The impact of selfadvocacy organizations on the subjective wellbeing of people with intellectual disabilities: A systematic review of the literature

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REVIEW ARTICLE

The impact of self-advocacy organizations on the subjective well-being of people with intellectual disabilities: A systematic review of the literature

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Abstract

Background: A high sense of subjective well-being has been associated with more prosocial behaviours, better health, work productivity and positive relationships. The aim of this systematic review was to explore what impact self-advocacy has on the subjective well-being of people with intellectual disabilities.

Method: The authors reviewed articles focusing on the perspectives of adults with intellectual disabilities engaged with self-advocacy groups. Searches were performed in PsychINFO, Web of Science, SCOPUS, MEDLINE and CIHNL databases, resulting in 16 articles meeting the inclusion criteria. A framework synthesis approach was used to extract data deductively based on the Dynamic Model of Wellbeing.

Results: While self-advocacy has a positive impact on all domains of the Dynamic Model of Wellbeing, negative impacts associated with participation in a self-advocacy group were also reported.

Conclusions: The benefits of participating in self-advocacy groups on the well-being of individuals with intellectual disabilities outweigh the disadvantages.

KEYWORDS

inclusive research, intellectual disabilities, self-advocacy, subjective well-being

1 | INTRODUCTION

This is the first systematic review to focus explicitly on the impact of self-advocacy on the subjective well-being of people with intellectual disabilities. It builds upon another recently published systematic literature review that explored the psychological and social impact of self-advocacy on its members (Fenn & Scior, 2019). While some of the outcomes reported in this study overlap with the previous review, this article further contributes to knowledge regarding the impact of self-advocacy by identifying the ways in which it influences members' subjective sense of well-being, particularly in relation to outcomes concerned with good functioning, satisfaction of needs, and overall feelings of happiness (Abdallah et al., 2011). The present authors believe this review is timely because, although self-advocacy is arguably more important than ever in the light of receding specialist services in some international contexts like the UK (Power, Bartlett, & Hall, 2016) and the faltering progress of inclusion (Strnadová, Johnson, & Walmsley, 2018; Power & Bartlett, 2018b), there has never been a focussed examination of its significance for the well-being of adults with intellectual disabilities, as measured by themselves. Subjective well-being refers to individuals' feelings and cognitive evaluations of their life (Diener, 2012). It is increasingly acknowledged that monetary measures alone, such as GDP,

are inadequate in determining the progress of societies and one's quality of life (OECD, 2013). Instead, it is necessary to consider the subjective well-being of members of society. Not only is high subjective well-being a desirable outcome, it benefits one's health (Chida & Steptoe, 2008), income (Diener, Nickerson, Lucas, & Sandvik, 2002), work productivity (Oswald, Proto, & Sgroi, 2015) and social behaviour (Aknin, Sandstrom, Dunn, & Norton, 2011).

Self-advocacy for people with intellectual disabilities emerged in Scandinavia, North America and the UK in the 1980s (Buchanan & Walmsley, 2006) as institutions were closing. Almost four decades later, the backdrop has shifted to include equality legislation in many countries (Soldatic & Johnson, 2019), changed attitudes, international commitments to citizenship (Department of Health, 2001; United Nations, 2006), exposure of institutional abuse and economic austerity. However, in the UK at least, self-advocacy groups are in many areas seen to be under threat—although no systematic research into this has been published since 2012 (National Forum, 2011). Studies of the history of the self-advocacy movement in Denmark (Bylov, 2006), England (Buchanan & Walmsley, 2006) and in the Australian state of Victoria (Henderson & Bigby, 2016) indicate that self-advocacy evolves over time in response to a variety of external factors, including funding, policy context, availability of suitable support staff and relationships with other advocacy organizations. Initially, there was significant interest in whether self-advocacy groups were independent of services (Crawley, 1988). An early focus was also pedagogic—how to run good meetings, or how to "stick up for yourself" for example (Buchanan & Walmsley, 2006; Simons, 1992). In Victoria, its focus migrated from energetic political campaigning in the 1980s to an emphasis on improving the lives of those inside the organization in the 2000s (Henderson & Bigby, 2016, p. 55). In Denmark, Bylov (2006) argues that there was a maturing of the movement, enabling it to free itself from the parents' organization, which had given it birth and early nurturing. Relationships with parents' organizations have surfaced as a major and fraught issue in the UK (Walmsley, 2016), as well as globally (Walmsley & Jarrett, 2019). In the recent context of UK austerity policy, Power and Bartlett (2018b) and Walmsley (2020) have observed that self-advocacy is morphing once more, this time in response to the retreat of the welfare state which has left many people with intellectual disabilities searching out new spaces of support and belonging.

Many definitions of self-advocacy can be found in the literature, but common—and enduring—components include the notion of speaking up for yourself or others, standing up for your rights, making choices, being independent and taking responsibility (Ryan & Griffiths, 2015; Simons, 1992; Williams & Shoultz, 1982). Self-advocacy has been described as "a space in which people with intellectual disability can develop not only their confidence, skills and leadership capacity, but also a collective identity, providing an essential foundation for grassroots activism" (Tilley, 2013, p. 470). In this way, self-advocacy can be seen as an activity and a process that is both personal and political (Frawley & Bigby, 2015). However, it is important to note that the existing literature on self-advocacy suggests that it is largely confined to people with mild or moderate intellectual disabilities (Walmsley & Downer, 1997); it has been dominated by men and, in the United Kingdom and United States, by people with Caucasian backgrounds (Caldwell, 2011; Goodley, 2000). This has to be born in mind when considering its impact on well-being.

In this systematic review, the authors explore what impact self-advocacy has on the subjective well-being of people with intellectual disabilities, as measured by themselves. The research question guiding this review was: "*What difference does self-advocacy make to self-advocates' subjective sense of wellbeing?*"

The review examines the published academic research on self-advocacy. For the purposes of this review, self-advocacy is understood specifically as an organized activity in which people with intellectual disabilities participate in a structured self-advocacy group or organization. This review did not include papers that are focused solely on self-advocacy as the development of new skills (i.e. self-advocacy as a learning process). The review was underpinned by the Dynamic Model of Wellbeing, described below (Abdallah et al., 2011).

2 | METHOD

2.1 | Conceptual framework

The Dynamic Model of Wellbeing, developed by the New Economics Foundation—or NEF—integrates different theoretical approaches to well-being into one single coherent explanatory model (Abdallah et al., 2011). It emerged from the UK Government's 2008 *Foresight Project on Mental Capital and Wellbeing*, which tasked NEF's Centre for Wellbeing to consider the relationship between different approaches to measuring well-being (e.g. objective indicators; eudaimonic accounts; hedonic accounts; evaluative accounts) and policy-making. NEF's Centre for Wellbeing concluded that these different (and often competing) approaches to measuring well-being could be brought together "to depict the emergence of well-being through a dynamic system" (Michaelson, 2013, p. 100). The resulting model outlined the critical feedback loops that exist between emotions, functioning and external conditions. This has practical implications for policy-making as it emphasizes the importance of improving people's material conditions *and* their personal resources in order

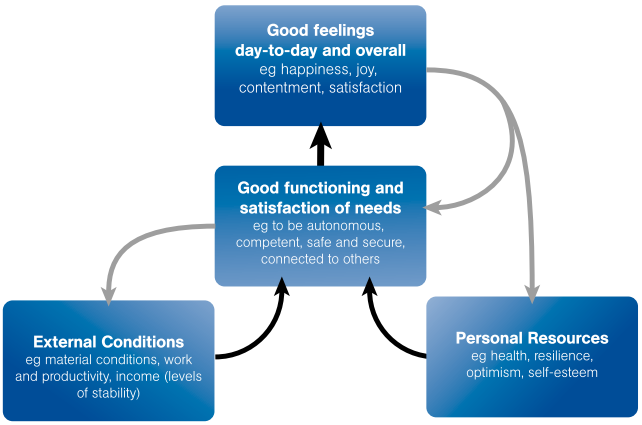

FIGURE 1 The Dynamic Model of Wellbeing

to positively affect well-being. For the purposes of this review, the Dynamic Model provided us with a practical and accessible framework, grounded in theory and empirical research, to help us identify the ways in which self-advocacy might influence well-being.

