The psychological and social impact of self-advocacy group membership on people with intellectual disabilities: A literature review

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Abstract

Background: There is no one agreed definition of self-advocacy, but it can be taken to include actions and concepts such as standing up for one's rights and self-determination.

Method: A review of studies examining the psychological and social impact of self-advocacy group membership on people with intellectual disabilities was conducted. Systematic searches of electronic databases (PsycINFO, Scopus, Web of Science and ProQuest's Sociology Database), together with manual searches of reference lists and citations, identified 12 studies all of which used a qualitative methodology.

Results: The most frequently reported outcomes were 'empowerment' and the associated outcome of 'increased confidence'. 'Belonging' and increased opportunities for social connections were also key themes in the literature. A final key outcome was changed self-identity, which appeared to be associated with changes to activities and occupations.

Conclusions: Limitations of the review included difficulty categorising outcomes. Limitations of the evidence base included a lack of quantitative studies making it difficult to assess outcomes. Implications of the review include an observation that the literature has focused on self-advocates lived experiences via qualitative interviews; this role in research could be extended to co-construction of research agendas with self-advocates.

1. Introduction

Despite increased physical integration and improvements in service provision and societal views, people with intellectual disabilities continue to experience social exclusion and marginalisation, often with limited engagement in employment, social relationships, and leisure pursuits of their own choosing. Through speaking and standing up for themselves and others with intellectual disabilities and their rights, self-advocacy by people with intellectual disabilities aims to redress inequalities and discrimination, and has been described as a social movement (Beart, Hardy & Buchan, 2004). This is echoed in Anderson and Bigby's (2017) description of self-advocacy groups and networks, such as People First, as the main avenue for collective action of people with intellectual disabilities and their connection with the broader disability rights movement. Self-determination, having a say in decisions that affect one, is central to self-advocacy (Wehmeyer & Abery, 2013). Self-advocacy within the intellectual disability field seems to have been recorded first in the late twentieth century, with organisations such as People First in the UK or Reinforce in Australia starting in the 1980s (Anderson & Bigby, 2017; Barnes & Walmsley, 2006). In contrast, self-advocacy by people with physical disabilities can be traced back to the nineteenth century (Campbell & Oliver, 1996).

Crawley (1990) set out a typology of self-advocacy groups, focusing on their constitutional and structural facets. Firstly, some self-advocacy groups are politically, financially and organisationally 'autonomous', e.g. the People First movement. Secondly, some groups developed out of existing, professionally- or parent-led organisations (e.g. Mencap in the UK, or FUB in Sweden, Mallander et al., 2018). Thirdly, some groups follow a 'coalition model' which is affiliated with wider disability civil rights organisations (e.g. citizen advocacy). Finally, some groups continue to be 'service-based' (e.g. within day centres or clinical services).

To appreciate the current impact and positioning of self-advocacy groups, Goodley (1997) argued that they must be considered in the context of wider societal and theoretical discourses about disability. In particular, the individual model of disability (which locates disability *within* the individual), gives rise to discourses of impairment and dependency which are in contradiction with the values of self-advocacy (e.g. self-determination and capacity). It has been argued that self-advocacy is best understood and practised when it is grounded in a social model of disability (Oliver & Barnes, 1998), which attends to the ways society disables people with disabilities (e.g. through exclusion, discrimination and stigmatisation). The social model of disability focuses on the need for societal change and encourages contexts for the basic rights of self-expression and growth (Oliver & Barnes, 1998). Within this model, people given a disability label are seen as the most able people to explain the effects of a disabling society and self-advocacy is seen as a continually progressive and emancipatory activity (Goodley, 1997).

The current aims and effects of self-advocacy by people with intellectual disabilities have been studied at the individual, collective and public level. At the individual level, studies have looked at the impact of membership of self-advocacy groups on self-advocates themselves. For example, Anderson and Bigby (2017) found that engagement with self-advocacy groups provided members with access to collegiality, respectful relationships, interesting activities, a sense of ownership, and control. Some researchers (e.g. Goodley, 1997) have described a tension between self-advocacy as a means for *individuals* to 'speak up' and affirm their preferred identities, and self-advocacy as a *collective* movement representing the interests of a particular group. Others have focused on the importance of action and change at the public level resulting from self-advocacy, including a shift in power, with self-advocates influencing services and structures (Aspis, 2002). It has been observed that self-advocates can challenge stereotypes through such shifts in power and by having more control about the narratives that are told about people ascribed the label of intellectual disability. In this way, it is hoped that there are 'spillover' effects of self-advocacy groups in breaking down stigma associated with intellectual disability (Anderson & Bigby, 2017).

