

Being a member of a self-advocacy group: experiences of intellectually disabled people

Accessible Summary

People with intellectual disabilities talked about how it felt to be a member of a self-advocacy group.

They felt their lives had improved and were more fulfilled as a result of being part of their self-advocacy group.

It is important that people know how self advocacy groups help people with intellectual disabilities

Summary

A phenomenological methodology was used to explore the lived experiences of belonging to a self-advocacy group for people with intellectual disabilities. Thirteen persons with intellectual disabilities who attend three self-advocacy day centre based groups in a city in the west of Ireland were the sample identified for the study.

Changes affected by self-advocacy group membership occurred in the day centres the self-advocating participants attended. In addition being a member of a self-advocate group was found to enhance the personal lives of the participants. Empowerment occurred for the participants' both at an individual and collective basis. The evidence produced suggests that opportunities should be provided for adults with an intellectual disability who are not attending day services to join self-advocacy groups in a community setting as there were clear benefits identified in this study from group membership. A recognition that service providers need to take on board the value that can result from self-advocacy groups was apparent. The need to conduct larger scale studies over larger geographical areas and longitudinal research in this area is highlighted.

Keywords: Empowerment, intellectual disabilities, lived experiences, self advocacy groups.

Introduction

Self-advocacy according to Buchanan and Walmsley (2006) is considered a phenomenon unique to the late twentieth century. It is important to note that now in the early twenty first century the concept of advocacy features prominently in community care strategy initiatives and policies with regard to service provision for people with intellectual disabilities.

Positive benefits have been reported for people with intellectual disabilities who belong to self-advocacy groups (Preston, 1998; McNally, 2003; Beart, et al, 2004). Stalker (1997) stated the benefits include feeling more confident, speaking up and asserting one's rights. Beart et al (2004) claims this change in self concept occurred when members gained new roles and responsibilities that gave them a feeling of status as well as friendship and support.

Goodley (2000) stated that concerns have been raised about service system models of self-advocacy constraining the development of "real" self-advocacy in that the group concentrates on the service centres matters as opposed to real self-advocacy issues about their personal lives. However, Stalker (1997) suggests that adults with intellectual disabilities should have opportunities to participate in self-advocacy groups in service settings considering this is where a large number of people spend their day.

McNally (2003) claims that an advantage of a self-advocacy group being based in a service setting is ease of access to recruitment of members and availability of resources. The disadvantages are the potential for conflict between the group and facilitators who are usually staff. Another negative aspect of centre based advocacy groups is that they do not advocate for members of the intellectually disabled population who do not attend the service centres and thus they are advocating for a circumscribed group.

A concept closely integrated with self-advocacy in fact it might be considered an outcome to positive self-advocacy, is empowerment. The essence of empowerment as stated by Stainton (2005) is about enhancing, securing and legitimating the power of oneself, another or collectively. There are strong links between empowerment, choice and self-advocacy as each offer opportunities for people with intellectual disabilities to exert control over their lives (Henderson and Pochin, 2001; Wehmeyer and Garner, 2003).

In reality however, Brandon (2005) alludes to the fact that people with an intellectual disability may be given choice but are less often involved in the construction of such choices. He suggested that we should be concerned with how choices are made not what choice is made. Nevertheless, Stalker (1997) and Preston (1998) indicated that there was evidence to suggest that self-advocacy groups helped to foster greater self esteem and more confidence in making choices among members. McNally (2003) highlighted the significance members of self-advocacy groups placed on choice making. An example of choice is the labels used to refer to intellectually disabled people as is demonstrated by the Author's use of the term "People with intellectual disabilities". Goodley (2005) provides an example of self-advocacy, empowerment and choice making by the self-advocacy movement. The common choice of People First as their identified group name and their slogan "label jars not people" has challenged professional's use of labelling.

