

Scoping review of health outcomes for people with disabilities in user-led organisations

Michael Crowe  ^{A,C,*} and Lorraine Sheppard ^{B,*}

^ACollege of Healthcare Sciences (Physiotherapy), James Cook University, Townsville, Qld 4811, Australia.

^BSchool of Health Sciences (Physiotherapy), University of South Australia, Adelaide, SA 5001, Australia.

^CCorresponding author. Email: michael.crowe@jcu.edu.au

Abstract. A user-led organisation (ULO) may be defined as an organisation that is run and controlled by the people who use the services provided by that organisation. ULOs provide services to their members, such as information, advice, support, treatment and training. ULOs may also be involved in advocacy, influencing local service provision, government policy and public perceptions of disability. This scoping review concentrated on health outcomes achieved by ULOs for people with disabilities, including physical, sensory, cognitive, intellectual, neurological or mental health impairments. Based on a search of the academic literature up to 30 June 2020, 26 articles were included. Twenty-four articles were on ULOs for mood disorders, schizophrenia or psychosis, and there was one article each on ULOs for cross-disability and chronic non-malignant pain. There was some evidence that peer-run and inclusive ULOs for members with mood disorders, schizophrenia or psychosis can reduce the number of times people with these illnesses access traditional mental health services. There was no evidence that ULOs can replace traditional mental health services. Therefore, ULOs for mood disorders, schizophrenia or psychosis could be considered an adjunct to traditional mental health services, not a replacement. For other disabilities, a lack of evidence means that no recommendation can be made. However, the organisational structure of ULOs may be as important as the support and services offered.

Keywords: disability, advocacy, National Disability Insurance Scheme, NDIS, user-controlled, user-driven, peer-led, consumer-led.

Received 18 August 2020, accepted 25 May 2021, published online 15 October 2021

Introduction

People with disabilities have the same rights as people without disabilities, and therefore have the right to an ‘ordinary’ life, whatever that may mean for the individual, rather than relying on paternalism, charity or familial duty (National Health Committee 2003). For organisations that involve people with disabilities, there are nuances in what to call these organisations and what constitutes such an organisation. Since the 1970s, people with disabilities have led political, advocacy and service movements with the aim of full recognition of the rights for people with disabilities in economic, human and community integration (Union of the Physically Impaired Against Segregation and Disability Alliance 1975; Bott *et al.* 2010).

A general name for organisations involving people with disabilities has been a sticking point because the organisations want to reflect the rights of people with disabilities. Names that invoke images of passivity, reliance or victimhood are not appropriate. In the UK, the dominant term is ‘user-led organisation’ (ULO). Some organisations do not like this term because it

does not reflect that service users also control the organisation. For example, the term used by *Shaping Our Lives* (2013) is ‘user-controlled organisation’ and Woodin (2006) used ‘service user-led organisations’. However, ‘ULO’ is the term used in this article because it is extensively used in the UK and sometimes used in Canada, and ULO can be changed into ‘non-user led organisation’ (NULO) to indicate organisations that do not have users making decisions, whereas terms such as ‘non-service user organisation’, ‘non-service user-led organisations’ or similar are clumsy or ambiguous.

A ULO can be defined as an organisation that is run and controlled by the people who use the services provided by that organisation. ULOs can provide services to their members, such as information, advice, support, treatment and training. ULOs may also be involved in advocacy for their members by attempting to influence local service provision, state and federal policy and public perceptions of disability (Fig. 1). In the UK, government guidelines state that 75% of a ULO’s management committee must be made up of users (Social Care,

*Joint first authors.

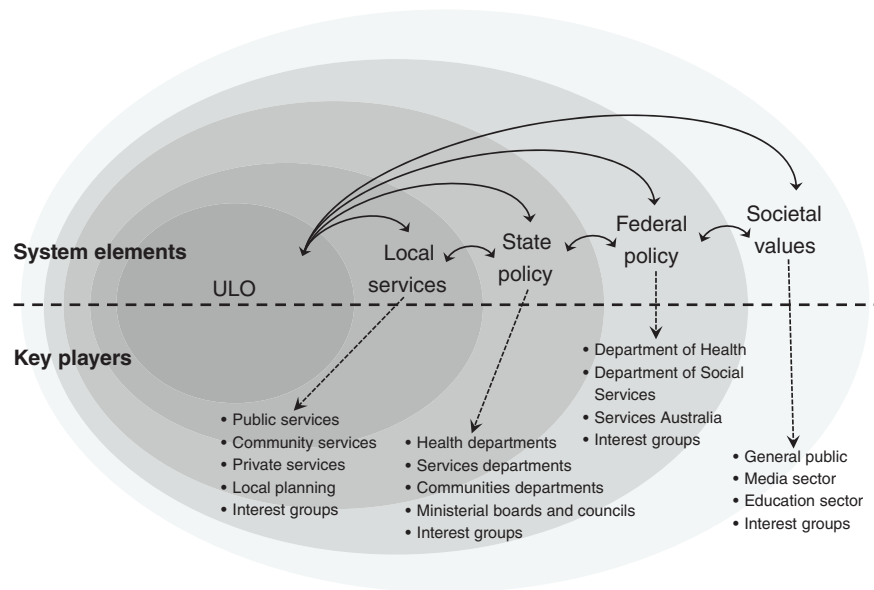


Fig. 1. The system around ULOs, based on Janzen *et al.* (2007).

Local Government and Care Partnerships Directorate and Department of Health 2007). In the US, Ostrow and Hayes (2015) based their research using a definition of a peer-controlled organisation as having at least 91% of the board of directors as users and that of a peer-directed organisation as having 51–91% of the board of directors as users. There are no known restrictions on management committees or directorships for ULOs in Australia.

In the UK there is also debate over whether ULOs should allow carers to be members (Morris 2006). People with physical and sensory impairments have stated that if they are to be considered equal to people without disabilities, then they should not need to rely on unpaid assistance from family members or friends. Furthermore, the interests of carers may, from time to time, conflict with the needs of users, and having carers in a ULO may change the dynamic of or power relationships in the organisation. There are two main counter arguments to these positions: (1) although carers may not have any disability, they require services, support and advice just like someone with disabilities; and (2) having carers involved has not been a problem for people with learning disabilities and, if a problem did occur, then the ULO should have processes to prevent or manage these conflicts. ULOs have been established that do not allow carers to be members, and these groups are known as ‘disabled peoples’ user-led organisations’ (DPULO; Office for Disability Issues 2012).