The impact of self-advocacy at the political level, and indeed the impact of policy and legislation on self-advocacy groups, has been considered. Some researchers have written about the challenges of government support which necessitates, to some degree, partnership between government and self-advocacy organisations which somewhat paradoxically aim to speak out against existing societal views and structures (Barnes & Warmsley, 2006). On the one hand, there is a responsibility on central government to foster inclusive values and create the conditions within which self-advocacy can develop. On the other hand, self-advocacy groups can become subject to the same conditions as other services, dominated by contracts, targets and imposed deadlines (Barnes & Warmsley, 2006). Limited and diminishing government funding and in many places a lack of explicit policy support has meant that remaining financially afloat rather than engaging in radical action has become a dominant theme for self-advocacy groups in recent years (Anderson & Bigby, 2017).

The current review aims to draw together the existing literature on the impact of self-advocacy group membership. The scope of the review is limited to psychological and social effects on self-advocates themselves. The review seeks to draw together the evidence on the range of effects of self-advocacy group membership and to consider the strength of the evidence base. This is important to enhance our understanding of self-advocacy groups and for informing future decision-making. Firstly, elucidation of what the positive effects of self-advocacy are may help evidence the need for continued support and funding. Secondly, highlighting the nature of these effects may help consideration of whether and how existing policy supports the conditions for these effects to occur. Moreover, it may inform changes to policy on how best to create the contexts for self-advocacy. Finally, it is hoped that the review will highlight any areas that have so far been neglected in research and therefore inform future research objectives.

1.1. Review questions

This review set out to address two questions:

1. What is the psychological and social impact of self-advocacy group membership on group members with intellectual disabilities?
2. What are future research directions that would advance the literature base?

2. Method

2.1. Search strategy

Figure 1 illustrates the search strategy and study selection process. The review is based on a search of the literature originally conducted in August 2017. The search was re-run in March 2019, with no new articles identified (some articles published in print in late 2017 had already been picked up in the earlier search). The electronic databases searched were PsycINFO, Scopus, Web of Science and ProQuest's Sociology Database. Search terms were used to identify articles pertaining to the key words: (i) intellectual disabilit* or learning disabilit*, (ii) self-advocacy, and (iii) psychological or social impact (search terms used: identity, sense of belonging, empowerment, self-esteem, confidence, mental health, wellbeing, engagement in community, and activism). The search terms regarding psychological and social impact were identified as key areas of interest in discussion between the first and second authors.

From the search of electronic databases, 350 articles exported to EndNote and 40 duplicates were removed, leaving 310 articles. After screening the titles for eligibility, 277 articles were removed, leaving 33 articles. After this stage, twenty additional studies were identified for potential inclusion in the review by searching for the term 'self-advocacy' on key journal websites (British Journal of Learning Disabilities; Disability and Society; and Journal of Applied Research in Intellectual Disabilities) and within the publications of a key researcher in the field, Christine Bigby. In March 2019, the websites of four further journals (American Journal on Intellectual and Developmental Disabilities; Intellectual and Developmental Disabilities; Journal of Intellectual and Developmental Disability; Scandinavian Journal of Disability Research) were searched for the term 'self-advocacy', and no further articles were identified.

2.2. Study selection

The above search and selection process yielded 53 articles in total. The abstracts and full texts of these articles were read, with consideration to the parameters of the current review, and therefore the inclusion and exclusion criteria listed below. After reading the abstracts and full texts of the 53 studies, 45 were excluded: 16 of the articles were excluded because they were discussion papers; twenty articles were excluded because they did not describe the impact of self-advocacy group membership (as the independent variable); three articles were excluded because the participants did not have intellectual disabilities; five articles were excluded because they did not report psychosocial outcomes; and one study was excluded because it was not publish in English. Finally, four further studies were identified from a manual search of the reference lists and citations of the eight eligible studies. This process resulted in 12 studies being retained which assessed the impact of self-advocacy group membership on people with ID.

The following inclusion criteria were employed when selecting papers to be included in the review: a) Papers were published in English, given the first language of the reviewer; b) Papers were published before August 2017, the time at which the search was conducted (as noted, a repeat search conducted in March 2019 did not identify any further articles for inclusion); c) Participants were described as having ‘intellectual disabilities’, ‘intellectual disability’, ‘learning disabilities’ or ‘learning disability’; d) Papers considered self-advocacy groups to be the independent variable; e) All designs were permitted in the current review, including experimental and retrospective designs; f) All methods were permitted in the current review, including quantitative and/or qualitative methods; g) Papers reported original data on any measure of impact or outcome of self-advocacy group membership.

