

## Disabled People's Organisations Grow Social Connectedness for People with Disabilities: Evidence from South Asia

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### Abstract

Paper examines the social connections developed through two Disabled People's Organisation programs in low-income, rural communities of Nepal and India. Mixed methods: network mapping surveys and Focus Group Discussions (FGDs) are used to compare between before joining group and time of study. Results clearly suggest positive impacts on social networks.

*Keywords:* social network analysis, low-income, DPOs

Social networks (collections of social connections) have been demonstrated to be important indicators of a person's health and wellbeing, with a variety of studies across multiple settings demonstrating a direct correlation between fewer social connections and increased morbidity and mortality (Berkman, 1983; Holt-Lunstad et al., 2010; House et al., 1988; Perkins et al., 2015; Seeman et al., 1993). A myriad of health conditions including depression (Dalgard et al., 1995; Rosenquist et al., 2011), cardiovascular conditions (Knox & Uvnas-Moberg, 1998), cancer (Ell et al., 1992) and infectious diseases (Cohen, 2004; Patterson et al., 1996), have been found to correlate with having fewer social connections.

The positive health benefits of social connections have been acknowledged as related to the social support that a person receives through relationships (e.g., emotional support, practical assistance and health advice) (Schaefer et al., 1981) as well as the interconnectedness that comes from social participation, which promotes a sense of purpose and meaning in life (Cohen, 2004; Holt-Lunstad, 2015). Social networks have also been found to have a direct physiological effect on health, through complex interactions with immune, endocrine and cardiovascular processes (Uchino et al., 1996).

Studies from a variety of different contexts have shown that people with disabilities are more likely to have smaller and less diverse social networks compared to people without disabilities (Chen et al., 2017; Eisenman et al., 2013; Kreider et al., 2016; McCausland et al., 2016; Miles et al., 2012; Mithen et al., 2015). It has been theorised that the limited social networks of people with disabilities are a function of both physical and attitudinal barriers in society (Miles et al., 2012).

Disabled People's Organisations (DPOs) are organisations that are established by and for people with disabilities, emerging as part of a social movement in response to disability related discrimination (Shakespeare, 1993). Formation of DPOs in low-income settings has become a key strategy in disability inclusive community development programs in low and

middle income countries (LMICs) (Cornielje, 2009; Henderson et al., 2017; Young, Reeve, Devine, et al., 2016). While the function of DPOs varies depending on the context in which they operate, generally DPOs have served to give people with disabilities a platform to share their priorities, as well providing opportunities for solidarity, accessing rights and advocating for change (Cornielje, 2009; Grills et al., 2020; Leung et al., 2019; Shakespeare, 1993; Young, Reeve, & Grills, 2016).

Very few studies directly investigate the effects of DPOs on social networks. Young et al.'s 2016 literature review into the function of DPOs in LMICs, however, suggested that participation in DPOs may play a role in providing a platform for people with disabilities to develop social connections, with the authors recommending further research into the impact that DPOs can have in developing social capital. This study investigated the impact of participation in two DPOs on the social networks of people with disabilities in a rural South Asian context.

### **Research Methods**

This study used a mixed methods approach to investigate the impact of DPO participation on the social networks of people with disabilities. Firstly, descriptive Social Network Analysis (SNA) was used to map the results of surveys measuring the social connections of DPO members, comparing the social networks that existed before participants joined the DPOs with their social networks after several years of group participation. Secondly, thematic analysis of Focus Group Discussions (FGDs) with DPO members and key staff of the two NGOs facilitating the DPO programs investigated qualitative changes in social networks. This use of mixed methods, as well as investigating DPOs in two different settings, serves to validate the study findings through data triangulation.

### **Ethics approval**

Ethics approval for this research was obtained through the University of Melbourne's

Medicine and Dentistry Human Ethics Sub-Committee, the Community Health Global Network (CHGN) Ethics Committee (Uttarakhand, India) and the Nepal Leprosy Fellowship (NLF) board (Nepal).

### **Study setting**

Two different community level DPOs were selected for the study, one in the state of Uttarakhand in India and the other in the district of Sunsari in Nepal. Both locations are poor, rural, mountainous areas. In both settings, DPOs have been established with the support of local Non-Government Organisations (NGOs); Agnes Kunze Society (AKS) in India (part of the Uttarakhand Community Health Global Network (CHGN)) and Nepal Leprosy Fellowship (NLF). In both settings, the process that the NGOs used to establish the DPOs began with community consultation to identify people with disabilities at a village level. Once people with disabilities were identified, they were invited to join the DPO in which they received education on their rights and available disability services (which included linking to healthcare and income generating opportunities). Though AKS/NLF staff are involved in the facilitation of group formation and capacity building of groups, it is the intention of both programs that DPOs will eventually be run and sustained independently by the people with disabilities who are members. The two groups selected for this study do not strictly meet some definitions of DPOs; they were not established solely by people with disabilities themselves. Much of the literature focussed on DPOs in LMICs include organisations that have external facilitation in their establishment as these are typical of DPOs in low-income, high discrimination settings where self-established DPOs are rare (Young, Reeve, & Grills, 2016). Therefore, the inclusion of the two groups selected for this study under the definition of DPO is in line with existing literature.

### **Study population**

The primary study population was people with disabilities who are members of DPOs

which have been established with the support of AKS and NLF. DPO members were from ethnic groups based in the communities of Uttarakhand and Sunsari, speaking Hindi and Nepali respectively.

The population for the study also included staff members of AKS and NLF who have participated in the facilitation of the DPO programs of the NGOs. Both NGOs have established multiple village level DPOs, so some staff are directly involved with the two DPOs selected for the study, while others have supported similar groups.

### **Sampling**

Purposive sampling was used for both the selection of DPOs (within the broader DPO programs of each of the NGOs) as well as for the selection of members within the DPOs. For the selection of DPOs, AKS and NLF staff were each asked to identify a DPO which had been relatively active in community engagement (to ensure that a broad as possible range of social connections could be analysed). Then for the sampling of members within each of the DPOs, staff were asked to select a representative sample of group members who were willing to voluntarily participate in the study. These were stratified according to age groups, gender and type of impairment prior to random selection; (final sample included men and women with physical disability, sensory disability, psychosocial disability and disability as a result of leprosy). Where people with psychosocial disability (cognitive impairment) were selected, carers acted as assistants for surveys/FGDs.

For study recruitment, participants were invited to participate by NLF/AKS staff and provided with a translated (Hindi/Nepali) Plain Language Statement which was explained by the Indian/Nepali research assistant in gaining consent. No incentives were provided for study participation as incentives can be coercive in this context, though snacks and tea were provided during FGDs.

A total of 16 individual DPO members with disabilities (eight representatives from the Indian DPO and eight from the Nepali DPO) were selected for the social network surveys and DPO FGDs. The inclusion criteria for the selection of this sample were: members of DPOs who identify themselves as having a disability (together with carers where required); including physical, sensory or psycho-social disability; who were at least 18 years old, had joined the DPO at least 12 months prior to the study, and were regular in attending DPO meetings (at least 50% of meetings in the last year).

For the staff FGDs, all AKS/NLF staff who were directly involved in facilitation of the DPO programs were approached to voluntarily participate in interviews and also completed the consent process outlined above. Nine staff attended the AKS staff FGD and seven staff attended the NLF staff FGD. These staff, despite not being people with disabilities themselves, were selected to participate in the study as it was felt that they would have unique perspectives on the changes in social networks for people with disabilities participating in the DPOs, as they had been involved in working together with people with disabilities to establish these DPOs.

### **Data collection**

For the SNA aspect of the study, modified 'position generator' (Lin et al., 2001) surveys were developed (one for each setting) to gather data about the social connections of DPO members (surveys available on request). The lists of potential DPO social connections included in the surveys were developed through consultation with AKS and NLF staff as well as through reviewing project documentation. As well as basic demographic data, participants were asked to list contacts according to the pre-identified positions. Once a name was listed, the interviewer would ask the participant to determine whether the contact was an acquaintance, friend or family member (definitions included in surveys), then ask them to recall whether each contact was known before joining the DPO (as well as relationship type

at this time) to establish a baseline list of social connections to compare to the time of study list. In both settings, the SNA survey was piloted with two DPO members (from different DPOs to the ones selected for the study), and then refined following dummy-analysis and according to feedback from interviewers/interviewees.

For the FGD component of the study, questions (and theme-lists for prompts) were developed based on a literature review around social aspects of DPO involvement. Separate FGD question guides were developed for the DPO members and for NGO staff (available on request). The DPO member FGD question guides (for Nepal and India) were revised after analysis of the SNA results and staff FGDs.

Following a process of construct validation and localisation through consultation with key AKS/NLF staff, the SNA surveys and FGD guides were both translated into Hindi/Nepali and then independently back-translated to English for validation. Prior to survey interviews and FGDs, local research assistants (fluent in English as well as Hindi/Nepali) were trained in correct use of the tools.

## **Data analysis**

### *SNA surveys*

Results of the SNA surveys were collated and analysed using the open-source SNA tool NodeXL (an add-in for Microsoft Excel) (Smith et al., 2010). Data were cleaned for invalid results; for example, where participants listed 'manager sir' for financial institution staff rather than a name that could be matched with the results of other members. Using NodeXL, egocentric (Marin & Wellman, 2011) network maps were developed according to a Harel-Koren Fast Multiscale algorithm (Harel & Koren, 2002). The SNA survey analysis included a comparison of survey results for participants at baseline compared to time of study, both through looking at numbers and types of connections, and at the differences in network maps (e.g., degree of network centrality for people with disabilities).