In Australia, the National Disability Insurance Scheme (NDIS), which supports people aged <65 years with permanent and significant disability, committed A\$100 million over 3 years to support ULOs and NULOs (NDIS 2019). Although a commitment to ULOs and NULOs is commended, this still leaves the question of what evidence exists that involvement with a ULO improves health outcomes for individuals or groups of people with disabilities?

Methods

Given the wide scope of the question, health outcomes were defined as those achieved by ULOs that were comparable to those from programs led by a health professional (Pistrang *et al.* 2008). The research question is not meant to deny other benefits ULOs provide, such as information, advice, support, training and advocacy. These functions of ULOs are not considered in this review to concentrate instead on health outcomes only. Furthermore, this is not to say that the interventions provided by ULOs are, or should be, the same as interventions by health professionals. This is simply not possible because there are interventions by health professionals that are not and cannot be replicated in a ULO for legal or ethical reasons. Similarly, there are interventions that ULO members can undertake that may be unavailable to health professionals. The purpose of this position was to set a standard for evaluating health outcomes achieved by users of these services.

This scoping review was based on the search strategy and synthesis commonly found in systematic reviews. However, where a systematic review requires a detailed critical appraisal of the research retrieved to assess the rigour of the research, that was not done in this instance because the objective was to examine the range of health outcomes reported and the *prima facie* evidence for those outcomes.

This research did not require ethics review because the data were collected from existing published materials and not from individuals.

Inclusion criteria

To be included in the scoping review, a study had to: (1) be based on one or more impairments, including physical, sensory, cognitive, intellectual, neurological or mental health, whether present from birth or acquired; (2) be based on a ULO where people with a disability must decide the strategy for and manage

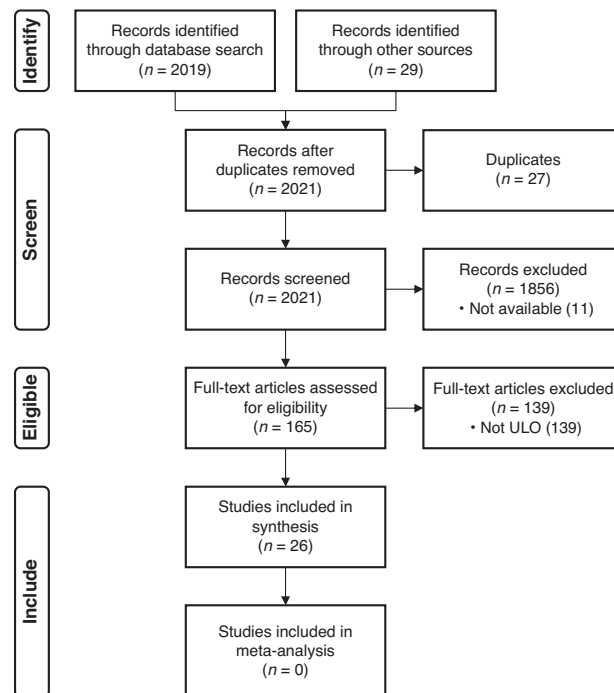


Fig. 2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram.

the running of that organisation; (3) report on health outcomes that can be attributed to a service or services run by a ULO, or through involvement in a ULO (see also exclusion criteria); (4) be of any research design; and (5) be published in English, because neither author was fluent in another language.

Exclusion criteria

Given that the aim of the study was to determine ULO-based health outcomes, the following were excluded: (1) opinions, reportage or anecdotes: these materials were not considered appropriate for appraising health outcomes achieved; (2) interventions researched within one or more ULOs but not instigated or run by a ULO: these studies focus on the interventions rather than the ULOs themselves; (3) public or private user-led programs: although called ‘user-led’, these services do not meet the definition used for a ULO (i.e. run by and for the users); (4) cooperation between traditional service providers and ULOs: this was considered an organisational or structural issue rather than a measure of ULO health outcomes and, furthermore, may be a confounding factor for health outcomes attributed to ULOs; and (5) studies reporting on health service delivery: ULOs that provide services to non-users because the scope of a ULO is usually much broader (e.g. advocacy).

Search strategy

CINAHL, Scopus, Medline (via Ovid), Centre for Reviews and Dissemination and the Cochrane Library databases were searched for articles published up to 30 June 2020. The reference lists of identified articles were also searched to find further articles that may not have been found in the database searches.

A full account of the search strategy used is provided in Supplementary Appendix S1. The grey literature was searched using Google and the references in articles were accepted for inclusion in the review. The terms used in the search of the grey literature were the same as those for the search of the academic literature.

Synthesis of results

Articles were screened, assessed and analysed, and data were extracted by both authors. Data were explored through thematic analysis and investigation of quantitative results.

Results

Of the 2048 articles retrieved, 26 were accepted for inclusion in this review (Fig. 2): 14 were from the US, five were from Canada, three were from the UK, two were from Australia, one was from New Zealand and one was a multicountry review (Table 1). The research methods used in the articles varied; nine were qualitative studies, five were mixed-methods studies, four were reviews, four were exploratory studies and another four were experimental studies. Twenty-two articles were on mental health, two were on cross-disability and one was on chronic non-malignant pain. The articles are discussed based on the disability covered. It should be noted that the statistics presented are based on those available in the articles included in this review and may not meet current standards for statistical reporting. A formal critical appraisal of the articles was not undertaken because this is a scoping review. Therefore, the results and the conclusions drawn in the cited articles should be interpreted with this in mind.

