



**COMMUNITY-BASED  
REHABILITATION AND PERSONS  
WITH INTELLECTUAL  
DISABILITIES**



**PRE-CONGRESS WORKSHOP**

**AGRA, INDIA**

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# **Community-Based Rehabilitation (CBR)**

**&**

# **Persons with Intellectual Disabilities**

# **International Workshop Report**

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## ACRONYMS

AIFO	Italian Association Amici di Raoul Follereau
CBM	Christoffel Blinden Mission
CBR	Community-based rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Peoples' Organization
ID	Intellectual disability
ICF	International Classification of Functioning, Disability and Health
IDDC	International Disability & Development Consortium
PHC	Primary Health Care
PwD	Person with disability
PwID	Person with intellectual/learning disability
SHG	Self-help group
WHO/DAR	Disability & Rehabilitation Team of the World Health Organization

## INTRODUCTION AND OVERVIEW

Intellectual disabilities or learning disabilities are associated with brain functions such as remembering, counting, reasoning, understanding, problem solving and decision-making. In community-based rehabilitation (CBR) programmes, persons with intellectual disabilities may be -

- Children who either have these disabilities since birth or who develop problems in early childhood (such as children with Down syndrome, some children with cerebral palsy and some autistic children)
- Children or adults, after an illness (such as meningitis) or an injury (such as a head injury in a traffic accident) or due to certain other conditions (such as lead poisoning or lack of iodine in the diet)
- Older adults and elderly persons (such as persons with senile dementia and Alzheimer's disease).

On the occasion of First World CBR Congress held in Agra (India), this international workshop on "CBR and Persons with Intellectual Disabilities" was organized from 24 to 25 November 2012. Around **90 persons from 26 countries** participated in this workshop.

Persons with intellectual disabilities often face barriers in accessing CBR programmes. The aim of the workshop was to discuss the key issues facing persons with intellectual disabilities at community level and the ways in which CBR programmes can work together with them, their families and communities to promote inclusion and participation.

The issue of correct **terminology** is an important one. In this report, the terms '**intellectual disabilities**' and '**learning disabilities**' have been used in an interchangeable way, while recognizing that there may be certain limits in the meanings commonly ascribed to each of these terms.

The workshop was **organized in four sessions** - a session on health care needs led by Alaa Sebeh; a session on inclusive education led by Katharina Pfortner; a session on livelihoods and economic independence led by Philipa Bragman; and lastly, a session on social participation and empowerment led by Kathy Al Ju'beh.

This report presents a summary of the main issues and conclusions from the four sessions. All the presentations made during this workshop can be accessed from the following **webpage**: [http://www.aifo.it/english/disability/documents/cbr\\_id\\_workshop/index.htm](http://www.aifo.it/english/disability/documents/cbr_id_workshop/index.htm)

At the end of the two-day workshop, participants agreed to establish an electronic **group/network on CBR and Intellectual Disabilities**. Annie Pascaline Sandjok offered to facilitate this group/network ([sanniepascaline@yahoo.com](mailto:sanniepascaline@yahoo.com)) with support from Alaa Sebeh ([alaa1234@gmail.com](mailto:alaa1234@gmail.com)).

### Participants' expectations

*Barney McGlade* facilitated this discussion. The participants' expectations from the workshop were related to five areas -

- (1) Sharing knowledge with each other
- (2) Clarification of some basic concepts, issues and strategies related to persons with intellectual disabilities
- (3) Developing and strengthening DPOs for persons with intellectual disabilities

- (4) Changing attitudes towards persons with intellectual disabilities
- (5) Learning about practical tools and what can be done by CBR programmes including examples that work and examples that do not work.

### **Feedback about the workshop**

Feedback received after the workshop is reported here for comparison with the expectations. Participants expressed a high level of overall satisfaction about the workshop, comments included:

*The richness and openness of discussions I saw in group work was a great plus.*

*This was a very interesting workshop, well organized and good mix of CBR practitioners and others.*

*Very interesting because of the eye opening experiences of DPOs that are working with persons with intellectual disabilities.*

*I think a better communication between the presenters would have improved the presentations. ... some of the presentations did not focus on ID in relation to CBR.*

*Discussions were good but time was very limited – especially when we came back to the plenary after the group work – we couldn't really finalize on some of the ideas coming out of the group work – but maybe the presenters can do this in their reports.*

*The diversity of culture within CBR – this was not new but somehow you forget – seeing the very different examples and discussions reminded me of how diverse, challenging but also rich CBR pool can be as a means for exchange and learning.*

*Liked the great work that CHANGE are doing in the UK – their powerful approach to employment and voice of people with learning disabilities and fantastic materials on often sensitive subjects that are so well developed with people with learning disabilities and for people with learning disabilities.*

*I learned a lot about livelihood and possibilities to adapt the situation to the needs and rights of PwDs.*

*I think the contribution of CHANGE was interesting but how applicable can it be in a developing country / CBR context – i.e. partnership between an intellectually disabled employee and an able employee – how can we do this in our own organizations and in the community?*

*The main learning for me was to take a fresh look at how we are doing the intellectually impaired activities in our programmes – identify what are their needs, build up the peer groups if possible, make information more accessible for intellectually disabled persons etc. So to add this dimension on to our work – rather than saying that it is too difficult.*

*I plan to share materials with Disabled Peoples' Organizations and try and use them in training and project activities.*

The authors wish to thank **Robin Lauckner** for editing support for the preparation of this report.

## CBR AND HEALTH CARE FOR PERSONS WITH INTELLECTUAL DISABILITIES

*Alaa Sebeh*

There are different issues for persons with intellectual disabilities related to health care needs and access to health care services, where CBR programmes can play a role.

