

Intellectual disability in Community Activities

4. General Information

(1) Name of Country: Nepal

Location

Latitude 26° 22' N to 30° 27'N

Longitude 80° 4'E to 88° 12'E

Border

China in the North and India in the South, East and West.

(2) Area (Sq. Km.): Size

Area = 147, 181 SQ. km.

Average Length = 885 Km.(East to West)

Average Width = 193 Km. (North to South).

(3) Population:

According to the national census 2001, total population of Nepal on the is 23,151,423.

(22 June 2001)

Currently the population of the country is estimated at 27504280, considering 3790836 male and 13713444 female. This current figure is based on the growth rate 2.24% reported by the central bureau of statistic (CBS) in

Urban Population: 3936610

Rural population: 23567670

(4) Life expectancy: At birth (yrs.) - 62.20 (Reported by CBS in)

Male Life expectancy: At birth (yrs.) - 61.76

Female Life expectancy: At birth (yrs.) - 62.50

(5) Infant mortality rate: 64.4 per 1000 live birth

(6) Maternal mortality rate: 0.4%

(7) Literacy rate: 54.1% (M: 65.5%, F: 42.8%)

(8) Education (Compulsory): Primary level

(9) Unemployment rate: NA

(10) Laws concerned with persons with Intellectual Disabilities

In Nepal there are no any exclusive laws for the persons with intellectual disabilities. The provisions regarding the issues of intellectual disabilities are found in other exclusive laws made for all disabled people and some common laws. Some provision for the persons with intellectual disabilities are found in the following laws and policies :

Disabled Welfare and Protection Act 1982:

This is the first law made in Nepal to address disability issues. This is a common for all types of people with disabilities. In this Act there are no enough provisions particularly related to the issues of children with developmental disabilities.

Clause 6 (3): The provision of special education can be made to the blind, deaf and the children with intellectual disabilities.

Education Act 1964 (2028 B.S.)

In this act only in definition part the children with intellectual disabilities are addressed .

Clause 2, Definition, d (1) : Special Education refers to the education to be provided for blind, deaf, disabled and the children with intellectual disabilities.

Child Act 1991 (2048)

This Act has made some provision of child welfare home.

According to clause 36 of this act the children will be kept in child welfare home until he/she is 16 years. In the sub clause 2 it has again said that in the case of deaf, blind and children with intellectual disabilities they would be kept in the child welfare home until they are sent to other child welfare homes which are specially made for them.

In the clause 43 (1) of this Act the provision of Orphan house and center for the children with intellectual disabilities has been made. According to this clause the government shall establish the orphan homes and center for the children with intellectual disabilities as per the necessity.

Education Bylaws 2002 (2059 B.S.)

Rules 47 : Abandoned and the mentally retarded children are entitled to enjoy the additional extra time in written examination in their school considering their physical problem in writing.

Special education policies 1996 (2053)

This policy was brought for the education of people with disabilities and particularly for deaf, blind and children with intellectual disabilities. This has set its objective of mainstreaming the education of disabled people in the main education system. The main policies have been described in 33 points and there are no any special points for the children with intellectual disabilities. The policies are common for all. Mainly the data survey, making the special education as a part of EFA, provision of free education, scholarship, improvement of physical condition and infrastructures of schools, human resources development in special education, mobilization of NGOs are the main issues addressed by this policy.

Interim Constitution of Nepal 2006 :

At present Politically Nepal is in transitional phase and in the process of making new constitution. The constitution of 1990 was dismissed after the great movement of April 2006. At present the Interim Constitution has been activated. This constitution has also spoken some points about some issues of people with intellectual disabilities.

Fundamental Rights, Article 13 (3) Says : The State shall not discriminate among citizens on grounds of religion, race, caste, tribe, gender, origin, language or ideological conviction or any of these.