### *FGDs*

Audio was recorded from the four FGDs (NGO staff and DPO member FGDs for Nepal and India). The Nepal based and India based research assistants then completed verbatim transcription and translation of the results to English. Following multiple readings of the translated transcript, a thematic analysis approach was used to identify and analyze emerging themes. These emerging themes were used to develop a coding framework, which was used to manually code data from the transcripts, refining the emerging themes. Once coding was completed the themes were further refined through the development of sub-themes under each of the broad themes. Further analysis occurred through the write-up of themes, which included comparison of themes between the different FGDs as well as to existing literature related to the themes (continuing literature reviews).

## **Results**

### **Social network survey results**

Analysis of the social network surveys using NodeXL yielded the social network maps displayed below (Figures 1, 2, 3 and 4) which illustrate a comparison of the social networks of DPO members (in both settings) at baseline (before joining DPO) with the time of study. For each of the social network maps, nodes represent the social connections that DPO members have in their communities; color-coded according to the 'position' or role of the person. Positions were classified as DPO members, health service staff, NGO staff (AKS/NLF as well as other NGOs), government staff, community services staff (school teachers, religious leaders, financial institution staff) and community organisation members (women's groups, youth clubs, ethnic groups and agricultural groups).

Comparing the baseline social network maps (Figures 1 and 3) to the time of study maps (Figures 2 and 4) for both Nepal and India, there was a marked difference not only in



the number of connections that each study participant had, but also in the interconnectedness of study participants. The Harel-Koren algorithm, which has been used to map the social networks, plots nodes that have a greater number of common social connections more centrally within a network (Harel & Koren, 2002). Thus the clustering towards the center of the maps by DPO members at time of study demonstrates a greater 'degree centrality' (Hanneman & Riddle, 2011) or connectedness of group members.

Tables 1 and 2 provide further insight into the changes in social networks of study participants, through showing a breakdown of the total numbers of connections reported for baseline compared to the time of study. Tables 1 and 2 also show the relative change in networks of members. For example, overall, there was a 225% increase in the number of connections for the Indian DPO members, and a 93% increase in the total number of connections for the Nepali DPO members. A common theme across both groups was a relatively high increase in number of connections with NGO workers, with a 2400% increase in India and a 275% increase in Nepal. It should be noted that most of these connections are with staff members of AKS and NLF.

Tables 1 and 2 also show that participants from both settings had a marked increase in the total number of connections between participants and other DPO members, with a 579% increase in India and a 294% increase in Nepal. Another common theme between the two settings is that both groups had a relatively low increase in the number of connections with 'community services' (7% increase for India, 22% increase for Nepal), suggesting that DPO participation had little impact on connections between DPO members and community services (financial institutions, religious leaders and school teachers). There was also commonality in the relatively similar level of increases in the connections between group members and 'community organisations' with relatively modest increases of 48% and 58% for India and Nepal respectively. Similarly, increases in connections with 'health services'

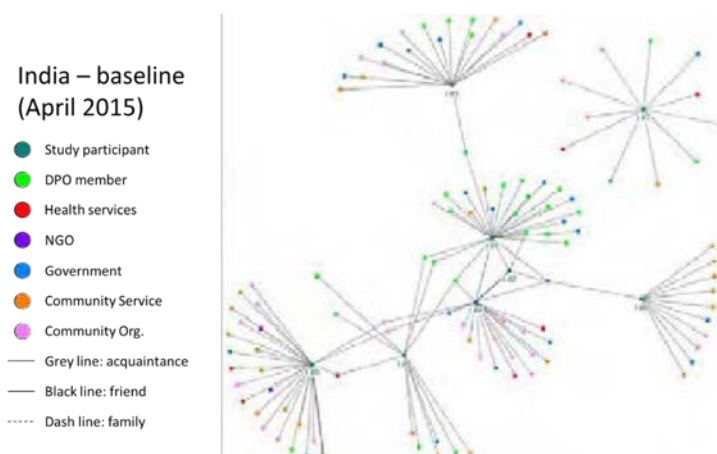
were also modest for both settings, with a 20% increase for the India DPO and a 45% increase for the Nepal DPO.

Where the results for the total numbers of connections most markedly diverged between India and Nepal was in the total number of connections with government staff, with the Nepal DPO showing a 150% increase and the India group showing a modest 24% increase. However, this appears to be largely a function of the India DPO members having more connections to government staff before joining the DPO. Moreover, the increase in connections with government staff for the Nepal DPO was primarily due to connections of two participants (N #1 and N #7).

Within each of the DPOs, there was considerable variability between individuals in terms of increases in connections at time of study compared to baseline. For example, in Figure 3 for the India DPO, one member (I #2) had a 900% increase in connections (from 3 connections at baseline to 30 at time of study), while another member (I #7) had a 46% increase in connections (from 26 at baseline to 38 at time of study). Similar variability can be seen between individuals in the Nepal DPO (Figure 6), with increases in the number of connections ranging from 38% to 167%.

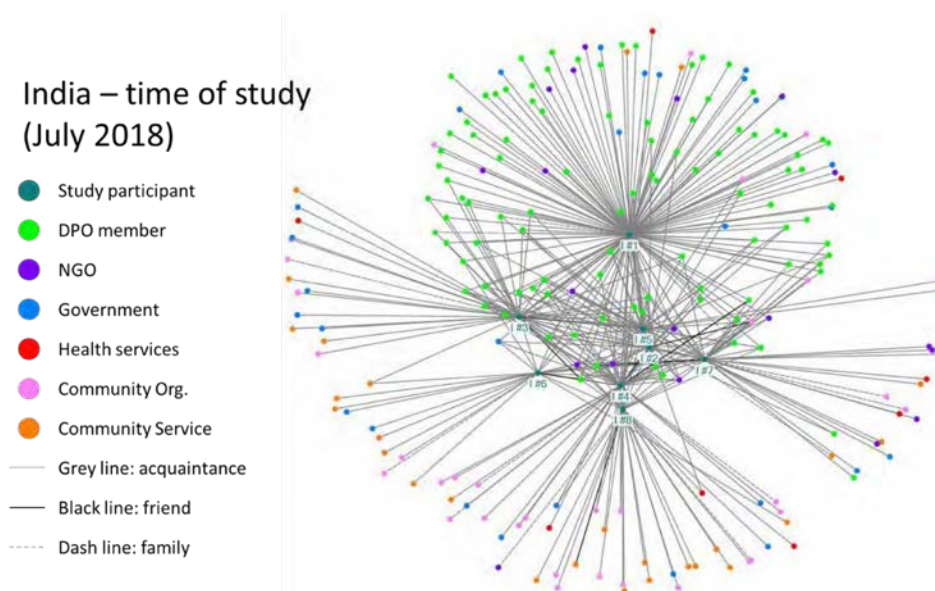
### Figure 1

*Social network map of India DPO members at baseline*



**Figure 2**

*Social network map of India DPO members at time of study*



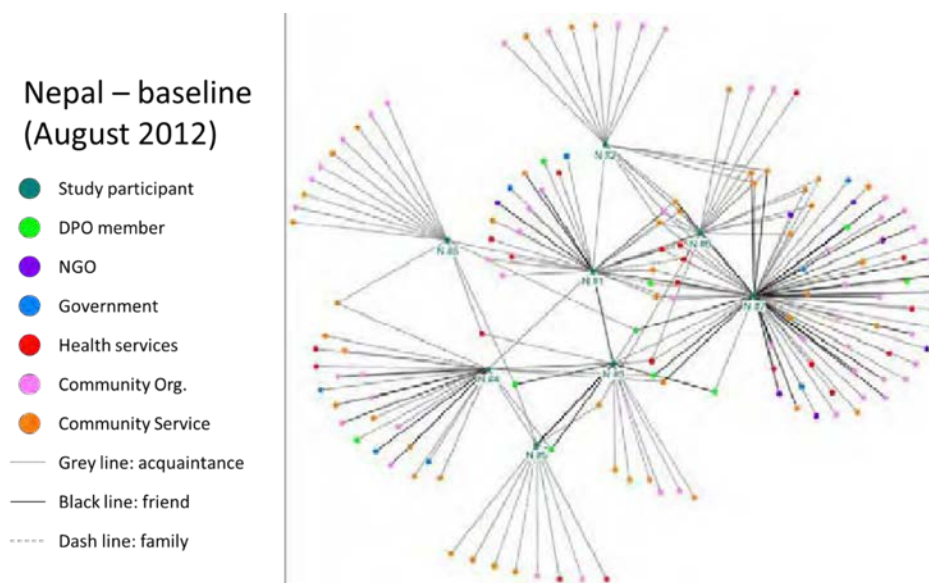
**Table 1**

*Comparison of number of connections per positions for DPO members at baseline vs time of study – India DPO*

<i>Baseline</i>	<b>I #1</b>	<b>I #2</b>	<b>I #3</b>	<b>I #4</b>	<b>I #5</b>	<b>I #6</b>	<b>I #7</b>	<b>I #8</b>	<b>TOTAL</b>
<i>DPO</i>	19	2	5	3	7	0	2	1	<b>39</b>
<i>Health services</i>	0	0	1	3	1	0	2	3	<b>10</b>
<i>NGO</i>	0	0	0	0	0	0	0	2	<b>2</b>
<i>Government</i>	7	1	5	4	1	3	2	2	<b>25</b>
<i>Community orgs.</i>	1	0	4	8	0	2	3	9	<b>27</b>
<i>Community services</i>	2	0	4	3	3	6	2	9	<b>29</b>
<b>TOTAL</b>	<b>29</b>	<b>3</b>	<b>19</b>	<b>21</b>	<b>12</b>	<b>11</b>	<b>11</b>	<b>26</b>	<b>132</b>