Table 1. Literature summary by year published

Study	Country	Research type	Sample	Area	Outcomes
Subramaniam <i>et al.</i> (1999)	New Zealand	Mixed-methods, prospective study Standard measures and interview at baseline and 5 months	13 participants	Chronic non-malignant pain	Less functional disability ($t_{12} = 2.68, P < 0.04$) 50% decrease in pain-related contact with family doctor
Powers <i>et al.</i> (2002)	USA	Survey	3 studies	Cross-disability	'The importance of personal control...' Themes: self-directed, empowerment, liberation, peer-run, self-determination
Eysenbach <i>et al.</i> (2004)	UK	Review	45 articles	Mental health	'No robust evidence... because most peer to peer communities have been evaluated only in conjunction with more complex interventions...'
Goering <i>et al.</i> (2006)	Canada	Multisite evaluation	4 CSI, 73 participants 4 ACT, 48 new and 134 ongoing participants	Mental health	ULOs serve '... a broader population of individuals who include a significant subgroup of persons with severe mental illness along with others with a mixed picture of higher functioning and greater instability'
Nelson and Lomotey (2006)	Canada	Mixed-methods, prospective study Quality and quantity of participation every 2 months Baseline and 9 and 18 months	4 CSI, 79 participants (new members)	Mental health	'... driven by the needs of members'
Nelson <i>et al.</i> (2006)	Canada	Mixed-methods study (scales, interviews, participatory action research) Baseline and 9 and 18 months	4 CSI, 61 active participants, 57 non-active participants	Mental health	Active vs non-active: <ul style="list-style-type: none"> • Use of emergency room ($t_{62} = 2.38, P < 0.05$) • Social support ($t_{60} = 2.55, P < 0.05$) • Quality of life – daily activities ($t_{60} = 2.51, P < 0.05$) • Psychiatric hospitalisation days ($t_{56} = 2.81, P < 0.01$) • Involvement employment or education ($t_{48} = 3.46, P < 0.0001$) Dropped out: <ul style="list-style-type: none"> • Younger ($t_{159} = 2.60, P = 0.01$) • Lower scores for • Social support ($t_{159} = 3.53, P < 0.0001$) • Community integration ($t_{147} = 2.26, P < 0.01$) • Personal empowerment ($t_{158} = 2.56, P < 0.05$) • Quality of life – living situation ($t_{159} = 3.17, P < 0.01$) • Quality of life – safety ($t_{159} = 3.47, P < 0.0001$) • Quality of life – daily activities ($t_{159} = 2.91, P < 0.01$) • Higher symptom distress ($t_{159} = 2.49, P < 0.05$) • Less likely to have a primary therapist ($\chi^2 = 8.37, d.f. = 1, P < 0.01$) • More likely to be hospitalised in past 9 months ($\chi^2 = 4.72, d.f. = 1, P < 0.05$)
Ochocka <i>et al.</i> (2006)	Canada	Mixed-methods study (scales, interviews, participatory action research) Baseline and 9 and 18 months	4 CSI, 15 active participants, 12 non-active participants	Mental health	ULOs provide safe environments, social outlets, opportunities for participation and contribution and community integration

ACT, assertive community treatment; CMHS, community mental health service; COSP, consumer-operated service program; CRO, consumer run organisation; CRP, crisis residential program; CSI, consumer/survivor initiatives; DBSA, Depression and Bipolar Support Alliance; GAIN-I, Global Appraisal of Individual Needs-Initial; LIPF, locked inpatient psychiatric facility; MHO, mutual-help organisation; NULO, non-user led organisation; Q-LES-Q, Quality of Life Enjoyment and Satisfaction Questionnaire; SHA, self-help agency; SWLS, Satisfaction with Life Scale; ULO, user-led organisation

Hutchison <i>et al.</i> (2007)	Canada	Qualitative case study	4 ULO, 5 NULO	Cross-disability	ULOs focus on quality of life, equality, participation and human rights.
Rogers <i>et al.</i> (2007)	USA	Trial, multisite Baseline and 4, 8 and 12 months	8 sites, 1827 participants	Mental health	Time × Group interactions: <ul style="list-style-type: none"> • Making decisions empowerment ($F_{1,3815} = 5.68, P = 0.02$) • Personal empowerment – Choice ($F_{1,3818} = 5.41, P = 0.02$) • Organisationally mediated empowerment ($F_{1,4075} = 4.75, P = 0.03$) Time × Engagement interactions: <ul style="list-style-type: none"> • Making decisions empowerment ($F_{2,1306} = 7.03, P = 0.02$) • Personal empowerment – choice ($F_{2,1316} = 3.15, P = 0.04$) Empowering experiences ($z = 3.00, P < 0.05$) Socially supportive experiences ($z = 5.93, P < 0.05$) Loss to follow-up at 1 month ($\chi^2 = 6.67, P = 0.01$) Brief Psychiatric Rating Scale ($b = -0.11, P < 0.05$) Hopkins Symptom Checklist-40: <ul style="list-style-type: none"> • Psychoticism ($b = 0.20, P < 0.001$) • Depression ($b = 0.16, P < 0.01$) • Anxiety ($b = 0.15, P < 0.05$) Uniform Client Data Inventory – Social Activity ($b = 0.31, P < 0.05$) Rosenberg Self-Esteem Scale ($b = 0.64, P < 0.05$) ‘Improved’ psychological and social functioning Survival: <ul style="list-style-type: none"> • Hierarchical ULO, median 26 months (95% CI 8.5–43.4) • True ULO, median 36 months (95% CI 21.6–50.5) See Table 2
Brown <i>et al.</i> (2008)	USA	Survey	20 CRO, 250 participants	Mental health	
Greenfield <i>et al.</i> (2008)	USA	Randomised control trial Baseline and 1, 6 and 12 months	196 CRP participants, 197 LIPF participants	Mental health	
Pistrang <i>et al.</i> (2008)	USA	Review, quantitative studies	12 studies	Mental health	
Salem <i>et al.</i> (2008)	USA	Mixed-methods study	Case study of an MHO and advocacy group partnership	Mental health	
Brown (2009a)	USA	Survey, especially two short answer questions	20 CRO, 194 participants	Mental health	
Brown (2009b)	USA	Grounded theory	1 CRO, 7 participants	Mental health	See Table 2
Munn-Giddings <i>et al.</i> (2009)	UK	Qualitative	4 ULO, 48 participants, organisation documents	Mental health	Four themes: <ul style="list-style-type: none"> • Led by and for people with the same health or social issues • Provide solutions and coping strategies • Complement traditional services • Staff/members are non-judgemental, supportive, understanding, peers ‘...some psychiatrists and other providers...fear potential liability if they make referrals [to ULOs] and something harmful occurs.’ N/A
Salzer and Kundra (2010)	USA	Review	N/A	Mental health	
Segal <i>et al.</i> (2010)	USA	Randomised control trial Baseline and 1, 3 and 8 months	Baseline: 1042 8 months: 403 SHA-CMHA, 102 CMHA	Mental health	
Taylor <i>et al.</i> (2010)	Australia	Participatory action research	14 participants (plus informal input from others)	Mental health	ULOs develop because of lack of traditional services Mental health service involvement gave ULO legitimacy ULOs as good as traditional services for: <ul style="list-style-type: none"> • Outcomes such as employment or living arrangements • Reduced hospitalisations • Reduced cost of services
Doughty and Tse (2011)	n/a	Review, controlled studies	29 studies	Mental health	

(continued next page)

Table 1. (Continued)