The following exclusion criteria were applied when selecting papers: a) Participants had specific learning difficulties (‘dyslexia’, ‘dyspraxia’ and ‘dyscalculia’), as opposed to intellectual disabilities; b) Studies which investigated clinical interventions, i.e. group programmes or interventions in healthcare settings; c) Discussion papers.

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INSERT: Figure 1. Search strategy and study selection process

1. Results

The search identified 12 studies, all of which used qualitative methodologies. Four of the studies took place in the United Kingdom (UK), two in the United States (US), two in Sweden, one in Poland, one in Ireland, one in Australia, and one study had participants from both Australia and the UK. The earliest study took place in 2003, one in 2004, one in 2009, one in 2010, one in 2013, four in 2015, one in 2016 and two in 2017.

Three of the studies broadly focused on the lived experiences of belonging to a self-advocacy group. One stated its focus was on both the experience of belonging to a self-advocacy group and the influence on members' lives. Three of the studies looked at the effects and influence of self-advocacy group membership on social identity, social participation and social inclusion. One study specifically focused on the impact of engagement in a self-advocacy group on identity and daily life. The four remaining studies each had a specific focus, respectively looking at the impact of self-advocacy group membership on: leadership development, empowerment, change in organisational culture, and within a new (Swedish) welfare context.

Two of the studies did not report their sample sizes. Among the remaining ten studies, the sample sizes ranged from six to 53 self-advocates, with an average sample size of 19. Seven of the studies did not report how long the participants had been members of a self-advocacy group. Three studies' participants had been members of self-advocacy groups for at least six months; one study's participants had been involved in self-advocacy for more than 25 years; and one study recruited participants who had been identified as leaders in the self-advocacy movement.

Six of the studies collected data solely via semi-structured interviews; two used both semi-structured interviews and group interviews; one used observations of monthly group meetings; one used repeated interviews and observations of meetings; one used observations, semi-structured interviews and focus groups; and one study collected data via a postal survey. To analyse the data, five of the studies used (constructivist) grounded theory; two used thematic analysis; one used cooperative inquiry; one used a phenomenological methodology; one used an interpretative abductive approach; the survey study used narrative description of responses; and one study did not report how the data were analysed. See table 1 for an overview of the studies

Table 1. Samples, data collection and analysis methods of the studies

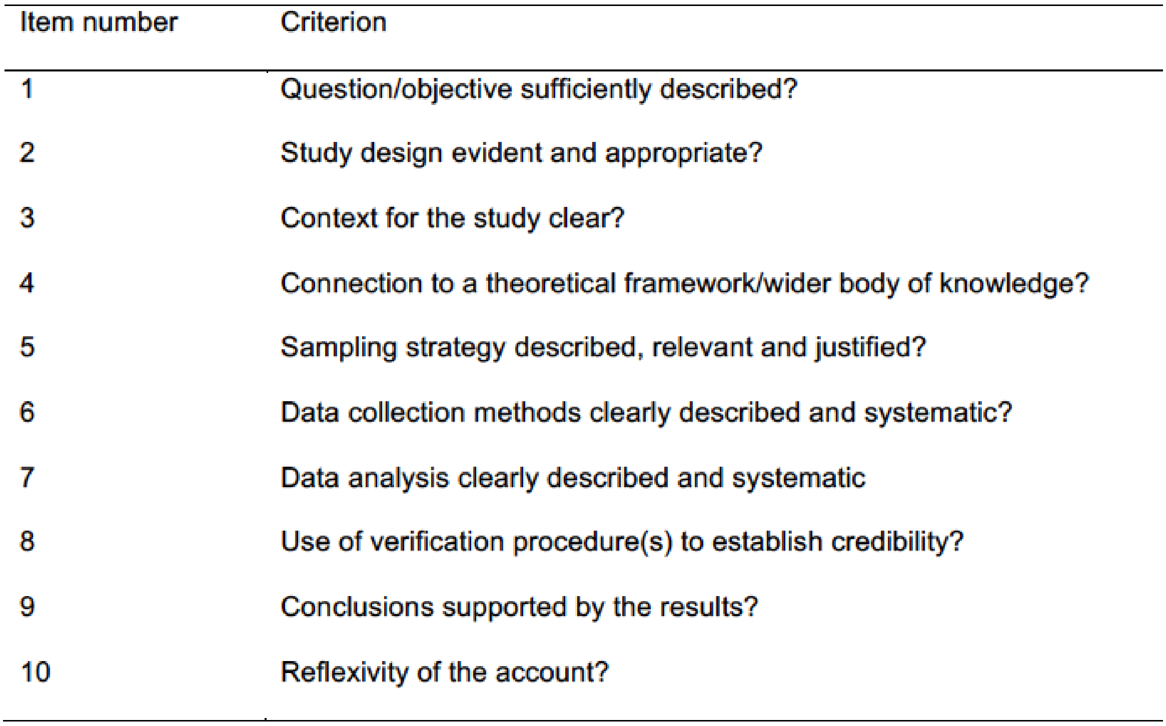
Authors (year)	Study focus	Location and Sample	Data collection methods	Data analysis
Anderson & Bigby (2017)	Effects of self-advocacy group membership on social identity	Australia and UK; 25 members from 6 self-advocacy groups	Semi-structured interviews	Constructivist grounded theory
Beart, Hardy & Buchan (2004)	Experience and individual impact of self-advocacy group membership	UK; 8 members involved in self-advocacy for at least 6 months	Semi-structured interviews	Grounded theory
Caldwell (2010)	Leadership in self-advocacy	US; 13 leaders in the self-advocacy movement	Semi-structured interviews	Grounded theory
Clarke, Camilleri & Goding (2015)	Experiences, benefits and difficulties, of being part of a self-advocacy group	UK; 6 members involved in self-advocacy for at least 6 months	Semi-structured individual and group interviews	Thematic analysis
Clifford (2013)	Acts of empowerment	US; A self-advocacy group observed over a two-year period	Observations of a monthly group meeting	Grounded theory
Frawley & Bigby (2015)	Reflections on being long-term members of a self-advocacy group and how membership influenced social inclusion	Australia; 12 members involved in self-advocacy for more than 25 years	Interviews	Thematic analysis
Gilmartin & Slevin (2009)	Lived experiences of belonging to a self-advocacy group	Ireland; 13 members from 3 self-advocacy groups based in day centres,	Semi-structured interviews	Phenomenological methodology

