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The Functions of Disabled People's Organisations (DPOs) in Low and Middle-income Countries: a Literature Review

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ABSTRACT

Purpose: *The aim of this study was to review peer-reviewed literature on the roles and functions of Disabled Peoples' Organisations (DPOs) in low and middle-income countries, and their outputs and outcomes for people with disabilities.*

Method: *Online databases were searched without date or language limiters (Medline, CINAHL, Scopus, Embase and Cochrane), using a combination of two key word search strategies. Eleven studies were selected for inclusion in this review on the basis of predetermined inclusion and exclusion criteria. Included studies underwent quality assessment using the Critical Appraisal Skills Programme (CASP) and Downs and Black's criteria for quality assessment. Data for thematic analysis was then grouped under the broad themes of: participation and factors that facilitate participation; development of partnerships and connections; and self-development and self-help.*

Results: *There was some evidence within the included studies to suggest that DPOs can produce significant, positive outcomes for persons with disability in terms of factors such as employment rates, access to microfinance and bank loans, accessibility of housing, acquisition of orthopaedic devices, involvement in civil society, development of friendships and networks, and participation in training programmes. Although the studies under review largely did not investigate the long-term impact of the reported DPO functions and outputs, some of the short-term outputs may be considered proximal indicators of outcomes such as increased empowerment and well-being.*

Conclusion: *The 11 studies in this review suggested that DPOs can be effective in achieving their stated aims of promoting well-being, participation and rights of people with disabilities in low and middle-income countries.*

Key words: *Disability, rights.*

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INTRODUCTION

Disability is a complex and evolving issue, resulting from the interaction between persons with impairments and attitudinal, institutional and environmental barriers that impede their ability to participate fully in society on an equal basis with others (United Nations General Assembly, 2006). Disability affects over one billion people worldwide and the World Health Organisation (WHO) estimates that over 80% of people with disabilities live in low and middle-income countries (LMICs), where access to health and social services is restricted (World Health Organisation, 2011, 2016). There is evidence to suggest that in comparison with their peers without disabilities, people with disabilities in LMICs are more disadvantaged in terms of their involvement in civil society and their access to education, healthcare, employment, income, and social supports (Groce et al, 2011). These factors create layers of disadvantage, resulting in people with disabilities experiencing multidimensional poverty and exclusion (Mitra et al, 2013). Even in higher-income countries, people with disabilities are disproportionately represented among the poorest members of society (Rioux et al, 2011). As well as experiencing lower levels of income, people with disabilities often experience higher personal costs associated with their disability (such as expenses related to personal supports, medical care, assistive devices and home modifications) and consequently are likely to be poorer than people without a disability on a similar income (World Health Organisation, 2011).

Following the Disability Rights Movement of the late 1970s, a new paradigm for thinking about disability emerged, namely, the rights-based approach to disability. This paradigm emphasises the dignity of people with disabilities and their right to enjoy life on an equal basis with others (United Nations General Assembly, 2006). One way in which the rights-based approach to disability is realised is via the active involvement of people with disabilities through representative organisations such as Disabled Peoples' Organisations (DPOs) (World Health Organisation, 2011; CBM, 2012; People with Disabilities Australia, 2015).

DPOs are organisations established by and for people with disabilities (People with Disabilities Australia, 2015). They are composed of and governed by a majority of people with disabilities at the membership and leadership level (People with Disabilities Australia, 2015), but may also include family members or carergivers where individuals have less agency to represent

themselves (e.g., children with disability or individuals with profound or intellectual disabilities) (CBM, 2012; Deepak et al, 2013; People with Disabilities Australia, 2015). DPOs can be single-disability organisations (i.e., formed of members with a single type of impairment) or cross-disability organisations (i.e., formed of individuals with different types of impairments) (People with Disabilities Australia, 2015), and may be stand-alone organisations or may exist in connection to Community Based Rehabilitation (CBR) programmes (World Health Organisation, 2015). In many countries, DPOs will undergo a process of formal registration, but this is not the case for all groups. Organisations of persons with disability may go by a number of different names such as disability Self-Help Groups (SHGs), savings and lending groups or Disabled Peoples' Groups (DPGs). While the structure of each of these types of organisations may differ slightly, for the purposes of this review the general term DPO will be used to describe all types of organisations of people with disabilities that seem to fit the criteria for definition as a DPO.

The specific functions of DPOs can vary markedly from context to context and group to group; however, the general roles of DPOs can be said to include: identifying the needs of people with disabilities; providing a voice for people with disabilities to express their views and priorities; evaluating services and systems; advocacy; raising public awareness and providing support for people with disabilities to develop agency to exercise their rights (Enns, n.d.; World Health Organisation, 2011; People with Disabilities Australia, 2015). Fundamentally, DPOs can be said to have an overarching focus on promoting the rights and improving the lives of people with disabilities. In this way, DPOs differ from organisations such as support groups which primarily aim to provide psychosocial support to their members.