Well-being is understood in the Dynamic Model as "flourishing": feelings of happiness, joy, contentment and satisfaction that are achieved when sufficient personal resources and positive external conditions are in place to enable good functioning and satisfaction of needs (Figure 1). The model describes how:

> an individual's external conditions—such as their income, employment status, housing and social context—act together with their personal resources—such as their health, resilience and optimism—to allow them to function well in their interactions with the world and, therefore, experience positive emotions. The model shows how different aspects of our wellbeing interlink and how improvements in one area influence other parts of an individual's experience (NEF, 2019).

The four key domains of the Dynamic Model (personal resources; external conditions; good functioning and satisfaction of needs; and good feelings day to day and overall) provided the analytic framework for this review. When reviewing the included papers, the authors identified examples of well-being that corresponded with these four domains.

2.2 | Search strategy and eligibility criteria

The method used for the review aligns with the recommendations on preferred reporting items for systematic reviews and meta-analyses

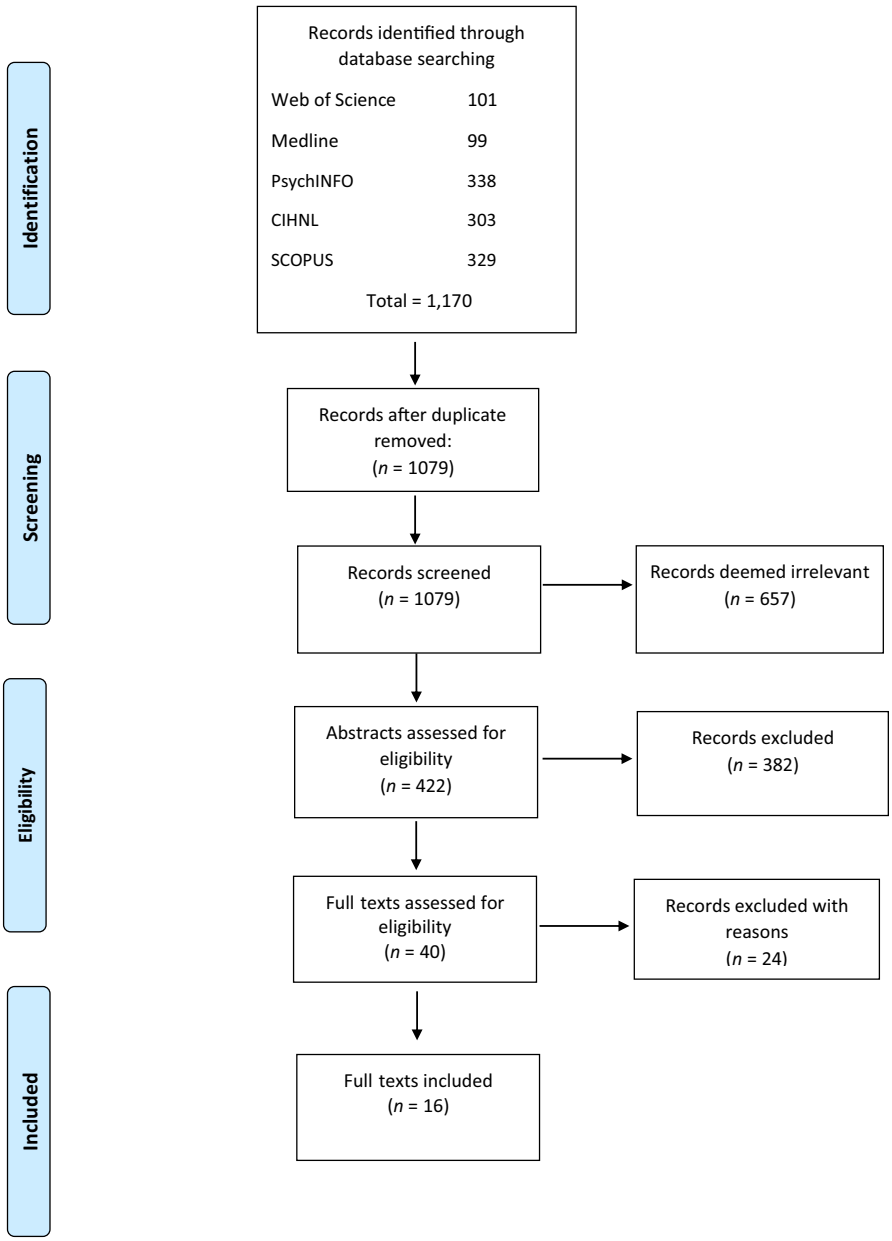

FIGURE 2 Flow diagram of search results

documented in the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). A systematic literature search in five databases (PsychINFO, Web of Science, SCOPUS, MEDLINE and CIHNL) was conducted between April 2019 and May 2019.

Predefined inclusion criteria were that articles needed to: (a) be research articles (not opinion pieces or literature reviews), published in a peer-reviewed journal; (b) be written in English; (c) include adult participants with intellectual disabilities engaged with self-advocacy groups; and (d) draw on empirical data that include the perspectives of people with intellectual disabilities. In terms of publication dates, papers were included if they were published up to May 2019. The search was conducted in title, keywords and abstracts and English language only was the sole limitation applied. The keywords used to perform the electronic database search:

- (Self advoca*) OR (Self-advoca*) OR (Peer advoca*) OR (Peer-advoca*) OR (Peer support*) OR (Peer-support*); AND
- (Intellectual disabilit*) OR (Learning disabilit*) OR (Learning difficult*) OR (Developmental disabilit*) OR (Cognitive disabilit*) OR (Cognitive impairment*) OR (Mental retardation) OR (Mental Handicap) OR (Developmental Delay); AND
- (Wellbeing) OR (Well-being) OR (Wellness) OR (Physical Health) OR (Mental Health) OR (Happiness) OR (Thriv*) OR (Flourish*) OR (Joy) OR (life satisfaction) OR (satisfaction with life) OR (Strength*) OR (Voice) OR (Self-concept) OR (Good life) OR (Fulfilment) OR (Self-esteem) OR (Social capital) OR (Capabilities) OR (Belonging) OR (Connectedness).

Papers were excluded if (a) they were discussion papers; (b) they focused on self-advocacy as a learning process only; c) they included participants with specific learning difficulties ("dyslexia," "dyscalculia," "dyspraxia") and not intellectual disabilities.

2.3 | Study selection

The asterisk symbol was used in many of the keywords/phrases to account for suffix variations of keywords. A total of 1,170 articles were identified from the electronic search. 91 duplicate articles were removed, and a further 657 articles were deemed irrelevant and removed. 422 abstracts were examined against the eligibility criteria independently by the first and second author, and 382 were excluded. Cohen's kappa was used to calculate inter-rater reliability, with the average inter-rater reliability score at this stage of screening being high with $\kappa = 0.7737$. All disagreements were discussed and resolved.

In the second stage, the first and the second author independently examined the full text of 40 included articles. Inter-rater reliability for this stage was very high with $\kappa = 0.8977$. 16 articles met the criteria for this study. Figure 2 details the search strategy and results.