		involved in self-advocacy group for at least 6 months		
McNally (2003)	Experience of self-advocacy and its influence on self-advocates' lives	England; 53 self-advocates	Survey	Narrative description of responses
Miller (2015)	Impact of a self-advocacy group introduced to change organisational culture (openness and transparency)	UK; A monthly self-advocacy group in an inpatient, low-secure service for men with ID and mental health needs. Participants were group members, facilitators and staff.	Observations, semi-structured interviews and focus groups.	Not stated
Mineur, Tideman & Mallander (2017)	Impact of engagement in a self-advocacy group on daily life and identity	Sweden; 26 members from 6 self-advocacy groups	Semi-structured nterviews	Interpretative abductive approach
Tideman and Svensson (2015)	The significance of self-advocacy in a new (Swedish) welfare context	Sweden; 12 members of two self-advocacy groups	Repeated interviews and observations of meetings	Cooperative inquiry
Zyta and Ćwirynkało (2016)	Social participation and social identities	Poland; 18 members of self-advocacy groups	Semi-structured focus group interviews	Constructivist grounded theory

1.1. Quality rating of the studies

The QualSyst (Kmet, Lee & Cook, 2004) tool was employed to appraise critically the quality of the articles in this review. This tool assesses the quality of research articles of various designs and describes quality criteria for quantitative (14 items) and for qualitative (10 items) research articles. For the current review, the qualitative criteria were employed, see Table 2.

Table 2. QualSyst criteria for assessing quality of qualitative studies



Item number	Criterion
1	Question/objective sufficiently described?
2	Study design evident and appropriate?
3	Context for the study clear?
4	Connection to a theoretical framework/wider body of knowledge?
5	Sampling strategy described, relevant and justified?
6	Data collection methods clearly described and systematic?
7	Data analysis clearly described and systematic
8	Use of verification procedure(s) to establish credibility?
9	Conclusions supported by the results?
10	Reflexivity of the account?

Each article was scored on the 10 criteria, with possible item scores ranging from 0 to 2 (0 = No; 1 = Partial; 2 = Yes). Items include ratings of the sampling strategy, data collection methods and reflexivity of the account (see table 2 for full list of items). The scoring system has been shown to have good inter-rater reliability (Kmet et al., 2004). In order to increase the reliability of the ratings, a second reviewer used the QualSyst to independently rate 25% of the articles. Discrepancies between scores assigned by the primary and secondary reviewer were discussed and agreements reached before the primary reviewer scored the remaining articles. A total quality score for each article was calculated by summing individual item scores and dividing the sum by the possible total score (20). The ratings were used to provide some indication of the quality of the articles, although Kmet et al. did not provide cut-offs. Table 3 shows each article's scores and overall quality rating, the latter of which ranged from 0.4 to 0.9 (from a possible range of 0 to 1), with an average of 0.66, suggesting the quality of the articles was variable.