Provided that nothing shall be deemed to prevent the making of special provisions by law for the protection, empowerment or advancement of women, Dalits, indigenous ethnic tribes [Adivasi Janajati], Madhesi or farmers, labourers or those who belong to a class which is economically, socially or culturally backward, or children, the aged, disabled or those who are physically or **mentally incapacitated**.

Article 22: Rights of Children, (4) : Helpless, orphaned or **mentally retarded children**, children who are victims of conflict or displaced and street children at risk shall have the right to receive special privileges from the State to ensure their secure future.

National Policy and Plan of Action 2006 :

The Ministry of Women, Children and Social Welfare has brought a separate policy for the promotion and empowerment of people with disabilities in 2006. This policy and action plan has not described any policy and action plan indicating any specific category of disability. All the policies and action plan are common for all. It has identified 17 prioritized area including

education, health, employment and training, Information and communication, accessibility, women and disability, sports and recreation, transport, disability prevention, assistive devices.

(2) **Outline of your organization**

(1) Background:

Community Based Rehabilitation (CBR) has become an internationally effective strategy for the holistic development of children/persons with disabilities (C/PWDs) and on the top of that it is more effective in developing countries. Patan Community Based Rehabilitation Organization (Patan CBRO) was established in 1995 in the initiation of Patan Lady Jayceets and started its services since then in the regular support of Save the Children Norway (Now Save the Children in Nepal) CBR Patan is a non profit and non political organization and dedicated basically for increasing the access of CWDs to education including other rehabilitation services by mobilizing local communities and resources as well in Lalitpur, Kathmandu and Nuwakot district. As a registered NGO this organization started its works since 1999 with the affiliation to Social Welfare Council (SWC). At the beginning it provided rehabilitation services to 60 CWDs mainly in 12 wards of Patan (historical town of Lalitpur district). The services were expanded in 22 wards of Lalitpur sub-metropolitan city and 7 adjoining Village Development Committees (VDCs) of Lalitpur district since 1999. During these years Patan CBR has been able to establish a good relationship with all its stakeholders including parents of CWDs, GOs, I/NGOs, local governments agencies, Individuals and private sectors as well. Patan CBR has been running Pravamaya Inclusive Pre-Primary School for children with multiple disabilities and a Children with Intellectual Disabilities which is also registered in the Department of Education and (DEO). There are 5 classes such as Play Group, Nursery "A", Nursery "B", LKG, UKG and a vocational. At present altogether 55 children are enjoying these services. Beside this Patan CBRO has been running disability survey, disability assessment, referral services, distribution of assistive devices, family counselling, home visit, advocacy and physiotherapy services according to the needs identified.

Vision:

Create a suitable environment for differently able children of Lalitpur, Kathmandu, and Nuwakot by developing Patan CBR Organization into a CBR Resource Center in collaboration with various INGOs, NGOs and GOs.

Strategy:

Programme will be implemented on the basis of the fundamental principles of Community based rehabilitation (CBR) approach and rights based approach that meet the legal and agree with all kind of government Constitution, Acts, policies.

- Maximum resources will be generated and mobilized for the best interest of the children with disability, local level community and other stakeholders.
- Influence and lobby with local, district level government agencies for effective implementation of existing laws & policies to cater the needs of children with disabilities policies of local development ministry on allocation of fund for disability issue and support to the related organization's work.
- ✚ Village Disability Rehabilitation Committee (VDRC) are being formed and strengthened to take the responsibility of protecting rights of children with disabilities and handed over all the responsibilities to VDRCs phase-wise for long term program sustainability in respective VDCs.
- ✚ Inclusive Education will be highly promoted for the rights of children with disabilities through bringing changes in the attitude, Knowledge and capacity of teachers, School management committees & DEO authorities by availing the support of District Education Office.
- Patan CBR is being developed itself as a District Resource centre in Patan to build up the capacities of disability related organizations, Government, NGOS, CBOs to promote the rights of people with disabilities and effective implementation of CBR programs in working areas.