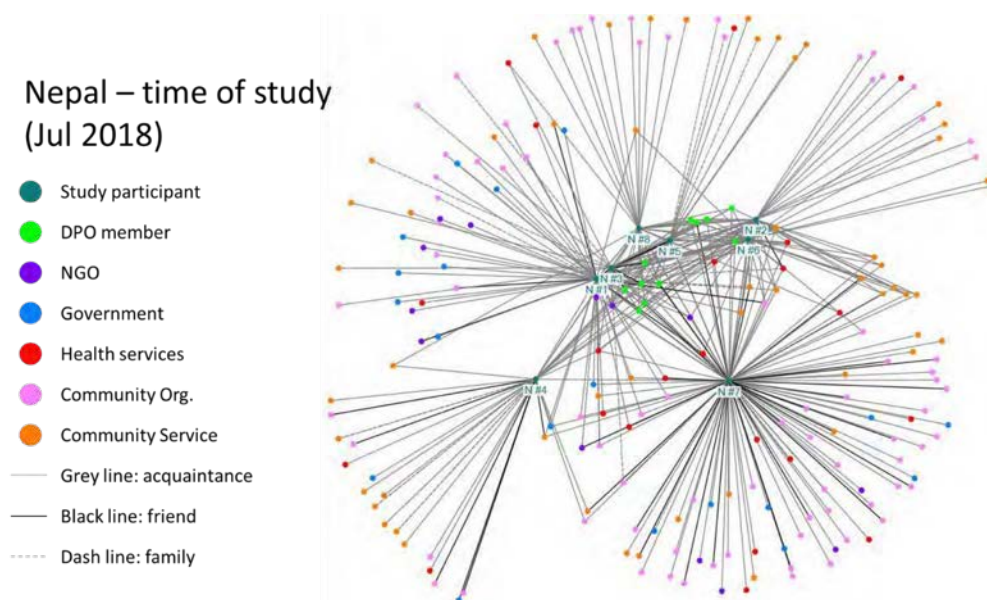
Time of study	I #1	I #2	I #3	I #4	I #5	I #6	I #7	I #8	TOTAL	% change
DPO	104	25	30	26	33	10	27	10	265	579%
Health services	2	0	1	3	1	0	2	3	12	20%
NGO	15	3	4	5	5	4	10	4	50	2400%
Government	12	1	5	4	1	3	2	3	31	24%
Community orgs.	6	1	4	10	2	2	6	9	40	48%
Community services	2	0	5	3	3	7	2	9	31	7%
<b>TOTAL</b>	<b>141</b>	<b>30</b>	<b>49</b>	<b>51</b>	<b>45</b>	<b>26</b>	<b>49</b>	<b>38</b>	<b>429</b>	<b>225%</b>
% change	386%	900%	158%	143%	275%	136%	345%	46%	225%	

**Figure 3**  
Social network map of Nepal DPO members at baseline



**Figure 4**

*Social network map of Nepal DPO members at time of study*



**Table 2**

*Comparison of number of connections per positions for DPO members at baseline vs time of study – Nepal DPO*

<i>Baseline</i>	<b>N #1</b>	<b>N #2</b>	<b>N #3</b>	<b>N #4</b>	<b>N #5</b>	<b>N #6</b>	<b>N #7</b>	<b>N #8</b>	<b>TOTAL</b>
<i>DPO</i>	4	1	8	6	4	2	6	3	<b>34</b>
<i>Health services</i>	8	0	2	3	2	5	12	1	<b>33</b>
<i>NGO</i>	1	0	0	0	0	1	6	0	<b>8</b>
<i>Government</i>	1	0	0	3	0	0	4	0	<b>8</b>
<i>Community orgs.</i>	6	6	2	6	2	3	24	6	<b>55</b>
<i>Community services</i>	7	11	4	6	5	12	24	5	<b>74</b>
<b>TOTAL</b>	<b>27</b>	<b>18</b>	<b>16</b>	<b>24</b>	<b>13</b>	<b>23</b>	<b>76</b>	<b>15</b>	<b>212</b>

<i>Time of study</i>	N #1	N #2	N #3	N #4	N #5	N #6	N #7	N #8	TOTAL	% change
<i>DPO</i>	17	18	16	12	17	17	20	17	134	294%
<i>Health services</i>	11	5	2	3	3	6	16	2	48	45%
<i>NGO</i>	10	2	3	1	2	1	9	2	30	275%
<i>Government</i>	8	0	0	3	0	0	9	0	20	150%
<i>Community orgs.</i>	15	6	3	6	2	4	44	7	87	58%
<i>Community services</i>	11	15	4	8	6	14	27	5	90	22%
<b>TOTAL</b>	<b>72</b>	<b>46</b>	<b>28</b>	<b>33</b>	<b>30</b>	<b>42</b>	<b>125</b>	<b>33</b>	<b>409</b>	<b>93%</b>
% increase	167%	156%	75%	38%	131%	83%	64%	120%	93%	

Analysis of the social-network survey results also included a comparison of the types of relationships (acquaintance, friend or family) between baseline and time of study. Tables 3 (India DPO) and 4 (Nepal DPO) display a breakdown of the total numbers of connections according to these categories. Note that details of the definitions of acquaintance/friend/family are included in the social network questionnaires and are available on request.

The most notable change in numbers of connections according to relationship type (between baseline and time of study) was for connections to ‘acquaintances’, with a 260% increase in India (Table 3) and a 135% increase in Nepal (Table 4).

While there was a marked change in the number of connections to ‘friends’ for India (300% increase), there were no changes in connections to ‘friends’ in Nepal. Of the six new ‘friend’ connections at time of study for the India DPO, five of the connections were with other DPO members.

**Table 3***Comparison of types of connections at baseline vs time of study – India DPO*

<i>India baseline</i>		<i>India time of study</i>		<i>% change</i>
Acquaintance	112	Acquaintance	403	260%
Friend	2	Friend	8	300%
Family	18	Family	18	0%
<b>Total</b>	<b>132</b>	<b>Total</b>	<b>429</b>	<b>225%</b>

**Table 4***Comparison of types of connections at baseline vs time of study – Nepal DPO*

<i>Nepal baseline</i>		<i>Nepal time of study</i>		<i>% change</i>
Acquaintance	145	Acquaintance	341	135%
Friend	43	Friend	43	0%
Family	24	Family	25	4%
<b>Total</b>	<b>212</b>	<b>Total</b>	<b>409</b>	<b>93%</b>

**Focus Group Discussion results**

In opening all FGDs, respondents were asked whether DPO membership had increased or decreased the social networks of participants; exclusively, the response was that DPO participation had increased the social networks of people with disabilities. Table 5 provides a breakdown of themes that emerged during FGDs, demonstrating which FGDs the themes arose in, as well as whether the themes were considered to be positive or negative impacts. Detailed descriptions of each of the themes listed in Table 5 is provided below.

Discussions in the FGDs around this theme were prompted by the following questions:

1. Have there been any positive effects of your DPG's increasing social network?
2. If so, what have been these effects?
3. Have there been any negative effects of your DPG's increasing social network?
4. If so, what have been these effects?

**Table 5**

*Impact of increased social networks – categorisation of themes emerging from FGDs*

	<i>DPO members</i>		<i>As reported by staff</i>	
<i>Nepal</i>	Positive	Negative	Positive	Negative
	Improved self-esteem Improved community perception Access to government entitlements Access to health services Friendship opportunities Advocacy opportunities Access to employment opportunities	Time burden	Improved self-esteem Improved community perception Access to government entitlements Access to health services Advocacy opportunities Access to employment opportunities Increased independence	Time burden Burden on govt. services
<i>India</i>	Positive	Negative	Positive	Negative
	Improved self-esteem Improved community perception Access to government entitlements Access to health services Friendship opportunities Advocacy opportunities Access to employment opportunities	Time burden	Improved self-esteem Improved community perception Access to government entitlements Friendship opportunities Increased independence	Burden on govt. services

The data for India and Nepal are reported together below, given the near complete overlap of themes.



*Positive impacts***Improved self-esteem.**

The strongest theme emerging across all four FGDs covering both research sites, and repeated by several participants from each group, was that of improved self-esteem as a result of an increased social network. DPO members and staff alike discussed the improvement in self-esteem (or self-confidence) that came from being better connected to others.

From the time I have joined this group, I got the chance to meet people from outside, to meet new people. Like before we could not talk to people but now our confidence has increased.

(India DPO member)

While not directly discussed here, improved self-esteem was also listed as a cause of increasing social networks (as well as an outcome) thus suggesting a cyclical relationship between increasing self-esteem and increasing social networks.

**Improved community perception.**

Directly related to improved self-esteem and also occurring across all four FGDs was the theme of improved community perception of people with disabilities (as a result of increased networks). This was often discussed in relation to how people with disabilities were viewed before they became a part of the DPOs.

Until I was involved in the group people often said what would I do with my life but now people say that I will do something. They have become more positive towards me. (Nepal DPO member)

Another stated "...people in the society have started to respect us and accept us" (India DPO member).

**Access to government entitlements.**

The final theme to occur across all four FGDs was that of access to government entitlements as a result of increased social networks. Discussions around this theme were related to both the increased awareness of entitlements as a result of being connected to the DPO, as well as improved access to entitlements through established connections.

In the meeting they discuss on [sic] topics like MNREGA scheme, Pradhan Mantri Yojna [Government of India welfare programs]. Before when they were at home, they didn't know about these schemes, but now after attending these meetings they are aware about different schemes for them [people with disabilities].