Study	Country	Research type	Sample	Area	Outcomes
Henderson and Battams (2011)	Australia	Qualitative	10 interviews	Mental health	Competition for resources (state vs Commonwealth) Clinical silos, lack of coordination Mental health advocacy need to use the <i>Disability Discrimination Act 1992</i> (Commonwealth)
Segal <i>et al.</i> (2011)	USA	Randomised control trial	1 CMHA + COSP, 86 participants	Mental health	Independent social integration ($F_{1,123} = 16.94, P < 0.001$) Personal empowerment ($F_{1,123} = 7.98, P < 0.006$) Self-efficacy ($F_{1,123} = 12.16, P < 0.001$) Traditional mental health services promoting community and socialisation is artificial; ULO is authentic or real
Lewis <i>et al.</i> (2012)	USA	Baseline and 8 months Ethnography (observe, interview, participation)	1 CRO, 25 in semi-structured interviews, 22 in focus groups, 17 in dramatic skits	Mental health	See Table 2
Behler <i>et al.</i> (2017)	USA	Grounded theory, constructivist	4 groups (43 participants, 20 in-depth interviews)	Mental health	See Table 2
Budge <i>et al.</i> (2019)	UK	Participatory appraisal (participatory action research)	1 organisation, 9 in focus groups, 7 interviews, 3 community documents	Mental health	See Table 2
Kelly <i>et al.</i> (2019)	USA	Cross-section, cohort study	202 DBSA MHO 105 non-DBSA	Mental health	GAIN-I, Q-LES-Q, SWLS, DBSA attendance and involvement Spearman $r = 0.26$, Q-LES-Q and DBSA involvement Spearman $r = 0.22$ SWLS and DBSA involvement

Cross-disability and chronic non-malignant pain

In the study on chronic non-malignant pain (Subramaniam *et al.* 1999), 13 participants who had recently joined a ULO were enrolled in a prospective, mixed-methods before-and-after study with data collected at baseline and 5 months. The measures used were the Multidimensional Pain Inventory and interviews regarding participants' experiences of living with pain. Participants had less functional disability at follow-up than at the beginning of the study ($t_{12} = 2.68, P < 0.04$). In addition, participants had 50% fewer GP visits in the 2- to 5-month period after joining the group than in the 3-month period before joining the group. This was attributed to participants gaining greater support within the ULO and seeking less support from their GP. This conclusion was based on participants' stated major reasons for joining the ULO of discovering new information on pain management, having an opportunity to learn from others with a similar problem and helping each other through social contact and friendship (Subramaniam *et al.* 1999).

Of the two cross-disability studies, one was a qualitative case study of ULOs and NULOs in Canada (Hutchison *et al.* 2007) and the other consisted of three surveys exploring the involvement of people with disabilities in organisations for those with disabilities (Powers *et al.* 2002). The authors of both studies came to similar conclusions, stating that the reasons people with disabilities became involved in and remained members of ULOs was because the organisations were peer-run and emphasised quality of life, equality, participation, self-direction, self-determination empowerment and human rights.

Mental health

Mental health ULO research was primarily focused on mood disorders (e.g. depression, bipolar disorder), schizophrenia and psychosis.

Benefits from services and involvement

To gain a theoretical understanding of how ULOs can benefit their members, Brown (2009b) used a grounded theory approach that involved observation and life history interviews of seven participants with severe and persistent mental illness from a single ULO in Kansas in the US. In a follow-up study to test the validity of the conceptual model built from grounded theory, Brown (2009a) conducted a survey of 192 users with severe and persistent mental illness from 20 ULOs in which two open-ended questions were analysed in-depth. Although each participant had different ULO experiences and achieved different health outcomes from their involvement, the model was useful in conceptualising how these changes occurred (Brown 2009a). This resulted in a three-tier, seven-step and 18-personal-change-category concept of benefits to members of ULOs (Table 2).

The tiers represent a deepening involvement in a ULO, starting with person-environment interaction and then role and relationship development. The third tier is the greatest level of involvement, where individuals choose or can fall into different roles in the ULO. The seven steps and 18 categories of personal change are the benefits that members realise due to their membership and involvement in the organisation (Brown 2009a, 2009b).

Behler *et al.* (2017) also undertook a grounded theory examination of four ULOs, with 20 in-depth interviews of

Table 2. ULO involvement

Brown (2009a, 2009b)	Behler <i>et al.</i> (2017)	Budge <i>et al.</i> (2019)
1. Person–environment interaction (interpersonal interaction, positive atmosphere, recreation activities, work activities)	1. Being with peers who have shared the same experiences of mental illness and can relate in a more direct way than family and professionals, who have only observed others having these experiences, provides a unique and desirable benefit towards wellness, functionality, and recovery	1. Negotiating relationships
2. Role and relationship development (help provider, increased activity, social networks)	2. Peer support facilitates social identification with others who share the same diagnoses, thereby promoting wellness, function and recovery 3. Watching other people help themselves and get well encouraged and promoted normalisation of one's own behaviour	
3a. Resource exchange (information, paid employment, social support)	4. People within peer-support groups provide suggestions, share experiences and give tips that are more meaningful than those that come from professionals who do not have lived experiences 5. Participants shared information and experiences with psychiatric medications and used the groups to become more informed consumers and to take more agency in managing their medications 6. Group members shared information about positive and negative experiences with mental health professionals and used the group to become more informed and selective consumers of psychotherapy and psychiatry services, educating each other in what good services were and how to recognise bad services	
3b. Self-appraisal (optimism, self-esteem)	7. Good peer group leaders are in recovery from mental illness; they welcome, accept, support, are non-judgmental, understand, listen, attend to group tasks and have good people skills, whereas clinicians do not generally reveal personal attributes or tell personal experiences, and may or may not have had experience with mental illness	2. Feeling the responsibility of involvement
3c. Build role skills (coping skills, job skills, social skills)		3. Sharing power
3d. Identity transformation (conscientious, independence, outgoing, sense of belonging)	8. Peer groups do not last forever; the lifecycle of a group depends on the leader and the group dynamics and can change frequently, unlike professional services, which are more consistent unless a provider relocates 9. These groups are a positive, helpful and powerful force in the lives of the participants (who continue in these groups)	

people with mental illness. Behler *et al.* (2017) established nine themes (Table 2), which overlapped with those of Brown (2009a, 2009b), particularly Concepts 1–3a of Brown (2009a, 2009b) and Themes 1–6 Behler *et al.* (2017), which emphasise the shared experience in the ULO.