However, it should be kept in mind that there can be drawbacks to any group taking power. For example, Jackson (1999) suggested that what is not widely appreciated is that if one group in society is empowered then another must be disempowered. Jackson (1999) suggests an inevitable consequence of achieving empowerment for a person with an intellectual disability is professional disempowerment. However, this need not be seen as negative as in the past professionals have been perceived to hold too much control over the lives of intellectually disabled people. In fact, many professions are deeply committed to enhancing the empowerment of persons with an intellectual disability by working in partnership with the individual and their families in meeting their diverse and sometimes complex needs. However, some professionals may also wish not to relinquish power and control. Such professionals should examine their own practice with regard to the power and control they exert in their day to day involvement with people with intellectual disability.

Beart et al (2004) in a study of self-advocacy groups found that learning to self advocate was an important factor in the lives of all the participants.' This was also reflected in McNally's (2003) survey of self-advocacy groups. Stalker's (1997) case study on a self-advocacy group revealed that despite the structural constraints of the organisation the members of the group could exercise choice although they had limited power to challenge major service issues. A number of studies report that self-advocacy can enhance self-confidence and other positive outcomes (Stalker,1997; Booth and Booth, 1999; Beart et al, 2004).

Goodley (2005) portray life stories that support the positive influences on the family that can result when a family member with an intellectual disability self-advocates. Indeed Gray and Jackson (2002) suggest that the keenest advocates of person's with an intellectual disability have been a parent who's effort to gain a stronger and louder voice have played a significant part in the growth and acceptance of advocacy services.

The importance of evaluating the human impact of advocacy on people's lives is emphasised by Rapaport et al (2006). Yet in a review of the literature for the study reported here it was established there has been no research undertaken with self-advocacy groups for people with intellectual disabilities in Ireland. Bearing this in mind and considering the increased growth of self-advocacy groups for this population in Ireland today, justification is warranted to undertake a study to explore the lived experiences of belonging to a self-advocacy group for a person with an intellectual disability.

Aims of the study

The aim of this study was to explore the lived experiences of belonging to a self-advocacy group for a person/s who have an intellectual disability. This aim was achieved by investigating the following research questions.

How does a purposive selected sample of people with an intellectual disability feel about being a member of a self-advocacy group?

What are the salient experiences of the selected participants in their day-to-day lives that can be attributed to membership of a self-advocacy group?

Are the experiences of self-advocacy reported by these participants reflected in previously reported literature?

In addition the study aimed to make recommendations based on the findings that relate to the need for services to recognise the sensitivities of self-advocacy and what future research and potential training/education issues might emerge.

Study Design

Methodology

A phenomenological approach was considered the most appropriate methodology to meet the aims of the study. Parahoo (2006) states that phenomenology as a philosophy stresses that only those that experience phenomena are capable of communicating them to the outside world. The research was concerned with the lived experience of the participants thus supporting the rationale for employing a phenomenological approach.

Sample

In this type of study the actual numbers to be interviewed are usually not specified beforehand and it is common to interview until saturation is reached. Saturation as explained by Polit and Beck (2004) is when a point is reached in the data collection stage of the research where no new information can be gleaned by further data collection. This process led to 13 people with an intellectual disability (participants) being interviewed for the study. The participants ranged in age from 32 to 60 years of age and they resided in a city in the West of Ireland. These individuals live at home with their families or in community group homes and attend three local day services on a daily basis. Each of the three day services had a service user self advocacy group established that was supported by an independent facilitator. Two of the groups met on a weekly basis and one group met on a fortnightly basis. All meetings were held in a designated room in each of the day services. The researcher had a service planning input that involved liaising with staff in the day centres but was not actively involved in any of the advocacy groups. The criteria applied for participation in the study was that each participant was a member of a self-advocacy group for a minimum of 6 months so that they would have adequate experience to draw on in interviews (Beart et al, 2004) and also have the ability to participate in an interview. The only exclusion criterion applied was individuals who did not possess the ability to participate in an interview.