(AKS staff)

[P]eople with disability [sic] and leprosy used to request for loan; due to their physical condition no one would provide them with loan but now due to ... the groups' relationship with other bodies, they ... have received the seed capital amount from different related organizations. (NLF staff)

**Access to health services.**

Improved access to health services as a result of increased social networks was a theme occurring across three of the FGDs (both DPOs and the NLF staff FGD). Discussions related to this theme included access to medical care as well as counselling and access to assistive devices for people with disabilities:

...having a positive relationship with the local health post the members of the DPO and leprosy affected people have been able to get assistive devices [and] necessary counselling. (NLF staff)

Discussion also included improved access to health services for family members of people with disabilities, for example:

When my daughter got sick many others were sick too. Others took them to the witch doctors, and I took my daughter to the doctor. And mine survived and theirs died. (Nepal DPO member)

### **Friendship Opportunities.**

A theme also occurring across three of the FGDs (both DPOs as well as the AKS staff FGD) was that of friendship opportunities arising from increased social networks. DPO members from both India and Nepal compared the connections developed in their groups to being part of a family:

Now after coming to the group we can gather together with our brothers and sisters, our sons and nephews... we can be as if we are relatives. (Nepal DPO member)

Participants also discussed friendships that had developed with people outside of the DPOs: “There are lots of benefits after being in the group, we have come to know people, people in different organizations, come to know friends and colleagues etc.” (Nepal DPO member).

### **Advocacy opportunities.**

Another theme arising from three of the FGDs (both DPOs as well as the NLF staff FGD), was that of advocacy opportunities as a result of broadening social connections. For example:

Now we can take stand for our rights. Like for the electricity connection we went to the authorities. The work that was supposed to be finished in 8 days was completed in 3 days because of the good connections. (India DPO member)

As well as advocacy opportunities arising through being connected to people in positions of power, discussions related to this theme also centered on the benefit of having a collective voice with other people with disabilities, for example: “it is said if one spits it dries, but if many do it flows. So if one speaks the voice cannot be heard but if everyone does the voice is heard” (NLF staff).

### **Employment opportunities.**

A theme also arising across three FGDs (both DPOs and NLF staff FGD) was improved access to employment opportunities as a result of increased social connections. For example: “...relationships developed [with] different organizations that provide vocational trainings, provide the opportunities of employment...” (NLF staff).

### **Increased independence.**

Increased independence for people with disabilities as a result of increased social connections was a theme that only arose from the two staff FGDs. Staff from India discussed the notion of independence in a very general sense: “they [DPO members] have become independent because before their family took them as a burden.”

While staff from Nepal discussed independence in relation to economic standing:

...those who were completely dependent upon others are now economically stable and are actually able to support their family. They have become self-dependent after being involved in the groups.

### *Negative impacts*

#### **Time burden.**

The theme of increased time burden as a negative impact of increased social connections arose across three of the FGDs (both DPOs and the NLF staff FGD). Increased time burden was discussed in relation to family time as well as work time, e.g.,

...we cannot give time at home and this starts fights. I myself have faced a huge issue on [sic] it. There was a time I had to give time somewhere and someone in my home was sick and I had to go home but I reached late. I had a group meeting here and I reached home late and I had issue on it. (Nepal DPO member)

Due to the increase of network of relationship of the group members, during their seasonal work the organizations and bodies call them for different programs, and this has created a bit ...problem of time management. (NLF staff)

#### **Burden on government services.**

An interesting theme emerging only from the staff FGDs was the issue of increased social connections for people with disabilities creating a burden on government services. For example:

Before these people never questioned the higher authorized people, but after growing their connections, they have realized their schemes and some people have even given RTI (Right To Information) to these authorities, which is a demerit for these people in authority. (AKS staff)

### **Discussion**

It is clear from the results of the social network surveys that DPO participation can make a marked difference on the social networks of people with disabilities both in terms of

the number of connections developed and the ‘interconnectedness’ of participants. The introduction of this paper has outlined the significance of social networks for a person’s health and wellbeing, as well as the fact that people with disabilities typically have smaller and less diverse social networks compared to the general population.

It is interesting to note that despite being facilitated by different NGOs in different (though somewhat similar) contexts, there are many similarities in the results of the social network surveys between the two different DPOs. A notable example of this is that the social network maps at time of study (Figures 2 and 5) are of a remarkably similar shape for both the Nepal and India DPOs.

In both settings, the changes in social connections between baseline and time of study varied quite markedly between individuals within each of the DPOs. This appears to be partly a function of how socially connected a DPO member was before joining the group, i.e., a person who already had multiple connections did not have a significant change through participation, while a person with very few connections did have a marked relative increase in connections. It should also be noted that the participants of this study were regularly attending DPO meetings. It is unclear if this increase would have occurred or be sustained for those who attended irregularly or dropped out of the DPO.

The most marked increases in connections between baseline and time of study for both settings is between DPO members and other people with disabilities (as well as AKS/NLF staff), which is unsurprising as one of the key functions of DPOs is to bring together people with disabilities to support each other (Young, Reeve, & Grills, 2016), a process which has been facilitated by AKS/NLF staff. SNA results have also demonstrated increases in the connections between DPO members and health services, community services, community based organisations and government staff, which have been found to be important functions of DPOs in other settings in seeking to empower people with disabilities to access

their human rights (Kleintjes et al., 2013; Polu et al., 2015; Young, Reeve, & Grills, 2016). Moreover, these increases in connections directly link to the results of the FGD section of this study, particularly the themes of ‘access to government entitlements’ and ‘access to health services.’

Results of the FGDs further align with the results of the SNA, with FGD participants confirming that participation in DPOs had increased the social networks of members and then discussing the impacts of these increased connections. The FGD results provide insight into the significance of the changes in social networks that are demonstrated by the SNA results. As per the results section above, FGD results were categorised under a list of themes that emerged under the broad theme of ‘impacts of increased social networks.’

The theme of ‘improved self-esteem’ as a result of increased social connections is echoed by Polu et al. in Bangladesh (another low-income South Asian setting), who suggested that DPO involvement resulted in a broadening of the social circle of group members, thus increasing self-esteem (Polu et al., 2015). Self-esteem has been described as a function of the degree to which an individual has experienced social rejection or acceptance in their community (MacDonald et al., 2003). Improvements in self-esteem as a result of increased social networks was discussed by multiple members across all four FGDs, suggesting a clear benefit of DPO involvement that is likely to be a sustainable change in the lives of study participants.

The theme of ‘improved community perception’ also corresponds to the findings of Polu et al. in addition to the findings of Dhungana and Kusakabe (2010) (investigating the roles of women’s DPOs in Nepal) with both studies suggesting that an impact of DPO involvement is increased respect from broader community members towards people with disabilities. While there is little in the literature to expand on the reasons why increasing social connections would improve community perception of people with disabilities, this

study's FGD results reveal that it can be partly due to community members recognising that people with disabilities have a role to play in society.

There have been multiple studies (in a variety of LMIC contexts) demonstrating that DPOs may improve access to different services for people with disabilities. These studies do not articulate the mechanism behind the DPOs increasing access to services; possible mechanisms include the direct advocacy activities of the DPOs as well as increased social connectedness and awareness of services and how to access them. Nonetheless, these studies directly align to the three themes listed above related to improved access to services: (1) 'access to government entitlements' (Kumaran, 2011; Leung et al., 2019; Polu et al., 2015; Young, Reeve, Devine, et al., 2016), (2) 'access to health services' (Armstrong, 1993; Deepak et al., 2013; Kleintjes et al., 2013; Polu et al., 2015) and (3) 'access to employment opportunities' (Cobley, 2013; Dhungana & Kusakabe, 2010; Kleintjes et al., 2013; Kumaran, 2011; Miles et al., 2012). These changes in access, correlated by the SNA section of this study, suggest a significant change in the lives of DPO members: empowerment to independently access resources through relationships.

Through the FGDs the theme of 'friendship opportunities' also arose, with descriptions of friendships developing within groups as well as with outsiders. Other DPOs in LMICs have been found to also serve a function of facilitating social connections between group members (Cobley, 2013; Deepak et al., 2013; Polu et al., 2015). For example, Cobley's study in India found that DPO members viewed meetings as 'important social occasions.' (Cobley, 2013). Notably, the theme of 'friendship opportunities' also specifically correlates to the SNA section of this study (see Figure 7 above) which demonstrates a marked increase in connections to 'friends' at time of study for the India DPO (which were primarily connections to other DPO members). It is interesting to note that while the theme of 'friendship opportunities' was also mentioned in the Nepal FGD, SNA revealed no increase



in the number of connections to ‘friends.’ Rather, a marked increase was seen in connections to ‘acquaintances,’ which is how most other DPO members were categorised by respondents. This discrepancy between the SNA results and the FGD results can likely be attributed to the definition of ‘friend’ compared to ‘acquaintance.’ In the social network survey, a specific definition of ‘acquaintance’ was given: “the respondent would know the person's name if he or she were to encounter the person by accident on the street and that both parties could initiate conversation with the other,” but ‘friend’ was left to be defined by the DPO member completing the survey.

In line with the theme of ‘advocacy opportunities’ (through increased social connections), studies of the roles of DPOs in multiple contexts discuss DPO participation as a means to advocate (particularly to government) for the rights of people with disabilities (Armstrong, 1993; Deepak et al., 2013; Kleintjes et al., 2013; Miles et al., 2012; Zhang, 2017). Further, a common theme emerging from the literature as well as the FGDs of this study is that of DPOs advocating in particular for inclusive education for children with disabilities (Deepak et al., 2013; Miles et al., 2012; Zhang, 2017). Through increased social networks, people with disabilities have access to a shared voice, empowering them to advocate for their own needs as well as for other people with disabilities in their communities.

