**"Disability Working Group"**

**"Terms of Reference"**

**Background**

Disability is a pertinent issue in all development efforts. There are series of efforts taken by many individuals and organizations along with the government to protect promote and ensure the rights of persons with disabilities, and to ensure their access to a life of dignity. Members of AIN and other non member INGOs together with their partners are working towards this issue. The Convention on the Rights of Persons with Disabilities (CRPD) has been ratified by 103 member states of UN including Nepal until August 2011. The recently launched ‘World Report on Disability’ by the World Bank and the World Health Organization illustrates a disability prevalence rate of 15.4; however this figure could go up to 19 percent in developing countries (WDR 2011). In addition to these two documents is the evidence of the link between disability and poverty: someone who has a disability is more vulnerable to poverty and someone who is poor is more at risk to acquire a disability. It is therefore essential to include persons with disabilities in all developmental endeavors. Since AIN members have made significant efforts towards transforming the lives of Nepalese population, it has become a matter both of importance and of high priority that they also do not overlook disability. This gives an ample justification to form a Working Group that will be inclusive of both AIN members, other INGOs along with the organizations/agencies working in this field.

**The context of Nepal:**

The GoN statistics of 1971 census estimated 1.5 % of the total population over 10 years of age had disabilities. Another census of 1981 estimated 5 % persons with disabilities. This figure came significantly lower to 0.45 % when GoN carried out another census in 2001. Apart from the government the UN and non government agencies/organisations have also undertaken surveys both general and specific. UNICEF's study in 2001 pointed out 1.63% prevalence of disabilities[[1]](#footnote-2). In contrast studies carried out by a specific impairment group in five districts stated that 16.6% of children aged 5 plus years were deaf. Asha Deep, an organisation working in mental health, found that 10-20% of people experience one or other forms of mental health disabilities. Similarly, the survey carried out by APPROSC in 1998 estimated a total of 3.4 % of the total population had disabilities[[2]](#footnote-3). Another study carried out in the area of deafness and ear diseases illustrated 16.6 % of people who were deaf or had ear diseases[[3]](#footnote-4).

The above studies demonstrate that there is no precise data to interpret the population of persons with disabilities in Nepal. In practice, the WHO estimate of 10% persons with disabilities in the developing world, which dates from the1970s, has been taken as a reference. However, the new World Report on Disability will now become the main reference in the field of disability, and therefore also for this TOR. With the world’s disability prevalence rate of 15.4, in Nepal the population of persons with disabilities could make up to 4.6 million (given that the total population of Nepal is 30 million). The prevalence of disability is slightly more in women compared to men. Geographically the prevalence of disability is remarkably higher in rural areas (92%) compared to urban areas (8%)1.

The government of Nepal has recognized and categorized disabilities into following seven categories:

1. Physical disability
2. Hearing disability
3. Visual disability
4. Deaf and blind
5. Vocal and speech disability
6. Mental disability - Intellectual disability – Mental Illness - Autism
7. Multiple disability

Accurate and current data on the prevalence of each of the different types of impairment should be available with the release of data from the census conducted in June 2011.

**Rationale**

The existing socio-economic condition of the persons with disabilities is very poor. Of the total school going aged children, hardly 15-20% have access to education. The Government of Nepal and the United Nations acknowledge that, while Nepal has made important progress toward achieving universal primary education as part of its commitment to the Millennium Development Goals (MDGs), children from marginalized communities, such as children with disabilities, represent a significant portion of the approximately 330,000 primary school aged children who remain out of school in Nepal (Human Rights Watch 2011). There are not exact figures on what percentage of Nepalese population lies below the poverty line, however disability rights experts claim that 80% or above of persons with disabilities fall below the poverty line.

The social dimension is even worse since the general perception of individuals, family and society towards disability is very problematic. Persons with disabilities are still primarily viewed as ‘objects’ of welfare or medical treatment rather than ‘holders’ of rights. The existing deep rooted conceptual barriers that generally exist both in the minds of individuals, even the educated, has seriously undermined this issue where the persons with disabilities are seen as ‘problem’. Contrarily, what is globally accepted is that the ‘problem’ of disability is not with a person, but in the society and in our existing mindsets. Therefore, there has been shift from viewing this issue in a traditional way i.e. sin of past generations or more religious based, to a ‘medical model’, i.e. that can be medically treated in the nature of the individual’s problem, and finally to the current ‘social model’. Since Nepal has ratified the UN CRPD and its optional protocol and become a state party, the issues of disabilities have to be taken as human right issues. Undoubtedly disability has therefore become a development issue. This demands change in the individuals, institutions and organizational level along with the external environment to include persons with disabilities, based on the common understanding that persons with disabilities have rights to have a life, to get job and to live in the society.

