



International Centre for the Advancement of Community Based Rehabilitation



CRP-BANGLADESH
Centre for the Rehabilitation of the Paralysed 

Exciting Projects, Inspiring People

ICACBR continues to work internationally by making a positive difference in the lives of men and women, girls and boys with disabilities. With two major projects in Bangladesh focusing on children and youth with disabilities, and funded by the Government of Canada through the Department of Foreign Affairs, Trade and Development (DFATD), ICACBR actively contributes to global solutions for mainstreaming disability into development.

2014 is upon us and the year promises to be both exciting and inspiring. As part of ICACBR's continuing work, we are excited to share with you the first edition of our 2014 newsletter. Specifically designed to inform readers about results the Centre has experienced, this newsletter also provides a personal glimpse into the experiences of individuals involved in teaching, working or participating in both the Access to Health and Education for all Children and Youth with Disabilities (AHEAD) and the Interprofessional Project on Disability, Maternal and Child Health (IPODMCH).

The launch of the AHEAD project and continuation of the IPODMCH project were major 2013 events for ICACBR and we are impressed with the continuing progress and success of both. Looking back, trainees and trainers, workers and contributors, and volunteers and students, have all learned, taught and advocated about the various abilities that every individual has, the challenges that many face, and how to improve everyday lives and experiences of men and women, boys and girls with disabilities in Bangladesh.

Thank you to all who contribute to ICACBR projects and we look forward to continuing to inform and inspire you with upcoming editions of the newsletter.

- The ICACBR Team



OUR PARTNER: THE CENTRE FOR THE REHABILITATION OF THE PARALYSED (CRP)

The Centre for the Rehabilitation of the Paralyzed (CRP) is the only non-profit national organization registered with the Government of Bangladesh (GoB) that provides specialized services for persons with spinal cord injury, neurological and orthopedic problems. Founded in 1979 in response to the desperate needs for rehabilitation services for boys and girls, men and women with disabilities, CRP has evolved into an internationally known and well respected organization for its efforts towards inclusion of persons with disabilities (PWDs) into mainstream society of Bangladesh. In addition to treatment, training and comprehensive rehabilitation services for PWDs, CRP offers world class academic programs at its academic unit, Bangladesh Health Professionals Institute (BHPI), an affiliate of Dhaka University. With almost 650 staff situated around the country, CRP is the only organization of its kind in Bangladesh, and is committed to the future development of services for people with disabilities.

ICACBR'S PARTNER IN BOTH THE IPODMCH AND AHEAD PROJECTS, CRP HAS MADE INVALUABLE CONTRIBUTION SINCE WE STARTED PROJECTS IN 2011. CRP WILL CONTINUE ALONGSIDE ICACBR ON THE JOURNEY TO BUILD STRONG AND SUSTAINABLE HEALTH SERVICES FOR CHILDREN, YOUTH AND ADULTS WITH DISABILITIES THROUGHOUT BANGLADESH WHILE IMPROVING THEIR EXISTING PROFESSIONAL SERVICES AT THE CENTRE.

INTERPROFESSIONAL PROJECT ON DISABILITY, MATERNAL AND CHILD HEALTH

The IPODMCH project continues to pioneer the use of community based rehabilitation (CBR) as a strategy to link disability to prevention, health and rehabilitation services, and establish referral links between rehabilitation and maternal and child health (MCH). The Project Team also continues to collaborate and enable the participation of both government and non-government sectors, a rare feature in Bangladesh development initiatives.

The IPODMCH project has implemented a series of community initiatives linking disability with maternal and child health, enhancing the interprofessional skills and attitudes of community personnel, and improving the quality of MCH and disability services available at the community level. In conjunction with community programs, the project continues to positively impact on public

awareness relating to disability and MCH. The establishment of effective working relationships with NGO's and government agencies is an important objective in building a broader awareness of both project's activities and partnerships.