Considering the 12 studies altogether, the quality was highest in relation to the descriptions of the studies' questions, designs and contexts. For each of these three criteria, at least eight studies fully met the quality standard and the remaining studies partially met the standard. For each of the following criteria, approximately half of the studies fully met the quality standard: connection to a theoretical framework; use of verification procedures to establish credibility; and conclusions supported by the results. Approximately half of the studies fully met the quality standard for describing the data analysis and it having been conducted in a systematic nature.

Overall, the quality of the studies was weaker in relation to the descriptions and nature of the sampling strategies and data collection methods. Two studies (Caldwell, 2010; Mineur et al., 2017) fully met the quality standard for describing their sampling strategies such that they were clearly relevant and justified. Three studies (Beart et al., 2004; Caldwell, 2010; Clarke et al., 2015) fully met the quality standard for clearly describing systematic data collection methods. The quality of the studies was lowest in the area of reflexivity of the accounts. One of the articles (Caldwell, 2010) explicitly assessed the likely impact of the researcher's personal characteristics and the methods used on the data obtained. In three of the studies (Beart et al., 2004; Clifford, 2013; Gilmartin & Slevin, 2009), there was mention of possible sources of influence on the data, but the likely impact of the influences was not discussed. The remaining eight studies showed no evidence of reflexivity in the reports.

Table 3. Quality ratings using the QualSyst criteria for qualitative studies

Study	QualSyst criteria item scores (0=no, 1=partial, 2=yes)										Quality score
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	(0-1)
Anderson & Bigby (2017)	2	2	2	1	1	1	2	0	2	0	0.65
Beart, Hardy & Buchan (2004)	2	1	2	2	0	2	2	2	2	1	0.8
Caldwell (2010)	2	2	2	2	2	2	1	2	1	2	0.9
Clarke, Camilleri & Goding (2015)	1	2	2	1	1	2	2	2	2	0	0.75
Clifford (2013)	1	1	1	1	0	1	1	0	1	1	0.4
Frawley & Bigby (2015)	1	2	2	2	1	1	1	2	2	0	0.7
Gilmartin & Slevin (2009)	2	1	2	1	1	1	2	2	2	1	0.75
McNally (2003)	2	2	1	1	1	1	1	0	1	0	0.5
Miller (2015)	2	1	2	2	1	1	1	0	1	0	0.55
Mineur, Tideman & Mallander (2017)	2	2	2	1	2	1	2	2	2	0	0.8
Tideman and Svensson (2015)	2	2	2	2	0	1	1	0	1	0	0.55
Zyta and Ćwirynkało (2016)	2	2	2	1	1	1	1	0	1	0	0.55

1.2. Overview of the studies' findings

Narrative synthesis was used to summarise the findings and to group them into different outcomes. Findings that fitted under two (or more) outcomes were coded under all relevant categories. A summary of the findings of the studies on psychological and social outcomes of self-advocacy group membership for people with ID is provided in table 4, along with details of which studies reported each outcome. Across the twelve studies, five psychosocial outcomes of self-advocacy group membership were reported. The most commonly occurring were 'empowerment and speaking up' (reported in eight studies) and 'belonging and mutual support' (in five studies). Changes to self- and social identity were reported in four and two studies, respectively. One study reported the outcome as increase in leadership. The only psychological outcome found was increases in confidence, which was reported in four studies. The social outcomes of ‘social connections and relationships’ and ’meaningful occupation/activities’ were reported in five and three studies, respectively.

Table 4. Summary of reported outcomes of self-advocacy group membership

Authors (year); quality rating	Psychosocial				Psychological		Social	
	Empowerment	Belonging	Self-identity	Social identity	Leadership	Confidence	Social connections and relationships	Meaningful occupation/ activities
Anderson & Bigby (2017); 0.65	Y	Y	Y	Y	-	Y	Y	Y
Beart, Hardy & Buchan (2004); 0.8	-	-	Y	-	-	-	-	-
Caldwell (2010); 0.9	-	-	-	-	Y	-	-	-
Clarke, Camilleri & Goding (2015); 0.75	Y	Y	-	-	-	Y	-	-
Clifford (2013); 0.4	Y	-	-	-	-	-	-	-
Frawley & Bigby (2015); 0.7	-	Y	-	-	-	-	Y	Y
Gilmartin & Slevin (2009); 0.75	Y	Y	Y	-	-	-	Y	-
McNally (2003); 0.5	Y	Y	-	-	-	-	Y	-
Miller (2015); 0.55	Y	-	-	-	-	Y	-	-
Mineur, Tideman & Mallander (2017); 0.8	-	-	Y	-	-	-	-	-
Tideman and Svensson (2015); 0.55	Y	-	-	Y	-	-	-	-
Zyta and Ćwirynkało (2016); 0.55	Y	-	-	-	-	Y	Y	Y