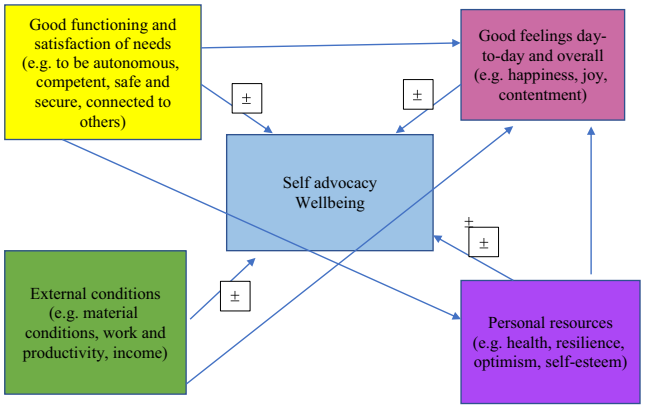

FIGURE 3 Adapted Dynamic Model of Wellbeing

2.4 | Inclusive approach to systematic review

When conducting this systematic review, the present authors used an inclusive research approach (Walmsley & Johnson, 2003). This was a critical and innovative element of this systematic review, which the present authors included to gain the insights and perspectives of a person with experience of self-advocacy. It corresponds with recent calls for increased co-construction of research agendas relating to self-advocacy (Fenn & Scior, 2019), and for transparency of the co-authoring process (Strnadová et a., 2018).

The fifth author is a self-advocate who has spent over 20 years working in a self-advocacy organization, supporting other self-advocates. She brought experiences not only of her own, but also of other self-advocates. Her contributions add a different and important perspective.

The process was as follows. The academic researchers undertook the systematic review. They then wrote the first draft of this article. The second author prepared an easy read version. Using this version, the second and fifth author discussed and commented on the review findings. The meeting was audio recorded. This discussion had two major outcomes.

First, the fifth author acknowledged the relevance of the Dynamic Model of Wellbeing Model's four domains but said that the visual representation (see Figure 1) was confusing for her. She suggested a different layout, which would better express well-being in relation to self-advocacy and better reflect the findings of this review (see Figure 3).

Second, her reflections were included in the paper's Discussion section, including direct quotations.

2.5 | Quality assessment

In order to assess quality of the studies, the present authors used The Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet, Lee, & Cook, 2004). This reliable tool designed for systematic reviews is unique in that it allows for both qualitative and quantitative studies to be assessed

according to design-specific criteria. The present authors have only used this tool to allow for richer description of the included articles, and not as a basis for their selection (McGarty & Melville, 2018). The first two authors independently scored the selected articles—whether they met the assessment criteria, met them only partially or not at all. The present authors used the approach of McGarty and Melville (2018) to compare the scores by comparing percentages in which the relevant criteria were met, with scores < 55% interpreted as weak, 55%–75% as moderate and > 75% as strong. The present authors agreed that 13 articles were strong, 2 were moderate and 1 weak (Kmet et al., 2004). The reached inter-rater reliability counted using Cohen's kappa was high at $\kappa = 0.828$ (Cohen, 1960; McHugh, 2012). The disagreements were resolved by discussion.

2.6 | Description of studies

All of the included papers, with one exception (McNally, 2003), reported on qualitative research. The reported studies were conducted in Australia (Anderson & Bigby, 2017; Frawley & Bigby, 2015; Strnadová et al., 2018), the Republic of Ireland (García Iriarte, O'Brien, McConkey, Wolfe, & O'Doherty, 2014; Gilmartin & Slevin, 2009), Sweden (Mineur, Tideman, & Mallander, 2017; Tideman & Svensson, 2015), the UK (Beart, Hardy, & Buchan, 2004; Chapman, 2004; Clarke, Camilleri, & Goding, 2015; Goodley, Armstrong, Sutherland, & Laurie, 2003; Hall, 2005; McNally, 2003; Power & Bartlett, 2018a) and the USA (Caldwell, 2010, 2011). Information about the articles included in this systematic literature review is provided in Table 1, including quality assessment scores.

2.7 | Data analysis

2.7.1 | Framework synthesis

The authors adopted a framework synthesis approach (Dixon-Woods, 2011), according to which the first stage is establishing a conceptual model a priori. The conceptual model—in this case the Dynamic Model of Wellbeing—provided a structure for data coding.

The first and second author independently completed a purpose-designed pro forma for each included article, providing information relevant to the focus of the systematic review. The pro formas were structured according to the Dynamic Model of Wellbeing and included space for additional well-being domains, as well as other relevant information. Completed pro formas were analysed by the second author. An initial overview of the data affirmed that the Dynamic Model of Wellbeing was a useful conceptual model. After this first stage of analysis, the four key domains of well-being and a broad list of emerging codes were identified by the first and second author and reviewed by the others. Any recurring themes that did not correspond with the four domains of the Dynamic Model of Wellbeing but which were relevant to our research questions were coded under "other." In line with Fenn and Scior's review (2019), the present authors identified that some outcomes were complex to categorize, potentially falling under multiple "domains." Examples include "learning new skills" and "acquiring knowledge." While both of these outcomes connect to an increase in personal resources, they also relate to self-advocates' sense of competency (associated with good functioning and satisfaction of needs in the Dynamic Model). In such incidences, the authors discussed and agreed upon a "primary" domain, while noting where it was important to draw attention to the interconnectedness of outcomes and their relationship with different domains.

2.7.2 | Coding

The form of synthesis was selected as it is related to the nature of the research questions posed (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). The present authors synthesized the extracted data by deductive methods. Once the data had been coded by the first and second author, all authors critically examined the coding and reached consensus.

3 | FINDINGS

The key findings are structured according to the domains of the Dynamic Model of Wellbeing, with additional issues unpacked during the data analysis.

3.1 | External conditions

According to NEF, the domain of external conditions includes the material, social and economic circumstances of a person's life, such as income, work, education, housing, social connections and living standards. In our review of the included papers, the present authors identified the following examples of how self-advocacy impacted upon people with intellectual disabilities' external conditions, for example:

- New friendships and expanded social networks;
- Opportunities for work (in paid or non-paid employment, volunteering);
- Support to access information and resources (e.g. information about benefits, housing);
- Support to make changes in external conditions (e.g. housing, relationships, work).

In relation to friendships and extended social networks, participants in Beart, Hardy, and Buchan's study (2004) describe the positive social environment that self-advocacy provides, enabling the creation new relationships. These relationships often became a new source of practical and emotional support for people with intellectual disabilities. This is also supported by other studies included in this literature review