ACCESS TO HEALTH AND EDUCATION FOR ALL CHILDREN AND YOUTH WITH DISABILITIES

The AHEAD project contributes to inclusion of children and youth with disabilities, ensuring their safe and secure futures as they are among the most marginalized populations. Successfully initiated under the extremely challenging political and security environment in the pre-election period, the AHEAD project engaged over 30 governmental and non-governmental organizations in health and education, organized numerous meetings with various stakeholders implemented over 15 activities and reached over 2000 participants.

The AHEAD Project has established contacts, received local registration, administrative support and approval, and organized a series of project activities that provide a solid foundation for the implementation of the future activities. Through implementation of activities in communities

throughout Bangladesh, the project created numerous opportunities to engage girls and boys, men and women with disabilities.



IPODMCH Key Milestones

- **18,000 beneficiaries** participated in 90 Public Awareness and Service Interprofessional Days
- **850 regional stakeholders** from over 100 government and non-governmental organizations participated in 12 Regional Networking Workshops
- Modular Training Program for MCHD workers at CRP Savar and five other locations
 - **75 MCHD service providers** participated in six five-day modules for Teaching Team in CRP Savar
 - **750 community service providers** participated in 24 district workshops at six locations



- **125 stakeholders** participated in two Annual Policy Forums and a Project Conference
- **56 participants** from Bangladesh participate in 8 month long Online Certificate Program on CBR and international development with special focus on maternal and child health and disability
- **24 women with disabilities** participated in three Workshops for women and mothers with disabilities

AHEAD Key Milestones

In the first 10 months of implementation, the project organized a series of activities involving over **2000 participants, 25% of whom had a disability**, including:

- **Over 600 participants** in three disability awareness days
- **50 participants with disabilities** in three peer support introductory training sessions
- **50 participants** in two disability and gender workshops
- **11 government teachers** supported to receive a CRP/BHPI Certificate in Special Education
- **11 young women with disabilities** supported to complete CRP industrial sewing training
- **Six mobile clinics**, providing services to the total of 1533 community members from over 300 villages
- **One classroom** with improved accessibility and ergonomics for students with disabilities in the William and Marie Taylor Inclusive School



IPODMCH PARTICIPANT EXPERIENCES

‘I LEARNED ABOUT CEREBRAL PALSY FROM IPODMCH TRAINING AND NOTICED THAT NAYAN CANNOT CONTROL HIS NECK AND IS UNABLE TO SIT. I REFERRED HIM TO CRP-SAVAR SUSPECTING HIM AS A CHILD WITH CEREBRAL PALSY’



AYNUN NAHAR A health worker and teaching team member from IPODMCH, Aynun met Nayan, a 12 month old child, at the local Welfare Centre. Nayan’s mother had joined an Interprofessional Day in a remote village of Savar Upazila organized by Aynun with the support of IPODMCH and learned about symptoms of developmental delay. Screening Nayan’s developmental status and knowing the obstructed delivery history of her mother, Aynun suspected that Nayan was a child with cerebral palsy. She told his mother about importance of rehabilitation services, advised basic positioning and referred him to CRP-Savar.

After 3 months of regular treatment at CRP-Savar, Nayan can now control his neck and sit independently. Nayan’s parents are very happy with the outcome. Although therapists suggested continuing treatment once a week, they cannot afford it because of poor economic conditions. Aynun is very happy with the Nayan’s outcome but she wonders if she could help this child further by providing some basic exercises.

“IPODMCH TRAINING HELPED ME UNDERSTAND THE IMPORTANCE OF EARLY IDENTIFICATION AND INTERVENTION. I LEARNED HOW TO PREVENT AND IDENTIFY DISABILITY. I AM VERY HAPPY THAT MY SIMPLE ADVICE CONTRIBUTES IN BRINGING HOPE TO THE CHILD’S LIFE.”



