Building linkages between HIV/AIDS and disability programs in India

**AIDS as a disability issue.** Many countries hard-hit by HIV/AIDS recognize the need to develop inclusive strategies to stop the spread of the virus. Special efforts are being made to integrate difficult-to-reach and vulnerable groups into programs. People with disabilities – 10 percent of the world’s population - are some of the poorest and most marginalized. Studies in Africa have shown that risk factors for HIV infection increase for persons with disabilities; these include poverty, illiteracy, lack of information on sexual and reproductive health, abuse, lack of access to health care, and stigma. People living with HIV/AIDS often develop disabilities as a result of disease progression or drug treatment, and it is often argued that AIDS is a disability issue. Yet, the intersection between disability and HIV/AIDS is poorly understood. Despite many shared concerns, contact and collaboration between the two sectors are slow to gain ground. In its recent global study, Health Canada found few examples of dialogue between the disability and HIV/AIDS movements at the international, country or grassroots level.

**The need for better knowledge.** During the 17th International AIDS conference in Mexico City in 2008, the double discrimination facing people with disabilities who are HIV positive was discussed for the first time. It was recognized that the low level of awareness in the HIV/AIDS community about disability contributes to the exclusion of people at-risk. Service providers report few cases of HIV positive people with disabilities and programmers often lack the appropriate knowledge and skills to meet the needs of people disabled people who may be at risk for HIV. Recent concerns from the HIV/AIDS community have, however, prompted calls for training and capacity building to develop appropriate prevention, care and support services to meet the needs of disabled people. While well organized, disabled people’s organizations have largely excluded sexual and reproductive health from their programs. Service is difficult to obtain due to the myth of asexuality - that those with disabilities are often dependent on others and may not be sexually active. Recent studies have shown, however, that in terms of relationships and sexual behavior, people with disabilities are as active as the general population.

**Integration and complexity.** Disability - visible and invisible - is a spectrum of physical, sensory and mental conditions with a variety of challenges and needs. Integrating HIV/AIDS and disability programming requires a range of approaches. The main concerns of people with physical and sensory limitations are that information and services should be in accessible formats. People living with mental or intellectual disabilities face issues of decision making ability, risky behavior, and poverty and social isolation that require different approaches. Globally, calls are growing for strengthened efforts to include individuals with disabilities as a target group in HIV/AIDS outreach efforts. In India, programs to mainstream HIV/AIDS and disability are in their early stages. Some disabled people’s organizations recognize the complexity of this issue and are developing and incorporating HIV/AIDS services into their programs. HIV/AIDS programmers face difficulties introducing new target groups due to insufficient funding for additional initiatives and by their mandates to focus on the traditional high-risk groups such as sex workers, injecting drug users, and truck drivers.

**Numbers and challenges.** India has the world largest population of people with disabilities, about 70 million. Between 1.8 and 3.2 million Indians are HIV positive, and out of those about ten percent live with a disability according to UN estimates. However, as early as 1999 almost 194,000 deaf Indians were reported to be HIV positive, the largest number of HIV positive deaf people in the world. These numbers are likely under estimates - no data is available on the
intersection of disability and HIV in India and formal linkages between the two sectors have been
until recently virtually non-existent. What is known is that people with disabilities face all known
risks at rates equal to or higher than that of the general population. Researchers caution that
failures by the HIV sector to include people with disabilities in its programs and lack of
knowledge of HIV among people with disabilities will continue to hamper progress in preventing
the spread of the disease.

**Efforts in the NGO community.** Civil society organizations in India have been instrumental in
the efforts to integrate disability and HIV/AIDS. Good examples have begun to emerge among
both large national NGOs with extensive partnerships as well as among small local organizations
targeting specific groups. Many interventions are comprehensive and inclusive with strong
collaboration from all levels of society. Projects range from regularly scheduled awareness and
education campaigns to prevention, care and support for people living with HIV/AIDS. Some are
still at the planning stages while others have been operational for several years. The brief case
studies below illustrate NGO focus areas in linking disability and HIV/AIDS.