**Barriers** faced by persons with intellectual disabilities, to access health services include -

- Learning and understanding difficulties leading to failure to realize the significance of symptoms and the importance of a healthy lifestyle
- Difficulty in communicating about discomfort or pain
- Poor support for carers
- Health professionals lack knowledge (misinterpretation of symptoms and wrong diagnosis of disabilities)
- Discrimination leading to neglect of their health needs
- Physical and information barriers such as unsuitable buildings and signs, lack of information about appointments, admissions and possible treatments
- Social services being insensitive to social, ethnic, cultural and economic backgrounds
- Economic, attitudinal, informational and environmental barriers.

Persons with intellectual disabilities may have some **specific health care needs**. These may arise from a higher incidence of mental health conditions, epilepsy or sensory impairments. Persons with Down syndrome are at greater risk of congenital heart disease, visual and hearing impairments, thyroid disorders, leukaemia and pre-senile dementia.

Promoting **early detection** of children with intellectual disabilities is important and CBR programmes can play a role. Accurate diagnosis can be important. Comprehensive or simple assessment of the newly diagnosed children through referral services or according to local capacities should follow.

**Breaking the news** about the disability to the parents and the families is another area that needs strengthening. Information about the disability of their child should be given to both parents in the same session lasting at least an hour. These sessions need to be well prepared and structured to inform the parents in a sensitive way and provide them with full information about their child. Medical staff should refer parents to parents' support groups or local CBR programmes. Therefore it is important for CBR programmes to inform health care services about their activities.

**Medical staff** is often reluctant to advise parents that their child has some disability and parents are left to discover this by themselves. This delays the parent's acceptance of the situation; acceptance is vital for the family to effectively support the child for the future. Medical staff may also promote the belief that impairments are curable and therefore encourage the families to proceed with lengthy and costly treatments that in the end are ineffective.

**Early intervention** is crucial and can result in significant improvements. Developmental checklists and simple, guided activities to promote child development have proved to be among the best tools in CBR for children with intellectual disabilities. Intervention is mainly provided through family members with external support and specialized guidance.

It should be preferably home-based and at an early age. CBR programmes can facilitate community and family support for children through mothers' support groups (mother to mother support) and the involvement of siblings and hopefully fathers.

**Responding to the health care needs** of persons with intellectual disabilities requires support from different health care services. CBR programmes can play an important role in this, especially at community level, by creating awareness among health care services. The following are needed -

- Equal access to all health services
- Disability awareness to be integrated in staff training
- Access to specialized health services through referral systems
- Community-health workers (CBR workers) to be linked to PHC centres
- Individualized intervention plans
- Partnerships, coordination and collaboration between various service providers
- Improvement of the understanding and communication of symptoms of persons with intellectual disabilities to clinicians (simple communication boards describing pain)
- Training for families and carers on key symptoms that could be overlooked such as sudden loss of appetite, weight gain or loss, dramatic changes in behaviour
- Building positive attitudes among health practitioners, particularly on the right of persons with intellectual disabilities to be free from pain in cases of debilitating conditions
- CBR programmes to address the increasing older population.

### **Challenges for health care for persons with intellectual disabilities in low-income areas**

Sunanda Reddy shared her experience from Delhi, India. Inclusive health care is needed. Health systems must recognize and accommodate the needs of PwDs in their policies, planning and service delivery. Health Care service providers need to have positive attitudes towards disability and appropriate skills to accommodate the needs of people with different impairments. PwDs, DPOs and SHGs should actively participate in the planning and strengthening of healthcare and rehabilitation services.

### **Inclusion of elderly persons with intellectual disabilities in CBR programmes**

Sunil Deepak shared information about the WHO publication "Dementia, A Public Health Priority", that provides simple information about supporting elderly persons with intellectual disabilities in the CBR programmes. With increased life expectancies and ageing of populations, the number of older adults and elderly persons with intellectual disabilities is increasing. However, often CBR programmes are not aware of the disability-related needs of these persons. This publication can be downloaded from the following website: [http://whqlibdoc.who.int/publications/2012/9789241564458\\_eng.pdf](http://whqlibdoc.who.int/publications/2012/9789241564458_eng.pdf)

## **Recommendations about improving access to health care services for persons with intellectual disabilities**

Workshop participants were divided into smaller groups and were asked to think about three groups of persons (stakeholders) and what role they could play in improving access to health care services for persons with intellectual disabilities -

- CBR implementers were asked - What could you do to improve the health component at your CBR programme in relation to intellectual disabilities?
- Duty bearers and authorities were asked - What would you advocate at national and local levels to improve health provision to persons with intellectual disabilities?
- Specialists and professionals were asked - What would be their roles in the context of CBR?

Based on these group discussions, the following recommendations were finalized for the three groups of stakeholders:

### **A. Recommendations to authorities and duty bearers -**

- Recognize and include issues related to persons with intellectual disabilities in national policies, strategies and plans
- Ensure that all health services are inclusive, accessible and well utilized by PwIDs
- Ensure that disability awareness, particularly in relation to PwIDs, is well integrated into staff training
- Provide referral systems ensuring access to specialized health services for those in need and those with more complex conditions
- University curricula for undergraduates and postgraduates as well as various training courses should include issues related to PwIDs
- Improve health information systems on disability, include data on age, gender, type and severity of disability conditions
- Establish mechanisms for PwIDs, DPOs, parent's organizations and SHGs of PwIDs to be fully involved and engaged in the planning, management, implementation and evaluation of various CBR programmes
- Inter-sectoral collaboration should be strengthened
- Clear guidelines, along with tools for monitoring and evaluation, should be developed to promote the implementation of national policies, strategies and plans
- Accessible information should be provided on the rights of PwIDs, existing services and other relevant topics using simple language and illustrations.