Budge *et al.* (2019) looked at ULOs from the perspective of participatory democracy. The study of one ULO was based on a form of participatory action research called participatory appraisal. Although narrower in focus than the studies of Brown (2009a, 2009b) and Budge *et al.* (2019), there are some overlaps (Table 2), especially with regard to the topic of shared experience, with Budge *et al.* (2019) stating:

...survivors involved in participatory democratic processes can experience meaningful social support, a sense of empowerment, and both choice and control in the ways in which they participate.

A survey of 250 members of 20 user-led mental health organisations showed that empowering experiences ($z = 3.00$, $P < 0.05$) and socially supportive experiences ($z = 5.93$, $P < 0.05$) were positively associated with mental health recovery (Brown *et al.* 2008). Kelly *et al.* (2019) also found some evidence that more involvement in a support group was associated with better health outcomes (Quality of Life Enjoyment and Satisfaction Questionnaire, Spearman $r = 0.26$; Satisfaction with Life Scale, Spearman $r = 0.22$; $n = 202$). In the qualitative portion of a mixed-methods study of four ULOs, 15 active

participants reported the benefits of membership as being more stable mental health, enhanced social support, sustained work, stable income and participation in education and training (Ochocka *et al.* 2006). In the quantitative part of the same study (Nelson *et al.* 2006), active and non-active participants were compared at baseline and at 9 and 18 months. At 9 months, active participants ($n = 64$), compared with non-active members ($n = 65$), had a reduction in the use of emergency room services ($t_{62} = 2.38$, $P < 0.05$). At 18 months, active participants ($n = 61$), compared with non-active members ($n = 57$), had improvements in social support ($t_{60} = 2.55$, $P < 0.05$) and quality of life – daily activities ($t_{60} = 2.51$, $P < 0.05$), as well as a reduction in days of psychiatric hospitalisation ($t_{56} = 2.81$, $P < 0.01$). Furthermore, at 18 months, non-active members were more likely to reduce their involvement in employment or education ($t_{48} = 3.46$, $P < 0.001$).

Nelson *et al.* (2006) also found differences between those participants who remained in the study ($n = 129$) and those who dropped out ($n = 32$). Those who dropped out were younger ($t_{159} = 2.60$, $P = 0.01$), had lower scores on social support ($t_{159} = 3.53$, $P < 0.001$), community integration ($t_{147} = 2.26$, $P < 0.01$), personal empowerment ($t_{158} = 2.56$, $P < 0.05$), quality of life – living situation ($t_{159} = 3.17$, $P < 0.01$), quality of life – safety ($t_{159} = 3.47$, $P < 0.001$) and quality of life – daily activities ($t_{159} = 2.91$, $P < 0.01$) scales, had higher scores on the symptom distress scale ($t_{159} = 2.49$, $P < 0.05$), were less likely to have a primary therapist ($\chi^2 = 8.37$, d.f. = 1, $P < 0.01$) and

were more likely to have been hospitalised for psychiatric problems in the past 9 months ($\chi^2 = 4.72$, d.f. = 1, $P < 0.05$).

Another study looked at the participation in four different ULOs based on measurement scales and interviews with 79 new members (Nelson and Lomotey 2006). In that study, the quality of involvement in the organisation (i.e. meaningfulness, as measured by a nine-point scale) was more important for recovery than the quantity of involvement (i.e. frequency). Although, how this conclusion was reached was difficult to determine from the article.

Whereas the articles described above reported on qualitative or within-subject studies, three articles retrieved had a research design consisting of an intervention and a control group. The first of these studies was an eight-site trial involving 1827 participants, with measures taken at baseline and 4, 8 and 12 months (Rogers *et al.* 2007). The study looked at traditional mental health services (control) compared with a combination of traditional mental health services and participation in one of several ULOs (intervention). One of the major problems encountered in the study was that 15% of the participants allocated to the control group joined a ULO (which they were not supposed to do) and 57% of the intervention group did not join a ULO (which they were supposed to do). There were positive time \times group interaction effects for the Making Decisions Empowerment Scale ($F_{1,3815} = 5.68$, $P = 0.02$), Personal Empowerment – Choice subscale ($F_{1,3818} = 5.41$, $P = 0.02$) and the Organisationally Mediated Empowerment Scale ($F_{1,4075} = 4.75$, $P = 0.03$). There were also positive time \times engagement interaction effects for the Making Decisions Empowerment Scale ($F_{2,1306} = 7.03$, $P = 0.02$) and Personal Empowerment – Choice Subscale ($F_{2,1316} = 3.15$, $P = 0.04$). The results showed that ULOs had a modest, positive effect on participants who were actively involved in the organisation on measures for global empowerment, such as a sense of self-efficacy, control, power and optimism about the future (Rogers *et al.* 2007).

In the second study (Greenfield *et al.* 2008), adults who were facing commitment for severe psychiatric illness were randomly assigned to an unlocked, ULO-managed, crisis residential program (intervention; $n = 196$) or a locked, inpatient psychiatric clinic (control; $n = 197$). Participants were interviewed at baseline and then again at 1, 6 and 12 months. Due to the nature of the participants' illness, loss to follow-up was high (e.g. 30% and 47% in the intervention and control groups respectively at 1 month, and 53% and 59% respectively at 12 months). The ULO had an extensive out-reach program, so loss to follow-up was less for that group (e.g. at 1 month, $\chi^2 = 6.67$, $P = 0.01$) and lower-functioning participants in that group were more likely to be interviewed, thereby potentially underestimating the effectiveness of the intervention (Greenfield *et al.* 2008). Hierarchical linear modelling over time indicated that participants in the ULO program showed improvements compared with control group for the Brief Psychiatric Rating Scale ($b = -0.11$, $P < 0.05$), Hopkins Symptom Checklist-40 (Psychoticism, $b = 0.20$, $P < 0.001$; Depression, $b = 0.16$, $P < 0.01$; Anxiety, $b = 0.15$, $P < 0.05$), Uniform Client Data Inventory – Social Activity Subscale ($b = 0.31$, $P < 0.05$) and Rosenberg Self-Esteem Scale ($b = 0.64$, $P < 0.05$). Greenfield *et al.* (2008) concluded that the participants in the intervention group had

significantly greater improvement and were markedly better satisfied with the service than those in the control group.

In the third article, Segal *et al.* (2010) stated they were creating a general linear model based on five different measurement instruments, namely the Personal Empowerment Scale, Self-Efficacy Scale, Independent Social Integration Scale, Brief Psychiatric Rating Scale and Hopelessness Scale. Participants were randomised to community mental health services only ($n = 102$ at the 8-month follow-up) or a combination of ULO and community mental health services ($n = 403$ at the 8-month follow-up). However, instead of a general linear model, the results were reported as within-subject univariate and between-subject multivariate analysis of variance (Segal *et al.* 2010). Furthermore, no correction was undertaken for multiple measures and, consequently, the results of the study are not included here.