Activities:

1. Access to education and vocational training

- School Enrolment Campaign to increase the access of C/PWDs in mainstream education system.
- Run and referral to transitory School / Resource classes / non formal / formal education for children with hearing, visual, Intellectual and multiple disabilities
- Follow up activities to Schools and CWDS
- Minis-study about the discrimination in the family and schools.
- Provide and facilitate getting scholarship for C/PWDs
- Orientation and sensitization on disability issues/rights and Capacity building of Teachers, SMC, students, CWDS, parents and Govt. authorities and the education partners of Save the Children.
- Support to schools for enhancing disability friendly school environment, physical structures, Education materials etc.
- Facilitate for getting access to PWDs in Vocational Training / IG Program
- Counseling and Physiotherapy Service
- Medical /Surgical Intervention by organizing mobile camps, through referral service and therapy
- Home/Center based primary rehabilitation services (Brail and sign language, Self-care, Behavior modification, Mobility skills & Speech & communication and learning skills trainings)
- Provide Assistive devices (Mobility/Hearing aids and Orthopedic appliances, etc)
- Organize Health Clinic / Camp / Preventive health education

2. Participation of C/PWDs and their parents in;

- Family counseling / awareness / sensitization
- Recreational / Extra curricular / sports Activities
- Orientation/capacity building/meeting
- Support Inclusive child clubs – Consultation in organizational matters
- Bi-annually meeting ,plan & report and child club member are also participation
- Social Audit program once a year

3 . Awareness /Advocacy

- Promotion and strengthening of Self-help groups/VDCs local level.
- Advocacy & networking and Lobbying with political parties, policy makers for the Promotion of new disability friendly policy and effective implementation of existing policies and provisions
- Development of Advocacy materials
- Media mobilization (Analysis of policy, plan budget and its effectiveness)
- through Joint coordination with district disability coordination committee for joint Planning and programming in Lalitpur and Nuwakot
- Coordination and collaboration with VDCs and wards of KMC.

4. Capacity Building

- Update and documentation of base line survey / Research on situation of disability in VDCs, Municipalities and district.
- Districts and national level mapping of political parties and Government offices.
- Inclusion of disability issues (included in 2 partners of SCIN.)
- Orientation and interaction on disability.
- Capacity building trainings on community based disability management
- Capacity building through technical support
- Facilitate to get ID card.

(2) Major programs: (Objectives)

1. To increase the access to education and vocational training for children and youth with disabilities.
2. To enable children with disabilities for their optimum independent living and prevented children from being disabled
3. Increased accountability and capacity building of families, communities and government towards fulfilling the rights of children with disabilities.

Covered areas:

Total 24 VDCs and 3 municipalities of three districts Lalitpur, Kathmandu and Nuwakot.

In which;

- Lalitpur :17 VDCs and 1 Municipality,
- Katmandu : 4 Ward of Kathmandu Metropolitan City and 5 adjoining of Kathamandu district. VDCs
- Nuwakot : 2 VDCs and 1 Municipality.

Target population of your organization:

Direct: Registered CWDs and YWDs :1574 (Since 1995)

- M- 912, F- 660, Inter sex- 2,

(3) **Target group**

Children with disabilities, families of CWDs, Schools and child club, VDRCs of communities, CBR and Self Help Organizations, Government Bodies from village to national level.

Number of beneficiaries

- 862 C/YWDs

(4) **Your position and duty**

Position: Coordinator

Duties : Planning, reporting, coordination, networking, management and monitoring over all program.

Community Development Program which include Intellectual Disability issue as one of the activities. (if you know any)

Patan CBR works with the coordination and collaboration with GO, NGO, INGO, CBO, local authorities and individuals for the improvement of the quality of life P/ CWDs in their communities. It helps to promote CBR program and to reach easily all over the local communities.

