From the Consulting Editor ...

2015... two decades since the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 received assent of the President of India on 1 January 1996. A big milestone on paper undoubtedly, but has this Act of Parliament actually succeeded in changing the mindset of people? Do people ‘see’ a person with disabilities differently? Or does a differently-abled person continue to be ‘seen’ as being different?

“The eye sees only what the mind is prepared to comprehend.” Laws are inconsequential when awareness is lacking, minds are closed and attitudes uncompromising. How else does one explain the insensitive behaviour of Airport authorities towards the young man with autism in Kolkata last December? This was just one ‘case’ that happened to grab media attention against countless others that go unnoticed and unreported.

This issue of *Deepshikha* carries a report on the protest and demonstration held in Kolkata airport. Offering quality services to improve the lives of children and adults with cerebral palsy and their families has not been the only objective of IICP. The organisation has actively endeavoured to increase awareness and, as a member of the Disability Activists Forum (DAF), it has played a significant role in raising the voice of protest against injustice many decibels higher and making important contributions in advocating equal rights. The protest at the airport was an effort to make an impact on the ‘eyes’ and ‘minds’ of people.

Like success, failure can be perceived differently by different people. One can accept failure as defeat. Or one can accept failure as a learning experience... a struggle that is a stepping stone to success. Rejection by the Indian Revenue Service (IRS) in 2010 on grounds of disability served to make Ira Singhal struggle harder and do better. Today, as the first physically challenged candidate to top the Union Public Service Commission (UPSC) examination, Ira Singhal is all set to become an IAS officer. As she says, “... every struggle teaches you something.”

Welcome 2016! A new opportunity to reach new heights... and change preconceived perceptions...

From the Editor ...

Good bye 2015. Hello 2016… bidding farewell to a year is tinged with mixed emotions. There is hope and anticipation for the year to come and a feeling of nostalgia and sadness as we move on, leaving memorable moments behind us. In IICP, it’s been busy, at times hectic, and I take this opportunity to thank our service users i.e. the children, adults and family members, my colleagues, our friends and well-wishers, donors and sponsors, faculty and the Governing Body and Advisory Committee. For myself… at the end of the day, to quote a song I had heard, – “There is no other place I’d rather be...”
A protest and demonstration was held in front of the departure area of Kolkata airport on 3 February 2016. The protest was organised by the disabled rights activists and their allies to raise a voice against repeated incidents of harassment of persons with disabilities by different airlines. IICP, as a member of the Disability Activists Forum (DAF) had taken a proactive role in its organisation. There was a congregation of over 50 people of different member organisations of DAF as well as Parivaa, the parent organisation of persons with intellectual disabilities. Tapan Banerjee, Secretary, Joint Council of Bus Syndicate also joined the protest as an ally of IICP.

The main demands were speedy and effective implementation of the guidelines formulated for persons with disabilities by the Director General of Civil Aviation (DGCA). A memorandum was submitted to the Airport Manager. IICP representatives also met the Indian Airlines authorities and demanded an explanation for the harassment of a 22-year-old man with autism at the Kolkata Airport in the month of December 2015.

The event received coverage in the Ananda Bazar Patrika, The Telegraph, Ehera, and Ei Samay (print media). The news was also covered by CNN IBN, Doordarshan and Aaj Tak.
IICP’s anniversary celebrations commenced on 18 November with the visit of Craig Hall, Consul General of United States of America, Kolkata. The photographs capture some special moments as Mr Hall went around IICP. A special issue of Deepshikha was released by Mr Hall. The celebrations continued till 20 November and IICP basked in the festivities. Visitors included donors, sponsors, friends, well-wishers, parents, grandparents, siblings and many children and youngsters from city schools and colleges. Parents’ groups were also present selling food, jewellery and other products.
Susan Balandin’s Visit and Report of Workshop

Professor Susan Balandin from Deakin University, Melbourne, Australia was back at IICP after almost a decade. During her visit, she worked on two major areas of mutual interest – aging and mealt ime management. She met adults with cerebral palsy individually and in groups, and addressed their concerns about advancing age and changing physical abilities. She also observed mealt ime practices with IICP’s physiotherapists and occupational therapists and gave advice and guidance on more effective management and dysphagia. Professor Balandin provided expert inputs in the ISAAC India Chapter meeting held at IICP.