Objective

Although the general aims and roles of DPOs are articulated in the literature, the specific ways in which groups embody these aims varies significantly. Much evidence pertaining to the function of DPOs is anecdotal in nature or presented in grey literature, and there is currently little peer-reviewed evidence to suggest how DPOs in LMICs function to fulfill their stated roles. This literature review was undertaken to assess peer reviewed evidence discussing how DPOs function in LMICs and what, if any, outputs and outcomes these groups achieve for people with disabilities in such settings.

METHOD

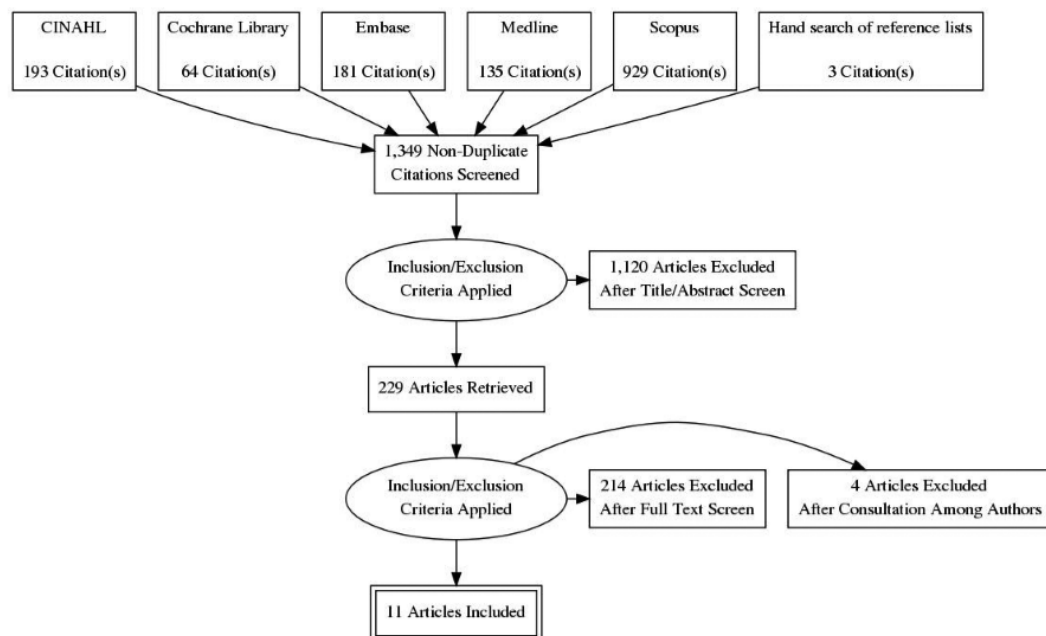
Online databases were searched without date or language limiters (Medline, CINAHL, Scopus, Embase and Cochrane), using a combination of two key word search strategies (Table 1) between August 2015 and April 2016. The search strategies were developed through an initial screening of the literature to identify different terminology that may be used to refer to DPOs. Online databases were chosen by reviewing the University of Melbourne's recommendations for systematic literature reviews (University of Melbourne, 2016). Titles and abstracts of papers identified through online database searching were screened against pre-determined inclusion and exclusion criteria (Table 2). The relevant studies underwent full text evaluation using the same inclusion and exclusion criteria (Table 2). To further identify suitable studies, a hand search of the reference lists of all relevant papers was undertaken. In cases where there was any uncertainty, three researchers collaborated to determine suitability for inclusion. Although certain guidelines were followed for undertaking a systematic review (PRISMA, 2015), the authors considered it more appropriate to define this study as a literature review because the literature searches were performed over a number of months and principally undertaken by a single researcher. Based on the inclusion and exclusion criteria, 11 papers were selected for inclusion in this literature review (Figure 1).

Table 1: Search Strategy

Search Number	Search Strategy
1	"disabled people* organi?ation*" OR "disability people* organi?ation" OR DPOs OR "disabled people* group*" OR DPGs OR "disability people* group*" OR "disability self help group*" OR "disability coalition"
2	("user led organisation" OR "user led organization" OR "self help group*" OR "community group") AND (disability OR disabled OR disabilities)

Table 2: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> Included a sample of individuals from a group that met the criteria for a DPO (i.e., composed of a majority of persons with disability or their carers or family members at the membership and board level) (Deepak et al, 2013; People with Disabilities Australia, 2015) ; 	<ul style="list-style-type: none"> Samples recruited exclusively from high-income countries;
<ul style="list-style-type: none"> At least one of the DPOs operated within a low, lower-middle or upper-middle income country as per the World Bank classification for the year that the study was published (World Bank, 2015); 	<ul style="list-style-type: none"> Sample was of internet-based groups;
<ul style="list-style-type: none"> Assessment of DPO function or effectiveness was reported; 	<ul style="list-style-type: none"> Groups that existed for psychosocial support only (i.e., groups that were not engaged in output-based activity);
<ul style="list-style-type: none"> Studies were published in a peer-reviewed journal; 	<ul style="list-style-type: none"> Non-English language papers.
<ul style="list-style-type: none"> Original research of any level. 	

**Figure 1: PRISMA Flow Diagram of Article Selection process**

In this review, the United Nations' definition of disability was adopted, whereby disability was defined as being the result of interaction between persons with impairments and attitudinal, institutional and environmental barriers that impede their ability to participate fully in society on an equal basis with others (United Nations General Assembly, 2006). This definition is broad in its scope and includes conditions such as intellectual disability and psychosocial illness – disabilities that are less visible and often excluded from cross-disability DPOs (Cornielje, 2009).