Data collection

Semi-structured interviews were used to collect data from all participants' and the interviews were audio taped in order to ensure all data generated was accurately captured. All participants' were offered the opportunity to have someone else present at the interview and

two participants' took up this offer and requested a member of staff be present, which was arranged.

Data analysis

The audio taped interviews were typed verbatim into transcripts on a computer. They were then analysed using Colaizzi's (1978) seven-stage process of analysis as follows.

- 1) The researcher read the participants' narratives to acquire a feeling for their ideas in order to understand them.
- 2) Words and sentences related to the phenomenon under study were extracted resulting in the identification of significant statements.
- 3) Each significant statement was then formulated into meaningful extracted comments.
- 4) The analysis process for each description from the participants' was then repeated and arranged into clusters that ultimately became themes.
- 5) Then all the resulting ideas/themes were integrated into an exhaustive description of the phenomenon.
- 6) The exhaustive descriptions were then reduced to an essential structure, which is an unequivocal statement of the expressed experiences of the participants as seen within their world.
- 7) The final stage involved returning to the participants' in the research for a further interview to elicit their views on the findings and to evaluate them.

It is important to note with respect to the last stage of Colaizzi's (1978) seven-stage process of analysis that in this study it was not feasible to return to all thirteen of the participants' given the specified timeframe allocated to the study. Therefore five participants' were returned to for a subsequent interview related to the findings from the analysis. All of the five participants' agreed the findings.

The analysis was undertaken by author one and as a reliability and validity (truth-value) check the second author undertook a similar analysis on the data. Both analyses, which concurred, together with stage 7 in the analysis process followed i.e. member checking indicated the findings had a high degree of truth value (validity) and consistency (reliability).

Ethical considerations

Ethical approval was sought before commencement of the study from the local Research Ethics Committee in the area where the research participants were selected. Approval was granted by the committee before the study proceeded.

The issue of consent was an important ethical consideration for this research. The Ability to Consent Questionnaire, Arscott et al (1999), (cited in Dye et al, 2007) was employed in the study. This questionnaire was developed by Arscott to assess the ability of people with intellectual disabilities to consent to participate in a research study. A consent passage adapted from Dye et al (2007) was presented to the proposed participants and all of the participants' demonstrated the ability to consent and this was documented. As part of the informed consent process the participants' were assured that their information would be kept confidential.

Speziale and Carpenter (2007) state that sensitive issues may arise in research conducted with vulnerable populations such as people with intellectual disabilities. Provisions were made in this study for the service providers to provide appropriate follow up to participants' if the need arose, however this was not required in the study.

Study Rigour

Endeavouring to improve the credibility of this study included allocating sufficient time with each participant during the interview process, ensuring they clearly understood the questions while also providing adequate time for them to give their responses to the questions.

Confirmability was achieved in the study by ensuring consistent use of bracketing as suggested by Speziale and Carpenter (2007). Polit and Beck (2004) refer to bracketing as identifying and holding in abeyance preconceived beliefs and opinions about the phenomena under study. Bracketing can be difficult to achieve as (Koch, 1995, p.833) states "one cannot separate description from one's own interpretation ." Polit and Becks (2004) acknowledge that

although bracketing can never be achieved totally, researcher's bracket any presuppositions they have to the best of their ability. The concept of bracketing was applied during the data collection and data analysis stages of this study. The researcher attempted to achieve this by being astutely aware of personal bias related to certain topics as they emerged in the study. Recognition of this fact ensured that personal beliefs and opinions of the researchers did not affect the process in as far as this was possible. Returning to some of the participants with the analysed data was also a means of enhancing the truth-value of findings.

Results

Descriptions from the participants' were arranged into two main categories: "*functioning as a group*" and "*impact of group membership on personal lives.*" The topic of functioning as a group had five subcategories namely, asserting self, role of members, interactions between members, affecting change, decision making and help with meetings. Similarly the impact of group membership had six subcategories; empowered, personal identity, learning about self-advocacy, perception of treatment of others, accepting current position and helping others.

