their own life with others both inside and outside the self-advocacy group also enabled self-advocates to see themselves as experts about their own lives. That this could be the case was an important shift in social identity as many had experienced lifetimes as service users, clients or patients of services where others were the expert about their life.

### Being a business-like person

Self-advocates deeply valued the business-like processes of their group: the rules, infrastructure and activities, whether they worked in a paid or voluntary capacity within it. The assignment of tasks gave them a sense of trusted self-determination, and their participation the identity of 'worker', an identity many had been told (or had understood) that they could never attain.

Groups' activities and meetings were meticulously planned to maximize both the number of self-advocates who could participate and the range of ways in which they did so. In all of the groups, members expressed a strong desire to be 'a worker' contributing to the groups' smooth running. Many gave examples of deriving a 'business-like' or worker identity from participating in the 'business' of the self-advocacy office such as answering the phone, passing on messages, buying coffee and stamps. As Anne from Red group said, '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'.

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 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 them. The trust and respect inherent in the way in which tasks were given to members by the supporters offered opportunities for people to feel they were regarded in a more positive way than they had ever been before. As Frank from Green group remarked,

'...they rely on me, they trust me as well. They know I can do it'.

### Being an independent person

There were many examples where belonging to a self-advocacy group had enhanced members' independence by promoting their confidence to make decisions, to travel and be included in a range of social groups. A number of the self-advocates described quite dramatic changes that stemmed from increased confidence and skills since becoming members of their group. For example, both Frank and Kevin from Green group had moved out of their parents' homes and embraced the social identity of an 'independent person'. Frank was enjoying the opportunity to prove that he really could manage on his own. He said,

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. I like being independent.

Kevin too was enjoying having a place of his own and said, 'I've been enjoying being out in the community, having my own front door key, what I'd never had before'.

For others, greater independence meant having the confidence to travel. For example, Liam from Red group clearly credited his greater capacity to travel around the city independently to his membership of self-advocacy, when he said, 'like before...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'. Similarly, William from Purple group said that now he could, '...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'.

For Rita from Red group, being able to confidently articulate her choice about 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. Her 'independence' may seem modest, but for her, the ability to be a person who was doing something different and of her own choosing after many years of frustration and unhappiness was a highly significant

change in her life that altered her identify in a positive way.

## Discussion

### New positive identities

The findings from this study paint a positive picture of self-advocacy enabling people with intellectual disability to assume positive identities which changed their own sense of self, expanded individual experiences of social inclusion, and had the potential in the longer term to counter stigmatizing labels that had obstructed acceptance as equal community members.

All of the participants had developed identities as self-advocates, 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 intellectual disabilities, arguing this does ‘a disservice’ to the resilience of members. The self-advocates in this study, however, relished the self-advocacy training, regarding it as an opportunity to hone statements of strength and to be ready to deliver them to the community outside the group. For these self-advocates, the 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. These findings are similar in some respects to other studies that have described the positive impact of becoming a self-advocate and having the chance to tell and share with others ones stories of resilience and survival (Booth 1996; Atkinson 2002; Chappell *et al.* 2002; Spedding *et al.* 2002; Mitchell *et al.* 2006). An added element in this study was the opportunity to assume the social identity of expert, through participation in community education programmes, which held considerable potential not only for the increased self-esteem of individual self-advocates but also to change the way professionals and service providers regarded people with an intellectual disability.

The findings showed that self-advocates were comfortable with the way in which the activities and offices of their organizations were administered and the opportunities for assuming a business-like identity that went with this. They clearly understood its significance in enhancing their engagement with life and developing

self-confidence. Whilst many authors, including Redley & Weinberg (2007), Hall (2004), Hall (2005), Laws & Radford (1998) and Ward (1988), are critical of the kind of social integrationist discourse that sees economic participation as a panacea for social exclusion, the findings in this study point to the great sense of satisfaction self-advocates derived from their adoption of a business-like identity. They understood the high social value placed on being a worker by the broader community and eagerly embraced its inclusive implications.

Opportunities to express opinions and preferences in the context of the self-advocacy group were significant in giving people a sense of independence they had not experienced before. For some, this had led to new possibilities such as living more independently or involvement in community activities. For others, independence took the form of feeling more comfortable being out and about in the community and using public transport or social spaces like pubs and cafes. The examples of independence in the findings are significant in the context of the highly constrained lives and controlled environments with little if any chance for self-determination that many of the self-advocates had lived, or still lived in.