TABLE 1 Information on reviewed articles

Study	Sample size	Location	Study design	Focus of the study	Key findings	Quality assessment
Hall (2005)	21 people with intellectual disabilities and their supporters; age and gender not provided	Scotland, UK	Group interviews; a narrative approach	To establish an account of various aspects of people's lives and the extent of their inclusion in particular socio-spatial contexts	Self-advocacy provided a space in which people felt respected, valued and connected. Self-advocacy was emerging as a site for collective action, but this was largely confined to awareness raising and improvements to services. While Hall acknowledges the significance of this, he argues that self-advocacy was limited in its possibilities for reimagining social inclusion at that point	Moderate: 60%
Beart et al. (2004)	8 self-advocates with intellectual disabilities; aged 24–44 years; 5 men and 3 women	UK	Interviews; a grounded theory approach	To examine the experience of belonging to a self-advocacy group	People's membership of a self-advocacy group changed their self-concept. The authors developed a model of the impact of belonging to a self-advocacy group on individual members' self-concept. The change of a self-concept of a self-advocacy group member involves 6 categories: (a) joining the group, (b) learning about and doing self-advocacy, (c) becoming aware of group aims and identity, (d) experiencing a positive social environment, (e) identifying positive change in self-concept and (f) seeing the future of self and group as interlinked	Strong: 95%
Caldwell (2011)	13 leaders in self-advocacy movement (10 with intellectual disability); aged 37–61 years; 5 men and 5 women	USA	Interviews; a life story approach; a grounded theory approach	To explore life stories and perspectives of leaders in the self-advocacy movement in order to enhance knowledge about disability identity formatio	Themes related to formation of disability identity within the life stories of leaders in self-advocacy movement: (a) resistance—claiming personhood and voice, (b) connection with disability community, (c) reclaiming disability and personal transformation, (d) interconnection with the broader disability rights movements and (e) bond with social justice and interdependency	Strong: 90%
Gilmartin and Slevin (2009)	13 people with intellectual disabilities; aged 32–60 years; gender not provided	The Republic of Ireland	Interviews; a phenomenological approach	To examine the lived experiences of belonging to a self-advocacy group for people with an intellectual disability	Self-advocacy group membership had an impact on the personal lives of self-advocates, as described in 6 categories: (a) empowered, (b) personal identity, (c) learning about self-advocacy, (d) perception of treatment of others, (e) accepting current position and (f) helping others The self-advocates also talked about functioning as a group. The topics covered were self-advocacy, members' responsibilities and interactions, activism, and involvement in making decisions and assisting with meetings	Strong: 100%
Tideman and Svensson (2015)	12 self-advocates—in the article 4 of them mentioned, who were aged 22—40 years, 2 men and 2 women	Sweden	Interviews with members and participation observations; a cooperative enquiry	To contribute to existing knowledge and a comprehensive understanding of the marginalization of Swedish young adults with intellectual disability	Involvement in self-advocacy groups and developing roles and identities associated with the involvement provided members with opportunities to promote their health and well-being, and sense of agency in their daily lives	Moderate: 70%
Frawley and Bigby (2015)	12 self-advocates; all but one aged over 55 years; gender not provided	Victoria, Australia	Interviews; a thematic analysis	To examine what involvement in a self-advocacy group meant to its long-term members	Involvement in a self-advocacy organization brought a sense of belonging, social connections and doing things that matter, in relation to their self-advocacy membership Another dimension of self-advocacy, discussed by the authors, was being a catalyst to social inclusion	Strong: 90%

(Continues)

TABLE 1 (Continued)

Study	Sample size	Location	Study design	Focus of the study	Key findings	Quality assessment
Clarke et al. (2015)	6 adults with intellectual disabilities; aged 36–70 years; 3 men and 3 women	UK	Individual and group interviews; a thematic analysis	To explore the experiences of people with intellectual disabilities in the context of a self-advocacy group, and to identify benefits and difficulties connected with being a member of the group	For self-advocates, being part of the group brought the experience of self-esteem, self-development and empowerment The authors also make links with developing a sense of self, self-determination, interpersonal learning and building resilience	Strong: 90%
Strnadová et al. (2018)	24 participants with intellectual disabilities; aged 20–61 years; 15 men and 9 women	New South Wales and Victoria, Australia	Focus groups; an inductive content analysis	To examine what belonging means to people with intellectual disabilities	The findings revealed four meanings of belonging: (a) belonging in relation to place, (b) as being part of a community, (c) as having relationships and (d) as identity. The paper also explored the impact on self-advocacy on a sense of belonging	Strong: 90%
Power and Bartlett (2018a)	Study 1–4 self-advocates; Study 2–17 adults with intellectual disabilities; age and gender not provided	Southampton, UK	Focus group interviews and photo-elicitation; inductive grounded theory approaches	To examine everyday experiences of inclusion by people with intellectual disabilities	The findings highlighted "moments" of inclusion through peer support (including self-advocacy) amidst a wider picture of exclusion and harassment	Strong: 80%
Mineur et al. (2017)	26 self-advocates; age not provided; 11 men and 15 women (estimated based on the names provided in the article, but not explicitly stated)	Sweden	Interviews; an interpretative abductive approach	To investigate the definition and importance of engagement for self-advocates in a self-advocacy group, and their impact on the identity and every life of self-advocates	The findings showed that the vast majority of participants experienced a change in self-perception through membership of self-advocacy, and became more confident, sociable and skilled	Strong: 85%
Anderson and Bigby (2017)	25 self-advocates; only average age provided—35 years for women and 39 for men; 15 men and 10 women	Victoria and Tasmania, Australia; UK	Interviews; a constructivist grounded theory approach	To explore the effects of membership in self-advocacy groups on the social identity of people with intellectual disabilities	Groups characterized by collegiality, ownership and control provided members with employment opportunities, skill development and friendships, which in turn led members to be more confident and engaged with life. Members were also more likely to develop various positive identities. Self-advocacy is a crucial way for people with intellectual disability to be socially included	Strong: 85%
García Iriarte et al. (2014)	168 people with intellectual disabilities; aged 18–50 + years; 83 men and 82 women	The Republic of Ireland; Northern Ireland	Focus group; a thematic content analysis	To examine the key concerns of people with intellectual disabilities in relation to their participation in society	The key themes identified were as follows: living options, employment, relationships, citizenship, leisure time, money management, self-advocacy and communication	Strong: 90%
Caldwell (2010)	13 leaders in self-advocacy movement (10 with intellectual disabilities); aged 37–61 years; 5 females and 5 men)	USA	Interviews; a life story approach; a grounded theory approach	To explore life stories of leaders in self-advocacy groups	Four key themes: (a) disability oppression and resistance, (b) environmental supports and relationships, (c) leadership skills and (d) advanced leadership opportunities	Strong: 100%

(Continues)

TABLE 1 (Continued)

Study	Sample size	Location	Study design	Focus of the study	Key findings	Quality assessment
Goodley et al. (2003)	Approach 1—4 self-advocacy groups (groups had between 8 and 23 members); Approach 2—17 people with intellectual disabilities; 8 men and 9 women; aged 20–63 years; accessible narratives or "lifelines" of 30 people with intellectual disabilities Group interviews with self-advocates (number not given)	UK	Approach 1—an ethnographical approach; Approach 2—a narrative enquiry	To explore self-advocacy as experienced and practiced by people with intellectual disabilities. To establish a theoretical understanding of the notion of learning disabilities derived by analysing the experiences and perceptions of individuals involved with self-advocacy. To use evidence and knowledge gained from the study to illuminate and support the moment on self-advocacy	The findings highlighted the relationship between self-advocacy and the construct of "learning difficulties" and emphasized the multi-located and distributed nature of self-advocacy	Strong: 85%
Chapman (2004)	24 self-advocates; age and gender not provided	England, Wales, Scotland and Northern Ireland, UK	Interviews, observations and focus groups; and accessible methods: (a) body mapping; (b) Photography; (c) "Communiogrammes." Data analysis approach not specified	To examine advocacy support workers' understandings of their roles. To examine self-advocacy group members' understandings of support workers' roles To examine lessons that could be learned about the operation and purpose of self-advocacy groups	Many crucial aspects of organizational practice and support remained hidden Greater reflexivity and co-supervision of supporters can increase opportunities for authentic collaboration with self-advocates	Strong: 85%
McNally (2003)	53 self-advocates; age and gender not provided	England, UK	Survey; aggregated responses to each item summarized; responses to open question analysed according to Robson (1993)	To explore experiences of self-advocacy for people with intellectual disabilities To examine the influence of self-advocacy in their lives	The participants provided information about self-advocacy groups' origins, structure and functioning. Majority wanted to engage in research. The richness and diversity of self-advocacy groups is not captured in previous typologies	Weak: 42.86%

(Caldwell, 2011; Frawley & Bigby, 2015; García Iriarte et al., 2014; Gilmartin & Slevin, 2009; Goodley et al., 2003). Mineur et al. (2017) in this context write about increased social capital, as people with intellectual disabilities engage in more social relationships (including online, via social media). Expanding people's social networks was also described as a key tool in relieving boredom (Anderson & Bigby, 2017, p. 115): "there's always something going on here. Outside, at home, there's nothing to do. It's really, really boring."