### **B. Recommendations to specialists and professionals -**

- Use a 'professionals to professionals' approach to convince the conservatives and those who strongly support the conventional medical and not the CBR approach - the experience and 'language of professionals' should be used
- Develop the tools normally used by professionals, such as 'standards', manuals, guidelines and research for a sensible and responsive approach to the needs and rights of PwIDs
- Develop training content and modules on the roles of professionals and specialists in dealing with PwIDs in the CBR context
- Ensure that professionals supporting CBR network and work together to encourage and help various mainstream services to open up their doors and include PwIDs

- Use the 'ICF' approach, but not necessarily the ICF tools until these are further simplified for use in the CBR context, for the assessment and development of 'Individual Intervention Plans'
- Support and provide training to CBR workers and ensure they only use approved methods for direct interventions with PwIDs
- Use the results of research and experience, expressed in the 'language of professionals', when approaching professionals about the CBR method.

#### C. Recommendations to CBR implementers -

- Support parents by establishing parents' groups and self-help groups
- Raise awareness at local levels
- Include parents, PwIDs, media, support groups and relevant government ministries in local CBR programmes
- Develop training tools for CBR workers on prevention, early detection, early intervention and assistive devices
- Provide training for parents of disabled children and for members of DPOs
- Lobby the government and advocate the rights of PwIDs
- Involve DPOs and SHGs in policy making
- Involve parents and PwIDs in all efforts to build positive attitudes
- Support and provide quality training to volunteers
- Promote networking, it is crucial to share experiences, knowledge and resource materials
- Address the needs of elderly PwIDs in the CBR context
- Collaborate with human rights organizations to take legal actions when necessary to protect the rights of PwIDs.

#### **Some other significant issues that came up during discussions**

It was not possible to discuss all the issues related to health care needs of persons with intellectual disabilities. There were other issues raised during the concluding discussions of this session including the following:

If there are no professionals, how can there be diagnosis and expert support?

Diagnosis also labels the persons and that becomes a barrier. How may this be overcome?

Sometimes parents ask for a hysterectomy of their daughters with intellectual disabilities. They are afraid that, if their daughters are raped or have unprotected sex and become pregnant, they may not know who is the father.

Sometimes, parents are afraid because they do not know how to manage periods (menstruation) and sexual abuse issues.

In some communities stigma is very strong. Sometimes, elderly persons with mental illness and dementia are left to die. Professionals may also need to address their own stigmatizing attitudes. They have knowledge but don't apply it.

Sometimes, when parents of persons with intellectual disabilities die, the PwIDs are pushed out into the streets, as they may not have a home or someone to take care of them. How can we lobby governments and others for their rights?

More national CBR programmes are needed. All countries that have signed CRPD must act in order to implement those rights. Health professionals need to understand and support CBR. Working in hospitals is very different from working in communities. Bringing together the two perspectives is important.

CBR programmes do not know how to support and work with persons with intellectual disabilities. Strong DPOs are needed. DPOs of persons with intellectual disabilities and their families are more interested in other issues - social security, jobs and livelihood. Self-advocacy skills are weak; issues such as the care of persons with intellectual disabilities as they grow older, are neglected.

# CBR AND INCLUSIVE EDUCATION OF PERSONS WITH LEARNING DISABILITIES

*Katharina Pfortner*

Seventy-two million children with disabilities are not enrolled in schools. In most documents about education for children with disabilities, intellectual disability is rarely mentioned. The data regarding access of children with intellectual disabilities to education are not clear and are often contradictory, because of different definitions and concealment of intellectual disability in society.

**School education** for children with learning disabilities is a problem in most countries. There are issues about crowded classrooms, teachers' attitudes, poor quality of their training, inaccessible environments, curricula of schools are rigid, teaching aids are lacking and parents are not involved. School education in general is of poor quality, and teachers and schools are not prepared to work with students with IDs.

Children with IDs and behavioural problems are the first to drop out of the education system, as they are not able to adapt to conditions at school. The education system is competitive, only taking into account the strong and 'better' learners, while the system discriminates against children with any kind of problem.

**Environments favouring inclusive learning** are needed to improve learning for all children and to create the necessary conditions for the participation of students with learning disabilities. School learning is far too theoretical. One aspect of learning-friendly environments is community-based learning for all children: that means, starting from real life situations while family and community members accompany children who have specific needs.

**Integration and inclusion:** Integration has ideas of equality while inclusion has ideas of diversity. Integration is about conditional insertion, about how to adapt to a system. Inclusion is unconditional insertion, everybody can participate. Integration asks persons to adapt to the situation, inclusion asks the situation to adapt to the person. Until now, inclusive education has not been realized; we are still in the system of integration, but with a strong will to overcome this system in order to accept diversity.

**Inclusive education** has prerequisites: neighbourhood schools, classes with children of the same age, diversity of children is accepted, necessary support is available, teacher training is possible including teaching methods for reaching out to individual students and resolving problems at school level. In reality these guidelines are not followed: children with intellectual disabilities often remain in lower classes and stay with younger children. Their needs are very different, which provokes problems and conflicts.

Dealing with 'necessary support' in regular schools we also need to discuss, according to our own cultures, the level of support that is really needed. Often we do not find specialists such as psychologists and speech therapists in a rural setting, but this should not limit inclusiveness. We have to aim for community-based local education, to work with the communities using local resources. Teacher training has to be practical, not theoretical, so that it is really being supportive in a rural situation.

**In CBR**, the first thing we do is try to understand the real needs of the persons, before worrying about diagnosis. People and family members have to decide themselves what are the important needs. Families are the experts at assessing the needs in this situation and

not the professionals. Individual learning programmes must be developed in collaboration with CBR fieldworkers, family members and schoolteachers. This development can be done in a participatory way, using pictograms and drawings. The activity plan should take account of the life situation, likes, dislikes and dreams. It also has to be linked to the school's situation, objectives have to be shared with the inclusive education setting.

**Early detection** and a functioning referral system are necessary to succeed in early intervention. Inclusive education should start in pre-school or even earlier with home-based learning. Children with intellectual disabilities are often not detected until they enter school, although children with Down syndrome are normally easy to detect. Awareness building between mothers and child health systems, paediatricians and primary health personnel is needed in order to improve the situation.