The theme of ‘increased independence’ for people with disabilities as a result of expanded social networks was only mentioned by the FGDs with AKS/NLF staff, where there was little expansion on what was actually meant by the term independence, apart from in the NLF FGD where it was specified to be a reference to increased economic independence. This theme correlates to existing literature on DPOs in LMICs only in the sense that often an aim of DPOs is to become independent of NGO support (Polu et al., 2015; Young, Reeve, Devine, et al., 2016). It is possible that a sense of independence is developed

through additional social connections leading to an increase agency for DPO members, e.g., if a DPO member was able to access resources themselves, through new connections, rather than relying on family members.

There is a dearth of published evidence on the negative aspects of DPO participation in LMICs. Thus, the themes related to negative impacts of increased social connections raised in this study ('time burden' and 'burden on government services') cannot be directly compared to other literature. The potential for negative impacts of expanding the social networks of people with disabilities through DPO participation is a unique finding of this study, and warrants further investigation, as the early recognition and mitigation of such issues may help improve the sustainability of DPOs in LMICs.

In the above discussion, it should be noted that (apart from theme of improved self-esteem) the cited papers speak more broadly to the impacts of DPO participation, rather than particularly to the impact of broadened social networks for people with disabilities. The fact, however, that overall, the themes of this study are echoed by the results of other studies on DPO participation suggests that there is a good case for transferability of these results to DPO programs in other settings.

A broad implication of the findings of this study is that the results provide further evidence to justify the use of DPO interventions to improve the social capital of people with disabilities in low-income settings, interventions which hitherto have had limited justification through published literature. Furthermore, the findings provide a greater understanding of the significance of the improvements in social networks that can result from DPO participation.

### **Study limitations**

The small sample size of the SNA component of this study (eight people with disabilities in each setting from two DPOs) means that statistical significance cannot be claimed for either the relative increases in the number of connections that group members

have or the degree of centrality in social network maps.

The use of purposive sampling to obtain participants with a range of different types of disabilities (as well as gender/age) meant that the results are not necessarily representative of the selected groups. Further, selection bias may have been increased both through the choice of DPOs relatively active in community engagement, as well as through sampling group members with relatively high attendance. DPOs less active in community engagement, and irregular attendees of groups may be quite different cohorts and the DPO intervention may not have been an effective intervention for these groups. Moreover, the involvement of NGO staff as researchers may have led to a response bias.

A further study limitation, particular to the SNA component, is the reliance on the recall of participants to establish the social network maps at baseline. It is conceivable they did not recall all the contacts they had at baseline. Also, because participants first listed their current connections and then were asked to reflect on whether they had the same connections before joining the DPO, they were biased towards reporting increased networks as they were not prompted to think of people that they were connected to before joining the DPO but were no longer connected to at the time of study. However, considering that the study covers a relatively short period of time (three years for India and six years for Nepal), it seems unlikely that a participant would have stopped being acquainted with another member of their community between baseline and time of study.

Another limitation of this study was the restricted scope to identify other causes of increased social networks in the target communities. The network may have increased due to a temporal trend or from other government programs. However, there is some evidence that the social networks of people with disabilities tend to naturally contract over time rather than grow (Saarinen et al., 2018). Thus, with no DPO involvement it could have been expected that the social networks of the people with disabilities would have dwindled. Furthermore,

the mixed methods approach revealed that FGD participants attributed the changes in social networks to DPO participation.

Further research is needed to determine the mechanisms behind DPO participation leading to increases in social networks, as well as the optimal ways to facilitate the development and deepening of social connections for DPO members. More research is also required to understand how connectedness leads to the positive outcomes listed in this study.

A further recommendation from this study is that SNA be used more widely by AKS/NLF (as well as other organisations facilitating the development of DPOs) in the analysis of DPO interventions. A specific application of SNA in DPOs could be to identify potential outliers in social network maps. For example, more targeted support for developing connections could be provided to a person with a disability who appeared to have markedly fewer social connections compared to other DPO members.

## **Conclusion**

Overall, the results of this study suggest that the AKS and NLF DPO programs have had a positive impact in terms of broadening and diversifying the social networks of people with disabilities. Furthermore, the themes emerging from FGDs revealed multiple positive benefits of these increased social networks which outweigh the possible negative impacts. Moreover, this study has demonstrated that social network mapping is a useful tool for assessing the impact of DPO interventions, providing a clear visual representation of the impact of DPO membership on the social networks of people with disabilities.

This study has demonstrated how DPO participation can grow social connectedness and in doing so have positive impacts for people with disabilities. It further strengthens the case for the development of DPOs in LMICs to promote the wellbeing, health and right to social participation of people with disabilities.

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 **Disabled People's Organisations grow Social Connectedness for People with Disabilities: Evidence from South Asia** by James Montgomery, Andrew Sithling, Fairlene Soji, Matthew Reeve and Nathan Grills

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**Contextualizing Principles:  
Lebanon and Social Justice Perspectives on Disability Reform**

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**Abstract**

The country of Lebanon continues to fall short in the implementation of rights-based legislation that supports persons with disabilities. This article presents a theoretical framework for contextualizing principles that have proven effective in the US and UK in order to mobilize social allies and reorient Lebanese societal perspectives on disability.

*Keywords:* Lebanon; socio-cultural context; disability reform

### Contextualizing Principles:

#### Lebanon and Social Justice Perspectives on Disability Reform

There has been negligible progress in the measurable outputs of disability reform in the Middle East. Data released from the Arab region in 2018 reveal a low percentage of reported disability, low rates of literacy for disabled persons, low rates of educational attainment, lower school attendance rates for children and youth with disabilities, and high rates of economic inactivity and unemployment (United Nations, 2018). In contrast, there has been slow and steady progress in asserting the rights of disabled persons in the United States and United Kingdom (Beyer, 2016; Chaney, 2011; Hertel & Libal, 2011; McLeskey et al., 2013). The UN Committee on the Rights of Persons with Disabilities has stressed the importance of changing attitudes towards persons with disabilities as an essential step toward lasting reform (United Nations, 2019; Koplewicz & Human Rights Watch, 2018). Looking at the specific case of Lebanon, I suggest that contextualizing approaches that have proven effective in the US and UK to the Lebanese socio-cultural context can help disability advocates in their efforts to mobilize social allies, reorient societal perspectives, and promote disability reform in the Arab world.

#### Lebanon

Lebanon presents an interesting case for examining the nexus of culture and social justice perspectives on disability. In an area of 4,036 square miles (slightly smaller than the US state of Connecticut), Lebanon contains eighteen different religious sects each vying to preserve its own distinctive identity while at the same time participating in the shared aspects of a Lebanese national and cultural identity. The country is governed under a confessional democracy where each religious community is entitled to particular political offices in proportion to its population demographic. There has not been an official census in Lebanon since 1932 for fear that any official recorded demographic shifts will disrupt the balance of power. Religious identity is a matter of public record with each child inheriting the religious affiliation of his or her father.

Lebanon also has a long history of political instability. From 1975 until 1990 Lebanon was embroiled in a sectarian civil war tied to regional events. Since 2005 there have been more than twelve political assassinations, a regular turnover in government, and a number of extended periods where the government has only existed in a caretaker role (“Timeline: Lebanon assassinations,” 2008). From 2014 to 2016, the country functioned without a president for 29 months (Nakoul & Perry, 2016). At present, the country is in the midst of protests in an attempt to overthrow the political class. Political instability has elevated and strengthened the importance of ethnoreligious affiliation for survival and vocational opportunities. Individual needs are met first and foremost through the community of origin instead of the political entity (Salloukh et al., 2015).

Lebanon’s long litany of conflicts has also destroyed its economic infrastructure. Many Lebanese citizens survive by depending on remittances from family members working in different countries. In 2010, Lebanon received 8.2 billion dollars in remittances with an estimated population of 4.3 million people, which constituted 22.4% of the country’s GDP, the highest in the Middle East/North Africa region (World Bank, 2011). A steady emigration of Lebanese citizens, who rely on education as a means to receive employment opportunities in more prosperous societies, has been a consequence of Lebanon’s failed economy.

As a result, Lebanon places a high value on privatized, formal education. In 2011, a World Bank report stated that approximately 61.3% of the secondary school population is enrolled in private schools (World Bank, 2011). These schools are generally run under the oversight of ethnoreligious communities (Frayha, 2016). Privatized education makes large-scale, systemic reform difficult. Abou Assali (2012), the first director of the Education Center for Research and Development (1993-1999), and Frayha (2016), the head of the ECRD from 1999-2002, provide accounts of the development, attempted implementation, and failure of educational reform in Lebanon. They contend that religious sectarianism is a formidable obstacle to achieving national

and civic goals and that the protectionist mentality bred by Lebanese sectarianism makes it difficult to promote reform beyond the boundaries of sectarian self-interest.

The culture of Lebanon is generally described as collectivist (Hofstede, 2001; Joseph, 1993; Khalaf & Khalaf, 2009; McCabe et al, 2008). Whereas individualism is characterized by the subordination of the goals of the group or collective to those of the individual, collectivism involves the subordination of individual goals to those of the group (Ayyash-Abdo, 2001). In Lebanon, a person's identity is primarily constructed through her identification with a particular ethnoreligious group and is characterized by "the primacy of the family over the person...the sense of responsibility for and to others, (and) the experience of one's self as an extension of others and others as an extension of one's self" (Joseph, 1993, p.479). The elevation of the group above the individual has wide-ranging social implications for the implementation of disability reform.