### Subtle radicalism? Eroding negative community perceptions about people with intellectual disabilities

These findings show that possibilities for self-advocates to assume more positive, included identities were produced without overtly radical roots. A subtle emerging political agenda worked to alter, albeit slowly, deeply held community perceptions of people with intellectual disabilities. Whilst much of the activity in the groups looked inwards, focussed on skills and personal development of individual members, there was a strong sense of this being undertaken with an important purpose. These personal development agendas sought to prepare people to live happier and more included lives in a society that disabled them through negativity and low expectations of their capacity. This was indeed the type of ‘radical meaning-making’ referred to by Goodley (2005) but lacking the kind of urgency and overt character that he and authors like Aspis (1997, 2002) might wish for. Characterizing idealized groups as working within a ‘rubric of sovereignty’, that promotes identification as a member of a disempowered group, Clifford (2013) argued that commentators would be ‘dissatisfied’ with what they observe in self-advocacy organizations. However, like

Clifford (2013, p. 5), this study found that a closer look revealed that the self-advocates in all six groups had reframed empowerment in a highly personal way and in so doing offered ‘...an engaging and highly dynamic vision of political action’.

The social model of disability (Rioux & Bach 1994; Oliver & Barnes 1998) underpinned the activities of the self-advocacy groups in this study. However, they challenged deficit focussed disability models in a highly personal way that at first glance does not look radical at all. 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, enabling them to embrace multiple, more positive and included identities that had the potency to subvert broader community perceptions of what lies beneath negative labels. This kind of outcome does not fit comfortably within some 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.

## Conclusion

The findings from this study support the view that self-advocacy ‘can be a pathway to empowerment’ (Miller & Keys 1996) and offers many supportive examples. 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 spillover effects in changing the way that they are perceived in the broader community and 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 *et al.* 2009 drawing on Moscovici *et al.* (1976)]. A challenge for research and policymakers is to understand further the conditions that enable independent self-advocacy groups to flourish. This involves questions about how best to develop capacity to ensure skilled support is available to self-advocacy groups and how to deliver core funding that ensures continuity of support and avoid the type of stop-start funding that renders them vulnerable to being used to serve the agendas of others (Bigby 2015).

Social identity theorists like Tajfel (1978, 1981) and Turner (1982, Turner *et al.* 1987) argue that it is difficult for people to whom negative social identities are attached to reclaim and develop more positive ones. The findings of this study of self-advocacy group members show that members resisted wearing as Shakespeare (2006) describes the ‘badge’ of activist, or the ‘label’ of a person with an intellectual disability, in spite of their clearly articulated sense of group ownership and collegiality towards the other members and supporters. By rejecting the ‘label’ with all of its stigmatizing connotations and the ‘badge’, with its collective identification and activist imperative, the self-advocates in this study had found an important space in which to build their own individual, more positive and included social identities. Darren from Indigo group, when asked to describe what members gained from engagement with his self-advocacy group remarked, ‘We just help them, be them really’. His beautifully understated description of significant personal transformation sums 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.

## Correspondence

Any correspondence should be directed to Sian Anderson, Living with Disability Research Centre, La Trobe University, Bundoora, Vic. 3065, Australia (e-mail: [sian.anderson@latrobe.edu.au](mailto:sian.anderson@latrobe.edu.au)).

## References

- Amado A. (2014) Building relationships between adults with intellectual disabilities and community members: strategies, art, and policy. *Research and Practice in Intellectual and Developmental Disabilities* 1, 111–122.
- Aspis S. (1997) Self-advocacy for people with learning difficulties: does it have a future? *Disability and Society* 12, 647–654.
- Aspis S. (2002) Self-advocacy: vested interests and misunderstandings. *British Journal of Learning Disabilities* 30, 3–7.
- Atkinson D. (2002) Self-advocacy and research. In: *Advocacy and Disability* (eds B. Gray & R. Jackson), pp. 120–149. Jessica Kingsley, London.
- Barnes C., & Mercer G. (2006) *Independent futures. Creating user-led disability services in a disabling society*. Bristol, The Policy Press.