In some studies (Beart et al., 2004; Frawley & Bigby, 2015), the participants mentioned that their self-advocacy organization provided them with supportive work opportunities. In addition, opportunities to sit on boards, reference groups and advisory committees, as well as to present at conferences and work on joint campaigns with other organizations, were provided by self-advocacy organizations (Frawley & Bigby, 2015; McNally, 2003), although one paper described these opportunities as "tenuous" (Caldwell, 2010). In some cases, self-advocacy organizations appeared to be providing opportunities for a different type of employment; work that people felt equipped and supported to do, in contrast to previous experiences:

> I can't even work either. I can't work. That's why I've got a job here (at the group). I used to work at… on 1998. I think 1998. I didn't like it there. We didn't have support. (Beart et al., 2004, p. 97)

This was reflected in a more recent paper, where a self-advocate spoke with great enthusiasm about her experiences of working at the organization: "That's why I love working here, because I come in and (…)… it's not like, "Oh, god, I've got to go to work!" It's like, "Alright! Let's go!" (Strnadová et al., 2018, p. 1,096).

People involved with self-advocacy organizations also received (Anderson & Bigby, 2017; McNally, 2003) or anticipated receiving support from these organizations in making changes to the external conditions of their lives, such as housing. In some cases, the changes in external conditions came on smaller, yet still significant scale—such as having an opportunity to make a choice about one's breakfast (Anderson & Bigby, 2017). McNally (2003) also mentioned the important role self-advocacy organizations played in supporting their members to access relevant information and resources. Finally, Power and Bartlett (2018a, p. 573) identified that self-advocacy was important in helping people to cope during difficult points in their life, primarily through providing a support network that people could rely on:

if there wasn't groups like that, at the Frog and Parrott [pub], helping me to tick on, especially when the lowest point of my life, I used to say I'd be looking for a dog and a cat and triangle and I'd be on the street. (Henry, 60s).

3.2 | Personal resources

According to the Dynamic Model of Wellbeing, personal resources are the attributes that individuals hold that have the capacity to support their well-being. In our reading of the literature, the present authors identified the following examples of self-advocacy's impact on individuals' personal resources:

- Developing self-esteem and the confidence to speak up for oneself (and others);
- Learning new skills;
- Acquiring new knowledge;
- Changes in self-concept.

A number of papers reported that participation in a self-advocacy group led to members gaining self-esteem and developing more confidence to speak up for themselves and others (Anderson & Bigby, 2017; Beart et al., 2004; Caldwell, 2011; Clarke et al., 2015; García Iriarte et al., 2014; Gilmartin & Slevin, 2009; McNally, 2003; Mineur et al., 2017). One self-advocate from Mineur et al.'s study (2017, p. 8) commented that joining a self-advocacy group resulted in "my self-esteem and my self-confidence (being) at its peak today." An increase in self-confidence resulted in people feeling more comfortable to articulate what would make their lives better, as well as to complain about issues they were unhappy about. In some cases, the literature reported tangible improvements to people's daily lives as a result of people's increased self-esteem and confidence to challenge the status quo (Beart et al., 2004, p. 37). This was shown to enable people to take more control of their lives, providing a foundation for greater levels of automony, an outcome of the well-being domain "good functioning and satisfaction of needs" (Beart et al., 2004). Increased levels of confidence could be also ascribed to a commonly experienced change of lifestyle, within a safe space (Anderson & Bigby, 2017).

Learning new skills through participation in self-advocacy was a common theme in the literature (Anderson & Bigby, 2017; Caldwell, 2011; McNally, 2003). People with intellectual disability learnt new skills in their self-advocacy organizations, such as decision-making (Gilmartin & Slevin, 2009; Mineur et al., 2017), making choices (McNally, 2003), skills for developing friendships (Anderson & Bigby, 2017), travel training and community safety (Anderson & Bigby, 2017), leadership skills (Caldwell, 2010) and research-related skills (García Iriarte et al., 2014), to name a few. This learning process was mutual and happened in a space of psychological safety (Clarke et al., 2015). Due to their involvement with a self-advocacy organization, they came across opportunities that they did not have before (e.g. speaking at conferences, taking part in training courses in order to develop self-determination and self-advocacy skills). This led to empowerment at an individual and collective level (Anderson & Bigby, 2017; Gilmartin & Slevin, 2009). Another skill set highlighted in the literature was that of "relational abilities," which entails developing greater empathy and understanding of others, and learning how to communicate more effectively with a wide range of people (Mineur et al., 2017). Another paper emphasized the importance of learning to say "no" when required (Clarke et al., 2015).

Self-advocacy also offers numerous opportunities for people to acquire new knowledge, either about oneself (Strnadová et al., 2018);

other people (Clarke et al., 2015); or the social world (Chapman, 2004; Tideman & Svensson, 2015). Papers described how self-advocacy taught people about their rights (Gilmartin & Slevin, 2009), different service models (Clarke et al., 2015) and supported people to view previous stigmatizing incidences through a different theoretical and experiential lens (Beart et al., 2004; Caldwell, 2010). This latter point was crucial in helping to shift people's self-concept.

The present authors were struck by the number of papers that reported the ways in which self-advocacy had changed people's self-concept, otherwise described as "self-identity." Being part of a self-advocacy group appears to open up possibilities for multiple new positive self-identities, such as becoming an independent person (Anderson & Bigby, 2017), becoming a more respected person with status (Beart et al., 2004) and becoming more skilled and socially confident (Mineur et al., 2017). Some research indicated that through self-advocacy group membership some individuals came to view their intellectual disability as an aspect of their lives to be celebrated, rather than something to be ashamed of (Caldwell, 2010; Gilmartin & Slevin, 2009; Tideman & Svensson, 2015). In the main, the literature suggests that self-advocates are somewhat ambivalent regarding their explicit embracing of an "intellectually disabled" identity following engagement with a self-advocacy group. However, some self-advocates did find new meanings in their previous experiences and began to imagine different and more positive futures for themselves as a result of participation in the group (Beart et al., 2004).

> ... 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." (Anderson & Bigby, 2017, p. 115)

3.3 | Good functioning and satisfaction of needs

In the Dynamic Model of Wellbeing, the domain of good functioning and satisfaction of needs relates to four core outcomes: autonomy; competency; safety and security; and connectedness to others. The present authors reviewed the included papers to find examples of these outcomes, such as:

- Self-advocates experiencing a sense of connectedness, particularly in terms of self-advocates positioning themselves within the wider intellectual disability community;
- Self-advocates using their increased confidence and self-esteem to take control and fight for their rights;
- Self-advocates acquiring competency through their involvement with the group;
- Self-advocacy providing a safe psychology space for people to try new things and to experiment with different social identities.

Most of the reviewed articles described diverse ways in which being a part of a self-advocacy organization contributed to people's good functioning and satisfaction of needs. Self-advocates talked about how participation in the organization had widened their social networks and helped them develop new friendships, both with other people with intellectual disability and with people outside their self-advocacy organizations. This was critical in combating loneliness (Mineur et al., 2017; Power & Bartlett, 2018b) and led to gaining a sense of camaraderie via shared stories, jokes and memories of the group that developed over time (Anderson & Bigby, 2017; Clarke et al., 2015; Frawley & Bigby, 2015; García Iriarte et al., 2014; Goodley et al., 2003; McNally, 2003; Power & Bartlett, 2018b). In Strnadová et al.'s study (2018, p. 1,096), the participants reported that self-advocacy provides friendships, respect, being valued and cared for, with some comparing self-advocacy organizations to home: "*I'm more happier here than home, actually*" (Tamara).