### **Disability in Lebanon**

Although there are currently no official statistics on disabilities in Lebanon, persons with disabilities can register at the Ministry of Social Affairs and receive a disability card if they meet the definition of disability outlined in in Lebanese law 220/2000 (Unesco, 2013, p.8). As of January 2013, the total number of registered persons with a disability card was 2%, roughly 80,000 people of the estimated population of 4 million (Unesco, 2013). The 2% percentage of registered persons with disabilities includes the elderly population as well as people who suffer from chronic diseases such as diabetes and kidney failure (Unesco, 2013). The number of persons registered as disabled in Lebanon is 13% percentage points below the estimated percentage of persons with disability worldwide (World Health Organization, 2011). In addition, the Lebanese government has stated that there are 8,558 school-age children registered with a disability. This is roughly 35,000 less than projected average estimated based on Lebanon's population of youth (Koplewicz & Human Rights Watch, 2018). It should also be noted that Lebanon has weathered a number of

political conflicts which would typically result in higher number of persons with disabilities as a result of violent acts or war. Based on these figures, it is clear that cases of disability are woefully unreported.

In 2000, the Parliament of Lebanon passed law 220/2000 dealing with the rights of persons with disabilities (PWDs). This law was heavily influenced by the *World Programme of Action Concerning Disabled Persons* (United Nations, 1997) and the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (Damaj, 2014; United Nations, 1996) and is one of the most progressive examples of disability legislation in the Middle East. In 220/2000, disability is addressed as a rights-based issue, and the government is required to adopt policies and programs based on integration. The legislation also includes the right to health care, rehabilitation, support services, transport, housing, education and sports, and the right to employment and social benefits for persons with disabilities (Unesco, 2013). In addition, Lebanon has signed and ratified the Convention on the Rights of the Child, which obligates states to make primary education compulsory and free to all without discrimination (Koplewicz & Human Rights Watch, 2018).

The definition of disability outlined in Lebanese law 220/2000 adopts a medical model of disability. According to the law a disabled person is defined as a

person whose capacity to perform one or more vital functions, independently secure his personal existential needs, participate in social activities on an equal basis with others, and live a personal and social life that is normal by existing social standards, is reduced or non-existent because of a partial or complete, permanent or temporary, bodily, sensory or intellectual functional loss or incapacity, that is the outcome of a congenital or acquired illness or from a pathological condition that has been prolonged beyond normal medical expectations. (Unesco, 2013, p. 8)

As the wording demonstrates, disability is constructed as the result of a congenital or acquired illness or a pathology that has not responded to treatment. Impairment is also conceptualized as



something abnormal or deviant in comparison to broadly accepted cultural norms. The law uses undefined and vague language such as *vital functions*, *existential needs*, and *equal basis*. It is unclear who decides what constitutes a vital function or existential need, although the definition seems to indicate that these terms are defined according to existing social norms.

Despite the wording in law 220/2000, over the past 21 years the state has failed to implement policies to ensure access to education or reasonable educational accommodations (Unesco, 2013). For example, the law calls on the state to provide PWDs a government issued disability card that entitles PWDs to full medical coverage. Although the government has issued disability cards, a report by UNESCO demonstrates that the card gives no indication of the extent of coverage to be provided and is not accepted in practice, even in most governmental hospitals (Unesco, 2013). Damaj (2014) argues that the use of a disability card in this context fits into a general societal pattern of segregation and disabling identity labeling that works against the empowerment of PWDs. The law also states that the government is responsible for providing integrative educational services for PWDs (Unesco, 2013). Virtually none of the clauses pertaining to education have been implemented, and schools continue to refuse to accept students with disabilities (Koplewicz & Human Rights Watch, 2018; Unesco, 2013). The law stipulates that government buildings must be adapted in order to make them accessible to persons with physical disabilities by the year 2005. A study conducted by the National Assembly for Rights of the Disabled in 2006 assessed the accessibility of 612 government institutions, public universities, hotels, restaurants, theaters, and public places. The study found that 95% of the buildings assessed still did not have proper accessibility measures (Unesco, 2013). A 2009 survey conducted by the Lebanese Physical Handicap Union revealed that only 5 of 997 public schools observed met all of Lebanon's physical accessibility standards for public buildings (Koplewicz & Human Rights Watch, 2018).

Furthermore, the law stipulates that both the public and private sectors “have to reserve 3% of jobs for people with disability in companies and firms where the number of employees exceeds 60.” If a company fails to implement the outlined requirements, the law states that the company will be fined (Unesco, 2013, p. 17). This provision has not been enforced, and there are currently no fines levied for violators of the law (Unesco, 2013). According to the law, PWDs have the right to political and civic participation. In 2013, a study revealed that most voting stations continue to be inaccessible to PWDs (Unesco, 2013). Finally, a study performed by the Human Rights Watch (2018) states that cultural stigma around disability is one of the main factors that has led to children with disabilities being denied admission to schools. What is evident is that there continues to be a vast discrepancy between what is written in Lebanese law 220/2000 and what is implemented in practice.

### **Obstacles to the Implementation of Disability Reform**

Lebanon’s social and educational context presents a number of challenges for the effective implementation of disability reform. Two significant obstacles disability advocates face are the societal fear of disrupting the status quo and the challenge of fighting for individual rights in a collectivist culture. Because of Lebanon’s long history of ethnoreligious conflicts, there is a general penchant to avoid upsetting the social order. For example, Lebanese mothers are not allowed to pass on citizenship to their children. Although this is partially due to the patrilineal ideology that is dominant in the Arab world, the justification for failing to give women their rights is a fear of disrupting the delicate demographics of the different religious communities (Khatib, 2008). This practice demonstrates how elevating what is construed as the collective good is seen as more important than individual rights. Disability advocates must work through how to argue for individual rights of PWDs in a culture that subordinates individual rights to what is believed to be in the best interest of the collective good.

Religious establishments in Lebanon largely dictate and control the social norms. Ethnoreligious groups are empowered by the state to create and manage their own religious courts and personal status and family laws (Nassar, 1995; Salloukh et al., 2015) For example, civil marriage is outlawed in Lebanon. If two individuals from different ethnoreligious groups want to get married, they have to get married in a different country. The social standards referenced in law 220/2000 are established and mostly controlled by the different religious establishments as opposed to a government-directed civil society. Any idea that is seen as threatening to a traditional religious belief is difficult to implement in practice (Abou Assali, 2012). A by-product of the failure of the state and the influence of the religious establishment is the primacy of one's ethnoreligious loyalty in both public and private spheres. For disability advocates this means that it is a challenge to construct an identity for the purpose of advocacy based on a shared experience of social discrimination that can compete with the deep-seated prejudices inherent in already constructed ethnoreligious identities. The influence of the religious authorities, the impotence of the state, and the broad spectrum of beliefs and prejudices represented among the different religious sects, make the implementation of a broad civil disabilities law difficult.

Another obstacle in implementing 220/2000 is Lebanon's anemic economy. As mentioned above, a large percentage of citizens are able to survive through money received from working relatives abroad. 27% of Lebanese citizens live below the poverty line (Unesco, 2013). This does not include the large number of non-citizens such as refugees and Palestinians that also live below the poverty line (Das, 2011). There is little manufacturing, a dearth of job opportunities, and a large discrepancy between average earned income and cost of living (Hess, 2011). Khochen (2011) points out that one of the challenges of providing training for educators in special education is the high turnover in the field of education. Employers do not believe it is worthwhile to invest in professional development since many employees leave the country for more profitable jobs abroad once they have received special training (Khochen & Radford, 2011). One of the results of

ethnoreligious loyalty is that jobs are often allocated based on family relationships instead of professional qualifications (Akar & Mouchantaf, 2014). Private schools are also often run like family businesses where the bottom line is more important than student welfare. These practices result in large classes, heavy teaching loads, minimal salaries, and a lack of professional development opportunities. Amr (2011) points out that according to many educators in Lebanon, “inclusive education is seen as a luxury” (p. 406).

In addition, education is highly competitive. Since education is tied to the livelihood of the extended family, there is a great deal of pressure placed on children to excel academically, primarily in the areas of medicine, business, and engineering. The high-stakes model adopted by Lebanon encourages a philosophy of teaching geared towards passing the government mandated tests thus creating an educational environment that leaves little room or financial support for addressing the needs of special education students. Students with disabilities are often seen as an unnecessary burden (Khochen & Radford, 2011). As a result, students with special needs are often segregated and removed from private schools. Damaj (2014) demonstrates this policy in her study of Lebanon’s primary school for the blind. In her research, she traces how this policy of segregation reinforces disabling social identities. Since private schools are not funded by the state, their funds come from families whose primary concern is that *their* children excel. These factors contribute to a stigma and shame surrounding students who struggle in a traditional educational environment. Khosen (2011) points out that 82% of educators believe that it is the perceptions of the local community that hinders inclusive education (p. 146).

The privatized and ethnoreligious nature of schooling elevates sectarian agendas (Abouchedid & Nasser, 2002). The long history of instability has resulted in religious communities, not the state, providing for many of the needs of sectarian groups in a patron-client relationship. These religious communities wield significant power over educational policy and have resisted national initiatives aimed at promoting pluralism and social cohesion (Shuayb,

2012). The threat of conflict, perceived or real, is used by those in power to maintain the status quo (Nagle, 2015). Polemical and rhetorical discourse is utilized to reinforce communal identity. The prevailing educational atmosphere is characterized by a lack of trust, conflict avoidance, and protectionism (Abouchedid & Nasser, 2002; Hage, 1996). In addition, Lebanon's sectarian system reinforces collective identity, uniformity, submission to authority, and fear of the other (Jurdak & El-Amine, 2005).