Finally, two literature reviews were found. One review was of 29 controlled trials (Doughty and Tse 2011) and the other was of 12 quantitative studies (Pistrang *et al.* 2008). The authors of both literature reviews reached the conclusion that ULO services had equal or better health outcomes than traditional mental health services, with a reduction in the overall cost to the health sector. No ULO services were found to have negative effects on participants. It is noted that three of the 29 trials in the review by Doughty and Tse (2011) are mentioned in the present review, namely Nelson *et al.* (2006), Ochocka *et al.* (2006) and Greenfield *et al.* (2008), as is one of the 12 articles in the review by Pistrang *et al.* (2008), namely the study by Eysenbach *et al.* (2004). Removing these articles from the analysis did not affect the conclusions reached by Doughty and Tse (2011) or Pistrang *et al.* (2008), or those reached in the present review.

Organisational structure

Although not explicitly stated in the research question or the inclusion and exclusion criteria, a theme was uncovered regarding the organisational structure of ULOs for mental health and how this could affect the health outcomes achieved by members. A hierarchical or bureaucratic organisational structure in ULOs was researched in two studies (Salem *et al.* 2008; Segal *et al.* 2011). The authors of the first study, a mixed-methods case study, concluded that hierarchical ULOs were likely to have a shorter existence than non-hierarchical ULOs, with a median survival period of 26 months (95% confidence interval (CI) 8.5, 43.4) compared with 36 months (95% CI 21.6, 50.5; Salem *et al.* 2008). In the second study, a randomised controlled trial ($n = 139$), the health outcomes were the same for traditional mental health services and a combined intervention of traditional mental health services and membership of a ULO (Segal *et al.* 2011). The results were based on based on the Personal Empowerment Scale, Self-Efficacy Scale, Independent Social Integration Scale, Brief Psychiatric Rating Scale and Hopelessness Scale. In particular, Segal *et al.* (2011) stated that 49 of 86 (57%) participants described the ULO as being preoccupied with organisational efficiency to the detriment of member participation, thereby lessening health outcomes for members.

The importance of member participation was further backed by an ethnographic study where the authenticity of interactions between members was seen as a key aspect of ULOs (Lewis *et al.* 2012). Members of the ULO specifically made distinctions

between 'real friends' (other members) and 'people you know from the outside' (non-members).

Two studies concluded that ULOs for mental health should be a complement to traditional mental health services rather than a replacement (Goering *et al.* 2006; Munn-Giddings *et al.* 2009). The first study was a multisite evaluation of ULOs ($n = 73$) and traditional mental health services ($n = 48$ new clients; $n = 134$ ongoing clients) in four communities in Ontario, Canada (Goering *et al.* 2006). At baseline and 9 and 18 months, participants were asked if they had used certain services in the previous 30 days. In traditional mental health services, 4% of new clients and 5% of ongoing clients had contacted a ULO, and 33% of ULO members had used a traditional mental health service (Goering *et al.* 2006). In the second article, a qualitative study of 48 participants across four ULOs from England, ULO members stated that their membership was a complement to traditional mental health services and not a replacement (Munn-Giddings *et al.* 2009).

Finally, there were two reviews on ULO structure (Eysenbach *et al.* 2004; Salzer and Kundra 2010). The first of these reviewed 45 articles on the use of computer-based ULOs and found no evidence for their effectiveness (Eysenbach *et al.* 2004). The second reviewed evidence for whether psychiatrists in the US could be held liable for referring patients to mental health ULOs (Salzer and Kundra 2010). The authors of that study found no evidence for legal liability because referrals to mental health ULOs were considered current standard of care, and so not referring a patient to a mental health ULO was being overly conservative.

Australian context

Two articles were found that related to the Australian context on mental health ULOs (Taylor *et al.* 2010; Henderson and Battams 2011). Henderson and Battams (2011) explored access to physical and mental health services for people with mental illness in South Australia through interviews with 10 stakeholders. Two of the findings relevant to this review were access to health services and 'clinical siloing' (Henderson and Battams 2011). First, living in a rural area and socioeconomic status were barriers to accessing health services. Once outside the main metropolitan area, mental health services were sparse and could be difficult to get to, but, even in the metropolitan area, those with lower incomes could not afford to visit private psychiatrists. In addition, those with lower incomes had less knowledge of what health services were available and therefore had less access to these services (Henderson and Battams 2011). That is, just because a universal health system exists and people with mental illness are entitled to access the health services does not mean that clients can access health services or know what health services are available. Second, there was 'clinical siloing' or a separation of health services that did not seem to communicate with each other. This was especially noted in relation to mental health and disability services, which meant that people with mental illness and a disability were often caught between the two (Henderson and Battams 2011). Furthermore, many people with a mental illness had physical ailments misdiagnosed because they were considered to be symptoms of mental illness rather than separate issues (Henderson and Battams 2011).

A participatory action research evaluation of a mental health ULO in rural South Australia, interviewed 14 participants and sought input from members of the organisation (Taylor *et al.* 2010). The first major finding of that study was that the ULO allowed the members to accept and be accepted as they were. Second, although the ULO provided activities, opportunities for members to develop support networks and helped build relationships, this was not the end in itself: it was through these means that a nurturing and empowering influence was cultivated that aided in recovery (Taylor *et al.* 2010). Third, the state mental health system supplied the ULO with most of its funding and, most importantly, fully supported its program, thereby legitimising its work and giving members confidence in its future (Taylor *et al.* 2010).

Discussion

The academic literature was concentrated around mental health ULOs in the US and Canada. Why this was the case is unknown. Speculatively, the reason may be due to differences in how health care is organised in the US and Canada compared with other similar systems in the UK and Australia.

Although the aim of this study was to explore whether health outcomes achieved by ULOs were comparable to health professional outcomes, there was a lack of evidence to decide whether ULOs improve health outcomes for people with disabilities. Furthermore, this is not the first review to have difficulty in finding evidence for health outcomes in disability services (Eysenbach *et al.* 2004; KPMG 2009).

