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THE ROLE AND FUNCTIONS OF DISABLED PEOPLE'S ORGANISATIONS AND ITS **OUTPUT AND OUTCOME FOR PEOPLE** WITH DISABILITIES: A PEER LITERATURE **REVIEW**

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Abstract

The aim of the study was to review the peer-reviewed literatures on the role and functions of Disabled People's Organisation (DPOs) and how these activities bring desired outcome and outputs in the day today life of the people with disabilities and their family members. Online database were searched without limits on date, language, state and country using combination of main two key words; ole and functions of DPOs. Twenty five studies were collected and from among them eleven studies were taken for inclusion in this review on the basis of predetermined inclusion and exclusion criteria. In this study The Critical Apprisal Skill Programme (CAPS) was used for assessing the quality of peer reviews studied. The analysis was conducted on the themes like; self-help, self-development, participation factors, Income Generation Programme and livelihood initiatives.

The study resulted in showing evidence from the within the studies stating that DPOs can bring a significant, positive outcome for persons with disabilities in terms of factors like; enrolment in SHGs, increased employment rates, access to microfinance and other bank loans, user-friendly housings, purchase of aids and appliances, involvement and participation in society and community around, development of peer groups, friendships and larger networks and participation in capacity building and other trainings. While the studies under this review largely did not investigate the long term outputs and impact of DPOs in the life of disabled population it spoke on their increased empowerment and well-being.

All the studies in this review suggested that the DPOs can be an effective medium to achieve their desired goal to bring an increased wellbeing, increase in participation and achieve the rights of people with disabilities especially in developing and countries.

Key Words: disabled people's organisation, role, functions, output, outcome.

Introduction

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 caregivers 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 (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.

Objectives of the Study

Although the general aims ad roles of the DPOs are spoken in various literature, the way in which these groups deal with these aims varies significantly. This literature review study was taken to assess peer reviewed evidence deliberating how the DPOs function and what if any output and outcome the PWDs achieve after being members n these DPOs.

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Methods

Online database were searched without limits on date, language, state and country using combination of main two key words; ole and functions of DPOs. Twenty Five studies were collected and from among them eleven studies were taken for inclusion in this review on the basis of predetermined inclusion and exclusion criteria. Titles and abstracts of the papers identified were screened against pre-determined inclusion and exclusion criteria. The chosen studies underwent full text evaluation. To further identify suitable studies a hand search of the reference lists of all relevant papers were assumed. Based on the inclusion and exclusion criteria twenty studies were selected for the study. In this study The Critical Apprisal Skill Programme (CAPS) was used for assessing the quality of peer reviews studied. The analysis was conducted on the themes like; self-help, self-development, participation factors, Income Generation Programme and livelihood initiatives. Studies were assessed using the Critical Appraisal Skills Programme (CASP) qualitative research checklist (Critical Appraisal Skills Programme, 2013). Two researchers evaluated the studies using 10 screening questions (answered 'yes', 'no', 'not assessed' or 'can't tell') to assess overall quality of the research.

Inclusion and Exclusion Criteria

Inclusion:

- Included a sample of individuals that met the criteria of a DPO.
- DPOs functioning effectively, especially in developing countries.
- Assessment of DPO functions and effectiveness was reported.
- Studies that published in peer-reviewed journals.
- Original researches of any level.

Exclusion:

- The research on DPOs from developed countries.
- Researches on samples was of internet-based groups.
- Groups that were not engaged on output based activities.
- Non-English language papers.

Results

This review shown a small body of literature relating to the roles and functions of DPOs. The selected studies perceived the role and functins of DPOs are by Dhungana and Kusakabe, 2010, Miles et al, 2012; Polu et al, 2015, Hemingway and Priestley, 2006, Stewart and Bhagwanjee, 1999; Kleintjes et al, 2013, Kumaran, 2011, Cobley, 2013, Deepak et al, 2013, Griffiths et al, 2009, Deepak et al, 2013, Armstrong, 1993, Hemingway and Priestley, 2006, Griffiths et al, 2009, Dhungana and Kusakabe, 2010, Kumaran, 2011, Miles et al, 2012, Cobley, 2013, Deepak et al, 2013, Kleintjes et al, 2013, Polu et al, 2015, Armstrong, 1993, Stewart and Bhagwanjee, 1999, Deepak et al, 2013, Kleintjes et al, 2013.

Quality assessment using the CASP checklist

Author	Year	1	2	3	4	5	6	7	8	9	10*
Armstrong	1993	Yes	Yes	Yes	Can't	Can't	No	No	Can't	Yes	M
et al					tell	tell			tell		
Cobley et al	2013	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Н
Deepak et al	2013	No	No	Yes	Yes	No	No	No	No	No	M
Dhungana	2010	Yes	Yes	Yes	Yes	Yes	Yes	No	Can't	Yes	Н
and									tell		
Kusakabe											
	2006	Yes	Can't	Yes	No	Yes	No	No	No	Yes	M
Hemingway			tell								
and Priestly											
Griffiths et	No	Can't	Can't	No	Can't	No	No	No	No	No	M
al 1993		tell	tell		tell						
Kleintjes et	2013	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Н
al											
Miles et al	2012	Yes	Yes	Yes	Yes	Yes	Yes	No	Can't	Yes	Н
			_						tell		
Polu et al	2015	Yes	Yes	Can't	Can't	Yes	No	No	No	Yes	M
				tell	ell						
Stewrt and	1999	Yes	Yes	Yes	Yes	Yes	Yes	Can't	Yes	Yes	Н
Bhagwanjee					/	-		tell			
Kumaran et	2011	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Н
al											

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?
- 1. Participation and Factors that facilitate Participation: In this review, participation was defined largely to include 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 indication 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.

- 2. 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).
- 3. Confidence for Participation: Dhungana et al (2010) found that members of a DPO 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 going out and visiting friends and neighbours.
- 4. Participation in Civil society, Political processes and Advocacy: Members of mental health selfhelp 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 audio visual 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).

- **5. Awareness-raising Activities:** Deepak et al (2013) highlighted the work of DPOs in facilitating major awarenessraising 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).
- **6. 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).
- 7. **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 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
- 8. 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.

- 9. 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 privatesector 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.
- 10.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).
- 11.Networks with Financial Institutions: Three of the DPOs sampled in Cobley 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 (Cobley, 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.

- **12.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.
- 13.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.
- 14.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 faciliate 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.
- **15.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.

- 16. 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: Kleinties 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).
- **17.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; Kleinties 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.

18. 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

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 peerreviewed 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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