– Reena Sen, PhD

Professor Susan Balandin holds the Inaugural Chair in Disability and Inclusion in the Faculty of Health at Deakin University. A speech pathologist by background, she worked as a clinician for many years before joining academia. Her research programme is focused on adults with a lifelong disability and community participation with a particular focus on the health and community interactions of people with little or no functional speech. She conducted some of the first research exploring the opportunities in virtual worlds for teaching and learning about disability and the affordances of virtual worlds for people with lifelong disability. She has been visiting IICP since 2000.

During her visit in November 2015, Dr Balandin conducted two workshops certified by Deakin University on Aging and Dysphagia. I give below salient points from each workshop. The workshops targeted health professionals, direct care staff, carers and family members, and adults with disability who wish to play a more active role in decision s related to their life.

Aging in Adults with Cerebral Palsy

It is reasonable in this day and age to expect persons with cerebral palsy to have a life expectancy compatible to the norm of the particular country in which they reside. Thus persons with cerebral palsy and primary caregivers must be aware of issues related to aging. The basic needs are the same as all adults:

- A decent quality of life that includes occupation and activities the person considers meaningful
- Good health
- Health care facilities
- Social connections
- Care at home
- Financial security

However people with cerebral palsy often have special needs when aging. Many are lonely, depressed and unemployed. Most have increased likelihood of stiffness, pain and fatigue. Chest and other
infections become more chronic. Many of them are extremely worried about the future – both financially and about their care once parents are deceased. For adults with high support needs, parents and caregivers have concerns about their son or daughter who is aging. Thus, this workshop dealt with:

- What is typical aging
- Do people with cerebral palsy experience aging differently
- When does the aging process start
- Common experiences of change
- Grief, loss and worry about the future
- Talking with health professionals
- Going to hospital
- A healthy old age with a good quality of life taking control

The key ‘take-home’ learnings comprised:

- People with cerebral palsy may experience changes that they may relate to aging early
- The importance of health checks and asking questions
- Keeping informed: The importance of sensible and correct information
- Families, especially siblings, are important
- Feelings of grief, loss and loneliness are common; it is important to listen
- Good support and good communication are important when people go into hospital and are discharged home

Mealtime Management

The workshop covered a range of issues related to eating, drinking and swallowing for individuals with severe cerebral palsy including:

- Dysphagia and choking – what they are and how to recognise the problem
- Why dysphagia is common in individuals with cerebral palsy
- Health consequences of dysphagia
- Signs of dysphagia
- Changes in eating, drinking and swallowing across the life course
- Social impact of dysphagia
- Safe mealtime practice
- Mealtime management plans
- Food textures and their management
- Modified diets
- Useful tools for assessment

The key ‘take-home’ learnings comprised:

- Why it is important to understand and recognise when a person has dysphagia
- Safe mealtime practice
- Mealtime plans, why they are important, and how to make and use them
- Modified textures – what they are and how to use them
- The social impact of dysphagia and its management
"We should not be looking at language as a developmental liability, but as an economic asset." Ganesh Devy, Founder Bhasha Research and Publication Trust.

Alright, you might be wondering what the above quote has to do with disability. Replace the word, 'language' with 'disabled' and the connection, or rather what the standpoint of this piece will be becomes clearer. Let's misquote and take literary licence: we should not be looking at the DISABLED as a developmental liability, but as an economic asset.

My fellow co-conspirators in the disability world, the fact is, we ourselves are guilty of this – of seeing the disabled as a developmental liability. We need to wake up, get out of the cozy bed, stretch and look out the window. Our years of awareness campaigns, of showing that persons with disabilities can perform, do street plays, have organised, small marches, in general trying to politely change mindsets, has perhaps made children less shy, ennobled the professionals who teach and care for the disabled but it hasn't made the disabled bolder or integrated them in the mainstream. And the mindsets still see the disabled with sympathy and charity. We need to be more communicative. We need to SHOUT and BE SEEN. Instead of doing awareness campaigns, let us take our kids out to public spaces; take them to cafes, restaurants, malls and multiplexes. When we are seen more, it isn't only awareness which is stirred but REALISATION occurs.

Awareness campaigns are just a beginning to including, or rather inserting, persons with disabilities into the collective consciousness. It needs to move forward; to have another developmental milestone.