**Support for children** with disabilities, including children with intellectual disabilities has to be organized in the communities. If the ministry of education collaborates, itinerant teachers are employed to visit and support schools that include children with disabilities. It is important to promote teamwork among teachers in this situation. Teams in schools need many participants including teachers, parents, children, CBR workers, DPOs, community leaders and faith-based leaders. Schools have a diversity of children who can be a resource if trained to become tutors for other children.

One of the most **important barriers** for persons with intellectual disabilities to be included into regular schools is the definition of intelligence. Intelligence is still measured by IQ numbers, an inflexible concept that does not refer to progressive learning processes. Other ways of looking at intelligence have been proposed, such as by Gardner, who talks about different kinds of intelligence such as logical, mathematical, visual, interpersonal, intra-personal, spatial. This way of looking at intelligence considers daily living skills.

**Curriculum adaptation** is a central issue – how to learn from each other, to understand what adaptation is needed for each child and at what moment. Assistance does not need to be forever, but it has its own timetable. Children with very severe IDs may not be able to attend schools, so their assessment has to show the possibilities of inclusion. How can we include them in our work and in community activities?

Most children with intellectual disabilities leave the school system before graduating; they are often stuck in first or second grade. Many adults with intellectual disabilities have never been to school, and often have never left their home. How can we promote inclusion? A possibility is to facilitate SHGs for adults with ID. We can make them aware of their needs and rights. We can bring them together to socialize, to communicate, to train for independent living and to share with the community.

We cannot wait for better systems, and we cannot wait until we have a perfect situation. We need to develop good practices even at local levels. We need to share these examples and develop concepts to convince schools and communities in order to create a situation that convinces the governments.

### **Key challenges for the CBR programme in Mongolia to support the right to education for persons with intellectual disabilities**

T. Batdulam presented the situation of children with learning disabilities, specifically the situation of children with cerebral palsy in Mongolia. The CBR programme works with parents and schoolteachers to promote inclusive education. However, many challenges still remain, especially in terms of secondary education, the large number of children in the classrooms and rigid school curricula.

## **Discussions about promoting inclusive education for persons with intellectual disabilities**

Workshop participants were divided into smaller groups and were asked to reflect on specific issues related to inclusive education for persons with intellectual disabilities. Different questions were posed to groups and the key issues emerging from the discussions are presented below.

### **Promoting community-based inclusive education -**

- Participation of parents in schools, involving them (in some regions the grandparents are the decision makers) in planning, implementation, monitoring and evaluation processes
- Community sensitization is important to prepare the inclusive education process
- Involving community leaders, religious leaders - community can provide pre-school volunteers
- It is important to use successful PwDs from community as role models to inspire others
- Adult persons with IDs can be involved in informal education in inclusive settings so that there are more opportunities for broader learning
- Involvement of DPOs in informal education in the community
- Networking with other organizations in communities can provide good models for community-based education.

### **Promoting early detection and involving communities -**

- Training of parents, grandparents, health workers and community members to screen children for intellectual disabilities
- Knowledge of experienced parents can be used for informal training of new parents
- A network for early education should be established with all community stakeholders, including PwDs, DPOs and families, to support and organize parent to parent counselling and sharing of information.

### **Including children with IDs in primary inclusive education -**

- Assessment has to detect the child's interests. Interactive teaching should be based on those interests. Using simple methods and audio-visual media can make the class more interesting. The role of teachers and their attitude are important. Teaching materials should include appropriate tools to track children's performance
- Diversity in school should be respected; if there is no respect in the community teachers, parents, and community members should be trained. A good quality education in general makes the system responsive to needs of children.

### **Alternative ways to define knowledge and intelligence -**

- Ways to define knowledge and intelligence have to include social and cultural factors. Children with IDs challenge the current system; they push us to refine our idea of quality education. If every child is unique, why do they all need to reach the

same level? The acceptance of and attention to the child by school, friends and family is important. Social participation and acceptance will be key indicators

- It is important to create a classroom environment encompassing all children. Participation of children in the processes is crucial for inclusive education.

Secondary, higher education and adult learning -

- There is a strong need for basic learning at the primary school level, only then can PwDs continue to secondary school. We also need good schools, good teachers and family support
- Different kinds of intelligence have to be recognized, all persons involved in the process should receive diversity training
- Systems of social protection and policy support should be in place
- Assistive technology should be provided at all levels
- To facilitate higher education, university grants, incentives and scholarships should be accessible to students with intellectual disabilities.

### **Some other significant issues that came up during discussions**

It was not possible to discuss all the issues related to inclusive education for persons with intellectual disabilities. There were other issues raised during the concluding discussions of this session. These included the following:

When we evaluate a child we use performance assessments or indicators. We should shift to evaluation of the environment, we need to evaluate the schools and their environments and not the children.

Special schools are exclusionary, which means that the pupils are not part of the society. We are all different, how do schools and teachers need to change in order to adapt to the rights of persons with intellectual disabilities?

The ICF is very useful for the management of inclusive education and different issues related to learning disabilities. We need to work on how to simplify it for use in CBR in order to focus on participation and activities adapted to personal and environmental factors.

# CBR AND LIVELIHOOD OPPORTUNITIES FOR PERSONS WITH INTELLECTUAL DISABILITIES

*Philipa Bragman*

**Barriers to employment** of persons with intellectual disabilities include -

- Low expectations: society, parents, teachers, employers and people with learning disabilities themselves have low expectations
- Lack of role models: children with learning disabilities need role models – adults with learning disabilities in valued roles
- Poor educational opportunities: there may be little or no education for children with learning disabilities, education is often segregated
- Lack of independent living skills: people with learning disabilities are often not given the opportunity to learn the life skills that make employment possible
- Lack of support for families
- Isolation: people with learning disabilities are often isolated, disempowered, unaware of their rights and do not have a voice individually or collectively
- Poverty: many disabled people are living in poverty, that creates additional barriers
- Unawareness: employers are often unaware of the benefits of employing people with learning disabilities.