Each of these outcomes will be considered in further detail below, with consideration of the meaning of concepts (e.g. empowerment), the ways in which the studies sought to assess the impact of self-advocacy, the quality of the studies and therefore weight of the findings.

1.3. Psychosocial Outcomes

1.3.1. Empowerment

Empowerment was described by social scientist, Julian Rappaport (1987), as a “concept (that) suggests both individual determination over one’s life and democratic participation in the life of one’s community…both a psychological sense of personal control or influence and a concern with actual social influence, political power, and legal rights” (Rappaport, 1987, p1). Furthermore, he suggested that, “empowerment is a process, a mechanism by which people, organizations, and communities gain mastery over their affairs. Consequently, empowerment will look different in its manifest content for different people, organizations, and settings” (Rappoport, 1987, p2).

Empowerment was reported as an outcome of self-advocacy in eight of the studies reviewed. As indicated in the definition provided above, ‘empowerment’ covers a broad range of phenomena and can be operationalised in different ways. The studies used observations, individual and group interviews to collect data, and a variety of qualitative methods to analyse the data, including grounded theory, thematic analysis and cooperative inquiry.

Empowerment was reported at an individual and group basis. For example, participants in Tideman and Svensson’s (2015) study reported increased power over personal economic resources; and self-advocates in Gilmartin and Slevin’s (2009) study shared experiences of learning about their rights and together affecting change (e.g. by writing a letter to the local authority. Miller (2015) assessed the impact of a self-advocacy group in an inpatient, low-secure service for men with ID and mental health needs. It was reported that self-advocacy group membership helped the group members influence service provision (e.g. leading to the refurbishment of an outside area) and increased use of the complaints process. The quality rating of these studies ranged from 0.4 to 0.75, with an average of 0.59, indicating mostly low to medium quality. Appearing in eight out of the twelve studies, the broad outcome of empowerment (in different forms) appears to be a robust finding, though mostly based on less than strong research methods.

1.3.2. Belonging

This has been defined as, “a feeling that members matter to one another and to the group, and a shared faith that members’ needs will be met through their commitment to be together” (McMillan & Chavis, 1986, p9). This definition of ‘belonging’ encapsulates an outcome of self-advocacy reported by five of the studies. For example, in Frawley and Bigby’s (2015) interviews with long-term self-advocates who had each been involved with a group for more than 25 years, they found that participants had gained a sense of belonging through their involvement in self-advocacy. In McNally’s (2003) survey of self-advocates in England, mutual support gained through self-advocacy group membership was reported to be an important issue for respondents. The quality rating of the studies ranged from 0.5 to 0.75, with an average of 0.67). Reported in five of the twelve studies, a sense of belonging appears to be an outcome that some self-advocates report benefitting from, but one that is not always spoken of as part of the experience of self-advocacy.

1.3.3. Changes to self-identity

Four studies reported changes to self-identity as an outcome of self-advocacy group membership. Also termed ‘self-concept’, self-identity can be taken to refer to a collection of beliefs about oneself (Leflot et al., 2010). For example, Anderson and Bigby (2017) found that self-advocacy group membership opened up possibilities for multiple positive self-identities for the self-advocates, including being an independent person. Beart et al. (2004) found that the core theme to emerge from all (eight) of their interviews with self-advocates was that of ‘changing selves’, which they concluded to be a process of change in individual self-concept. They found that participants described themselves in new ways in comparison to their past selves, for example as being respected and having status. In Mineur et al.’s (2017) study, the authors reported changed self-perceptions, with participants seeing themselves as more skilled, social and confident.

The quality ratings of these four studies ranged from 0.65 to 0.8, with an average of 0.75, which is higher than the ratings for some other findings in the current review. Lending particular weight to this outcome, the Beart et al. (2004) study had a quality rating of 0.8 and reported changes to self-concept to be a main finding.