Cost share in between the organizations. There are fewer possibilities in program duplication. Such as in Lalitpur district we submitted a joint proposal to district development committee (DDC) on disability program through district disability coordination committee. As a result DDC approved and release the 1st installment fund. So this is the better way to increase the access to the rights of the C/PWDs.

(1) Outline of the project and

a) Goal or purpose

To improve the situation of children with disabilities through the fulfillment of child rights.

b) Expected outputs

- Increased enrolment of CWDs
- Enhancement of educational performance
- Develop and retained inclusive Schools
- Enhanced access to Income Generation of youths and parents
- Enhanced daily living functional activities
- Reduced disability incidence through preventive measures
- Enhanced participation of CWDs in family, child clubs and in community
- Desired improvement in Policy and effective implementation
- Enhanced capacity of institutions (civil society and government) on management of disability issues in community level.
- Increased capacity of organization as a resource and referral centre.

c) Inputs of the implementing organization

Financial, human resource, technical and time.

d) Inputs of the community

- Human resource, Financial, Technical and time

e) Inputs of external agents

- Volunteers, Human resource, Financial, Technical and time

f) Budget and period

Patan CBR Organization Resources Mobilization 2009

SN	Donor	Annual fund	Remarks
1	ON-Q	15,05723.00	2009
2	DVC	2,50000.00	"
3	Japanese Volunteers	39800.00	"
4	Individual	4500.00	"
5	Save the children in Nepal	19,10000.00	"
6	Parents contribution	253166.00	2008
7	Individual supporters	69365.00	2008
8	DEO	2,00000.00	2008
9	DDC	150,000.00	2009

(2) Activities and consequence

a) The results / consequence (what has happened or been achieved)

Total No. of VDCs : (new addition or phased out in the review period).

Out of 24 VDCs and 3 municipalities: Lalitpur :17 VDCs and 1 Municipality, Katmandu : 4 Ward of Municipality and 5 VDCs
Nuwakot : 2 VDCs and 1 Municipality.

Total number of schools, ECDs, (new addition or phased out)

Out of 137 schools 115 Inclusive (ECD/PS/LSS/HSS) schools, 18 Special and resource Schools, one transitory Schools for children with multiple / intellectual / blind / physical disability(Intellectual/blind/deaf/physical),

Formation and mobilization of child clubs/youth groups (new and existing), child protection committees

In total 12 Child Clubs, 335 members

- M-202 F-133
- (Bramhan / Chhetri- 215, Janajati- 94, Dalit-26) general members and among them 35 are CWDs (M-31, F- 4)

2. Target groups reached (Direct and indirect)

a. Children: (Boys/girls, differently abled, dalit/janajati, affected). (Cumulative as well as new addition in the review year)

Direct: Registered CWDs and YWDs :1574(Since 1995)

- M- 912, F- 660, Inter sex- 2,
- Bramhan/Chhetri- 515, Janajati- 948 Dalit- 85 Madashi – 26
- New Registered -19
- M-11, F-8 Janjati-4 bharman/Chhetri-15

Indirect:

- 3000 P/CWDs/ parents / students / teachers /CC members / local authorities
- b. Strength and weakness (Good points and the major problems)

Strengths

- Trained human resource / Acceptance of community / Experience in CBR programs

Weakness:

- Lack of fund mobilization / Lack of Specialized human and technical resource
- Lack of Physical infrastructure / Lack of system development.

Process of monitoring and evaluationMonitoring meetings:

- General and board meeting: 6 times a year / Board, general and staff meeting: quarterly
- Staff meeting: Monthly / Supervision: Schools and home visits
- Local volunteer meeting: Quarterly / VDRCs meeting: Monthly

Review and report: Financial

- Monthly, quarterly, bi-annual, annual

Progress report

- Quarterly / bi-annual / Annual / prepare and submit to SCIN / On QHR / DDC/ CDO / BOD and other.