Being members of a self-advocacy organization, and mentoring and supporting others, allowed people to develop a much deeper understanding of the shared experience of disability. This is described by one of the participants in Caldwell's study (2011, p. 320):

> That was one of my first national experiences. Just going to that meeting. ... Just seeing all these people with disabilities. I guess that was one of the first times I realized that there are a lot of people in this world with disabilities and a lot of us have the same stuff in common.

Tideman and Svensson (2015, p. 4) in this context write about self-advocates' shared experiences of "otherness," disability and safe space to be themselves without a threat of authorities intervening:

> When they met at the self-advocacy group, they could show themselves to be vulnerable, strong, or lost without it being seen as a matter for the authorities or others who traditionally wanted to sort out their lives for them.

These shared experiences of people organising themselves in association clearly provided a sense of connectedness and seeing the bigger picture (Frawley & Bigby, 2015; Goodley et al., 2003; Tideman & Svensson, 2015). This led to acknowledged interdependency (Caldwell, 2011; Gilmartin & Slevin, 2009; Tideman & Svensson, 2015), a cultural value of supporting one another.

While acknowledging interdependency, the participants across the studies were proud of becoming more independent and having more control over their lives (McNally, 2003).

As discussed previously, self-advocacy provides many opportunities for people with intellectual disabilities to increase their personal resources. This includes acquiring new knowledge, learning new skills and gaining the confidence to ask questions and challenge the status quo. This increase in personal resources often went hand

in hand with individuals taking on a new role through self-advocacy, such as becoming a committee member or a chairperson. As demonstrated in this account, a sense of status often emerged through participation in self-advocacy, linked directly to the domain outcome of competency:

I was a director. I was a director of a role play, about bullying. Standing for your rights. I were very good. The present authors had about 70 people come (to a conference). To get our message across to social services and the police. To make things better for people with learning disabilities (Beart et al., 2004, p. 95).

In Hall's paper (2005, p. 112), Peter, a man with intellectual disabilities, talks about supporting others in order to "help them to get the best for themselves." This speaks to self-advocacy's role in enabling people with intellectual disabilities to acquire experience, expertise and credibility. This in turn gives self-advocates a platform to provide support to others. Providing support to others is not only an indicator of competency, but also implies the self-advocate has value and purpose through their role. In addition, supporting others serves to increase people's sense of connection to the wider intellectual disability and self-advocacy community, reinforcing a sense of connectedness.

Exemplifying the dynamic nature of well-being, as self-advocates became valued for their expertise and competency, they experienced not only an increase in self-confidence, but a change in social identity, leading to a virtuous cycle that served to increase well-being (Anderson & Bigby, 2017).

Evidence of competency is also cited in reports of self-advocates being connected to a social cause and affecting social change. In a number of papers, self-advocates described the ways in which they believed self-advocacy was a platform for social change, and gave them opportunities to influence policy, shift attitudes and help make tangible changes to people's day-to-day lives (Gilmartin & Slevin, 2009).

All of this happens within a space in which self-advocates can ask questions and voice opinions, and where they can learn to say "no." Self-advocacy provides the safety and security required for people to take risks and make mistakes. These opportunities for personal development and richer social experiences led to a more positive sense of self which can counter stigma (Clarke et al., 2015).

Efforts to help others demonstrated across a number of studies highlighted the importance of collective action to improve an individual's functioning, as mentioned by one of the self-advocates in Beart et al.'s study (2004, p. 97): "It would be suicidal if the present authors did things on our own. The present authors need support from a self advocacy group… and there should be other self advocacy groups around to give support." There was a sense of collective dimension of self-determination, as people with intellectual disabilities in studies included in this systematic review worked not only towards their own, but also the collective well-being for the group (Mineur et al., 2017). Strnadová et al. (2018) also acknowledged that self-advocacy provided peer support and opportunities for teamwork, both supporting a sense of connectedness.

3.4 | Good feelings day-to-day and overall

The present authors acknowledge that studies included in this systematic literature review were not attempting to measure or report on people's happiness. Nevertheless, a number of studies did discuss people's feelings of happiness, joy and satisfaction linked to self-advocacy.

People involved in self-advocacy organizations felt happy to be self-advocates (Anderson & Bigby, 2017). They felt respected and valued (Strnadová et al., 2018, p. 1,096), as expressed by one of the self-advocates:

> …since I've come into this group I've been part of the group, I feel loved and cared for and everyone here is so nice and caring and friendly, and they're always here for me, so I'm glad I'm here with you guys.

Self-advocacy organisations also relieved people with intellectual disability from boredom (Anderson & Bigby, 2017). The participants expressed being happy that they were doing things that matter. It mattered to them that they were helping other people (Anderson & Bigby, 2017; Frawley & Bigby, 2015). Some people talked about feeling good about themselves and realising their own potential through self-advocacy (McNally, 2003). Some experienced a personal transformation as a result of their participation in self-advocacy:

> Gosh, it really gave me a new way to think about myself. I love myself. I am not saying I am perfect. Nobody is perfect. I really like the person I see in the mirror. I hope to convey that to other self-advocates. They can be great too . . . It really did change my life.
>
> (Caldwell, 2010, p. 1008)

These studies demonstrate that participation in self-advocacy organizations did support increased feelings of happiness, joy and satisfaction amongst some people with intellectual disabilities.

3.5 | Other important considerations

In addition to identifying a number of themes across the papers that mapped directly onto the Dynamic Model of Wellbeing, the present authors also observed that the theme of bullying, oppression and victimization emerged in many of the papers the present authors reviewed (Caldwell, 2010; Clarke et al., 2015; García Iriarte et al., 2014; Goodley et al., 2003; Power & Bartlett, 2018a; Strnadová et al., 2018). While the present authors did not identify papers suggesting that self-advocacy had *reduced* people's experiences

of bullying or victimization, it was clear that self-advocacy sometimes provided a space in which these disturbing and traumatic experiences could be discussed and reflected upon. Sometimes self-advocates were able to re-frame these incidences through their self-advocacy group, enabling them to view their personal experiences as part of a wider system of oppression against people with intellectual disabilities. While the literature highlighted that bullying and abuse have been a feature of many self-advocates' lives, participation in a self-advocacy organization appeared to give some people new tools to manage past trauma more effectively and to take steps to protect themselves in the future.

4 | DISCUSSION

Our review indicates that self-advocacy may be making a difference to the subjective well-being of people with intellectual disabilities in a number of tangible ways. Studies showed that participating in self-advocacy organizations may change and improve people's external conditions, particularly with regard to the creation of new and supportive social networks, alongside opportunities for work and meaningful activity. Self-advocacy can also be seen to improve people with intellectual disabilities' personal resources, heightening self-esteem and increasing confidence. It also appears to provide an environment in which people learn new skills and acquire new knowledge. Crucially, this results in many self-advocates reporting a shift in self-concept following participation in a self-advocacy organization. Through self-advocacy people may develop capacities to focus upon and celebrate their strengths, and in some instances, come to have a more positive relationship with the label and experience of intellectual disability. The literature also suggests that self-advocacy enables people to develop new and sometimes multiples identities, while simultaneously connecting individuals to a wider disability community.