MONI A senior nurse and IPODMCH teaching team member, Moni met Rahima in her Urban Health Clinic in Barisal. Rahima, a 24 year old and mother of three children came to meet Moni with complaints of incontinence followed by obstructed delivery of her third baby over a year ago. Because of her incontinence, she was not being involved in household activities and was struggling to maintain a relationship with her husband. As Rahima stated -

‘IPODMCH TRAINING HELPED ME UNDERSTAND THE DISABLING CONSEQUENCES OF FISTULA. I AM REALLY VERY PROUD TO BE PART OF THE PROGRAM. I AM AMAZED HOW A FAMILY WELFARE ASSISTANT TAKING PART IN A IPODMCH DISTRICT WORKSHOP HELPED RAHIMA TO GET APPROPRIATE TREATMENT’

‘BECAUSE OF THE INCONTINENCE AND BAD SMELL, I WAS ALWAYS IN FEAR AND USED TO FEEL THAT I AM IN PRISON. MY HUSBAND STARTED AVOIDING ME AND BEGAN THREATENING DIVORCE. AT ONE POINT, I CONSIDERED COMMITTING SUICIDE.’

Rahima was sent to Moni by a Family Welfare Assistant who took part in a IPODMCH district workshop in Barisal. Moni suspected Rahima was suffering fistula as a result of delivery complications. Moni referred Rahima to Sher-A Bangla Medical College Hospital for surgery. After a small surgery and three months of treatment, Rahima recovered from her incontinence and regained her active family and social life. She is very thankful to Moni for helping her to regain her almost ‘lost’ life. Moni is extremely proud to be part of IPODMCH training, enabling her to provide further instruction to community health workers, such as those who played an amazing role in bringing Rahima to Medical treatment.

SHARIFUL ISLAM, IPODMCH COUNTRY COORDINATOR

I am very proud to be part of IPODMCH, a unique initiative which mainstreams disability into Maternal and Child Health programs in Bangladesh. I am amazed when realizing the impacts of front line health worker capacity building in both governmental and non-governmental sectors. It is my privilege to work with ICACBR staff and Queen’s University contributors. Their work not only makes the IPODMCH training program effective but also builds the capacity of local staff, such as myself, in working towards success and sustainability of the project overall. I am sure that IPODMCH will be a role model project not only for disability mainstreaming, but also its unique contribution in disability prevention while making services more accessible for all women and men, girls and boys with or without disability.

“I NEVER EVEN HEARD ANY INFORMATION ON PEER SUPPORT BEFORE THE AHEAD TRAINING.”



FARIDA AKTER ASMA Following her spinal cord injury 15 years ago, Asma has been working in the Centre for the Rehabilitation of the Paralysed (CRP) to train and support patients in using of their wheelchairs and is one of CRP's Peer Support trainers.

During her time at CRP, Asma has only felt comfortable talking with patients. She thinks this is the only job that she could do with her wheelchair. She never felt comfortable sharing or supporting other persons with disabilities who do not have a spinal cord injury. However, after participating in four introductory sessions on Peer Support and is a core member of the AHEAD Peer Support Trainer of Trainers Teaching Team.

“I BELIEVE EACH PERSON WITH DISABILITIES SHOULD HAVE THIS TRAINING ON PEER SUPPORT. THEY SHOULD LEARN ALL THE KNOWLEDGE AND INFORMATION OF THIS. BECAUSE BEFORE HAVING THE AHEAD PROJECT PEER SUPPORT TRAINING, I NEVER SHARED MY FEELINGS OR MY THOUGHTS WITH ANY OTHER PERSON WITH DISABILITIES. I HAVE BEEN USING MY KNOWLEDGE GAINED IN THIS TRAINING AND NOW I FEEL CONFIDENT AND COMFORTABLE TO TALK WITH ANYONE WHO IS FACING DIFFICULTIES WITH HIS OR HER DISABILITY. I SHARE MY EXPERIENCE WITH THEM AND TRY TO SUPPORT THEM TO FIND OUT WAYS THEY CAN OVERCOME THEIR BARRIERS.”

KUSHI AKTER A 19 year old woman, Kushi has a shorter left leg and walks with a modified gait. She was selected for the Sewing Machine program in the Madhab Memorial Training Centre of CRP, which is supported by the AHEAD project. After the completion of the four-month training, she found a job in a garment factory as a sewing operator. She was extremely happy to obtain this job as she lives with her brother and family and never thought that she would be able to earn money independently.