Functioning as a group

Asserting self

All thirteen participants' referred to speaking out at meetings. There was evidence that group membership facilitated this process in that participants' felt supported and comfortable to express their views and opinions. Participant 10 referred to the fact "*You can speak about things maybe that you would not normally speak about outside of the meeting because anything discussed at the meeting does not go outside the meeting.*" This statement reflects similar findings from advocacy support group of parents with intellectual disability as described by Booth and Booth (1999) whereby the process of individuals sharing experiences with their group created the opportunity for showing mutual support among members.

Affecting Change

The process involved in affecting change appeared to be as important to the participants' as the affect of change itself. This finding is supported by previous research undertaken by Stalker (1997) on a self-advocacy group." Evidence of this was provided by participant's 2

account of writing a letter on behalf of her self-advocacy group to the local authority regarding inadequate outside lighting and the frequency and speed of traffic passing by the day service. She stated the group decided she would write a letter outlining their concerns. When asked how she felt about writing the letter, she said *“It was great the encouragement and getting the experience of doing something like that.”* The emphasis the participants’ placed on the process itself was again referred to by participant 11 when he related the measures his self-advocacy group took when seeking the installation of a water machine at the day service for service users. He recalled:

“We went around and asked everyone in the centre we’d get names down; we couldn’t go to the manager without talking to everybody in the centre to see what they think about it. It had to go to the head office you know. When we put our minds to it we got it. It was great the day the machine arrived.”(P.11)

When participants’ were asked would there be anything that you would like to change about the self-advocacy group? The following responses were given:

“I suppose we would like if there could be a lot more done for the service users. Maybe if it was brought at Government level if there were more staff workers to help the service users maybe bring them out more. Participant 7 stated “I’d like to see people get new simple jobs from the centre here.” Skelton and Moore (1999) concur with this view by stating that sufficient numbers of people with intellectual disabilities exist who want to increase the quality of their lives through participation in work and therefore better mechanisms needs to be put in place to facilitate this.

Decision making

For some participants the opportunities the group provided for them to make choices were demonstrated by their greater sense of self-determination and autonomy in their lives. This view is supported by Wehmeyer and Garner (2003) who outlined, that there is a connection between the ability to make meaningful choices and self-determination. When the participants’ were presented with a question relating to how the group decide on what it is going to do? Participant 4 said *“we decide ourselves.”* Participant 12’s answer encapsulates

the general response of the majority of participants' stating "*well they talk about it first and then probably some people ask questions and then we decide.*"

Some participants' alluded to a clear recognition of the important role that their centre's manager and their group facilitator had in relation to decisions made by the self-advocacy group that were considered by participants' as out of their control. This could be interpreted as the organization interfering in the group's affairs by exerting a certain element of policing and control over the group's decision making process. However, it could also be viewed that the participants' were adopting, in their own way, a pragmatic approach when making choices related to complex issues by recognising the need to involve the relevant individuals who they feel have the necessary skills, competence and power to assist them in making the right decision. This view is supported by Harris (2003) who stated when seeking to promote choice and decision making for people with intellectual disabilities, opportunities should be created to enhance and extend the supports available in social settings.

The following excerpts from participants illustrate this point. Participant 13 referred to the fact that when a decision was made by the group they would "*take it to the boss man*" and participant 12 stated that "*Well if there is a big issue came up, let's say something connected with money or allowances, I mean we wouldn't be able to take that on ourselves. So you would have to go to the manager.*" Participant 7 highlighted "*the facilitator would call a meeting and we would settle it and ever since she's done that everything is A.I.*"

Help with meetings

In this study the findings indicated that the independent facilitator made an enormous contribution to the self-advocacy groups. All thirteen participants' comments reflected positively on the support and help the group received from the facilitator e.g. "*I find it very good help actually.*" The groups in this study appear to have adopted an interdependence model in the relationship that has developed between participants' in the self-advocacy group and the group facilitator. Such a model is described by Tsuda and Smith (2004) as one where

the members of the self-advocacy group and the group facilitator are seen as partners and the partnership is seen to last over time in building the group.