In light of what has been outlined above, it is important to examine how the cultural, religious, economic, educational, political, and social contexts of Lebanon contribute to the widespread discrepancy between the legal rights of persons with disabilities and the ongoing perpetuation of disabling social practices in Lebanese society. It is also worthwhile to explore the extent that advancement in disability rights in the US and UK can help inform disability activism in Lebanon as well as whether contextually relevant approaches to the advocacy of the rights of persons with disabilities can be developed that will prove effective in the Lebanese context.

### **Disability Rights in the USA and UK**

There has been a good deal of progress made in the US and UK in the field of disability advocacy (Chaney, 2011; McLeskey et al., 2013; Watson & Vehmas, 2013). In spite of continuing challenges, there is a growing awareness of the importance and value of persons with disabilities. For example, many schools are moving away from the practices of mainstreaming and segregation and are moving toward the practice of inclusion (McLeskey et al., 2013). One justification for this move is the idea that education must be concerned with a broader focus than a defined (and limited) measure of intellectual achievement. Instead, it is argued that education must be concerned with the broader question of what is in the best interest of civil society. Proponents of inclusion have demonstrated the benefits to students, both disabled and able-bodied, when they are able to interact with a diverse student body (McLeskey et al., 2013).

The passing of legislation such as the Americans with Disabilities Act (ADA), which prohibits discrimination on the basis of disability; The Individuals with Disabilities Education Improvement Act (IDEA 2004), which provides federal financial assistance to guarantee special education and related services to eligible children with disabilities; and Section 504 of the Rehabilitation Act (U.S. Department of Education, 2010) which, among other things, seeks to create opportunity for the needs of students with disabilities to be met as adequately as the needs of non-disabled students, attempt to insure that PWDs are provided with rights under the authority and protection of the federal government (IDEA, 2004). These pieces of legislation are built on the belief that it is the responsibility of the state to both care for and protect the rights of its *individual* citizens, without discrimination. The implementation of this legislation works in conjunction with a judicial system in the United States that provides citizens a way to address issues of social injustice when civil rights are violated. It is the ability to enforce laws that gives legislation social power. It is also legislation like IDEA 2004 that empowers parents and gives them the authority to request testing and appropriate accommodations for their child, without personal cost. This educational paradigm conceptualizes school as a service that is set up to meet the needs of its constituents who have the right to a free appropriate public education.

Another push by disability advocates in the United States is the move away from the stigmatization that comes with creating the categories of normal and abnormal (Baynton, 2013). Disability advocates such as Lennard Davis are arguing for the normalization of diversity (Davis, 2013). The argument made is that diversity is one of the central and defining characteristics of humanity. Davis challenges the socially constructed hierarchies that use the concept of normal as a way to marginalize and oppress groups that do not fit within the categories established by those in power. The normalization of diversity attempts to elevate and develop an appreciation for the variety of ways that humanity is expressed and the worth of every individual. This approach

attempts to provide a justification for the inherent worth of a person that is not measured by her ability to conform to existing social hierarchies.

A similar move made by disability advocates in the UK is to make a distinction between impairment and disability (Gleeson, 1999). The social model of disability “involves nothing more or less fundamental than a switch away from focusing on the physical limitations of particular individuals to the way the physical and social environment impose limitations upon certain categories of people” (Oliver, 1981). In this context, impairment is defined as physical, social, or emotional limitation whereas disability is understood as social exclusion (Shakespeare, 2013). The social model of disability is built on a set of dichotomies such as: (1) impairment as individual and private versus disability as structural and public; (2) a rejection of the medical model of disability and an adoption of disability as a social creation; and (3) the conviction that civil rights, rather than charity or pity, is the way to solve the disability problem (Shakespeare, 2013). In addition, the social model accepts that concepts of impairment are historically, culturally, and socially variable (Barnes, 2013). Disability is presented as a social construction that is imposed on persons with certain types of impairments. Impairments can be visible or invisible, socially accepted or socially stigmatized. Impairment becomes a disability when societal norms or actions create a situation where a person suffers discrimination as a result of impairment. For example, a person may lack certain social skills (a social impairment) but be naturally gifted and excel in an area that does not require highly developed social skills. In this situation, an impairment (a lack of social skills) is not be construed as a disability. Whereas a different individual may excel in an area but may not be offered a promotion because of the stigma associated with his being in a wheelchair. In this example, impairment becomes disability.

The social model as outlined here is not without its critics. The rigidity of the impairment/disability dualism has the potential to normalize impairment in a way that ignores the role of the body in disability (Anastasiou & Kauffman, 2013) and diminish the personal

experience of pain which is often a part of impairment (Crow, 1996). Conceptualizing disability as a social construct can also trivialize, or even stigmatize, the benefits of treatment for debilitating conditions (Shakespeare & Watson, 2002). In spite of these critiques, the social model has generated a number of positive shifts in perceptions about disability in the UK (Barnes, 2013).

It is worthwhile to consider how advancements in the field of disability studies in the US and UK that focus on the value of persons with disability, the best interest of civil society, the protection of individual rights, the normalization of diversity, and the social construction of disability can be contextualized and applied in Lebanon's complicated social-cultural context.

### **Contextualizing Principles: A Way Forward**

The UN Committee on the Rights of Persons with Disabilities has stated, "it is necessary to change attitudes towards persons with disabilities in order to fight against stigma and discrimination, through ongoing education efforts, awareness-raising, cultural campaigns and communication" (Koplewicz & Human Rights Watch, 2018, pp. 25-26), a task easier said than done. I want to conclude by discussing approaches to disability reform that attempt to contextualize principles from the advancements made by the US and UK disabilities movements in ways that are relevant in Lebanon's socio-cultural context. Although these approaches will not solve the multifaceted complexities of promoting social justice in Lebanon, they offer a possible way forward in working to reorient perspectives, develop a communal sense of responsibility, and provide for the rights of persons with disabilities in light of the limitations of Lebanon's state institutions.

Damaj (2014) applauds the legal gains made by disability activists in Lebanon but argues that "legislation and policy need to be backed up with social measures at the field level that actively work towards redefining disability in the society" (p. 998). Damaj's observation highlights one of the central differences between the societies of Lebanon and the US. The US system is established on the belief that power, to a large extent, resides in the law and that the state



is responsible to care for the needs of its citizens without discrimination. The enforcement of the law is therefore instrumental in challenging and changing social norms. In the US, citizens generally accept the importance of the separation between religion and the state and acquiesce to the primacy of the state in enforcing law and protecting civil rights. As demonstrated above, Lebanon does not function according to these principles. Power does not primarily reside in the law but instead resides in the social norms defined by a multiplicity of ethnoreligious sects. Although the law carries some weight, it generally lacks the power to influence large-scale societal change. As a result, advocates of disability reform must find a way to assert the rights of PWDs within the religious worldviews of different ethnoreligious communities in tandem with their efforts to advance disability legislation. For example, instead of arguing that it is in the best interest of civil society for the state to care for the needs of its individual citizens without discrimination, advocates must find a way to argue that it is in the best interest of a sectarian society for ethnoreligious sects to care for the needs of its collective members *without discrimination*.

### **From Affliction to Worth**

The social model of disability in the UK is built on the conviction that civil rights, rather than charity or pity, is the way to solve the disability problem (Shakespeare, 2013). In Lebanon, disability is often associated with the concept of *haram*. In a religious context *haram* can mean forbidden or accursed (Wehr et al., 2012). In the Lebanese social context, *haram* is an expression of pity. In the religion of Islam, there is a general emphasis on God's control of all things (Ormsby, 1984). Within the Christian tradition, there is a debate concerning the extent of God's intervention in the world (Adams & Adams, 1996) but there is still a widely accepted belief that disabilities may somehow be connected to divine intervention (Moss, Schipper, & Service, 2011). As a result, it is easy to see how disability can be construed in religious terms as God's judgment

or divine affliction and, in turn, can lead to approaching disability through the lens of charity (Schumm, Stoltzfus, & Service, 2011).

I would suggest that in Lebanon it is not productive to spend a great deal of energy challenging the religious narrative of God's involvement in some capacity in disability. A focus on changing this narrative could create a dichotomy where support of the rights of PWDs is seen as threatening to religious belief. Instead, I would suggest advocates focus on reorienting religious perspectives by challenging the affliction narratives often associated with disability and, instead, push religious leaders to embrace the inherent worth of all people based on their status as creations of God. This approach roots the UN concept of the inherent rights of all people in the religious concepts of the *Imago Dei* in the Christian tradition and *Fitrah* in the Islamic tradition. In addition, I suggest presenting research that demonstrates the ability of PWDs to engage in a multiplicity of productive and valuable activities. By educating religious authorities on the proven abilities of PWDs in conjunction with an emphasis on the uniqueness and worth of PWDs as creations of God, disability activists can seek to reorient the religious perspective on disabilities from affliction to worth and from charity and pity to honoring God, all while working toward the collective good.

This approach of dealing with the tension between religious views of morality and moral norms and the promotion of libertine freedom as an expression of individual right may not sit well with disability advocates wanting to challenge the norms and metanarratives of religious groups. Even so, I contend that it is important to find common ground among different interpretive paradigms to collaborate toward promoting social change.