A number of studies (Anderson & Bigby, 2017; Clarke et al., 2015; Frawley & Bigby, 2015; García Iriarte et al., 2014; Goodley et al., 2003; McNally, 2003; Power & Bartlett, 2018b; Strnadová et al., 2018) demonstrated how self-advocacy can impact upon good functioning and satisfaction of needs. Improved personal resources provide the basis for more automony. The safe space of self-advocacy can provide an environment in which people share previous experiences of abuse and bullying, re-framing these events through a more political and structural lens. Self-advocacy may provide tangible opportunities for people to develop and showcase competency. But perhaps most strikingly, the studies the present authors reviewed suggested that self-advocacy offers powerful mechanisms for connectedness. Some individuals reported the result of such connectedness as quite transformational.

The studies highlight the relationship between social interaction and self-development that can occur through self-advocacy. There is evidence that self-advocacy can provide an environment and a context to build meaning; learn about other people's lives; acknowledge the resilience of people with intellectual disabilities; develop inter-personal relationships; develop identity; and explore new roles. It can also be a space in which to try out "new ways of being" (Clarke et al., 2015, p. 242). Studies show that self-advocacy can also be the basis for "subtle radicalism," both supporting individual change ***and*** social activism (Anderson & Bigby, 2017).

It is important to note that some studies touched briefly upon what might be described as the potential negative impacts associated with participation in a self-advocacy group, which may serve to reduce a person's well-being. For example, Beart et al. (2004) discussed the riskiness for some people of getting involved in self-advocacy, particularly in relation to managing other people's concern or distrust of the group (e.g. families or professionals), the stirring up of past memories, comparisons with the past and the sense of anger that may emerge as people become more aware of social injustices. Tideman and Svensson (2015, p. 5) raise the potential vulnerability that comes along with new identities obtained via self-advocacy:

> Even though we have left the epoch of the institutions behind us, the way of thinking that characterized this epoch still remains within certain arenas. In our observations and interviews, we find many examples of how remaining elements of an overprotective care mentality are still being reflected in society's view of young adults with intellectual disability. Time after time, we are also reminded of just how fragile the newly achieved identity of opposition actually can be.

Mineur et al. (2017) suggested that the impacts of self-advocacy may be mediated by a number of factors, including people's role and level of responsibility within the group, and the model of self-advocacy organization in operation. This is an area of study that warrants further research. However, despite the potential negative impacts associated with self-advocacy in relation to well-being, our systematic review provides evidence that for many people these appear to be outweighed by the positive impact on well-being as a result of participation in a self-advocacy organization.

The strengths of the papers reviewed here are that they highlight the ways individuals across groups in different countries have experienced self-advocacy over several decades. While our review focused on research that includes the direct contributions of people with intellectual disabilities (in order to capture data on subjective well-being), the present authors are mindful that this raises further issues for consideration. For example, is possible that one consequence of a review based on self-report alone is an overstatement of the positive aspects of self-advocacy, and a failure to consider its weaknesses. Redley and Weinberg's (2007) paper, not included in this systematic review because it related to a study of a UK Learning Disability Parliament, pointed to a tendency amongst academic studies of self-advocacy to favour liberal

models of citizenship which prioritize voice over care, security and well-being. Furthermore, as Walmsley and Downer pointed out in 1997, few self-advocates have severe and profound learning disabilities—which would preclude their responding to the verbally based research methods exclusively relied upon for the papers reviewed here. The present authors found no evidence as to whether membership of a self-advocacy group supports the well-being of such individuals—indeed, they are largely absent in the literature on self-advocacy. One might add that there is an extensive grey or non-peer-reviewed literature on self-advocacy, which, for practical reasons, was excluded from the systematic review, but which might possibly shed different light.

As part of an inclusive process, the findings from this systematic review were discussed with the fifth author who has intellectual disabilities. She reported that her own experiences of being a member and an employee of a self-advocacy organization for over 20 years aligned with the conclusions of the systematic review that being a member of a self-advocacy group has a positive impact on one's well-being. She also highlighted the critical issue of someone's agency to be able to engage with a self-advocacy group. She remarked that "If people don't want support, then you can't help them. And it's their choice." As demonstrated in the review, self-advocacy can positively influence well-being, yet is not always accessible for those in a need of more substantial support.

Last but not least, she reflected that she was surprised that within the 16 articles reviewed, there had not been more discussion about what the self-advocacy groups "stand for, what is their mission and what are their objectives." As an example, she talked about her self-advocacy organization, which is grounded in person-centredness; that is, a person with intellectual disability and their needs and priorities are at the centre of their work. She acknowledged that other self-advocacy organizations take a different approach, and rather than supporting individual self-advocates in their goals, they instead focus is on a particular issue, for example rights of people with intellectual disabilities to be parents. She suggested that future research should examine the relationship between the model of self-advocacy organization in operation, and its impact of people's well-being.

5 | CONCLUSION

This systematic review has shown that participation in self-advocacy organizations does appear to have significant impacts on the subjective well-being of people with intellectual disabilities across the four domains of the Dynamic Model of Wellbeing. In addition, self-advocacy groups can provide a space for people to discuss and re-theorize painful experiences of bullying and abuse. The present authors have highlighted both the strengths and limitations of the literature reviewed, notably its reliance on self-reporting. More research is needed to explore the potential impact of self-advocacy on people with profound intellectual disabilities, and different methodological approaches are required to capture more diverse perspectives. The present authors also argue that research is needed to explore the relationship between different self-advocacy models and well-being, as well as self-advocacy's impact on people with intellectual disabilities' physical and mental health in the contemporary context. In the meantime, self-advocacy organizations, statutory authorities, commissioners and other funding bodies should be made aware of the positive impacts of self-advocacy people's well-being as reported in the literature.

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REFERENCES

Abdallah, S., Mahony, S., Marks, N., Michaelson, J., Seaford, C., Stoll, L., & Thompson, S. (2011). *Measuring our progress: The power of wellbeing*. London UK: New Economics Foundation.

Aknin, L. B., Sandstrom, G. M., Dunn, E. W., & Norton, M. I. (2011). Investing in others: Prosocial spending for (pro) social change. In R. Biswas-Diener (Ed.), *Positive psychology in social change* (pp. 219–234). Dordrecht, The Netherlands: Springer.

Anderson, S., & Bigby, B. (2017). Self-advocacy as a means to positive identities for people with intellectual disability: 'We just help them, be them really'. *Journal of Applied Research in Intellectual Disabilities*, *30*, 109–120. https://doi.org/10.1111/jar.12223

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.

Buchanan, I., & Walmsley, J. (2006). Self-advocacy in historical perspective. *British Journal of Learning Disabilities*, *34*(3), 133–138. https://doi.org/10.1111/j.1468-3156.2006.00410.x

Bylov, F. (2006). Patterns of culture and power after the great release: The history of movements of subculture and empowerment amongst Danish people with learning difficulties. *British Journal of Learning Disabilities*, *34*(3), 139–145.

Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*, *49*(5), 315–326. https://doi.org/10.1352/1934-9556-49.5.315

Caldwell, L. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, *54*, 1004–1014. https://doi.org/10.1111/j.1365-2788.2010.01326.x

Carroll, C., Booth, A., & Cooper, K. (2011). A worked example of" best fit" framework synthesis: A systematic review of views concerning the taking of some potential chemopreventive agents. *BMC Medical Research Methodology*, *11*(1), 29. https://doi.org/10.1186/1471-2288-11-29

Chapman, R. (2004). An exploration of the self-advocacy support role through collaborative research: 'There should never be a them and us'. *Journal of Applied Research in Intellectual Disabilities*, *27*, 44–53.