The definition of DPOs that was used in this review included a variety of different types of organisations of people with disabilities such as SHGs and savings and lending groups, provided they fit the criteria for being composed primarily of people with disabilities at the membership and leadership levels (People with Disabilities Australia, 2015). Groups that were established primarily for the purpose of providing psychosocial support to members were not considered to fulfil the expected functions of DPOs, and were excluded from the review.

Studies undertaken in countries classified by the World Bank (2015) as low, lower-middle or upper-middle income (LMICs as per the WHO classification) (World Health Organisation, 2016) in the year the study was published were included in this review. Studies undertaken in high-income countries were not included as it was thought that the higher social progress status of these countries limited their comparability to low and middle-income countries (Social Progress Imperative, 2016).

A single researcher extracted data pertaining to the roles and functions of DPOs from the selected studies. The broad themes of participation and factors that facilitate participation, development of partnerships and connections, and self-development and self-help emerged as overarching concepts discussed in the literature, and were used to group together the varied data.

Qualitative studies were assessed using the Critical Appraisal Skills Programme (CASP) qualitative research checklist (Critical Appraisal Skills Programme, 2013). Two researchers (RY and MR) evaluated the studies using 10 screening questions (answered 'yes', 'no', 'not assessed' or 'can't tell') to assess overall quality of the research. One paper presented quantitative findings (Kumaran, 2011) and was assessed for quality using Downs and Black's (1998) checklist of 27 screening questions for assessing the quality of randomised and non-randomised studies. In cases where the study design was not clear (Deepak et al, 2013) articles did not undergo any further quality assessment.

RESULTS

This review revealed a small body of literature pertaining to the roles and functions of DPOs in LMICs (see Table 3). The 11 selected studies looked at DPOs operating in: Nepal (Dhungana and Kusakabe, 2010); Bangladesh (Miles et al, 2012; Polu et al, 2015); the South Asian coastline (Hemingway and Priestley, 2006); Africa (Stewart and Bhagwanjee, 1999; Kleintjes et al, 2013); India (Kumaran, 2011; Cogley, 2013; Deepak et al, 2013); Bolivia (Griffiths et al, 2009); Brazil and India (Deepak et al, 2013); and Malaysia (Armstrong, 1993). Thus, 9 studies involved DPOs operating in low or lower-middle income countries (Hemingway and Priestley, 2006; Griffiths et al, 2009; Dhungana and Kusakabe, 2010; Kumaran, 2011; Miles et al, 2012; Cogley, 2013; Deepak et al, 2013; Kleintjes et al, 2013; Polu et al, 2015) and four included DPOs operating in upper-middle income settings (Armstrong, 1993; Stewart and Bhagwanjee, 1999; Deepak et al, 2013; Kleintjes et al, 2013).

Table 3: Study Characteristics

Author	Year	Country and Income Classification	Study Design and Methods	Sample Size	Demographics of DPO(s)
Hemingway and Priestley	2006	South Asian coastline	Qualitative study, key informant interviews and literature search (including grey literature)	-	-
Stewart and Bhagwanjee	1999	South Africa, upper-middle income country	Mixed methods study, self-administered questionnaire and focus group discussion	12 persons with disability	Persons with disability only, single-disability DPO (spinal cord injury)
Kumaran et al	2011	Andhra Pradesh (India), Lower-middle income country	Quantitative study, survey questionnaire	100 persons with disability	Persons with disability and family members in the case of individuals with

					severe intellectual disability or multiple disabilities, cross-disability DPO
Griffiths et al	2009	Bolivia, lower-middle income country	Qualitative study, semi-structured interview with key informants	-	-
Deepak et al	2013	India, Lower-middle income country, and Brazil, upper-middle income country	Case study, methods unstated	Brazil - DPO with 500 members, India - DPO with 160 members	Persons with disability and family members, cross-disability DPOs
Armstrong et al	1993	Malaysia, upper-middle income country	Qualitative study, interviews, observation and use of archival sources	DPO with around 1000 members	Persons with disability and family members, single-disability DPO (orthopaedic disability)
Cobley et al	2013	India, lower-middle income country	Qualitative study, interviews, FGDs, documentary analysis and observation	136 (included persons with disability, project staff, government representative, etc.)	Persons with disability and family members, cross-disability DPO
Kleintjes et al	2013	7 African countries ranging from low income to upper-middle income	Qualitative study, semi-structured interviews	11 members of mental health self-help group	Persons with disability, single-disability DPO (psychosocial disability)
Miles et al	2012	Bangladesh, lower-middle income country	Qualitative study, interviews	37 participants (included people with disabilities and representatives of disability-focussed organisations)	-

Dhungana and Kusakabe	2010	Nepal, low-income country	Mixed methods study, in-depth interviews	58 women with disabilities	Persons with disabilities, cross-disability organisations
Polu et al	2015	Bangladesh, lower-middle income country	Qualitative study, focus group discussions and key informant interviews	-	-