With the exception of the three controlled trials (Rogers *et al.* 2007; Greenfield *et al.* 2008; Segal *et al.* 2011), extensive mixed-methods research by Nelson *et al.* (2006) and Ochocka *et al.* (2006) and a correlational study by Kelly *et al.* (2019), the studies only take into account the experiences of active participants in ULOs. Confirmation bias may result because active participants are more likely to be favourable towards involvement in ULOs. However, only Brown (2009a) mentioned this as a potential problem. No research was found that looked at why people left ULOs or why people did not join ULOs to begin with.

The literature examined on ULOs for mood disorders, schizophrenia or psychosis suggested that major strengths were in supporting organisation members emotionally, in practical activities and empowerment to live more meaningful lives. This emphasis is apparent in the characteristics of the ULOs' structure, which suggest that ULOs can: (1) be safe and non-judgemental environments (Ochocka *et al.* 2006; Hutchison *et al.* 2007; Taylor *et al.* 2010; Behler *et al.* 2017); (2) provide support from peers and staff (Ochocka *et al.* 2006; Hutchison *et al.* 2007; Munn-Giddings *et al.* 2009; Taylor *et al.* 2010; Behler *et al.* 2017; Budge *et al.* 2019); (3) help with integration into the community and provide a social outlet (Ochocka *et al.* 2006; Taylor *et al.* 2010; Lewis *et al.* 2012); and (4) allow members to participate on an equal footing with other members, have a say in how the organisation is run and empower and provide role models for members (Powers *et al.* 2002; Ochocka *et al.* 2006; Hutchison *et al.* 2007; Taylor *et al.* 2010; Behler *et al.* 2017; Budge *et al.* 2019).

Therefore, rather than the narrow focus of the present scoping review on health outcomes similar to health professionals, a

greater emphasis should be placed on the totality of what ULOs do, and can do, for their members. Furthermore, the optimal organisational structure for these ULOs appears to be small, open and collectivist in nature (Salem *et al.* 2008; Segal *et al.* 2011; Lewis *et al.* 2012; Budge *et al.* 2019). However, it is unknown whether the structure for mood disorders, schizophrenia or psychosis ULOs would work for other ULOs.

Indeed, the results from the present scoping review raised many more questions than they answered. For example:

1. Are people with disabilities in Australia willing to engage with ULOs?
2. Do ULOs that exist have the capacity (e.g. skills, income, structure, communications, influence, reputation, approach, programs) to achieve the aims of NDIS users?
3. Do ULOs serve people that would and can access public or private services anyway? Or, do ULOs make services more accessible to people who would not or cannot access traditional or private services?
4. Do ULOs serve higher-functioning users so that those with more severe disabilities are restricted to traditional services? Would this lead to traditional services focusing on more severe disabilities and require changes in staffing, funding models or time required to support complex disabilities?

Finally, it is emphasised that a lack of evidence does not mean that ULOs are a waste of resources for people with disabilities, carers, the health sector or government agencies. It simply means that there is a gap in our knowledge: we do not know what the effect of ULOs is or can be for people with disabilities.

Conclusion

There is some evidence that peer-run and inclusive ULOs for members with mood disorders, schizophrenia or psychosis can reduce the number of times people with these illnesses access traditional mental health services, but there is no evidence that ULOs can replace traditional mental health services. Therefore, ULOs for mood disorders, schizophrenia or psychosis could be considered an adjunct to traditional mental health services. For other disabilities, such as physical, sensory, cognitive, intellectual and neurological, a lack of evidence means that no recommendation can be made. The organisational structure of ULOs may be as important as the support and services offered when looking at the health or other outcomes in ULOs.

Conflicts of interest

The authors declare no conflicts of interest.

Declaration of funding

This study was funded, in part, by the Department for Communities and Social Inclusion, South Australia.

References

- Behler J, Daniels A, Scott J, Mehl-Madrona L (2017) Depression/bipolar peer support groups: perceptions of group members about effectiveness and differences from other mental health services. *Qualitative Report* **22**, 213–236.
- Bott S, Sweeney A, Watts R (2010) A commissioner's guide to developing and sustaining user-led organisations. Social Care Institute for Excellence, London. Available at <https://www.scie.org.uk/publications/guides/guide36/assets/files/guide36.pdf> [Verified 16 August 2021]
- Brown LD (2009a) How people can benefit from mental health consumer-run organizations. *American Journal of Community Psychology* **43**, 177–188. doi:10.1007/s10464-009-9233-0
- Brown LD (2009b) Making it sane: using narrative to explore theory in a mental health consumer-run organization. *Qualitative Health Research* **19**, 243–257. doi:10.1177/1049732308328161
- Brown LD, Shepherd MD, Merkle EC, Wituk SA, Meissen G (2008) Understanding how participation in a consumer-run organization relates to recovery. *American Journal of Community Psychology* **42**, 167–178. doi:10.1007/s10464-008-9184-x
- Budge G, Mitchell A, Rampling T, Down P (2019) 'It kind of fosters a culture of interdependence': a participatory appraisal study exploring participants' experiences of the democratic processes of a peer-led organisation. *Journal of Community & Applied Social Psychology* **29**, 178–192. doi:10.1002/casp.2393
- Doughty C, Tse S (2011) Can consumer-led mental health services be equally effective? An integrative review of CLMH services in high-income countries. *Community Mental Health Journal* **47**, 252–266. doi:10.1007/s10597-010-9321-5
- Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A (2004) Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ (Clinical Research Ed.)* **328**, 1166–1170. doi:10.1136/bmj.328.7449.1166
- Goering P, Durbin J, Sheldon CT, Nelson G, Ochocka J, Krupa T (2006) Who uses consumer-run self-help organizations? *The American Journal of Orthopsychiatry* **76**, 367–373. doi:10.1037/0002-9432.76.3.367
- Greenfield TK, Stoneking BC, Humphreys K, Sundby E, Bond J (2008) A randomized trial of a mental health consumer-managed alternative to civil commitment for acute psychiatric crisis. *American Journal of Community Psychology* **42**, 135–144. doi:10.1007/s10464-008-9180-1
- Henderson J, Battams S (2011) Mental health and barriers to the achievement of the 'right to health'. *Australian Journal of Primary Health* **17**, 220–226. doi:10.1071/PY10063
- Hutchison P, Arai S, Pedlar A, Lord J, Yuen F (2007) Role of Canadian user-led disability organizations in the non-profit sector. *Disability & Society* **22**, 701–716. doi:10.1080/09687590701659550
- Janzen R, Nelson G, Hausfather N, Ochocka J (2007) Capturing system level activities and impacts of mental health consumer-run organizations. *American Journal of Community Psychology* **39**, 287–299. doi:10.1007/s10464-007-9107-2
- Kelly JF, Hoffman L, Vilsaint C, Weiss R, Nierenberg A, Hoepfner B (2019) Peer support for mood disorder: characteristics and benefits from attending the Depression and Bipolar Support Alliance mutual-help organization. *Journal of Affective Disorders* **255**, 127–135. doi:10.1016/j.jad.2019.05.039
- KPMG (2009) The contemporary disability service system: final report. Disability Policy & Research Working Group, Victorian Department of Human Services, Melbourne, Vic., Australia. Available at https://www.vgls.vic.gov.au/client/en_AU/search/asset/1161620/0 [Verified 16 August 2021]
- Lewis SE, Hopper K, Healion E (2012) Partners in recovery: social support and accountability in a consumer-run mental health center. *Psychiatric Services (Washington, D.C.)* **63**, 61–65. doi:10.1176/appi.ps.201000512
- Morris J (2006) Centres for Independent Living or local user-led organisations: a discussion paper. Department of Health, London. Available at https://webarchive.nationalarchives.gov.uk/ukgwa/20090704042545/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078838 [Verified 16 August 2021]
- Munn-Giddings C, Boyce M, Smith L, Campbell S (2009) The innovative role of user-led organisations. *A Life in the Day* **13**, 14–20. doi:10.1108/13666282200900026