**CHANGE**, a British NGO, has another experience of including persons with intellectual disabilities in the workplace. The workforce includes 16 staff members and 21 volunteers. Around 50% of persons working and collaborating with CHANGE are persons with intellectual disabilities. CHANGE runs campaigns and training courses and makes information accessible to persons with intellectual disabilities.

CHANGE uses the ‘**co-working**’ model where a person with intellectual disability is accompanied by a non-disabled co-worker. Co-workers divide their work to use each person’s strengths in the best way.

**Making information accessible to persons with intellectual disabilities:** All publications and information are made accessible, using images and simple clear language. Persons with intellectual disabilities work together with graphic designers, illustrators and communicators to ensure that all materials are accessible to PwIDs.

## **Persons with intellectual disabilities in Mandya CBR emancipatory research**

Sunil Deepak briefly presented his experience from a research project in Mandya district of India. The research showed that compared to other groups of persons with disabilities, persons with intellectual disabilities face greater barriers in accessing different CBR programme services and activities. He shared some excerpts from life-stories of persons with intellectual disabilities from this research that touched on different barriers to livelihood opportunities.

## **Discussions about barriers to employment for persons with intellectual disabilities and how to overcome those barriers**

Workshop participants were divided into smaller groups and were asked to reflect on the different barriers faced by persons with intellectual disabilities to accessing employment

opportunities and to propose strategies for overcoming those barriers. The key issues emerging from the discussions on each barrier are presented below.

(A) Group 1 focused on **barriers created by low expectations and strategies** to overcome them and came up with the following proposals.

There is need for change in the attitudes of families, professionals and the community.

We need to help people with learning disabilities to become role models. Adults with learning disabilities can become role models for children with learning disabilities. There is a need for peer support and support for families.

Using life-stories is important. We need to understand the skills and potential of people with learning disabilities.

We need early detection of children with learning disabilities, we need to educate families, education for young adults needs to be accessible and can be provided by governments, DPOs and NGOs.

It is important that the national laws and policies are in line with CRPD. The implementation of legislation needs to be monitored. Free legal aid is needed. It is also important to monitor that people with learning disabilities are not exploited.

Help people with learning disabilities to speak up for themselves. Make information on rights available in an accessible format.

Concerning the lack of work opportunities, we have to ask and understand what employers need. We need to work with and support employers. Technologies are changing, so the job markets are also changing. The skills that people with intellectual impairments are taught may need to change. There needs to be good networking with employers.

(B) Group 2 also focused on **barriers created by low expectations and strategies** to overcome them and came up with the following proposals.

It is important to build and promote self-esteem in persons with intellectual impairments and in families. Providing training that is delivered by people with intellectual impairments themselves is a good way.

Improve accessibility – through increasing mobility and by providing easy to read information about what is available in districts and locally.

Improve participation in communities – share good practices, innovative ideas and new ways of working. Look at how everyday activities can become more accessible and include people with intellectual impairments in all CBR activities.

Promote good practice; promote role models by compiling and sharing success stories through the media. Support and work within communities so that they become more open to change and are more aware of the benefits of including and employing people with intellectual impairments. Establish peer support groups and parents' associations. Raise the profile and visibility of persons with learning disabilities who are already working, this is important for convincing other employers.

There is a need to develop independent living skills by training people with intellectual impairments both in groups and individually. Work with and set up DPOs, and help them to include the participation of persons with intellectual impairments. They can also create their own specific DPOs.

The CHANGE co-worker model needs to be developed in different countries. People with intellectual impairments can be trained to deliver training to support workers.

(C) Group 3 also focused on **barriers created by low expectations and strategies** to overcome them and came up with the following proposals.

Promote and develop learning through formal and informal means. Promote role models at a local, national and international level by helping people with intellectual impairments to promote their work and share information with communities.

All countries that have signed CRPD need to take action to implement the articles.

Skills training should match the needs of the employment market.

(D) Group 4 focused on **barriers created by lack of knowledge and strategies** for overcoming them and came up with the following proposals.

Awareness raising is needed for family, communities and employers.

Look at practical training that is useful for the local work market, such as training health workers and carpenters.

Working through SHGs can be an important way to reach persons with intellectual disabilities. If SHGs are trained, they can support persons with learning disabilities.

Use CRPD to provide information to and for capacity building of employers through a human rights-based approach.

Promote self-employment in formal and informal areas.

(E) Group 5 focused on **opportunities for participation** and came up with the following proposals.

Relevant policies and structures need to be developed based on empowerment, accessible information and inclusion, both in the government and the private sectors including non-profit organizations.

Training and support for parents and families is a key area. Few DPOs think of including persons with learning disabilities and they need more support and awareness in this area.

Accessible resources on independent living issues are needed.

Self-employment and microfinance are areas to explore. Government schemes to subsidize and support businesses that employ persons with ID are needed.

### **Some other significant issues that came up during discussions**

It was not possible to discuss all the issues related to barriers to employment for persons with intellectual disabilities. There were other issues raised during the concluding discussions of this session. These included the following:

There are employment schemes in many countries such as the “MG Employment Scheme” in India that includes persons with intellectual disabilities over 18 years old. If their workplace is more than 5 km from their home, they receive a transport allowance. There is also easy access to loans for activities related to land, nurseries and other projects. CBR programmes should provide information about such schemes in their own countries.

Policies should include penalties if employers do not observe the laws. Governments and the implementation of laws need to be monitored. CBR programmes can promote advocacy of these issues.

Before organizing skills training courses, investigate employment conditions and opportunities. Often courses are organized without knowledge of the job market.

Positive role models can also exist among employers and in the corporate sector; we should not limit ourselves to NGOs and CBR programmes.

Task analysis of potential jobs is necessary and job coaching is also needed. Companies may not accept the idea of 'co-workers' as practised by CHANGE in UK, but NGOs and CBR programmes can do job coaching.

Governments and bureaucrats think of barriers exclusively in terms of ramps but not in terms of other barriers such as accessibility of information.