### **Universal Impairment**

I would also argue that the religious nature of Lebanese society makes Davis' attempt to normalize diversity complicated and potentially ineffective. Within the religious worldviews prominent in Lebanon there are shared eschatological views of perfection. As such, the natural world and human experience are understood as falling short of an ideal. This idea makes it

difficult to move from the concept of disability as a deficiency to disability as a mere difference (Bauman & Murray, 2013). I believe that it would be difficult to normalize what is seen in religious terms as a deficiency that falls short of the desired ideal. Again, the attempt to challenge or change this religious ideal is fraught with the potential difficulties of creating a dichotomy between religious understanding and disability activism that is disempowering for disability activists in Lebanon.

Instead, it may be constructive to consider the argument that impairment is an inherent characteristic of humanity (Shakespeare & Watson, 2002) and a common experience in human life (Waldschmidt, 2017). Here I believe that reorienting religious perspectives using the principles of the social model's impairment/disability paradigm can help religious leaders to understand that their religious views of the corruption in the world mean that *all* people exist on a continuum of *universal* impairment, but that it is the responsibility of the religious establishment to fight against the oppression of local, disempowering *constructions* of disability. The concept of universal impairment framed in the religious understanding of an imperfect world can help break down the stigmatization that comes from the categories of normal and abnormal and mobilize the support of religious communities in fighting against the inequities of social constructions of disability.

Again, this approach will not satisfy advocates who want to completely distance themselves from the medical model of disability or who embrace the social model because of its power to transform self-esteem. As alluded to above, the belief in healing and eschatological perfection is embedded in the prevailing Lebanese religious worldviews. These beliefs imply that impairment, on some level, is undesirable. In addition, a broad acceptance of universal impairment has the danger of trivializing the experiences and challenges related to how "different impairments impinge in different ways" (Shakespeare & Watson, 2002, p. 12; Wendell, 2013). As such, the discussion of universal impairment within the Lebanese religious context must occur hand in hand

with an emphasis on the inherent worth of all people, as well as an acknowledgement that different impairments require various levels of support.

### **Oppressed to Empowered**

A final way to engage the ethnoreligious establishment to promote the rights of PWDs is to build upon religious and moral sensitivities with the objective of developing a sense of responsibility to fight for the needs of the oppressed and empower the disempowered. Goodman (2011) contends that it is deeply held principles that are most influential in promoting action on issues of social justice. One of the problems that social justice advocates face is that there is often a disconnect between a person's moral principles and his awareness of how they relate to confronting systemic forms of injustice. Goodman (2011) argues that "for people to act on moral or spiritual principles, they need to be aware that a certain situation is, in fact, a violation of their values" and that "unless they perceive the discrepancy (of inequity) as an injustice, they will not feel that a moral wrong has been committed" (p. 142). It is therefore incumbent on disability activists to provide information, education, and research to ethnoreligious communities that challenge their status quo views on disability, that frame social justice issues in moral terms consistent with the values of their religious traditions, and that connect disabling social practice to the concept of injustice. What is helpful in Lebanon is that both Islam and Christianity have traditions of social justice as a central part of their religious ideals.

If social disability advocates in Lebanon can work to effectively reorient the status quo of religious perspectives on disability from affliction to inherent worth, disability to universal impairment, and inequity to social injustice, the potential to open the door to developing strong social allies in the fight for social justice for PWDs exists.

It is also important to discuss disability rights through a collectivist lens. The emphases in the US on individual rights and the importance of self-sufficiency do not translate well to the Lebanon context. In Lebanese society, it is interdependence, not independence, that is primarily

valued. As a result, I would not recommend that disability activists import the right to self-sufficiency as a central tenet in their platform. An overemphasis on individualism has the potential to stigmatize the disability movement as a Western idea with a hidden agenda. As stated above, I would argue instead that the emphasis needs to be on the benefit that is brought to the whole community when PWDs are given the opportunity to thrive. It may be helpful to develop a vision for the way that PWDs can contribute to the collective good when they are empowered through the provision of accommodations and services. The objective should be to reorient the cultural perspective that sees PWDs as the burden of the collective, to that of understanding and embracing the positive contributions that PWDs can make to both a particular social group and broader society when they are respected and empowered.

### **Economic Advantages of Reform**

At the state level, I suggest that disability activists attempt to make a case for the economic value of realizing the potential of PWDs. Goodman (2012) stresses the importance of the question *What's in it for me?* when individuals or groups consider social justice activism. Considering the limitations of the Lebanese state, it is helpful to demonstrate how providing for the rights of PWDs and implementing systemic changes in the state's approach to issues of disability is in the self-interest of those in power as well as the society as a whole (Goodman, 2011). The model of disabilities that is currently accepted on the state-level in Lebanon is short-sighted and based on an ideology that sees state-funded provisions for PWDs as a type of charity. When framed in these terms the importance of implementing legislation for PWDs is subordinated under more *pressing* economic needs. Goodman (2012) contends that it is important to shift the focus from only doing *it for them* (PWDs) to demonstrating how a commitment to social justice is ultimately an investment that is in the self-interest of the state. The challenge for disability activists is to make this argument in a country where an increasingly qualified work force is not necessarily

advantageous in an economic climate of scarcity; and where state-building is frequently disrupted by sectarian conflicts and regional wars.

In education, disability advocates must work to demonstrate that inclusion has both social and academic benefits for both disabled and able-bodied students. In lieu of a lack of state funding, advocates must wrestle with how to convince financial stakeholders, in the form of parents whose children may be considered *typical*, that it is in their interest and the interest of their children for a school to invest in special education services. Owners of private schools must be persuaded to look beyond the bottom line, to invest in professional development of educators in spite of high turnover, and to view education in terms that are broader than economic concerns. Considering that a large number of private schools are run under the auspices of religious institutions, if activists can effectively reorient the religious perspectives as outlined above, this may lead to positive change within educational institutions.

### Conclusion

In spite of rights-based legislation that supports persons with disabilities and a signed commitment to the Convention of the Rights of the Child, Lebanon continues to fall short in the implementation of its laws. Economic and political instability have created an environment of scarcity and self-interest. The primacy of ethnoreligious identity and a culture of collectivism leave disabled communities fragmented and lacking social capital. Decentralized power in the religious courts and the impotence of the state provide little recourse for those who suffer discrimination. A largely privatized educational system framed in the competitive, instrumentalist terms of a means towards an economic end has led to the perception that inclusion and special education services are a liability or an opportunity for profit. Twenty-one years of minimal progress in the implementation of disability legislation suggest that it is time to consider new approaches. I have suggested that, through contextualizing principles in the Lebanese socio-cultural context that have proven effective in the US and UK, advocates of disability reform can

mobilize allies from among its ethnoreligious communities. Challenging affliction narratives directed at PWDs and promoting the inherent worth of all people as God's creation can reorient religious perspectives of disability based on pity and charity. Deconstructing the categories of normal and abnormal under the concept of universal impairment can empower religious leaders to work against the oppression of social constructions of disability. Tapping into religious ideals of social justice can help promote a sense of responsibility to confront systemic forms of injustice against disabled persons. Moreover, presenting research that demonstrates the ability of PWDs to contribute to the collective good can help shift ideologies that see state-funding for PWDs as a type of charity. Through contextualizing principles and seeking common ground in the midst of ethnoreligious pluralism and the challenges of sectarianism, it is possible to achieve gradual, systemic change.

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**Notes from the Field:****World's Leading Disability Gathering Returns (Physically) to Hawaii****Abstract**

This announcement talks about the 38th Annual Pacific Rim International Conference on Disability and Diversity. The conference is hosted by the Center on Disability Studies, College of Education, University of Hawai'i at Mānoa. The conference takes place in person this year in Honolulu, Hawaii on March 6 and 7th, 2023 HST.

*Keywords:* conference, disability studies, diversity, Pacific Rim

The Center on Disability Studies, interdisciplinary research center in the College of Education, University of Hawai'i at Mānoa, announces the 38th Pacific Rim International Conference on Disability & Diversity March 6th & 7th, 2023 in Honolulu, HI.

For the first time in three years, people from around the globe join together physically for the World's Premier Gathering on Disability to celebrate the inclusive spaces and places we build together.

This year's theme, *Coming Together and Moving Forward - Ho'okahi ka 'ilau like 'ana. Wield the paddles together*, reminds conference participants to join together to coordinate our actions to move forward.

The Call for Presentations is now open for the Pacific Rim Conference's 6 major strands:

- Built Environment: Digital, Physical and Social;
- Deaf Innovations;
- Education;
- Employment First, Employment for All;
- Family, School, and Community Engagement; and
- Healthy Bodies and Minds: Access to All.

Each strand will focus on best practices, advocacy, research and capacity building. All submissions are invited to reflect the conference values of:

- honoring a strength-based approach,
- enhancing our understanding of intersectionality, and
- centering disability as a natural part of universal human experience.

In particular, submissions are encouraged that focus on indigenous knowledge & lived experience.

The deadline for Proposals is December 1st (October 1st for early consideration). You are invited to come share research, personal stories, practical strategies, and join the fellowship and aloha at the 38th Pacific Rim International Conference.


Leaders committed to equity & inclusion are invited to join this once-in-a-lifetime event.

Next:

- General conference registration open in November!
- Announcements about speakers and exclusive additional special events available to attendees will be coming in the weeks ahead.
- Sponsorship and Exhibitor inquiries may be directed to [prinfo@hawaii.edu](mailto:prinfo@hawaii.edu).

More information may be found @ [pacrim.coe.hawaii.edu](http://pacrim.coe.hawaii.edu), & you can sign up for updates at <http://eepurl.com/g79LAX>.



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