This review revealed that, as yet, there is no published literature above level three evidence on the Oxford Centre for Evidence-Based Medicine (OCEBM) hierarchy of evidence (2011) concerning the function of DPOs in LMICs (i.e., the highest level of evidence identified in this review was a cohort study design). The OCEBM hierarchy of evidence is a widely accepted tool for assessing levels of evidence. The studies included in this review were observational and, in general, did not investigate outcome data before and after the formation of DPOs, with the majority of papers presenting single point-in-time or short-term data. The majority were descriptive case studies or case series (Armstrong, 1993; Stewart and Bhagwanjee, 1999; Griffiths et al, 2009; Dhungana and Kusakabe, 2010; Miles et al, 2012; Cobley, 2013; Deepak et al, 2013; Polu et al, 2015). Three studies had features of cross-sectional design; however, the methodology was not clear (Hemingway and Priestley, 2006; Kumaran, 2011; Kleintjes et al, 2013). Of the 11 studies included in this review, the majority were qualitative studies (Armstrong, 1993; Hemingway and Priestley, 2006; Griffiths et al, 2009; Dhungana and Kusakabe, 2010; Miles et al, 2012; Cobley, 2013; Deepak et al, 2013; Kleintjes et al, 2013) with two papers reporting a mixed-methods approach (Stewart and Bhagwanjee, 1999; Polu et al, 2015) and one using quantitative methods (Kumaran, 2011). Though considered acceptable for the purposes of this review, the quality of reporting was poor overall (Tables 4 and 5), which made it difficult to accurately assess the methodological quality.

Table 4: Quality Assessment using the CASP Qualitative Research checklist (Critical Appraisal Skills Programme, 2013)

Author	Year	1	2	3	4	5	6	7	8	9	10*
Hemingway and Priestley	2006	Yes	Can't tell	Yes	NA	Yes	No	No	No	Yes	L
Stewart and Bhagwanjee	1999	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	M
Griffiths et al	2009	No	Can't tell	Can't tell	NA	Can't tell	No	No	No	No	L
Armstrong et al	1993	Yes	Yes	Yes	Can't tell	Can't tell	No	No	Can't tell	Yes	M
Cobley et al	2013	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	H
Kleintjes et al	2013	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	H
Deepak et al	2013	No	No	NA	NA	NA	NA	NA	NA	NA	M
Miles et al	2012	Yes	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	M
Dhungana and Kusakabe	2010	Yes	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	H
Polu et al	2015	Yes	Yes	Can't tell	Can't tell	Yes	No	No	No	Yes	L

*L = Low, M= Moderate, H = High

Assessment Criteria

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

Table 5: Quality Assessment using Downs and Black's checklist (Downs and Black, 1998)

Author (year)	Kumaran et al (2011)
1	Yes
2	No
3	No
4	NA
5	NA
6	Yes
7	No
8	NA
9	No
10	No
11	Unsure
12	Unsure
13	Unsure
14	No
15	No
16	NA
17	NA
18	NA
19	NA
20	Unsure
21	NA
22	Unsure
23	NA
24	NA
25	NA
26	NA
27	Unsure

Quality Assessment Criteria

1. Is the hypothesis/aim/objective of the study clearly described?
2. Are the main outcomes to be measured clearly described in the Introduction or Methods section?

3. Are the characteristics of the clients included in the study clearly described?
4. Are the interventions of interest clearly described?
5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?
6. Are the main findings of the study clearly described?
7. Does the study provide estimates of the random variability in the data for the main outcomes?
8. Have all important adverse events that may be a consequence of the intervention been reported?
9. Have the characteristics of clients lost to follow-up been described?
10. Have actual probability values been reported (e.g., 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?
11. Were the subjects asked to participate in the study representative of the entire population from which they were recruited?
12. Were those subjects who were prepared to participate, representative of the entire population from which they were recruited?
13. Were the staff, places, and facilities where the clients were treated, representative of the treatment the majority of clients receive?
14. Was an attempt made to blind study subjects to the intervention they have received?
15. Was an attempt made to blind those measuring the main outcomes of the intervention?
16. If any of the results of the study were based on “data dredging”, was this made clear?
17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of clients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls?
18. Were the statistical tests used to assess the main outcomes appropriate?
19. Was compliance with the intervention/s reliable?
20. Were the main outcome measures used accurate (valid and reliable)?
21. Were the clients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?

22. Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?
 23. Were study subjects randomised to intervention groups?
 24. Was the randomised intervention assignment concealed from both clients and healthcare staff until recruitment was complete and irrevocable?
 25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?
 26. Were losses of clients to follow-up taken into account?
 27. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?
-

A variety of different organisations met the criteria for definition of a DPO (People with Disabilities Australia, 2015). Five of the studies in this review included groups composed of both people with disabilities and individuals without disabilities who were mostly parents or carers of people with disabilities (Armstrong, 1993; Kumaran, 2011; Miles et al, 2012; Cobley, 2013; Deepak et al, 2013), whereas in three studies the DPOs were made up solely of people with disabilities (Stewart and Bhagwanjee, 1999; Dhungana and Kusakabe, 2010; Kleintjes et al, 2013). Group composition was not specified in the other studies (Hemingway and Priestley, 2006; Griffiths et al, 2009; Polu et al, 2015). Three studies looked at the roles of single-disability DPOs (Armstrong, 1993; Stewart and Bhagwanjee, 1999; Kleintjes et al, 2013) and three at the functions of cross-disability DPOs (Kumaran, 2011; Cobley, 2013; Deepak et al, 2013). The types of disabilities represented in the other studies were not reported.