**Summing up:** There is a need for easy to read information, the identification of role models and training for people with learning disabilities to become trainers. After training they can train employers, and play a more active role in making their communities become more inclusive.

Other needs are: relevant policies, help to implement and monitor policies, a bottom-up approach, peer to peer support for persons with learning disabilities and their families, incentives for employers and sharing life-stories of persons with learning disabilities and employers. Celebrating successes is equally important!

## CBR, SOCIAL PARTICIPATION AND EMPOWERMENT OF PERSONS WITH LEARNING DISABILITIES

*Kathy Al Ju'beh*

When starting to look at the social participation and empowerment of people with learning disabilities we must begin with rights and not charity. People with learning disabilities, women and men, girls and boys, have the same rights as everybody else: **full entitlement to freedom, respect, equality, dignity and autonomy**. However, whilst rights are indivisible, as enshrined in the CRPD '*... to ensure the full employment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity ...*' - when it comes to children and adults with learning disabilities their rights are often overlooked, denied or violated, or seen as a charitable act of mercy rather than an inherent right.

Given limitations of time, I have chosen a few key rights to focus on: Article 1 of the CRPD which calls for '*...respect for difference and acceptance of persons with disabilities as part of human diversity and humanity*'; Article 10, '*the right to life*'; Article 19, '*the right to live independently and being included in the community*'; Article 22 '*respect for privacy*'; Article 23 '*respect for the home and the family*'.

Whilst these are fundamental rights and usually unquestioned and taken for granted for the majority, the reality for many children and adults with learning disabilities is that these rights are often neglected. From conception and birth, through to life-saving medical treatment and surgery, people with learning disabilities are often not prioritized for treatment. Even in everyday matters, people with learning disabilities, even as adults, have **little choice or control over the most basic aspects of their lives**, such as when they get up, what they eat, how they dress and basic respect of privacy. When it comes to much larger questions of where people live and who they live with, people with learning disabilities are often not consulted. They know little about decisions concerning their lives until they have been taken by others, not always in their best interest, but rather to suit the best interests of others.

In some countries where state institutionalization still exists, people with learning disabilities have little or no control over their lives. Furthermore they have the vulnerability of being isolated from family and community, often out of sight and out of mind and with poor access to protection and representation. The worst **violations and abuse** of people with learning disabilities, especially people with complex impairments and high dependency needs are not exclusive to one culture. Sadly this is the reality of societies and communities who live with ignorance and fear of difference the world over.

However, today I am not focusing on the more serious violations and abuse of people with learning disabilities since this is to be the subject of the post-congress workshop. Rather I will focus on the more **mundane, day-to-day issues of rights and choice**. These need to be considered if we are to empower people with learning disabilities to have fulfilling participation in family and community life. I speak not only from my experience as a parent of a young woman with learning disabilities, but also as an activist for the rights of people with learning disabilities from my teenage years. At that time in the UK we mobilized as youth to question the role that institutions played in isolating and creating further vulnerability for people with learning disabilities.

The focus of the session will be on the practical ways that families, communities, local government and indeed DPOs can support this process of empowerment. Unfortunately, lack of voice, protection and right to choice are not only issues within state systems and family and community life. They are also issues even within the disability movement. At global and national level especially, people with learning disabilities are often at a significant disadvantage when it comes to voice and representation.

To start this reflection on what we can do to make change I would like to share with you some generic quotes that as a parent I have heard and shared so often with other parents from as far afield as Palestine, Uganda, UK, India and Bangladesh. Over the past 25 years I have been fortunate to share with many diverse communities. However when it comes to issues facing children and adults with learning disabilities and their families, despite the economic, political and cultural divides, there is a much more that binds us. The **factors that exclude our children both in childhood and adult life** are often similar in nature.

Firstly, some frequent comments from people with learning disabilities -

- *Often I don't understand. I don't know what is going on ... no one takes the time to explain*
- *People don't listen to me: they don't understand what I say*
- *There's no point in speaking up... people don't listen to what I think.*
- *People laugh at me, it makes me sad inside.*
- *I am always last, often I get forgotten*
- *I hate people talking to me like I am a child. I am an adult now*
- *I am lonely, I want to marry, to touch... to have a family.*

Secondly some frequent comments from parents of children or from adults with learning disabilities -

- *Now that she is older I don't go to weddings anymore... people don't want us around*
- *People can be so hurtful. They don't think we have any feelings for our children*
- *I am so tired, I have no time. I have not sat and talked with my neighbours for years*
- *I can't go to work in the fields, I can't earn money. I have to stay home, we are getting very poor*
- *Now he is getting very heavy to lift, we are scared that we can't look after him at home*
- ***What will happen when we die?***

The most important way to address these issues of marginalization and exclusion is through participation. **The right to participate in decision-making: the right to complain, to express an opinion, to have a say.** This may be as simple as listening to a gesture or an expression that shows that someone does not like something. Teaching basic communication signs of yes and no. Helping people to speak up, communicate or express preferences and to respect themselves. Help families to learn how to be sensitive to

tone of voice, body language and positive and negative preferences. Giving choices in everyday life - choices are not dictated by wealth, it may be as simple as giving choices on what we eat today - rice or potatoes, beans or vegetables? It may be the choice of which shirt or dress to wear - your green one or your blue one? Choices do not have to be complicated but they are essential in helping people with learning disabilities to develop pride of self and independence. Teaching people with learning disabilities that they have choice is an essential pre-requisite for their protection. Not doing so is not only an infringement on their right to self determination, but far more seriously can leave them very vulnerable to abuse and not understanding their right to say no.

**The right to participate in the community, in every-day life:** This may be as simple as attending weddings, religious services or going to market; helping the neighbour with some planting and gardening; joining everyone in the kitchen when cooking a large family meal; sharing a meal with the family and neighbours or sitting together at the end of the day to listen to everyone's news and the day's events. Participation, be it active participation or passive inclusion, does not have to be complicated.