(4) Intellectual Disability in your country

Please explain briefly on ID in your country regarding the items shown as below

(1) The present services for ID offered by both government / NGOs

The Ministry of Education is responsible for providing integrated education opportunity for CWD. However most of these services, when provided, are concentrated around the bigger towns. All children in Nepal are entitled to receive the disability identity card and these entitle them to free education and other services provided by the state. The government has three types of education policy for CWID (special education policy 2053/1996):

- (a) Resource classes, which have been developed in government primary school with hostel facilities(there are about 100 such schools with about 1000 children in about 64 districts)

- (b) Special education programs: In which NGOs have been mobilized and they are able to access government grants to run (for example, AWMR is one such pioneer NGO running such program. According to their report 2000 Children with Intellectual Disabilities have been benefited by education and other rehabilitation services.) this programs in various districts.
- (c) Inclusive education: In which the new inclusive education policy (effective in 2004) encourages inclusive education to Children with all types of disabilities, including Intellectual Disabilities. Though there are not accurate figures available but according to the source of Department of Education around 50000 CWDs have got access in education through this program including the children with intellectual disabilities (CWID). It is also good to recall here that the total number of disabled children in Nepal is estimated around 500000 (Source: RCRD Nepal). There is no special provision if a family can not look after their CWID. There is government and private has been running orphanages for abandoned children and admit CWID in this as well. There is provision within the government to run homes especially for CWID however are few such homes. CWDs are also entitled to have allowance of 200 rupees per month (approximately 3 US dollars). The reality is that very small number of children receives this assistance due to the quota system in district.
- (2) The respective roles of government, NGOs and residents (people in the community)
- To promote and protect the special rights of CWID by addressing their special learning needs and educational rights.
 - Reasonable Accommodation of the needs of CWID in the policy, program, laws, physical infrastructures etc.
 - Vocational Rehabilitation
 - Positive attitudes, behavior and cooperation of community people towards CWID and their parents.
 - Raise awareness on disability rights and for the prevention of intellectual disabilities.

5. Situation of Persons with Intellectual Disabilities

Describe as much as you know

(1) Finding and Diagnosis of I.D. early intervention: One study carried out by National Planning Commission has showed that 41.2 % of the cases it was mentioned that the onset of mental retardation in the person was from birth and the causes of most of the cases of intellectual disability are unknown. The other significant cause was disease which included high fever, diarrhea, typhoid, pneumonia, measles, polio, encephalitis, and paralysis. According to the study 71.4 % of the cases had been taken for treatment but the nature of treatment ranged from faith healers to doctors and to many kinds of households remedies as well. According to the study only 44.7 % of the total cases had gone to the doctors and health workers.

a) Prevalence of I. D. in your country / district: According to the survey held by National Planning Commission in 2001 the percentage of people with intellectual disabilities is 5.9 % in the total number of people with disabilities. (Source : Situation Analysis of Disability in Nepal) .

b) Persons / professionals responsible to diagnoses (doctors or health workers or social workers....)

Professionals (particularly the CBR workers mobilized by CBR organizations) help and facilitate to identify the cases in the area where the CBR program have been implemented. After this the types of interventions needed identified in the decisions of parents, CBR workers and community people and each intervention is made according to the short and long term plan. The doctors, health workers, parents and other stakeholders will also be involved as per the necessity. But in the area where the CBR program has not been implemented the parents themselves would initiate for the early intervention by taking the child in local health centers and hospitals.

c) Procedure after diagnosis: After diagnosis the rehabilitation plan is made by CBR workers sitting with the parents and local CBR committee's members and does as per the decision. In the case of Patan we after the discussion with parents to start the services according to C/PWDs need such as; home visit, referral to health centers for

medical surgical intervention, referral to special schools or general schools for their education and rehabilitation and vocational and income generating activities.