- National Disability Insurance Scheme (2019) '\$100 million in community grants to empower people with disability.' Available at <https://www.ndis.gov.au/news/3489-100-million-community-grants-empower-people-disability>
- National Health Committee (2003) To have an 'ordinary' life: community membership for adults with an intellectual disability. National Advisory Committee on Health and Disability No. HP: 3686, Wellington, New Zealand. Available at [https://www.moh.govt.nz/notebook/nbbooks.nsf/0/767269395A2349ABCC256DA2007133FD/\\$file/To-have-an-ordinary-life.pdf](https://www.moh.govt.nz/notebook/nbbooks.nsf/0/767269395A2349ABCC256DA2007133FD/$file/To-have-an-ordinary-life.pdf) [Verified 16 August 2021]
- Nelson G, Lomotey J (2006) Quantity and quality of participation and outcomes of participation in mental health consumer-run organizations. *Journal of Mental Health (Abingdon, England)* **15**, 63–74. doi:10.1080/09638230500512524
- Nelson G, Ochocka J, Janzen R, Trainor J (2006) A longitudinal study of mental health consumer/survivor initiatives: part 2 – a quantitative study of impacts of participation on new members. *Journal of Community Psychology* **34**, 261–272. doi:10.1002/jcop.20098
- Ochocka J, Nelson G, Janzen R, Trainor J (2006) A longitudinal study of mental health consumer/survivor initiatives: part 3 – a qualitative study of impacts of participation on new members. *Journal of Community Psychology* **34**, 273–283. doi:10.1002/jcop.20099
- Office for Disability Issues (2012) 'ODI projects – Strengthening disabled people's user-led organisations programme.' Available at <https://webarchive.nationalarchives.gov.uk/ukgwa/20130103055052/http://odi.dwp.gov.uk/odi-projects/user-led-organisations.php> [Verified 16 August 2021]
- Ostrow L, Hayes SL (2015) Leadership and characteristics of nonprofit mental health peer-run organizations nationwide. *Psychiatric Services (Washington, D.C.)* **66**, 421–425. doi:10.1176/appi.ps.201400080
- Pistrang N, Barker C, Humphreys K (2008) Mutual help groups for mental health problems: a review of effectiveness studies. *American Journal of Community Psychology* **42**, 110–121. doi:10.1007/s10464-008-9181-0
- Powers LE, Ward N, Ferris L, Nelis T, Ward M, Wieck C, Heller T (2002) Leadership by people with disabilities in self-determination systems change. *Journal of Disability Policy Studies* **13**, 126–134. doi:10.1177/10442073020130020901
- Rogers ES, Teague GB, Lichenstein C, Campbell J, Lyass A, Chen R, Banks S (2007) Effects of participation in consumer-operated service programs on both personal and organizationally mediated empowerment: results of multisite study. *Journal of Rehabilitation Research and Development* **44**, 785–799. doi:10.1682/JRRD.2006.10.0125
- Salem DA, Reischl TM, Randall KW (2008) The effect of professional partnership on the development of a mutual-help organization. *American Journal of Community Psychology* **42**, 179–191. doi:10.1007/s10464-008-9193-9
- Salzer MS, Kundra LB (2010) Liability issues associated with referrals to self-help groups. *Psychiatric Services (Washington, D.C.)* **61**, 6–8. doi:10.1176/ps.2010.61.1.6
- Segal SP, Silverman CJ, Temkin TL (2010) Self-help and community mental health agency outcomes: a recovery-focused randomized controlled trial. *Psychiatric Services (Washington, D.C.)* **61**, 905–910. doi:10.1176/ps.2010.61.9.905
- Segal SP, Silverman CJ, Temkin TL (2011) Outcomes from consumer-operated and community mental health services: a randomized controlled trial. *Psychiatric Services (Washington, D.C.)* **62**, 915–921. doi:10.1176/ps.62.8.pss6208_0915
- Shaping Our Lives (2013) 'About this site: definitions and meanings.' Available at <https://www.shapingourlives.org.uk/about/about-sol/definitions> [Verified 16 August 2021]
- Social Care, Local Government & Care Partnerships Directorate, Department of Health (2007) User-led organisations project. Department of Health, London. Available at https://webarchive.nationalarchives.gov.uk/ukgwa/20090501062629/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078804 [Verified 16 August 2021]
- Subramaniam V, Stewart MW, Smith JF (1999) The development and impact of a chronic pain support group: a qualitative and quantitative study. *Journal of Pain and Symptom Management* **17**, 376–383. doi:10.1016/S0885-3924(99)00012-3
- Taylor J, Jones RM, O'Reilly P, Oldfield W, Blackburn A (2010) The Station Community Mental Health Centre Inc.: nurturing and empowering. *Rural and Remote Health* **10**, 1411. doi:10.22605/RRH1411
- Union of the Physically Impaired Against Segregation, Disability Alliance (1975) Fundamental principles of disability. London. Available at <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf> [Verified 16 August 2021]
- Woodin SL (2006) Mapping user-led organisations. User-led services and centres for independent/ integrated/ inclusive living: a literature review prepared for the Department of Health. University of Leeds, Leeds, England. Available at <https://disability-studies.leeds.ac.uk/library/author/woodin.sarah/> [Verified 16 August 2021]