**Understanding Disability**

According to the International Classification of Functioning, Disability and Health (ICF), the problems with human functioning are categorised in three inter connected areas:

* **Impairment** are problems in body functions or alterations in body structure-i.e, paralysis or blindness
* **Activity limitations** are difficulties in executing activities-i.e, walking or eating
* **Participation restriction** are problems with involvement in any area of life, i.e.discrimination in work, transportation

Disability refers to the condition encountered in any or all above three areas of functioning, arising from the interaction between personal factors with the contexual factors-environment.

With the aforementioned developments, time has called AIN member organizations, and also its boundary partners who we interact with, to take initiatives to effectively promote, protect and ensure the rights of persons with disabilities. Since members of AIN carry a long history in transforming the social and economic life of many individuals and communities, it is a call for all of its members to mainstream these issues into their projects, programmes and organization, perhaps not in terms of millions of dollars but with a friendly and inclusive attitude in their actions.

"A society good for persons with disabilities is a better society for all." A common understanding of terms "disability" within I/NGO community would therefore facilitate concerted coordinated, social mobilization efforts. The twin-track approach is essential in order to make inclusion effective. This means that while removing barriers within mainstream programs, there should also be a specific focus on disability. So at the level of policy, disability should be mainstreamed into general development policy, as one cross cutting issues into gender, poverty-alleviation, health and education policies or in the projects and programmes of relevant areas where AIN members are involved. There should also be specific disability policy (rights-based and promoting inclusion) to ensure specific services or benefits for persons with disabilities in order for them to be truly included. In relation to strategy, barriers (e.g. access) should be identified and removed in the mainstream, and in addition, persons with disabilities should be empowered to participate and to claim their rights. In relation to budget, mainstreaming needs to be supported by appropriate funding, this could be by allocating a small percentage of every mainstream budget for disability.

Apart from the need for mainstreaming disability in all the development efforts, the Millennium Development Goals Report 2011 states that:

*“Already, the MDGs have helped to lift millions of people out of poverty, save lives and ensure that children attend school. They have reduced maternal deaths, expanded opportunities for women, increased access to clean water and freed many people from deadly and debilitating disease. At the same time, the report shows that we still have a long way to go in empowering women and girls, promoting sustainable development, and protecting the most vulnerable from the devastating effects of multiple crises, be they conflicts, natural disasters or volatility in prices for food and energy”.*

**Progress tends to bypass those who are lowest on the economic ladder or are otherwise disadvantaged because of their sex, age, disability or ethnicity” [Ban Ki Moon Secretary General United Nations]**

Therefore we need to pay special attention to this specific group, people with a disability. If not, the MDG will not be reached in the given time.

Nepal is in the process of writing a new constitution through an elected constituent body and, in the meantime, has decided to move into federal system of government. It has ratified the UN CRPD. Therefore, for policy and legislative guidance, for the equal enjoyment of all human rights and fundamental freedoms, establishing rights of persons with disability is important. It is within this context that the AIN could consider forming a Disability Working Group.

**Current Initiatives of AIN:**

AIN has already initiated some foundational work in the areas of disability. Some AIN members exclusively work in the areas of disability while some others have included a certain portion of their work to work in this area. Most recently, AIN has published a Workforce Diversity Survey Report, and the report also included persons with disability as one of its parameters/area. However, the results of that report itself calls AIN to take further action to increase the number of persons with disabilities within its workforce. In addition, AIN has also published a Workforce Diversity Guiding Document, where disability is included as one of the areas to consider when AIN members recruit staff in their organizations.

**Purpose / Mandate**

The purpose of **DWG** is to consolidate the current efforts that AIN members are doing, and to maximize the potentials that AIN member organizations possess. This would be directed by the general development approaches of ‘mainstreaming disability’ or ‘disability and inclusive development’ in line with an intervention both at the organizational and program level. The mandate of the **DWG** is not of limited duration but will continue to function as a standing group within AIN for as long as deemed necessary. The **DWG** will review its objectives annually to ensure the mainstreaming of disability issues in the projects and programs. Annual outcomes and quarterly milestones will be prepared based on identified priorities.