Khusi is happy working with her colleagues in the factory and finds her supervisor and other workers extremely helpful. She is very proud to be a part of the AHEAD project.

“MY FAMILY DOESN'T HAVE TO SUPPORT ME ANYMORE. I AM HAPPY THAT I CAN EARN AND SPENT MY MONEY AS I WANT”



“I WAS ENCOURAGED ON PROGRAM'S INAUGURATION DAY BY THE DIRECTOR OF THE AHEAD PROJECT'S SPEECH ON THAT DAY MY JOURNEY BEGAN WHEN I ALSO TALKED ABOUT MY FEARS AND HOPES FOR THE FIRST TIME.”

Khusi dreams of a good career and becoming an example for women with disabilities in Bangladesh, and is not interested in marrying right now. She wants to prove herself by furthering her education and then will marry.

“I TRAVEL EVERYDAY ON LOCAL TRANSPORT AND AFTER HAVING THE AHEAD SUPPORTED SEWING MACHINE TRAINING I KNOW HOW TO PROVE MYSELF. I AM NOT THINKING OF MARRIAGE RIGHT NOW.”

KORNY MARINA MOMEN, AHEAD COUNTRY COORDINATOR

I am extremely honored to be the part of AHEAD project working for accessible educational and health programs for children and youth with disabilities in Bangladesh. Through this project, everyone can take part equally in the development of this country, no matter their abilities. This is the place where we can use our experience in broader way with new dimensions. I am really grateful to ICACBR in giving me the opportunity to improve the quality of life of the children and youth with disabilities in our country. To me, AHEAD project is a great endeavour for persons with disabilities benefiting Bangladesh and improving the quality of life for person with disabilities.

IPODMCH EDUCATOR EXPERIENCES

JACKIE WHITTINGHAM, MODULE 2

I spent 11 days working with the Interprofessional Project on Disability Maternal and Child Health (IPODMCH) in Bangladesh. The group of trainees hailing from different regions of Bangladesh brought both enthusiasm and dedication to the training. Their commitment and eagerness to learn never faltered as we found ways to communicate with and without interpreters.

What I experienced inside the classroom was a microcosm of the greater CRP community. The compound is filled with rich greenery and brilliant colours of the traditional garments worn by women who come to tend to their family members afflicted with disabilities. I was struck by the innovation of people who could turn recycled paper into elaborate seating for children, and awed by how this contrasted with my previous perception of a country renowned for its rate of poverty and hardship. After just a few short days it was apparent that the proverb *Ability not Disability* is truly reflected in the work of the CRP team and the ICACBR/Queen's University staff who have made the IPODMCH initiative possible.

“WHAT I EXPERIENCED INSIDE THE CLASSROOM WAS A MICROCOSM OF THE GREATER CRP COMMUNITY”



ROSEMARY BRANDER AND ANNE O'RIORDAN, MODULE 3

For five days, we worked with 39 participants, teaching about interprofessional collaborative teamwork, early childhood development and identification of disabilities in newborns and young children. While we encountered challenges in understanding culture and language, our differences all but disappeared as everyone engaged in experiential learning.

There was laughter much of the time, but also tears and sadness as we learned of the many problems that the project is meant to alleviate in a country experiencing a lack of health care services alongside political uncertainties. Yet we

“WE ENCOUNTERED A WARMTH AND GENEROSITY OF SPIRIT BEYOND OUR EXPECTATIONS”

encountered a warmth and generosity of spirit beyond our expectations.

We took away much more than we left behind, including one realization that will last forever: every

person in this *oasis* that is called CRP is treated with respect, kindness and equality. The values evident in its Director and in ICACBR's work are brought to life here. This is a way of living and working that all individuals would do well to emulate, regardless of the country one calls home.