**Building knowledge**

**VSO-India.** Voluntary Service Overseas’ India branch works in collaboration with a host of local
organizations to integrate disability and HIV/AIDS. Volunteers have facilitated workshops on
inclusion, sensitized staff to diversity, and developed programs that serve disabled people and
people living with HIV. Networks of HIV-positive people have developed awareness materials
that are accessible to those with disabilities. Delhi-based **Score Foundation**, an organization that
serves those with visual impairments uses radio programs on AIDS information to raise
awareness about disability. **DeafWay**, present in several states, has produced video films to
educate the deaf about reproductive health and safe behavior by using simple sign language and
mime. Its ‘Relationships and Health’ course is taught by teams of deaf peer educators, a sexual
and reproductive health curriculum that covers body functions and systems, reproduction, health
and relationships, and HIV/AIDS. A variety of teaching methods are used including International
Sign Language, PowerPoint, slides, video, flip-charts, mime and role play. Using the full range of
communication techniques has been found to be creative and inclusive, enabling participants to
benefit to the fullest. HIV sensitization programs have been carried out by **NEEDS** in Jharkhand
using IEC mobile units and in collaboration with the state government. ‘Right to Information’
clinics have been also established and are managed by people with disabilities as resource centers
at the village level so that tribals, disabled people and people living with HIV can access legal
and social services and health information.

The management and executive body of the **Network of Persons with disAbility Organization**
in Hyderabad are people with cross disabilities. The organization collaborates widely with
government, local and community based organizations, and international organizations such as
ActionAid International. Focus is on prevention and access to programs and services. People with
disabilities are recruited for capacity building training on HIV/AIDS awareness, and counselling
is offered to those affected by the disease. Materials developed on HIV/AIDS are in Braille, tape
recordings, CDs, and pictorials. Campaigns and community- and parent-group meetings are
conducted and house-to-house dissemination is provided to those who are unable to access
service points due to severe disability.

**Strengthening capacity**

West Bengal based **Association of Women with Disabilities** aims to enable girls and women to
be empowered through capacity building and awareness-raising and to change attitudes towards
those with disabilities. A pocket-size pictorial in Hindi has been developed by individuals with
disabilities on preventing HIV and other diseases. The booklet also discusses in a non-intrusive
way relationships between men and women, providing information on reproductive health, violence and sexual abuse.

Through its A.H.E.A.D project, DeafWay conducts workshops and peer counseling regularly on general and reproductive health and HIV/AIDS. Special efforts are made to include those who are functionally illiterate and non-verbal. Deaf educators have been recruited and trained and teams of Deaf Peer Educators visit clubs for the deaf, schools, and associations to deliver a series of presentations in sign language. Those who have participated in training are then expected to function as trainer-of-trainers to help spread the messages throughout their communities.

Samadhan in Delhi has developed innovative models of service delivery that use locally available resources and materials. To identify those living with intellectual disabilities, student volunteers were recruited initially to conduct household and school-based surveys at regular intervals. A pool of trained survey workers has subsequently been created from within the community. A continuum of capacity building activities has been put in place ranging from early intervention to exploring employment opportunities for adults. These include medical and therapeutic support, counseling, identifying female trainees from target communities, and employing mothers of the disabled. HIV/AIDS will be included in the next round of surveys, and depending on findings, education and awareness programs will be designed on risks and prevention. Referral systems will be set up for those at risk, and family stress management workshops conducted for people with disabilities affected by HIV/AIDS.

Providing services

The LEIPRA Society – Health in Action is present in Andhra Pradesh, Orissa, Madhya Pradesh and Bihar and targets a population of about 12 million people. The organization has built extensive networks and linkages with other NGOs in its efforts to serve people with disabilities and those living with HIV/AIDS. It provides comprehensive clinical care and services, testing and counseling, nutrition support, and livelihood schemes. Partnerships have been created with the corporate sector resulting in added support for vulnerable groups such as the establishment of a vocational centre for people living with HIV/AIDS. LEIPRA supports affected women through strengthened access to funds, needs-based vocational training, community capacity building and nutrition education. Outreach workers conduct home visits, facilitate access to services and distribute 'new-born baby kits' to HIV positive mothers. Efforts are made to support affected families through a range of community strengthening programs.