**DWG Members, Coordinating Work and Human Resources**

The membership for this group is open to both AIN members and those INGOs not within the umbrella of AIN. Besides, other organizations/agencies could also attend this working group as observers or invitees. There will be a Coordinator to coordinate the DWG activities. This person will be selected by the participating members among them who will be mainly responsible to coordinate the DWG meetings, represent the DWG in SC or AIN plenary or to present on its behalf. The term period for the coordinator shall be for a year or a maximum period of two years. The staff of AIN Secretariat will extend their support when available or when requested by the Coordinator.

Besides, there will be at least one person from the Steering Committee of AIN to coordinate the work between DWG and SC.

**Objectives:**

Following are the objectives of the **DWG** to fulfill its purpose/mandate:

*Towards AIN Members*

To strengthen and invest in developing capacity of AIN member organizations on disability and inclusive development. This particular this will be supplemented by the following:

* Creating an environment for coordination and collaboration among members’ activities to establish synergies in the disability work, therefore to avoid possible duplication and overlapping.
* Mainstreaming disability within AIN members: Disseminate package and practices on disability to AIN members to promote the mainstreaming of disability issues into their programs and projects.
* Suggest and advocate for inclusion of disability in public policies and strategies as per the notions of CRPD
* Capacity building of AIN plus other members: Resource/Advisory group: Share and timely update the members about the new initiations, policies and information on disability and training opportunities
* Coordination and collaboration: Within members plus with other Working groups: Since disability is a cross cutting issue, therefore need to enter into the dialogue with other thematic working groups established within AIN. This will help other group members to integrate these issues in their actions.

*Towards Government of Nepal, local partners and stakeholders*

* Together with Nepali Disabled Persons Organizations (DPOs), lobby and advocacy for the formulation and effective implementation of the CRPD and government's disability related laws, plans, policies, programs and schemes, as well as the inclusion of the disability issue in all development sectors (health, education, etc)
* Support in National CBR policy, publication of CRPD tools, support to implement & advocate for National Childhood Disability Prevention Strategy of Government of Nepal.
* Engage ministry of health and population, ministry of women children and social welfare, ministry of local development, ministry of labour, ministry of physical planning and construction and ministry of education for the coordination and collaboration in disability related issues.
* Hold dialogue with Constituent Assembly members/parliamentarians in order to ensure rights in the new constitution.
* Hold dialogue and interaction with the bilateral and multilateral agencies, including UN agencies and donors, in order to including disability as a mainstreaming issue when they fund for the projects.

**General/Overall Activities**

* Create a resource bank on disability in the AIN website.
* Mapping of the different organizations working in the disability sector and mutual coordination among likeminded organizations.
* Liaise and coordinate common strategies with AIN taskforce for implementation of the UN CRPD.
* Liaise and organize with all other working groups formed under the AIN sharing on best practices on disability, and entering into the dialogue of how the working groups could consider disability issue in their working group actions.
* Prepare and formulate common position paper on disability to be submitted to the Government of Nepal
* Improve the availability of quality, standardized and disaggregated data on disability.
* Organize regular meetings - monthly or as required to update on development and progress in disability.
* Inform and facilitate the AIN members' participation on specific events and consultations at national and local level
* Conduct research; organize trainings, workshops and conferences in order to fill information gaps, update information, build capacity and empower its members on disability and development periodically.

**Fund and Management**

The funds for this DWG shall be managed as follows:

* In each year, DWG shall prepare an annual plan of action outlining the activities, months to be implemented along with key responsibilities to coordinate.
* At the same time, financial responsibility will also be allocated to participating members in a voluntary basis.
* The committed funds from the participating members shall be spent on their behalf directly at the time of organizing events/activities.
* The meetings expenses such as tea and snacks shall be the responsibility of the hosting member organizations. In general meeting will be on the rotational basis.
1. Situation Analysis of Disabled in Nepal. UNICEF. 2001 [↑](#footnote-ref-2)
2. Disable Situation Analysis of Nepal. 1998. Agricultural Projects Service Centre (APPROSC). Kathmandu, Nepal. [↑](#footnote-ref-3)
3. Prevalence of Deafness and Ear Diseases in Nepal. 1991. [↑](#footnote-ref-4)