AHEAD EDUCATOR EXPERIENCES

MEENU SIKAND, PEER SUPPORT MODULE 2

In first week of December my attendant Pari and I travelled to Bangladesh. Over the following two weeks, I met CRP Founder Ms. Valerie Taylor, the AHEAD Bangladeshi team, CRP staff and many residents whose resilience, courage, strength and unconditional friendship have touched me deeply and changed me forever. Everyone I met wanted to discuss various issues, obtain opinions, and learn lessons. Mothers who were learning advocacy skills to help their children or other women with disabilities wanted to engage in conversation about getting married, holding a job, or having children of their own. Others were looking to lead public education campaigns.

“IT FELT VERY SPECIAL THAT MANY PARTICIPANTS ALLOWED ME TO BE PART OF THEIR LIFE BY SHARING THEIR STORIES, DREAMS AND AMBITIONS”

Everyone embraced me with interest, respect and love. It felt very special that many participants allowed me to be part of their lives by sharing stories, dreams and ambitions. Many trainees reminded me of my own early struggles, doubts and ambitions concerning my disability. The participatory method used to deliver this training allowed all 29 participants to actively engage in the course and pre-training meetings.

The AHEAD project continues to equip participants with skills and tools that will allow them to become more financially independent and remove barriers in an educational system that is not inclusive. I am so honoured to be part of the AHEAD team, bringing my skills, expertise and knowledge of South Asian culture to deliver this much needed training.



PAOLA DURANDO, LIBRARY EXPANSION

It's hard to know who was more nervous, me or my Bangladeshi colleague Mohesana Mosammat when we first met. The apprehension quickly fell away as we discussed commonalities, our conversation peppered with familiar library jargon.

Whether located in Savar, Bangladesh or Kingston, Canada, both our libraries strive to meet the health information needs of students, faculty, researchers and clinicians. Both our libraries support occupational therapy, physical therapy, and nursing programs. Mohesana and I both teach information literacy skills, training library users to select and effectively search the best possible resources. We collaborated to develop an e-library, an extension of the CRP's physical library while opening up HINARI access to all members of the BHPI-CRP community. Introducing the e-library to groups of students and faculty, we provided awareness of the rich resources available and encouraged faculty members to incorporate enquiry-based learning in their instruction. If students explore quality resources on their own, they are far more likely to become lifelong learners and to contribute to their professional evidence base.

During one of our conversations, Mohesana referred to CRP founder Valerie Taylor as “sister Valerie”. Indeed, the staff and volunteers at the CRP work together as a family to pull off miracles on a daily basis. In January 2014 the BHPI-CRP Library and the Bracken Health Sciences Library became Sister Libraries. This designation cements the libraries' relationship, as both endeavour to positively impact the delivery of health care.

“INDEED, THE STAFF AND VOLUNTEERS AT THE CRP WORK TOGETHER AS A FAMILY TO PULL OFF MIRACLES ON A DAILY BASIS.”

COMMUNITY BASED REHABILITATION AND ICACBR

The World Health Organization (WHO) promotes community based rehabilitation (CBR) as a strategy for inclusive community development and mainstreaming of disability. CBR principles are based on human rights and reflect General Principles, Article 3 of UNCRPD:

- a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- b) Non-discrimination;
- c) Full and effective participation and inclusion in society;

CBR endeavours to change community attitudes and remove barriers towards disability, to empower persons with disabilities, to promote and protect their human rights, to assist in the change from users of services to participants in community development, to increase the level of stakeholder knowledge, to develop appropriate community support services, to generate, to transfer and apply knowledge and skills to persons with disabilities, families, practitioners, communities and to facilitate interprofessional and multisectoral collaboration.

Both AHEAD and IPODMCH projects use CBR as a strategy to mainstream disability into programs and services for children and youth with disabilities in maternal and child health, health, education, empowerment and livelihood sectors. Changing attitudes, improving access, increasing capacity of practitioners to provide quality services, and removing barriers will have a positive impact on participation and fulfilment of human rights of boys and girls, women and men with disabilities.



FOR FURTHER INFORMATION, PLEASE VISIT:

ICACBR's current projects page at <http://www.queensu.ca/icacbr/projects/current.html>

Centre for the Rehabilitation of the Paralysed at <http://www.crp-bangladesh.org/>

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