1.3.4. Changes to social identity

Tajfel and Turner (1979) described social identity as a person’s sense of who they are based on their group membership(s). Although group membership could be seen as central to self-advocacy groups, interestingly changes to social identity were reported in only two studies. Anderson and Bigby’s (2017) study which had a quality rating of 0.65, found that self-advocacy group membership and associated participation, e.g. in community education programmes, afforded members the opportunity to assume the social identity of ‘expert’, and the organisation of the meetings provided the opportunity for members to take up the social identity of ‘a business-like person’. Tideman and Svensson’s (2015) study which had a quality rating of 0.55, found that group members reported self-advocacy membership helped participants criticise and oppose the social identity they felt they had been assigned by society - that of an intellectually disabled person, with associated characteristics such as vulnerability – and to express a desire and endeavor to be seen as a person with many different roles and a unique multiple identity.

1.3.5. Leadership

This was specifically focused on in Caldwell's (2010) study. Four major themes were identified: disability oppression and resistance through self-advocacy; environmental support for leadership development and relationships afforded to members through the groups; leadership skill development (e.g. comfort in public speaking) and the need for advanced leadership opportunities (outside of the self-advocacy movement). This study had the highest quality rating (0.9) of the twelve studies. However, impact on leadership skills and opportunities was not reported as an outcome of self-advocacy group membership in the other studies reviewed.

1.4. Psychological Outcomes

1.4.1. Confidence

Four studies reported increased confidence as an outcome of self-advocacy group membership. The quality ratings of these studies ranged from 0.55 to 0.75 (average 0.63). From their interviews with self-advocates, Clarke et al. (2015) found that increased confidence, for example in speaking to other people, was reported by several participants. Participants in Miller's (2015) study reported increased confidence in self-advocacy group members to share their perspectives inside and outside of the group. Zyta and Ćwirynkało (2016) found that self-advocates in their study spoke of gaining confidence and courage to cope with difficult situations, including speaking publicly. It is interesting that in these three studies, increased confidence was in particular related to speaking to others, sharing perspectives and coping with difficult situations, including speaking publicly. These increases in confidence appear to overlap with aspects of what could be considered to be empowerment.

1.5. Social Outcomes

1.5.1. Social connections and relationships

Increases in social connections and relationships were found to be outcomes of self-advocacy group membership in five of the studies. The quality of the studies ranged from 0.5 to 0.75 (average 0.63). Participants in Zyta and Ćwirynkało's (2016) study reported that the groups provided new opportunities to develop relationships. Similarly, the self-advocates interviewed by Frawley and Bigby (2015) conveyed that they had gained new social connections through their involvement in self-advocacy. Expanded social networks emerged as a theme in all of the interviews conducted by Gilmartin and Slevin (2009), including subsequent socialising with other self-advocates outside of meetings. Increased social connections and relationships, specifically with other self-advocates, appears to be a robust finding.

1.5.2. Meaningful occupation and activities

Three studies found self-advocacy group membership resulted in increased opportunities for occupation and activities. The quality ratings of these studies ranged from 0.55 to 0.7 (average 0.63). Frawley and Bigby (2015) found that their participants spoke about gaining purposeful occupation through their involvement in self-advocacy, including paid project work, lobbying and management. The self-advocates in Zyta and Ćwirynkało's (2016) study reported that the groups provided new opportunities to participate in different activities, helping them to have interesting leisure time and contributing to the sense of being a useful person. Similarly, in Anderson and Bigby's (2017) study, increased occupation and activity related to self-advocacy involvement contributed to members viewing themselves as 'a person who is engaged in life'. Increased occupation and activity was reported by only three studies. However, it is interesting to note the relationship between increased occupation and how group members view themselves (i.e. their self-concept, changes to which were reported in four studies, as already discussed).

2. Discussion

2.1. Key findings

The twelve studies reviewed reported a range of psychological and social outcomes of self-advocacy by persons with ID. The consistency of findings and quality of the studies can help guide which findings to attach more weight to. The most frequently reported finding (found in eight studies) was the psychosocial outcome of empowerment. Additionally, increases in confidence were particularly in relation to aspects of empowerment such as sharing perspectives and speaking to others. Increases in empowerment and confidence in speaking up are perhaps not surprising outcomes as they are very much in line with the aims of the self-advocacy movement which include speaking and standing up for oneself, standing up for one's rights and making choices (Dybwad & Bersani, 1996).

A second key finding was the positive effect of self-advocacy on the psychosocial outcome of a sense of 'belonging' (to the self-advocacy group), reported in five of the studies, and the closely linked social outcome of increased social connections and relationships (reported in four of the same studies as 'belonging' and one other study). Increased opportunities for social connections and relationships, and a related sense of belonging, therefore appear to be key themes of self-advocacy group membership.