Chida, Y., & Steptoe, A. (2008). Positive psychological well-being and mortality: A quantitative review of perspective observational studies. *Psychosomatic Medicine*, *70*, 741–756. https://doi.org/10.1097/PSY.0b013e31818105ba

Clarke, R., Camilleri, K., & Goding, L. (2015). What's in it for me? The meaning of involvement in a self-advocacy group for six people with

intellectual disabilities. *Journal of Intellectual Disabilities*, *19*(3), 230–250. https://doi.org/10.1177/1744629515571646

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educational and Psychological Measurement*, *20*, 37–46.

Crawley, B. (1988). *The growing voice: A survey of self advocacy organisations in adult training centres and hospitals in Great Britain*. London, UK: Campaign for Mentally Handicapped People.

Department of Health (2001). *Valuing people: A new strategy for learning disability for the 21st Century*. London, UK: HMSO.

Diener, E. (2012). New findings and future directions for subjective well-being research. *American Psychologist*, *67*, 590–597. https://doi.org/10.1037/a0029541

Diener, E., Nickerson, C., Lucas, R. E., & Sandvik, E. (2002). Dispositional affect and job outcomes. *Social Indicators Research*, *59*, 229–259. https://doi.org/10.1023/A:1019672513984

Dixon-Woods, M. (2011). Using framework-based synthesis for conducting reviews of qualitative studies. *BMC Medicine*, *9*(1), 39. https://doi.org/10.1186/1741-7015-9-39

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B., & Sutton, A. (2005). Synthetising qualitative and quantitative evidence: A review of possible methods. *Journal of Health Services Research & Policy*, *10*(1), 45–53.

Fenn, K., & Scior, K. (2019). The psychological and social impact of self-advocacy group membership on people with intellectual disabilities: A literature review. *Journal of Applied Research in Intellectual Disabilities*, *32*, 1349–1358. https://doi.org/10.1111/jar.12638

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*, *40*(3), 254–264. https://doi.org/10.3109/13668250.2015.1028910

García Iriarte, E., O'Brien, P., McConkey, R., Wolfe, M., & O'Doherty, S. (2014). Identifying the key concerns of Irish persons with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *27*, 564–575. https://doi.org/10.1111/jar.12099

Gilmartin, A., & Slevin, E. (2009). Being a member of a self-advocacy group: Experiences of intellectually disabled people. *British Journal of Learning Disabilities*, *38*, 152–159.

Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties*. Buckingham, UK: Open University Press.

Goodley, D., Armstrong, D., Sutherland, K., & Laurie, L. (2003). Self-advocacy, "learning difficulties," and the social model of disability. *Mental Retardation*, *41*(3), 149–160. https://doi.org/10.1352/0047-6765(2003)41<149:SLDATS>2.0.CO;2

Hall, E. (2005). The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & Place*, *11*, 107–115. https://doi.org/10.1016/j.healthplace.2004.10.007

Henderson, D., & Bigby, C. (2016). 'We Were More Radical back then': Victoria's First Self-Advocacy Organisation for People with Intellectual Disability. *Health History*, *18*(1), 42–66.

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from variety of fields*. Alberta Heritage Foundation for Medical Research. Retrieved from https://www.ihe.ca/advanced-search/standard-quality-assessment-criteria-for-evaluating-primary-research-papers-from-a-variety-of-fields

McHugh, M. L. (2012). Interrater reliability: The kappa statistic. *Biochemia Medica*, *22*(3), 276–282.

McGarty, A. M., & Melville, C. A. (2018). Parental perceptions of facilitators and barriers to physical activity for children with intellectual disabilities: A mixed method systematic review. *Research in Developmental Disabilities*, *73*, 40–57.

McNally, S. J. (2003). A survey of self-advocacy groups for people with learning disabilities in an English region: Part II. *Journal of Learning Disabilities*, *7*(3), 231–250. https://doi.org/10.1177/14690047030073004

Michaelson, J. (2013). Forward from foresight: The uses of the New Economic Foundation's wellbeing work. *Journal of Public Mental Health*, *12*(2), 98–102.

Mineur, T., Tideman, M., & Mallander, O. (2017). Self-advocacy in Sweden - an analysis of impact on daily life and identity of self-advocates with intellectual disability. *Cogent Social Sciences*, *3*(1), 1–16. https://doi.org/10.1080/23311886.2017.1304513

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, *6*(7), e1000097. https://doi.org/10.1371/journal.pmed.1000097

National Forum (2011). *Staying strong: Taking self-advocacy into the future*. Shoreham-On-Sea, UK: National Forum.

NEF (2019) *Wellbeing at work*. Retrieved from https://www.nefconsulting.com/our-services/strategy-culture-change/well-being-at-work/

OECD (2013). *OECD Guidelines on measuring subjective well-being*. OECD Publishing, https://doi.org/10.1787/9789264191655-en

Oswald, A. J., Proto, E., & Sgroi, D. (2015). Happiness and productivity. *Journal of Labor Economics*, *33*, 789–822. https://doi.org/10.1086/681096

Power, A., & Bartlett, R. (2018a). Self-building safe havens in a post-service landscape: How adults with learning disabilities are reclaiming the welcoming communities agenda. *Social & Cultural Geography*, *19*(3), 336–356. https://doi.org/10.1080/14649365.2015.1031686

Power, A., & Bartlett, R. (2018b). 'I shouldn't be living there because I am a sponger': Negotiating everyday geographies by people with learning disabilities. *Disability & Society*, *33*(4), 562–578. https://doi.org/10.1080/09687599.2018.1436039

Power, A., Bartlett, R., & Hall, E. (2016). Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity. *Journal of Intellectual Disabilities*, *20*(2), 183–189. https://doi.org/10.1177/1744629516634561

Redley, M., & Weinberg, D. (2007). Learning disability and the limits of liberal citizenship: Interactional impediments to political empowerment. *Sociology of Health & Illness*, *29*(5), 767–786. https://doi.org/10.1111/j.1467-9566.2007.01015.x

Ryan, T., & Griffiths, S. (2015). Self-advocacy and its impacts for adults with developmental disabilities. *Australian Journal of Adult Learning*, *55*(1), 31–53.

Simons, K. (1992). *Sticking up for yourself: Self-advocacy and people with learning difficulties*. York, UK: Joseph Rowntree Foundation.

Soldatic, K., & Johnson, K. (2019). *Global perspectives on disability activism and advocacy: Our way*. New York, NY: Routledge.

Strnadová, I., Johnson, K., & Walmsley, J. (2018). ".. but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities? *Journal of Applied Research in Intellectual Disabilities*, *31*, 1091–1102.

Tideman, M., & Svensson, O. (2015). Young people with intellectual disability. The role of self-advocacy in a transformed Swedish welfare system. *International Journal of Qualitative Studies on Health and Well-being*, *10*(1), 1–8.

Tilley, E. (2013). Management, leadership and user control in self-advocacy: An english case study. *Intellectual and Developmental Disabilities*, *51*(6), 470–481. https://doi.org/10.1352/1934-9556-51.6.470

United Nations (2006). *Convention on the rights of persons with disabilities*. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Walmsley, J. (2016). Speaking with one voice. *Community Living*, *29*(4), 12–13.

Walmsley, J. (2020). From 'nice to have' to life saver. *Community Living*, *33*(2), 23.

Walmsley, J., Downer, J. (1997). Shouting the loudest: Self advocacy, power and diversity. In P. Ramcharan (Ed.), *Empowerment in everyday life* (pp. 35–47). London, UK: Jessica Kingsley.

Walmsley, J., & Jarrett, S. (2019). *Intellectual disability in the twentieth century. Transnational perspectives on people, policy, and practice*. Bristol, UK: Policy Press.

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures*. London, UK: Jessica Kingsley Publishers.

Williams, P., & Shoultz, B. (1982). *We can speak for ourselves*. London, UK: Souvenir Press.

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