Role of members

It was clear that the participants' developed a sense of status, as suggested by Beart et al (2004) emanating from the involvement with their self-advocacy group. It was evident from the findings that participation in their self advocacy group helped to foster an increased level of confidence and self esteem among all members. Previous research also found this to be the case (Stalker, 1997). An example of this in the study reported here is Participant 1, 12, 13 who conveyed their experiences of being in the advocacy group:

“ It’s helping us you know. Its really good therapy for us all.(P.1). I think it’s a good thing to speak up for yourself rather than people talking up for you. (P.12)

“It has done a lot for us unless you speak up nobody will know what you are thinking. (P.13)”

Interaction among members

The findings indicated there was a general consensus among members that they interacted and related well with each other. Goodley (2000) also alluded to the fact that at times group dynamics of self-advocacy groups can be complex and difficult. This was evident in this current study in that participants' indicated that nerves can become fraught and tensions rise when some member's behaviour become irritating for other members of the group.

Participant 1 explained *“You get some people that can be looking for notice or attention, but you get that everywhere.”* When asked how she felt about that she replied *“I’m well used to it”* She believed the most appropriate way to deal with this type of behaviour was to *“just talk to them, if they’re not well you should talk to the staff, they can help them.*

Impact of group membership on personal lives

Empowered

The opportunities presented to participants' in this study to meet with other groups, attend and speak at conferences, participate in training courses for developing self-advocacy skills, and learn about their rights and entitlements contributed to their personal development. The skills and knowledge they acquired was evidenced by the experiences they choose to share in the course of their interviews. This empowerment occurred for the participants' both at an individual and collective level. One participant sums up his recognition of the importance and significance of meeting other people from other self-advocacy groups on a national basis by asserting that:

“Yes it seems like we weren't alone. It was an important thing to see how other people feel. We picked up an awful lot from other people around other centres.” (P.11)

The self-advocacy group affirmed the person-hood of many of the participants' empowering them to feel they could speak out and more importantly that they are listened to. Four participants' reported they had undertaken a course in self-advocacy that was delivered externally to their normal centre based activities. The four individuals expressed favourable views about this experience indicating that it had a positive impact on their lives Participant 6 stated:

“It was absolutely amazing it opened our eyes to a lot of things. There were a lot of things now going back a couple of years ago that we were not able to do and have our rights. Now everybody has a right of their own.”(P.6)

Personal identity

Participant 7 felt membership of the self-advocacy group increased awareness of her personal identity *“It has made me more aware of who I am.”* She indicated that the self-advocacy group assisted her in gaining a deeper insight into her strengths and weaknesses. Recognition

of this fact has prompted this participant to prioritise an area in her life that she has identified as requiring further development. This can be seen in the following statement:

I can do more for myself ...be more independent ... I wanted to learn ... more to do with my money, to do with writing and reading but ... X (the facilitator) is getting me there.”(P.7)

Expanded social networks

This theme emerged in all interviews with the participants.’ When Participant 9 was asked how self-advocacy helped her she responded “*to get out with and mix with people that I like, my friends it’s very important to get on well with your good friends* Moore and Carey (2005) highlight the importance of creating opportunities for people with intellectual disabilities to develop friendships. Participant 1 indicated that membership of her self-advocacy group has expanded her social network of friends outside the day service; she stated “*I like to meet up with them for a chat and a cup of coffee some Fridays and Saturday in town.”*

Perception of treatment by others

Participant 13, while reflecting on issues that were discussed in her self-advocacy group referred to her perception of how she felt she was not treated well by people. Indeed Clegg et al (2008) refers to the fact that people with intellectual disabilities can encounter problems that stem from being viewed as “others.” Participant 13 stated that she had experience of people not listening to her. When asked why did she think that was the case? She replied:

“People are so wrapped up in themselves people are selfish now people don’t want to know you now as simple as that.”(P.13)

When participant 13 was asked how she felt about that, the deep seated emotions she expressed was evident in her response:

“I feel angry and I feel hurt sometimes but what can you do you just have to make the best of it get on with it.”(P.13)

These people's attitudes and behaviour she interpreted stem from their own limited understanding and knowledge into the abilities and strengths of person's with intellectual disability

"The way people will treat you, it's where they're at in life, its true now, its not only us like, its everywhere in life."(P.1)

The grim reality of the effects such behaviour has on the lives of people with an intellectual disability in terms of the feelings of hurt and rejection was highlighted in the findings. The participants' ability to transcend these difficulties demonstrates the sheer resolute of this population. Goodley (2000) refers to this as the resilience of people with intellectual disability.

Acceptance of current position

Many participants' alluded to the fact that changes they request or require may take a considerable length of time or may not happen at all. Participant 13 indicated that *"most things do get sorted but some things don't."* She stated this makes her feel angry but *"you can't do anything much you just let it go."* Such delays led participants' to feel frustrated and disempowered. The following excerpt illustrates participant 11's frustration and helplessness when changes suggested in his self-advocacy group doesn't occur.

"It feels like it's a waste of time, it feels like one thing that you think to yourself ah God why am I doing this. Why am I trying to push something when nothing happens?"(P.11)

The views expressed by participant 4 suggest that participants' tend to accept they may have to wait a long time before change *"It could be a year or it could be a while before it happens. We don't mind waiting but we have to wait you know"* (expressed wearily). It is important for practice that there is an awareness and understanding among service providers and supporters of self-advocacy groups of the impact on the personal lives of people with intellectual disabilities who sometimes are forced into accepting that they cannot collectively affect real change for their members.

Helping others

It is the collective response of the group that ensures that others, who cannot speak for themselves are represented. It was apparent in this study that interdependence existed among members whereby some members, as stated by Goodley (2000), were able to draw on the skills and abilities of others in their group when the need arose. The sensitivity participants' conveyed to their peers in their groups is demonstrated in the following excerpt taken from an interview.

“X might get annoyed over things you have to write something down in a note book. That helps her... I have to write a note out to her house. She does calm down a bit then.” (P.3)

Implications for the future

Supporting self-advocacy group initiatives from a service provider's perspective has the potential to contribute positively to person centred approaches by enabling persons with intellectual disabilities to individually and collectively experience membership of such groups. It is also important that service providers, health and social care professionals, and families develop an awareness and understanding of the impact of membership of self-advocacy groups for persons with intellectual disability.

Future research on self-advocacy groups incorporating a larger urban rural spread may illuminate a much broader perspective on this phenomenon. It may also be considered useful if a longitudinal study was undertaken with this target group to determine the long term impact, or lack of impact, of membership of self-advocacy groups over time.

Opportunities should be provided for adults with an intellectual disability who are not attending day services nor have involvement with services to join self-advocacy groups in a community setting. Service provider support will be necessary in order to address the practicalities of setting up these groups.

Conclusions

Employing a phenomenological approach to the study enabled and enhanced the ability of participants' to participate in inclusive research. An insight and understanding of the participants' lived experiences as members of self-advocacy groups was illuminated. The findings of this research echo similarities to the results of previous studies by demonstrating that membership of the group promoted and enhanced the participants' personal development. A greater sense of self-determination and autonomy was evident in the participants' lives by the opportunities afforded to the self-advocacy group members to make choices. Empowerment occurred for the participants' and recounted how they perceived a positive change in their own personal identity. There are messages from the expressed life experiences of these participants that indicate how important and valued self-advocacy groups are. Such groups have the potential to empower the un-empowered and in so doing make real differences to peoples lives. Services need to listen to the voices of these intellectually disabled people and carefully consider the need to roll out of self-advocacy groups across all services.

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