- 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, 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, 91–100.
- Beresford P. (2012) The theory and philosophy behind user involvement. In: *Social Care, Service Users and User Involvement* (eds P. Beresford & S. Carr), pp. 21–37. Jessica Kingsley, London.
- Bigby C. (2008) Known well by no one. Trends of the informal social networks of people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability* 33, 148–157.
- Bigby C. (2015) *Self-Advocacy and Inclusion: A Summary of the Study 'What Can Be Learned from Speaking up Over the Years'*. La Trobe Living with Disability Research Centre, Bundoora.
- Bigby C. & Frawley P. (2010) *Social Work Practice and Intellectual Disability*. Palgrave Macmillan, Basingstoke.
- Blumer H. (1969) *Symbolic Interactionism. Perspective and Method*. Prentice-Hall Inc, Englewood Cliffs.
- Booth T. (1996) Sounds of still voices: issues in the use of narrative methods with people who have learning difficulties. In: *Disability and Society: Emerging Issues and Insights* (ed. L. Barton), pp. 237–255. Longman, London.
- Bradley V., Ashbaugh J. & Blaney B. (eds) (1994) *Creating Individual Supports for People with Developmental Disabilities. A Mandate for Change at Many Levels*. Paul H. Brookes Publishing, Baltimore.
- Butera F., Levine J. & Vernet J.-P. (2009) Influence without credit: how successful minorities respond to social cryptomnesia. In: *Coping with Minority Status. Responses to Exclusion and Inclusion* (eds F. Butera & J. Levine), pp. 311–332. Cambridge University Press, New York.
- Caldwell J. (2010) Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research* 54, 1004–1014.
- Chappell A., Goodley D. & Lawthorn R. (2002) Making connections: the relevance of the social model of disability for people with learning difficulties. *British Journal of Learning Disabilities* 29, 45–50.
- Charmaz K. (2000) Grounded theory: objectivist and constructivist methods. In: *Handbook of Qualitative Research*. 2nd edn (eds N. Denzin & Y. Lincoln), pp. 509–536. Sage Publications Inc, Thousand Oaks.
- Charmaz K. (2006) *Constructing Grounded Theory. A Practical Guide through Qualitative Analysis*. SAGE Publications Ltd, London.
- Clifford S. (2013) A narrative inquiry of a self-advocacy meeting: rethinking empowerment from sovereignty to spontaneity. *Disability Studies Quarterly* 33, 1–15.
- Davies C. & Jenkins R. (1997) 'She has different fits to me': how people with learning difficulties see themselves. *Disability and Society* 12, 95–109.
- Dudley J. (1997) *Confronting the Stigma in their Lives. Helping People with a Mental Retardation Label*. Charles C Thomas Publisher Ltd, Springfield.
- Frawley P. & Bigby C. (2015) Reflections on being a first generation self-advocate: belonging, social connections and doing things that matter. *Journal of Intellectual and Developmental Disability* 43, 254–264. doi:10.3109/13668250.2015.1028910.
- Gibbons F. (1985) Stigma perception: social comparisons among mentally retarded persons. *American Journal of Mental Deficiency* 90, 98–106.
- Goffman E. (1961) *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Penguin Books, London.
- Goodley D. (2000) *Self-Advocacy in the Lives of People with Learning Difficulties*. Open University Press, Maidenhead.
- Goodley D. (2003) Against a politics of victimisation: disability culture and self-advocates with learning difficulties. In: *Disability, Culture and Identity* (eds S. Riddell & N. Watson), pp. 105–131. Pearson Education, Harlow.
- Goodley D. (2005) Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities* 9, 333–343.
- Goodley D., Armstrong D., Sutherland K. & Laurie L. (2003) Self-advocacy, "learning difficulties", and the social model of disability. *Mental Retardation* 41, 149–160.
- Hall E. (2004) Social geographies of learning disability: narratives of exclusion and inclusion. *Area* 36, 298–306.
- Hall E. (2005) The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health and Place* 11, 107–115.
- Harris J. & Roulstone A. (2011) *Disability, Policy and Professional Practice*. SAGE Publications, London.
- Hubert J. (2000). The social, individual and moral consequences of physical exclusion in long-stay institutions. In: *Madness, Disability and Social Exclusion. The Archaeology and Anthropology of 'Difference'* (ed. J. Hubert), pp. 196–207. Routledge, London.
- Johnson K., Walmsley J. & Wolfe M. (2010) *People with Intellectual Disabilities. Towards a Good Life?*. The Policy Press, Bristol.
- Kozma A., Mansell J. & Beadle-Brown J. (2009) Outcomes in different residential settings for people with intellectual disability: a systematic review. *American Journal on Intellectual and Developmental Disabilities* 114, 193–222.
- Laws G. & Radford J. (1998) Place, identity and disability. In: *Putting Health into Place. Landscape, Identity, and Well-Being* (eds R. Kearns & W. Gesler), pp. 77–101. Syracuse University Press, Syracuse.
- MacIntyre G. (2008) *Learning Disability and Social Inclusion*. Dunedin Academic Press, Edinburgh.
- Moscovici S., Mucchi-Faina A. & Maass A. (eds.) (1994) *Minority Influence*. Nelson-Hall Publishers, Chicago.
- McNally S. (2002) A survey of self-advocacy groups for people with learning disabilities in an English region. *Journal of Intellectual Disabilities* 6, 185–199.
- Miller A. & Keys C. (1996) Awareness, action, and collaboration: how the self-advocacy movement is