(2) Education

a) Percentage of children with I.D. who attend school: It is very hard to find the actual data in national context but in the context of Lalitpur district where Patan CBR has implemented it's CBR program 46% PWDs have education.

b) Type of education for children with I.D. Special education or Integrated education?

They have been admitted in both special and integrated education system which depends upon the availability of the school near the house. If the school is running special class the parents prefer to admit ID children in special class.

c) Placement procedure

Distribution of Type of Education

<u>Type of education</u>	<u>Frequency</u>	<u>Percent</u>
<u>Informal education</u>	<u>18</u>	<u>21.18</u>
<u>Child education</u>	<u>6</u>	<u>7.06</u>
<u>Special education</u>	<u>8</u>	<u>9.41</u>
<u>Formal education</u>	<u>54</u>	<u>63.53</u>
<u>Total</u>	<u>85</u>	<u>100.0</u>

Source: Field Study 2003

Within the type of education, formal education holders are 63.53% followed by informal education accounting to 21% approximately. Similarly, proportion of Child and special education are 7% and 9% respectively. It is pleasant to note that 51.9% (28 out of 54) are from the age group of 15-49, which is the most active age group.

Formal Education Level

<u>Formal education level</u>	<u>Frequency</u>	<u>Percent</u>
<u>Primary level</u>	<u>22</u>	<u>40.74</u>
<u>Lower secondary level</u>	<u>13</u>	<u>24.07</u>
<u>Secondary level</u>	<u>11</u>	<u>20.37</u>
<u>College level</u>	<u>8</u>	<u>14.81</u>
<u>Total</u>	<u>54</u>	<u>100.00</u>

Source: Field Study 2003

Among the formal education holders, the least is in the college level, which accounted to 14.81% and the majority is found in primary level constituting 40.74%. Among the PWDs studying in the college level, 50% are from the age group of 15-49.

(3) Vocational training

a) Do I.D. people receive vocational training? If not, what is the reason?

The government has a policy on paper of providing vocational training and employment for PWID. However this has not yet come into practice. Families of adults with ID can claim the 200 Rupees (approx. 3 US dollars) disability allowance, but no money is given directly to the adult WID. A few NGOs has run sheltered workshops, thus creating some employment options for adult in a specialized settings. These works get paid a small stipend. However these workshops are located in the towns and provide for a very small number. Special services for older PWID, as such are not available in Nepal.

Although service structures do exist for children and adolescents with ID, these services have not yet anticipated an adult or ageing client population. In one study of older adults with ID, Shrestha and Weber (2002) observed that the family was the prime resource for support for older pWID, that the family's attitude plays a central role for the use of existing service provision, and that most parents of PWID have made no plans for the future situation of their adult children (except that parents of adult sons with ID have often arranged or are planning a marriage for their son in order to assure his social security in adulthood and old age).

(4) Support organizations

a) Governmental agencies concerned with I.D. people :

b) Number of non-governmental organizations concerned with I.D. people

Around more then 100 NGOs are registered to work for the promotion and protection of the rights of CWID but the number of organizations who are really working direct with the CWID and their parents is very few. Some of the pioneer organizations are CBR Patan, CBR Bhaktapur, CBR Biratnagar, CBR Palpa, Sankalpa CBR Sunsari, Association for the Welfare of Mentally Retarded (AWMR), Down syndrome society Parents Association for the Mental Retarded (PAFMR), Parents group of Intellectual Disabilities etc.

4. Based on the information of above items 1-5, please explain the issues / problems to solve in order to conduct effective supports to I.D. people.

Issues needs to be addressed

- Daily care of ID people
- Education according to their learning needs
- Skill development vocational rehabilitation
- Regular health care and essential therapy
- Social Inclusion and attitude change

Problems

- Poverty and lack of time and resource with parents and family members for daily take care to ID people
- Lack of flexible education system to address the learning needs of ID people and no proper attention by the state to their special issues.
- Lack of strong self advocacy from parents groups
- Negative attitudes of society, community people towards ID people