LEIPRA’s projects linking HIV/AIDS and disability focus on sexual and reproductive health, HIV prevention, and HIV-TB co-infection. Prevention and early identification of HIV among people with disabilities is facilitated through local discussion groups where health workers are the change agents at the community level. Family Health Awareness Camps are conducted regularly with condom demonstration and distribution. LEIPRA recognized early on the difficulties for disabled individuals to gain access to antiretroviral therapy and embarked on a project to develop referral systems. Community centers were established for the care, support, treatment, and referral and follow up for people living with HIV/AIDS. Ashavini, a project to provide HIV counseling and testing services was developed in partnership with Andhra Pradesh State AIDS Control Society (APSACS) and the private sector. A mobile van with a laboratory, staffed with a medical officer and a counselor, cover high-risk and slums areas in East Godavari, West Godavari, Krishna and Hyderabad districts of Andhra Pradesh.
Reaching out
The School for the Blind in Hyderabad, run by the Devnar Foundation, ensures that their adolescent students have equal access to information about HIV/AIDS to that of their non-disabled peers. Efforts to provide education materials in Braille had been unsuccessful, and the foundation decided to produce appropriate materials for their students on its own. APSACS was approached for copies of education materials distributed to all mainstream schools. Devnar reproduced these in Braille and the APSACS agreed to pay for production and distribution costs. Materials were sent to all fifty schools for blind children in Andhra Pradesh with accompanying teaching aids for staff and teachers. The Devnar Foundation has also developed HIV education material in sign language, video cassettes, and captions of messages on television for the deaf. Messages on sexual and reproductive health have been developed for those with mental or intellectual impairments using appropriate language and content.

As part of its efforts to integrate disability into its HIV/AIDS programming Nethrajothi in Chennai widened its engagement with the disability movement and strengthened collaboration with state AIDS agencies and disabled people’s organizations. An innovative peer support strategy has been developed to provide HIV awareness training to blind people who manage meeting points and centers for the blind. A range of information and education materials, as well as condoms are made available to center visitors.

As part of its HIV/AIDS work, YRG CARE in Chennai has developed programs to reach adolescents who are deaf or hearing impaired. To address practices and behaviors that put adolescents and young people with disabilities at greater risk for HIV, a collaborative program was established involving teachers. Training was offered to teachers on HIV and sexual and reproductive health in of two-day workshops. Interactive adolescent-focused training modules covered basic facts about sexual and reproductive health including HIV/AIDS, voluntary counseling and testing, and prevention. The workshop was a first step towards mainstreaming individuals within the deaf community into HIV/AIDS programming. Plans are underway to strengthen collaboration with a range of institutions, organizations, and members who work for the deaf community. The aim is to put in place a system where teacher-trainers address HIV and sexuality issues as part of the school curriculum.

**Conclusion.** People with disabilities and people living with HIV/AIDS share similar concerns. Global calls are growing for the integration of outreach and services by exchanging knowledge, strengthening collaboration, and replication of promising results. The Convention on the Rights of Persons with Disabilities is an important step towards mainstreaming people with disabilities into regular programming - some countries have begun to develop strategies to provide equal access to services. In South Africa, people with disabilities have been included as a group at-risk in the government’s HIV/AIDS Strategic Plan 2007-2011. Other countries are likely to follow as recognition grows further of the need to link the two sectors.

AIDS programmers can learn from people with disabilities about physical, sensory and mental conditions that may increase vulnerability to HIV/AIDS. The disability movement can learn from HIV/AIDS programmers about sexual and reproductive health and rights, and HIV prevention and care. In India, strategies are being developed in the NGO sector towards mainstreaming disability and HIV/AIDS into regular programming. Support has been provided by various levels of government, and the private sector is becoming increasingly involved. Where linkages have been formed, vulnerable groups are being reached, strong partnerships and networks have been established, and good results are emerging.

*Maj-Lis Voss*
Tasks ahead are to strengthen access to information, improve contacts and collaboration across organizations and service providers, and build on multi-sectoral engagement in integrating HIV/AIDS and disability. A variety of low-cost and easily implemented programs are needed, and special efforts are required to address the wide range and different needs associated with specific impairments. In India, recent experience and efforts to integrate HIV/AIDS and disability provide important lessons and possibilities for replication and scaling up.
Sources

7 Shodhana Consultancy (2007) HIV/AIDS & DISABILITY, UNICEF Maharashtra, Pune
10 Information obtained through personal communication and the web (key websites are listed below)

Key websites:

http://cira.med.yale.edu/globalsurvey
http://www.worldbank.org/AIDS
http://www.unaids.org
http://www.worldbank.org/disability
http://www.leprasociety.org/about.htm
http://www.thedeafway.org/
http://www.samadhanindia.org/
http://www.vso.org.uk/where-we-work/india.asp
http://www.devnarfoundationfortheblind.org
http://www.nabindia.org
http://http://www.ncpedp.org
http://http://www.awwd.org
http://http://www.inclusion-international.org
http://http://www.handicap-international.org
http://http://www.aidsalliance.org