Information regarding the demographic composition of the DPOs was minimal in most of the papers. Only three studies reported the age ranges and gender representation in the DPOs (Stewart and Bhagwanjee, 1999; Dhungana and Kusakabe, 2010; Kumaran, 2011). One additional study reported on gender representation alone (Deepak et al, 2013). Three studies reported the educational backgrounds and socio-economic status of group members Stewart and Bhagwanjee, 1999; Dhungana and Kusakabe, 2010; Kumaran, 2011).

Data presented in the 11 studies were grouped under three broad themes: participation and factors that facilitate participation; development of partnerships

and connections; and self-development and self-help. These themes encompassed the majority of subthemes and findings that emerged from the literature and provided a means of organising diverse findings into coherent groups. Data was analysed according to these broad categories and wherever data overlapped with multiple themes, the authors subcategorised data to highlight differences in findings (Table 6).

Table 6: Thematic Grouping of Data

Broad Theme	Sub-categories	References
Participation and factors that facilitate participation	• Knowledge of rights	(Cobley, 2013; Kumaran, 2011)
	• Confidence for participation	(Dhungana and Kusakabe, 2010)
	• Participation in civil society and political processes and advocacy activities	(Armstrong 1993; Griffiths et al, 2009; Dhungana and Kusakabe, 2010; Kumaran, 2011; Deepak et al, 2013; Kleintjes et al, 2013)
	• Awareness- raising activities	(Dhungana and Kusakabe, 2010; Deepak et al, 2013)
Development of partnerships and connections	• Networks between DPOs	(Armstrong, 1993; Hemingway and Priestley, 2006; Miles et al, 2012; Cobley, 2013; Deepak et al, 2013; Kleintjes et al, 2013)
	• Social connections and relationships between groups	(Cobley, 2013; Deepak et al, 2013; Polu et al, 2015)
	• Creation of networks with experts and consultants	(Stewart and Bhagwanjee, 1999; Polu et al, 2015)
	• Networks with government agencies	(Armstrong, 1993; Polu et al, 2015)
	• Networks with schools, training and education facilities	(Griffiths et al, 2009; Dhungana and Kusakabe, 2010; Miles et al, 2012; Deepak et al, 2013; Kleintjes et al, 2013; Polu et al, 2015)
	• Networks with financial institutions	(Cobley, 2013; Polu et al, 2015)
Self-development and self-help	• Self-determination and self-governance	(Stewart and Bhagwanjee, 1999; Kleintjes et al, 2013)
	• Service delivery of mobility aids	(Armstrong, 1993; Deepak et al, 2013)

	• Empowering members to take responsibility for their own disabilities	(Dhungana and Kusakabe, 2010)
	• Facilitating personal knowledge about disability and its management	(Armstrong, 1993; Kleintjes et al, 2013; Polu et al, 2015)
	• Income generation and employment	(Dhungana and Kusakabe, 2010; Kumaran, 2011; Miles et al, 2012; Cobley, 2013; Kleintjes et al, 2013)

Participation and Factors that facilitate Participation

In this review, participation was defined broadly to encompass participation in all aspects of community life, such as political processes, social and cultural activities (Governance and Social Development Resource Centre, 2016). There was some evidence that DPOs were involved in a range of different activities that promoted the participation of people with disabilities either directly or by facilitating upstream factors of participation, such as increasing knowledge of the rights of people with disabilities or increasing their confidence.

Knowledge of Rights

To advocate effectively for their participation in society, people with disabilities need to first know about their rights. Two studies reported that DPO members were more aware of their rights and privileges after joining groups (Kumaran, 2011; Cobley, 2013).

Confidence for Participation

Dhungana et al (2010) found that members of a SHG reported being more connected with society in general after joining the groups. It was suggested that the group helped members get used to participating in activities outside their homes, and increased their confidence to be involved in activities such as shopping and visiting friends.

Participation in Civil society, Political processes and Advocacy

Members of mental health self-help organisations in seven African countries, in the study by Kleintjes et al (2013), were involved in political processes by representing their organisations in local, national and international forums to lobby for their rights to education, housing, employment and basic mental health

services. Kleintjes et al (2013) reported that two DPO members were involved in global discussions pertaining to the implementation of the Convention on the Rights of Persons with Disabilities.

