

# An interventional study on the effects of a disabled people's network in promoting well-being and participation of People with Disability (PWD) in Uttarakhand, North India

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		<input type="checkbox"/> Protocol
<b>Registration date</b> 08/10/2019	<b>Overall study status</b> Completed	<input type="checkbox"/> Statistical analysis plan
		<input checked="" type="checkbox"/> Results
<b>Last Edited</b> 03/02/2020	<b>Condition category</b> Musculoskeletal Diseases	<input type="checkbox"/> Individual participant data

## Plain English summary of protocol

### Background and study aims

People with disability (PWD) amount to 15% of the world population and World Health Organization (WHO) estimates that 80% of them live in developing countries (World Health Organization, 2016; World Health Organization and the World Bank, 2011). In India, there are about 26.8 million persons with disability which is about 2.21% of its population (Government of India, 2011). Evidence suggests that PWDs are more likely to experience adverse socioeconomic outcomes such as less education, poorer health outcomes, lower education achievements, less employment and higher rates of poverty than persons without disability (Government of India, 2011; World Bank, 2009; World Health Organization and the World Bank, 2011). Additionally, People with disability face barriers accessing health and rehabilitation services (World Health Organization, 2018).

This study aims at understanding the potential of Disabled People's Networks in promoting disability inclusive development in Uttarakhand state, North India.

### Who can participate?

Using a lottery system, we randomly allocated 20 villages to the intervention arm and 19 to the control arm. Based on an adapted Key Informant methodology, we identified all people with disability who were not currently involved in a disabled people's organisation to participate. The minimum age for participation was 15.

### What does the study involve?

In the intervention clusters, local non-government organisations (NGOs) facilitated the formation of Disabled People's Organisations (DPO) and motivated study participants to be involved in the activities of the DPOs. A curriculum and training program was also developed. Five NGOs, each within one of the intervention sites were selected to assist in the intervention study, involving support in DPO formation.

In the non-intervention clusters, no DPOs were facilitated but the ongoing disability work continued. The control group only received referrals for disabilities detected by RAD screening, but no additional assistance. They will receive the interventions at the end of this study.

#### Possible benefits and risks of participating

Disabled People's Organisations could promote wellbeing, participation, and rights of people with a disability. DPOs also empowered people with a disability to actively express their priorities and needs.

#### Location of study centre

The study took place in 39 villages purposively selected from five distinct areas located in New Tehri and Dehradun districts of Uttarakhand.

#### Source of funding

The study was funded by Christian Blind Mission India.

#### Main contact

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## Contact information

#### Type(s)

Public

#### Contact name

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## Additional identifiers

#### Protocol serial number

IIPHH/TRCIEC/10/2014

## Study information

#### Scientific Title

A randomised controlled trial to assess the impact of DPO formation using the RAD and other evaluation tools

## **Acronym**

NIDPO

## **Study objectives**

Activities and services facilitated by Disabled People's Network (DPN) improve PWD's (people with a disability) well-being, community participation and access to services

## **Ethics approval required**

Old ethics approval format

## **Ethics approval(s)**

1. Approved 28/01/2015, Community Health Global Network, Uttarakhand Cluster (CHGN Uttarakhand Cluster, Disability Advisory Committee, India; +91 (0) 1360-253323; robert@eha-health.org), ref: n/a
2. Approved 26/06/2015, Indian Institute of Public Health – Hyderabad (ANV Arcade, Plot No.1, Amar Cooperative Society, Kavuri Hills, Madhapur, Hyderabad - 500081, A.P., INDIA; +91 40 49006003; murthy.gvs@iiphh.org), ref: IIPHH/TRCIEC/10/2014-1

## **Study design**

Cluster randomized interventional trial

## **Primary study design**

Interventional

## **Study type(s)**

Quality of life

## **Health condition(s) or problem(s) studied**

Disability

## **Interventions**

A cluster randomized interventional trial in the Dehradun district of Uttarakhand state in North India to evaluate the impact of DPOs (Disabled People's Organisations) on inclusion, wellbeing and participation.

Intervention arm: Participants in the intervention group would receive services facilitated by Disabled People's Networks. DPNs is a participatory model and participants were encouraged to ultimately determine the activities they undertake.

Uttarakhand Cluster of NGOs and Public Health Foundation of India would provide training in community mobilisation, advocacy of rights to health and education, bookkeeping, awareness-raising and access to government programs.

Local NGOs facilitated the DPO formation by regular home visits to individual families to motivate them to be involved in the activities of the DPOs. A curriculum and training program were also developed. Five NGOs were selected to assist in the intervention study, involving support in DPO formation.

The DPOs were encouraged to conduct regular disability group meetings to facilitate problem solving, advocacy and planning. As a part of the DPOs, persons with disabilities were encouraged to visit the block and district office and make at least three visits to the disability commissioner.

Control arm: For participants in the control group, current disability work would continue but no DPNs would be facilitated.

### **Intervention Type**

Behavioural

### **Primary outcome(s)**

Well-being, community participation, and access to services assessed at baseline and endline (after DPN implementation) using the rapid assessment of disability (RAD) tool

### **Key secondary outcome(s)**

none

### **Completion date**

31/05/2017

## **Eligibility**

### **Key inclusion criteria**

1. Have a disability
2. Currently living in the selected villages
3. Aged  $\geq$  15 yrs
4. Not currently involved in a disabled people's organisation

### **Participant type(s)**

Other

### **Healthy volunteers allowed**

No

### **Age group**

Adult

### **Sex**

All

### **Total final enrolment**

527

### **Key exclusion criteria**

1. Guardian unwilling or unable to give consent

### **Date of first enrolment**

01/04/2015

### **Date of final enrolment**

30/04/2017

## Locations

### Countries of recruitment

British Indian Ocean Territory

India

### Study participating centre

#### India

Community Health Global Network

KHW, Rajpur Rd

Rajpur

Dehradun

India

248139

## Sponsor information

### Organisation

Nossal Institute for Global Health

### ROR

<https://ror.org/01ej9dk98>

## Funder(s)

### Funder type

Charity

### Funder Name

CBM India

## Results and Publications

### Individual participant data (IPD) sharing plan

All data generated or analysed during this study will be included in the subsequent results publication

## IPD sharing plan summary

Available on request

### Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
<a href="#">Results article</a>	results	31/01/2020	03/02/2020	Yes	No