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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

Submission date
03/10/2019

Recruitment status
No longer recruiting

Registration date
08/10/2019

Overall study status
Completed

Last Edited
03/02/2020

Condition category
Musculoskeletal Diseases

[_] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[X] Results
[_] 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.

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Type(s)
Public

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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

Primary study design
Interventional

Study design
Cluster randomized interventional trial

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 faciliated 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 >= 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?
Results article	results	31/01/2020	03/02/2020	Yes	No