Several DPOs were reported to be involved in advocacy activities. Advocacy took many different forms including developing written and audiovisual material and running public awareness campaigns (Armstrong, 1993; Griffiths et al, 2009; Dhungana and Kusakabe, 2010; Kleintjes et al, 2013). In several studies, the advocacy activities of DPOs were credited with bringing about significant disability-inclusive policy changes. Armstrong et al (1993), for example, reported that the work of DPOs in Malaysia resulted in the development of a Code of Practice for access to public buildings, re-classification of motorised mobility aids to reduce registration costs for people with disabilities, and adoption of a policy of reduced public transport fares for people with disabilities. According to Armstrong et al (1993), in addition to achieving changes in the physical environment, the advocacy activities of DPOs also resulted in the introduction of a 1% quota of jobs in the public sector for people with disabilities in Malaysia. In the study by Deepak et al (2013), advocacy from persons with disability in Brazil resulted in the installation of accessible public telephone booths and an accessible ATM, as well as wheelchair accessible ramps in the city. Members of a SHG in Nepal who had experienced exclusion from temples were permitted to enter places of worship after advocating for their rights to local religious leaders (Dhungana and Kusakabe, 2010).

Awareness-raising Activities

Deepak et al (2013) highlighted the work of DPOs in facilitating major awareness-raising activities for society in general. In this study, DPOs in Brazil and India were involved in organising events such as public meetings, theatre and cultural activities for World Disability Day with the aim of encouraging society at large to engage with disability issues (Deepak et al, 2013).

Development of Partnerships and Connections

There was evidence to suggest that DPOs often contribute to the development of networks and relationships among people with disabilities and their families, as well as forming networks and alliances with external, non-disability related organisations (Armstrong, 1993; Stewart and Bhagwanjee, 1999; Cobley, 2013; Deepak et al, 2013; Kleintjes et al, 2013).

Networks between DPOs

In several papers, DPOs were able to collaborate or ally with similar groups in their local areas to develop supportive partnerships (Armstrong, 1993; Hemingway and Priestley, 2006; Miles et al, 2012; Cobley, 2013; Deepak et al, 2013; Kleintjes et al, 2013). In one study, representatives of the village DPOs participated in a district-wide meeting in order to create a network between the district-level and the local village-level DPOs (Deepak et al, 2013). In South Africa, DPOs joined together to form a regional body for collaboration between psychosocial disability groups (Kleintjes et al, 2013). In the study by Armstrong et al (1993), a DPO in Malaysia maintained a number of alliances with other disability-related groups and agencies and joined together as a recognised confederation (within Disabled Peoples International) with two other disability societies. These alliances were vital for the group's legitimacy in the eyes of the Malaysian social services scheme, although the reasoning for this was not reported.

Following the tsunami on the South Asian coastline in 2004, the extensive networks developed by local disability groups and people with disabilities were used to help identify and meet the needs of people with disabilities affected by the tsunami who received little targeted assistance from mainstream relief organisations (Hemingway and Priestley, 2006).

Social Connections and Relationships within Groups

In addition to facing exclusion from broader society and its activities, persons with disability often experience social exclusion due to a range of attitudinal, institutional and environmental factors (Deepak et al, 2013). One study (Cobley, 2013) suggested that DPO meetings are significant social events that are looked forward to by members. Polu et al (2015) suggested that people with disabilities experienced improved social connections and self-confidence after joining DPOs because their social network was expanded. A DPO in Brazil organised regular leisure activities such as picnics, sporting events and cultural activities to promote social relationships among members (Deepak et al, 2013).

Creation of Networks with Experts and Consultants

Two papers discussed the ability of DPOs to create networks with specialists who acted as invited consultants for the groups, giving advice on issues such as accessing technical and human skills such as teaching good self-care techniques (Stewart and Bhagwanjee, 1999; Polu et al, 2015). Stewart et al (1999) reported

on a DPO that was initially facilitated by a therapist, who eventually went on to serve as a consultant once members began to govern the group themselves. In Polu et al (2015) field workers from a large NGO were engaged to train SHG leaders in ways to undertake disability-specific self-care practices such as wound care, exercise and massage and then, more importantly, how to pass along this knowledge to other group members.

Networks with Government Agencies

Two studies suggested that DPOs can facilitate the development of links between government agencies and people with disabilities (Armstrong, 1993; Polu et al, 2015). A DPO in Malaysia reported having strong links to the Ministry of Youth and Sport of Malaysia (Armstrong, 1993). By coming together as a DPO with a strong presence in the world of sport and disability, the organisation was able to develop links with government as well as private-sector firms to leverage support (such as finances and access to facilities) for their pursuits. Polu et al (2015) mentioned how networks between SHGs and the Departments of Social Welfare and Agriculture and Livestock facilitated SHG functioning.

Networks with Schools, Training and Education facilities

Two DPOs created networks with local schools to promote inclusion of children with disabilities in mainstream schools (Miles et al, 2012; Deepak et al, 2013). Deepak et al (2013) reported that a DPO in Brazil organised several workshops in schools every month to educate the public about inclusion of children with disabilities in mainstream classrooms. The DPO also served as a contact point for families of children with disability who attend mainstream schools, to provide them with information about the rights of their children. Miles et al (2012) observed that SHGs helped parents to approach local schools to raise awareness about the particular needs of individual children with disabilities. The groups were also involved in teaching Braille to children with visual impairment to facilitate their inclusion in schools.