- empowering for persons with developmental disabilities. *Mental Retardation* **34**, 312–319.
- Milner P. & Kelly B. (2009) Community participation and inclusion: people with disabilities defining their place. *Disability and Society* **24**, 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*. Jessica Kingsley, London.
- Morse J., Stern P., Corbin J., Bowers B., Charmaz K. & Clarke A. (2009) *Developing Grounded Theory. The Second Generation*. Left Coast Press Inc, Walnut Creek.
- Nind M. & Seale J. (2009) Concepts of access for people with learning difficulties: towards a shared understanding. *Disability and Society* **24**, 273–287.
- OECD (2010) *Sickness, Disability and Work: Breaking the Barriers: A Synthesis of Findings across OECD Countries*. OECD Publishing, Paris.
- Oliver M. & Barnes C. (1998) *Disabled People and Social Policy: From Exclusion to Inclusion*. Addison Wesley Longman, Harlow.
- Poetz C. (2003) Reflections on 30 years of involvement in self-advocacy. *Journal of Intellectual and Developmental Disability* **28**, 84–86.
- Redley M. & Weinberg D. (2007) Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment. *Sociology of Health and Illness* **29**, 767–786.
- Rioux M. & Bach M. (eds) (1994) *Disability is not Measles*. L'Institut Roehar Institute, North York, ON.
- Rodwell M. (1998) *Social Work Constructivist Research*. Garland Publishing Inc./Taylor Francis, New York.
- Shakespeare T. (2006) *Disability Rights and Wrongs*. Taylor and Francis Routledge, London.
- Söder M. (1989) Disability as a social construct: the labelling approach revisited. *European Journal of Special Needs Education* **4**, 117–129.
- 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: *Advocacy and Learning Disability* (eds B. Gray & R. Jackson), pp. 137–151. Jessica Kingsley, London.
- Tajfel H. (ed.) (1978) *Differentiation between Social Groups. Studies in the Social Psychology of Intergroup Relations*. Academic Press Inc., London.
- Tajfel H. (1981) *Human Groups and Social Categories*. Cambridge University Press, Cambridge.
- Turner J. (1982) Towards a cognitive redefinition of the social group. In: *Social Identity and Intergroup Relations* (ed. H. Tajfel), pp. 15–41. Cambridge University Press, Cambridge.
- Turner J., Hogg M., Reicher S. & Wetherell M. (eds) (1987) *Rediscovering the Social Group. A Self-Categorization Theory*. Basil Blackwell, Oxford.
- Ward L. (1988) Developing opportunities for an ordinary community life. In: *An Ordinary Life in Practice. Developing Comprehensive Community-Based Services for People with Learning Disabilities* (ed. D. Towell), pp. 68–79. King Edward's Hospital Fund for London, London.
- Wolfensberger W. (1972) *The Principle of Normalization in Human Services*. National Institute on Mental Retardation, Toronto.
- Wolfensberger W. (1983) Social role valorization: a proposed new term for the principle of normalization. *Mental Retardation* **21**, 234–239.

Copyright of Journal of Applied Research in Intellectual Disabilities is the property of Wiley-Blackwell and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.