**Challenging the deficits:** Unfortunately, although people are often in theoretical agreement, when it comes to participation we often hear the same old excuses of not enough time or not enough money. *We don't have time to let him dress himself* - then what's wrong with taking two hours to get dressed? Or letting him get up earlier? *We don't have the money to include her* - how much does it cost to walk with someone in the fields, go to market, or to go to the temple, mosque or church? Or just simply to sit together and share a sunset, or a cup of tea? These simple everyday tasks do not need lots of money, just a little time, some interest and some concern for inclusion.

**Strategies:** Key strategies that CBR teams can use are detailed here.

Helping people with learning disabilities to speak up -

- Build pride in self - the importance of self confidence, speaking up, signing and communicating preferences and choices
- Build trust
- Support communication and voice
- Develop recognition of preferences - giving choices
- Develop awareness of self, dignity and autonomy.

Helping families to -

- Stop being over protective - allow space for children and adults with learning disabilities to grow, to explore and to develop
- Recognize the importance of respite, rest and support – be a listening ear and not a font of all knowledge
- Create opportunities for peer friendships
- Plan ahead - to face the future, to make plans and build a trusted network of carers and supporters within the community
- Stand up to stigma - challenge myths, stereotypes and fears surrounding learning disability.

Supporting Communities \_

- Create links and positive exposure to challenge negative attitudes, assumptions and stereotypes
- Awareness training and self advocacy - break the cycle of fear and lack of confidence
- Work with civil society organizations, local government institutions, police and social services to create links within the community and to develop trust and relationships.

#### Working with institutions -

- Build mechanisms to link institutions to communities - planned shared activities, open days, community visits
- Develop mechanisms to support accountability - advocating the role of key public service institutions: police, local authorities, social services and schools in supporting private institutions
- Create mechanisms to support accountability within institutions, especially private institutions by linking them with social services and civil society initiatives
- Provide training, capacity development for staff of institutions – do not allow them to remain isolated.

Finally, but not least, please remember that people with learning disabilities are unique individuals with unique talents who like to challenge themselves and you. Be open, be creative and always ready to learn.

#### **A rural community-based innovation including adolescents and adults with multiple disabilities**

Zulekha Islam presented an experience from a Rural Development Trust in Andhra Pradesh that reaches out to about 30,000 persons with disabilities. They recognized the difficulties of reaching out to persons with severe and multiple disabilities. Based upon the life-span approach, they have started a supported-living programme involving community volunteers.

#### **Discussions about social participation and empowerment of persons with learning disabilities**

Workshop participants were divided into smaller groups and were asked to reflect on help needed at different levels to promote social participation and empowerment of persons with learning disabilities. They were asked to reflect on the support needed by communities, families and CBR programmes, by people with learning disabilities, by law-order agencies - police, courts, and judiciary and by institutions.

## CONCLUSIONS AND THE WAY FORWARD

This workshop on “CBR and Persons with Intellectual Disabilities” was organized in four sessions focusing on health, education, employment, and social participation and empowerment. At the end of the workshop some time was devoted to reflections on the presentations and discussions that had taken place over the two days. Additionally there were discussions about the conclusions and the next steps.

The participants agreed that issues related to inclusion of persons with intellectual disabilities in CBR programme activities and also in DPOs, have been neglected for a long time and need to be addressed. This international workshop has been a good start but the discussions must be continued.

There is a great diversity of cultures that influences the way CBR works. The variety of examples presented and the discussions at the workshop are a reminder of the challenges of CBR. Such a workshop provides a rich opportunity for exchange and reciprocal learning.

For the four areas discussed during the workshop - health, education, livelihood, social participation and empowerment - specific tools related to inclusion and participation of persons with learning disabilities in CBR programmes are needed. Some organizations and CBR programmes have developed expertise, good practices and specific materials, such as the ‘easy read’ materials developed by CHANGE in UK, but information about these materials and experiences must be shared much more widely.

At the end of the two-day workshop, participants agreed to establish an electronic **group/network on CBR and intellectual disabilities**. Annie Pascaline Sandjok offered to facilitate this group/network ([sanniepascaline@yahoo.com](mailto:sanniepascaline@yahoo.com)) with support from Alaa Sebeh ([alaa1234@gmail.com](mailto:alaa1234@gmail.com)).

## WORKSHOP SPEAKERS

### A brief introduction to the speakers of the International Workshop

**Alaa Sebeh** MD Ph.D., Independent International Consultant for Disability and Rehabilitation, Chair-person of the Consultative Committee of the National Council of Disability Affairs in Egypt, formerly the Regional Disability and Advocacy Adviser for Save The Children UK in MENA Region, has been involved in establishing CBR programmes and providing consultations and technical assistance to various governmental and nongovernmental organizations since 1989.

**Batdulam Tamenbayar**, National CBR Programme Manager, Mongolia CBR Programme and mother of a child with an intellectual disability.

**Katharina Pfortner**, Coordinator of CBM Advisory Working Group of Inclusive Education and CBR advisor, experienced special and inclusive education teacher, since 1989 in Central America.

**Kathy Al Ju'beh**, Senior Advisor for Inclusive Development, CBM.

**Philipa Bragman**, Project Director, CHANGE, UK.

**Sunanda Reddy**, Paediatrician and founder of CARENIDHI, an organization working with persons with disabilities in a low-income area of Delhi, India.

**Sunil Deepak**, Scientific and Medical Advisor for AIFO/Italy (Italian Association Amici di Raoul Follereau), involved in monitoring, evaluations, training and research activities related to CBR in Asia, Africa and South America since 1988.