Five studies demonstrated that DPOs can provide a link to training and education for members, which may assist in developing skills and income-generation for them as well as sustainable functioning of DPOs (Griffiths et al, 2009; Dhungana and Kusakabe, 2010; Deepak et al, 2013; Kleintjes et al, 2013; Polu et al, 2015). A DPO in Nepal, for example, organised vocational training courses for its members to learn skills (such as tailoring, handicrafts, waitressing, computer

and secretarial work) that could be used for income-generating endeavours (Dhungana and Kusakabe, 2010).

Networks with Financial Institutions

Three of the DPOs sampled in Copley et al (2013) developed partnerships with local banks to help members of savings groups access mainstream loans to support their income-generating activities. Due to the formation of SHGs in India, around 50,000 people with disability received individual financial assistance from mainstream banks to establish income-generating activities such as shop keeping, farming and brick making (Copley, 2013). The mechanism by which this financial assistance was obtained by DPOs was not discussed. Polu et al (2015) suggested that participating in SHGs gave members increased knowledge and confidence to engage with banks.

Self-development and Self-help

In this review, self-development and self-help activities were considered to be any activities that contributed to the development of skills and capacity for persons with disability. This encompassed all training and education events or programmes, and any activities that contributed to employment or income generation. Self-governance and empowerment were considered to be key facilitating aspects of self-development and self-help for groups.

Self-determination and Self-governance

Members of DPOs considered that assuming sole responsibility for group management and leadership was important for self-determination. In two studies undertaken in African countries, DPO members reported that taking responsibility for group governance and leadership allowed for self-determination within the group and also created new roles and opportunities for capacity building of individual members (Stewart and Bhagwanjee, 1999; Kleintjes et al, 2013). Stewart et al (1999) suggested that group work and self-governance may create opportunities for persons with disability to develop self-reliance and empowerment. While self-reliance may be considered to lead to empowerment, there were no direct measures of empowerment in the study.

Service delivery of Mobility Aids

Three studies emphasised the work of DPOs in facilitating physical functioning

and mobility for people with disabilities through improving access to medical and orthopaedic services (Armstrong, 1993; Dhungana and Kusakabe, 2010; Deepak et al, 2013). Armstrong et al (1993) reported that a DPO in Malaysia was involved in distributing and servicing exercise equipment, prostheses, wheelchairs and other locomotor aids for those with physical or musculoskeletal disabilities. Members of the DPO also accessed house modification and repair services to facilitate independent community living by modifying traditional Malay houses to make them accessible for those with mobility impairments. A Brazilian DPO partnered with local organisations to facilitate access to wheelchairs and orthopaedic appliances for members (Deepak et al, 2013). As a result of such partnerships, in 2012, 40 wheelchairs were distributed to members.

Empowering Members to take responsibility for their own disabilities

Dhungana et al (2010) reported that women in a SHG invested in buying hearing and mobility aids with their own income after joining the group.

Facilitating Personal Knowledge about Disability and its management

In addition to facilitating training and education for group members, DPOs were also able to facilitate training sessions for families and carers of group members on disability and its management (Armstrong, 1993; Kleintjes et al, 2013; Polu et al, 2015). DPOs of persons with psychosocial disability across seven countries in Africa offered education and training to members and their carers on the management of psychological symptoms (Kleintjes et al, 2013). SHGs in Bangladesh trained members on self-care of physical symptoms and complications related to disability (Polu et al, 2015).

Income-generation and Employment

Several studies suggested that forming disability SHGs or group savings and lending groups could be a way for persons with disability to generate income and support livelihood activities by developing savings, increasing confidence and facilitating access to microfinance and mainstream bank loans (Dhungana and Kusakabe, 2010; Kumaran, 2011; Miles et al, 2012; Cobley, 2013; Kleintjes et al, 2013). One member of a SHG in Nepal reported that due to her income generation after joining the group, her voice carried more weight in the family (Dhungana and Kusakabe, 2010).

In the study by Kumaran et al (2011), DPOs in India established income-generating microenterprises as a result of group savings alone, without having to access bank loans. After joining a DPO, the monthly income of all members increased as a result of the income-generating activities they had started.

Armstrong et al (1993) reported that the Ability Bhutan Society contributed to the employment opportunities of people with disabilities by encouraging those with skills in the group (e.g., tailoring, radio or TV repair skills) to train other members as their apprentices, providing job placement for them after their training was completed.

Barriers to DPO Functioning

All studies cited barriers to effective DPO functioning. Most of them mentioned lack of financial and human resources as negatively impacting upon the functional capacity of DPOs (Armstrong, 1993; Hemingway and Priestley, 2006; Griffiths et al, 2009). Other barriers included the lack of empowerment experienced by people with disabilities when SHGs or DPOs were led by professionals external to the group (Stewart and Bhagwanjee, 1999); difficulty in maintaining continuity of group members (Dhungana and Kusakabe, 2010); attitudinal barriers in society promoting discriminatory practices towards people with disabilities (Griffiths et al, 2009; Kumaran, 2011); poor access to DPOs for people with disabilities living in rural areas (Deepak et al, 2013); difficulty in accessing venues and transport for group meetings (Dhungana and Kusakabe, 2010; Deepak et al, 2013); exclusion of people with disabilities from mainstream SHGs (Cobley, 2013); and lack of accurate raw data on disability type and prevalence in developing countries (Cobley, 2013). There was little evidence in the studies however, to suggest the extent to which each of these factors impacted upon the ability of DPOs to function.