A final key benefit of self-advocacy reported by the reviewed studies area concerns changes to self-identity, which appear to be brought about by changes to activities and occupations with which members were engaged. Changes to self-identity were reported in four studies with relatively high-quality ratings (average of 0.75, compared to the average of all twelve studies which was 0.66). Changes to self-identity included seeing oneself as more skilled, respected and having status. Changes to activities and occupations as a result of self-advocacy group membership (reported in three studies) appear to be one mechanism through which group members experienced changes to self-identity.

Interestingly, changes to social identity were reported in only two of the studies which included changes such as seeing oneself as 'business-like person' and an 'expert'. Given the group nature of self-advocacy, it is perhaps surprising that changes to social identity were not reported in more of the studies. However, it may be that changes to social identity were captured under other themes such as 'belonging' and changes to self-identity. For example, seeing oneself as 'respected' and ‘having status’ is clearly grounded in social appraisals and therefore could be considered to relate to social as well as self-identity.

2.2. Limitations of the current review

A difficulty encountered in conducting the current review related to these issues of interpretation; when reviewing the studies, it was difficult to decide how to group the outcomes. For example, one study reported “changes in self-perception”, with participants seeing themselves as more confident (a psychosocial outcome), whereas another study reported “an increase in confidence” (a psychological outcome). When these differences in categorisation arose, the outcomes were categorised in line with the authors’ interpretations, where indicated being placed in two categories. It may have been beneficial for thematic analysis to have been used to review the findings and group together themes emerging across the twelve studies. However, it could also be argued that doing so would have moved away from the original authors’ interpretations of self-advocates’ experiences.

Two reviewers conducted the quality rating for 25% of the studies. The current review was otherwise conducted by one reviewer, increasing the chance of individual bias and the possible occurrence of human error. Furthermore, only studies published in English were included which may have limited the comprehensiveness of this review.

2.3. Limitations of the evidence

Given the important place self-advocacy has assumed within the ID field, the fact that only 12 studies were identified that assess the outcomes of self-advocacy for group members indicates that the evidence for self-advocacy in this field is thin. It is notable that none of the reviewed studies used a quantitative methodology. Whilst randomised controlled designs (RCTs) are often taken to the be gold standard for evaluating the outcome of an intervention, such a design would be difficult to implement when assessing the impact of self-advocacy (for example, the need to identify a 'control' group). Furthermore, a quantitative methodology may be less appropriate as the use of pre-determined outcome measures might limit the scope of results. Considering the qualitative methodology employed by the reviewed studies, there was an overall need for more detailed descriptions and justifications of data collection methods and analysis, with clear links to how conclusions were drawn. Such descriptions may be aided by the inclusion of researcher reflexivity in the accounts to help the reader understand why the researcher chose a particular sample, line of enquiry and interpretive framework, and the implications of these decisions on their findings.

2.4. Implications for future practice and research

The studies at the heart of the current review constitute an emerging evidence base; indeed, seven of the twelve studies were published within the preceding three years. The findings reported help to elucidate the substantial and wide-ranging positive impact that self-advocacy group membership has on the psychological and social wellbeing of people with ID. Although the limitation of only having qualitative evidence has been noted above, the use of qualitative methods does allow exploration of the lived experiences of self-advocates, in line with Goodey's (2005) assertion that the lived reality of self-advocacy needs to be foregrounded in any attempt to understand its impact.

Extending this central role of self-advocates, future research may benefit from a collaborative action-oriented reflexive approach to researching the lived experience of people with ID (Dowse, 2009). Such an approach places greater emphasis on mutuality and the co-construction of research agendas together with self-advocates, including interpretative frames and assigned meanings. Indeed, given the inclusion of "speaking for yourself" and "making choices" in People First's (1996) definition of self-advocacy, an explicitly emancipatory approach to research may be pertinent to research in this area.

In relation to policy and the practice of self-advocacy, it is interesting to note that empowerment was indeed reported most frequently in the studies reviewed, as one might expect. Within an emancipatory and social model of disability, how other people such as healthcare professionals and policy makers position themselves in relation to self-advocates is important, as ‘empowerment’ can be seen as based on an assumption of the powerful giving power to the weak (Bhavnani, 1990). For example, others seeking to ‘empower’ people with ID can risk yet again ascribing a victim status to people with ID, yet the politics of self-advocacy clearly indicate a resilience in the face of a disabling world (Goodley, 2005). Therefore, in practice and policy as well as research, there should be efforts for others to take an ‘ally’ role with clear opportunities and support for self-advocates to drive the political agenda and direction of self-advocacy.

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