**Zulekha Islam**, Project Officer, Rural Development Trust, Ananthpur District, Andhra Pradesh, India.

## Annex 1

# WORKSHOP PROGRAMME

**Workshop Coordination:** Alaa Sebeh, Kathy Al Ju'beh, Sunil Deepak

24 November 2012	
Opening session	<ul style="list-style-type: none"><li>• Welcome: <i>Enrico Pupulin</i></li><li>• Introduction of participants and their expectations: <i>Barney McGlade</i></li></ul>
Session 1 on Health coordinated by <b>Alaa Sebeh</b> with support from <b>Sunanda Reddy</b>	<ul style="list-style-type: none"><li>• Children with learning disabilities and their families: some key issues - <i>Alaa Sebeh, Egypt</i></li><li>• Challenges to health care for persons with intellectual disabilities in low-income areas - <i>Sunanda Reddy, India</i></li><li>• Group discussions and plenary session</li></ul>
Session 2 on Education coordinated by <b>Katharina Pfortner</b> with support from <b>T. Batdulam</b>	<ul style="list-style-type: none"><li>• Key issues in relation to education for persons with intellectual disabilities - <i>Katharina Pfortner, Germany/Nicaragua</i></li><li>• Challenges for CBR programme for inclusive education for children with learning disabilities - <i>T. Batdulam, Mongolia</i></li><li>• Group discussions and plenary session</li></ul>
25 November 2012	
Session 3 on Livelihoods coordinated by <b>Philipa Bragman</b> with support from <b>Sunil Deepak</b>	<ul style="list-style-type: none"><li>• Barriers to employment for persons with learning disabilities and the CHANGE experience - <i>Philipa Bragman, UK</i></li><li>• Barriers faced by persons with intellectual disabilities in Mandya CBR research in India - <i>Sunil Deepak, Italy</i></li><li>• Group discussions and plenary session</li></ul>
Session 4 on Social participation and empowerment coordinated by <b>Kathy Al Ju'beh</b> with support from <b>Zulekha Islam</b>	<ul style="list-style-type: none"><li>• Promoting social participation and empowerment of persons with learning disabilities - <i>Kathy Al Ju'beh, Palestine</i></li><li>• Working with communities for persons with severe and multiple disabilities - <i>Zulekha Islam, India</i></li><li>• Group discussions and plenary session</li></ul>
Conclusions	The way forward

## Annex 2

### LIST OF REGISTERED PARTICIPANTS<sup>1</sup>

Country	Name
Afghanistan	Mutahar Shar Akhgar
Afghanistan	Mohammad Sadiq Mohibi
Afghanistan	Abdul Ahad
Afghanistan	Razi Khan
Afghanistan	Arsalah Habibi
Afghanistan	Muniruddin Burhani
Afghanistan	M. Ihsan Gulban
Australia	Tamara Jolly
Australia/Timor-Leste	Timothy Lawther
Cambodia	Dearozet Sok
Cambodia	Sambath Kao
Cambodia	Bhoomikumar Jegannathan
Canada	Marie Grandisson
Egypt	Alaa Sebeh
France	Dr Enrico Pupulin
India	Sneha Mishra
India	Zulekha Islam
India	Sunanda Reddy
India	Dasaratha Ramadu Rasineni
India	Isaac Gnanaprakasham

<sup>1</sup> Seven persons who had registered for the workshop were unable to participate or participate in only some sessions. Their names are also included in this list.

India	Poonam Natarajan
India	Neha Dwivedi
India	Sr Maria Kuttikkal
India	Nageshwara Rao
India	Fr Trevor
India	Sr Deepti Mary Verghese
India	Sr Ida Francis
India	K. Savithramma
India	Adi Sayanathan
India	Suresh
India	Praveen
India	Dr Anamma
India	Sr Lissy Francis
India	Dr N Manimozhi
India	M. V. Jose
India	Nyjil George
India	Sr Marykutty Abraham
India	Ramesh Giriyappa
India	Rajshekhar Jayaraman
India	Mamatha Eraiah
India	Kalavathi Jayashankar
India	Jayanth Kumar
India	Chaluvaraju Shivaramu
India	Basavaraju Kempaiaia
India	Nandini Ghosh

India	Byomendra Nayal
India	Usha Nayal
India	Aniket Nayal
India/Afghanistan	Fiona Gall
Iran	Mohammadreza Asadi
Iran	Ali Moshirihoodsari
Iran	Keyvan Davatgaran
Italy	Dr Sunil Deepak
Italy	Francesca Ortali
Italy	Giampiero Griffo
Italy	Clara Di Dio
Lao Republic	Caroline Guerin
Liberia	Janice Cooper
Liberia	Fallah Bomia Cymbianoh
Liberia	Ricardia B. Dennis
Liberia	Renato Libanora
Liberia	Mavi Casalieri
Mongolia	Dr T. Batdulam
Mongolia	Tulgamaa Damdinsuren
Mongolia	Enkhbuyanat
Mongolia	Narantuya Bayamagnai
Namibia	Tonderai Shumba
Namibia	Mercy Kufuna
Nepal	Bibek Kumar Paudel
Nepal	Sarmila Shreshtha

Nicaragua	Katharina Pfortner
Norway/Zambia	Jenny Schaanning
Palestine	Haneen Alsammak
Palestine	Husam Ai Shaikh Yousef
Palestine	Zaker Qalalweh
Peru	Mar Alonso
Philippines	Barney McGlade
Rwanda	Jean Baptiste Sagahutu
Sri Lanka	Ronald Sujeevan Pragatheeswaran
Sri Lanka	Amirthanathan Marianathar
Tanzania	Subira Mkumule
Timor-Leste	Joel Morais Fernandes
Timor-Leste	Joaozito Dos Santos
UK	Jane Crawford
UK	Philipa Bragman
UK/Palestine	Kathy Al Ju'beh
Vietnam	Minh Chau Cao
Zambia	Tom Lwendo Mungala
Zambia	Alick Nyirenda
Zambia	Masiliso Zaza
Zambia	Lucy Muyoyeta
Zambia	Yvonne Tomali Chingambu
Zambia	Muzaza Nthele
Zambia	Benson Zemba
Zambia	Celleb Callan Chabauni

Zambia	Felix Silwimba
Zambia	Stanfield Michelo
Zambia	Florence Chiwala Salati
Zimbabwe	Greaterman Chivandire





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