DISCUSSION

From the 11 studies included in this review, there is evidence to suggest that DPOs function in a variety of different ways that are likely to promote the well-being, participation and rights of people with disabilities. There was some evidence that DPOs can produce significant, positive outcomes for persons with disability in terms of factors such as employment rates (Armstrong, 1993), access to microfinance and bank loans (Kumaran, 2011; Cobley, 2013), accessibility of housing (Armstrong, 1993; Miles et al, 2012), acquisition of orthopaedic devices

(Armstrong, 1993; Deepak et al, 2013), involvement in civil society (Armstrong, 1993; Griffiths et al, 2009; Deepak et al, 2013; Kleintjes et al, 2013), development of friendships and networks (Armstrong, 1993; Kumaran, 2011; Deepak et al, 2013; Kleintjes et al, 2013), and participation in training programmes (Deepak et al, 2013). The findings in this study were consistent with the stated aims and roles of DPOs as outlined by several sources (Enns, n.d.; World Health Organisation, 2011; People with Disabilities Australia, 2015). Overall however, the reviewed studies reported more on the outputs of DPOs than they did on the impacts and outcomes associated with DPO activities. Future research efforts aimed at understanding the impact of DPO activities and interventions would be of great benefit.

The functions of DPOs are varied and often differ from one context to the other. In general, the papers included in the review did not report in detail on contextual factors of the DPO (such as group demographics and composition, group location, societal attitudes, etc.) or how these factors impacted upon the activities and functions of the group. Without an understanding of these contextual factors and their impact on DPO function, it is hard to tell why some DPOs choose to focus on particular activities. What works in one location will not necessarily work in another, but there is little explanation for this in the literature. Future research into the impact that contextual factors have upon DPO formation and functioning would be beneficial for those looking to establish new groups that are likely to be effective in their given contexts.

The rights-based approach to disability has significantly shaped discussions around disability in recent times, and often the activities of DPOs are directed towards promoting the achievement of equal rights for people with disabilities. Evidence suggests that while people with disabilities are more disadvantaged than individuals without disability in terms of accessing equal rights in society, the former also have lower levels of community participation and social interaction than the latter (Dor and Savaya, 2007). Findings from the reviewed studies suggest that an important function of DPOs may be to provide a platform for group members to develop friendships and social connections. These social factors are more difficult to measure than other indicators of equality such as employment rates, income levels and education; nevertheless, they may be just as significant in terms of group outcomes. Future research that investigates the impact of DPOs on the social capital and well-being of group members would be beneficial for an understanding of the range of possible DPO outcomes.

This review revealed that, as yet, there is no published literature above level three evidence on the Oxford Centre for Evidence-Based Medicine (OCEBM) hierarchy of evidence (2011) concerning the function of DPOs in LMICs. Although qualitative studies occupy a lower level on the OCEBM evidence hierarchy than do quantitative interventional studies, for the purposes of this review qualitative methodologies provided illuminating data regarding the personal experiences of people with disabilities in DPOs. Future randomised interventional studies may be able to support the reported findings of this review by investigating changes in measureable factors (e.g., participation of people with disabilities in education, training, income-generation, etc.) before and after DPO formation.

Limitations

Only published peer-reviewed articles were considered for inclusion in this review. This could have introduced a publication bias (i.e., increased the likelihood of including only papers that reported positive results, studies published by English-speaking authors and studies reporting on data from high-income settings). There is a significant body of grey literature surrounding DPOs and their functions in LMICs; however, an initial search of these sources revealed a generally low quality of evidence and reporting. To ensure a baseline quality of evidence, the authors decided that only peer-reviewed sources would be included. It must be acknowledged that by this restriction, the insights gained may be limited. Nevertheless, it demonstrates a clear need for high-quality research to be undertaken in this area.

Despite the benefits of qualitative research methodology in suggesting answers to the questions posed in this review, there are some limitations associated with it. The first limitation is that of generalisability. As the majority of the included studies undertook case study analysis of DPOs, the findings reported in each study are difficult to generalise to larger populations (Anderson, 2010). Most of the studies did not present adequate information regarding the demographic composition of the DPOs and the contexts in which they operated. The second main limitation is that there is no single standard tool used for the assessment of qualitative research, and determining the rigour of a qualitative study depends to a large extent upon the extent to which an author has reported key elements (Tong et al, 2007; O'Brien et al, 2014).

CONCLUSION

DPOs are organisations established by and for persons with disability, to assist them in exercising their right to participate in life on an equal basis with others (United Nations General Assembly, 2006). The functions and roles of DPOs vary widely across groups and contexts. However, this review provides some preliminary evidence that DPOs in LMICs are involved in undertaking activities to facilitate participation in society, develop partnerships and connections with external organisations, and provide a platform for self-development and self-help activities for people with disabilities. While there is currently little research that assesses the long-term impact of these activities, it is possible that some of the short term DPO functions and outputs may be considered proximal indicators of outcomes such as increased empowerment, well-being and participation for persons with disability.

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