Disability rights in India, has had a chequered history; it is not within this article's scope to cover that history but any discussion about rights cannot be done without mentioning, that movements have social and political contexts. In India, for instance, a more accountable State policy, the strong presence of Women's movements and also the presence of international agencies have
been the basis upon which, the rights movement has evolved on. The passing of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 happened more because of international pressure than to lobbying and protest movements by disability rights groups (Nilika Mehrotra, Disability Rights Movements in India: Politics and Practice 2011). The increased visibility and vocalisations of disability protests, developed against the background of Non-Governmental Organisations (NGOs), focussing their work on livelihood and development issues. Another powerful impetus came from political concerns of Dalits and other marginalised groups, for an equal and dignified life (in America, it was the Civil Rights movement which led to the landmark Law, PL 94-142).

The movements mentioned above, did not occur due to awareness campaigns. Also, by emphasising activities on campaigns, it limits impact and in a way, confirms the public sentiments of charity to and for the disabled.

Indian Institute of Cerebral Palsy is 41 years old; it has its first group of students who are now its first group of adults. An organisation that works with adults has to reflect on its strategies of activism because the work it does, influences and has the potential of developing into a social movement organisation. When I say this, I am not advocating that an institute adopt any specific political colour. It is paramount, indeed critical, that NGOs remain unbiased, apolitical and equal. This approach is also pertinent in semi-urban and rural parts of the country, if only because movements are based on the premise of humanity.

For advocacy groups, the realisation they must reach is that change is not simple and more often than not, it is slow, tedious and time consuming. When it is demanded that bus steps be lowered, it has to be known that buses, trains, planes and cars are engineering designs. Which brings me to the most important point – centres of Special Education have to consider including more creative subjects in their curriculum, particularly into their vocational training models. Is it possible to have Design and also, Management of small business as part of vocational training? Or: liaise with manufacturers of buses and automobiles and develop prototypes of accessible transport? The disabled must be active participants of change or as Gandhi said, we must be the change we want. Including more innovation in the education system for the disabled, would lead to a wider job market in the future and increased employment opportunities.

This dream is in the realm of possibility. All it needs is the possible to become a probability and the probable a reality. This can only be a dream come true when awareness emerges from encounters and experience.
Workshop on Inclusive Education by Bridge School Team

Presentation by the IICP Team

Working Together for Inclusion (Philosophy, Practice and Promise): A Focus on Persons who use Augmentative and Alternative Means of Communication (AAC)

A report of the Workshop held in the Indian Institute of Cerebral Palsy, Kolkata on January 11 and 12, 2016 by Madhumita Dasgupta, Special Educator, Roshni National Resource Centre for Augmentative and Alternative Communication, IICP and Teacher in Residence, Bridge School, USA, 2013

Participants:

Staff members of IICP, representatives from IICP’s partner organisations, and teachers of mainstream and inclusive schools of Kolkata.

The two-day workshop was held during the visit of a team from Bridge School, USA. It started with a presentation on IICP’s Media Lab, an innovative initiative to enable persons with disability to express their ideas creatively in prose or verse with the use of sound, visual images and assistive technology. This was followed by a presentation on IICP’s Bridging Programme with mainstream schools for more effective classroom management and inclusion of students who have special educational needs, particularly those who use AAC.

The Bridge School Team and a Brief Synopsis of Content:

- Dr Vicki Casella is Executive Director of Bridge School, San Francisco, USA – a school that focuses on optimal participation of students with complex communication needs in classrooms. Dr Casella's specialisation is in the integration of technology into the curriculum, adaptive/assistive technology, and the use of technology to deliver instruction via the Internet.

Dr Casella guided the participants through the Bridge School website. She stressed a consolidated curriculum to facilitate students’ participation in an academic classroom and in the community.

She also had an interactive session with IICP’s Ankur Advocacy team. She introduced concepts of Mentorship, Real World Opportunities and Guided Practice for self-determination. The Framing a Future (FAF) document aims at eliciting questions, concerns and responses from the youth and adult advocates about their own life issues.
Holly Peartree is a speech and language therapist at the Bridge School. Her clinical interests include self-determination, writing instruction, and participatory design of AAC systems. She has been successful in implementing Dr Janet Sturm’s ‘First Author – Writing Curriculum’.

Ms Peartree’s presentation demonstrated how a child who relies on AAC experiences the processes of being a writer and having her writing published, shared, critiqued upon, recognised and applauded. First, students choose a picture to anchor their topic, then they write and say more! At the end of the week, students select their favourite piece of writing and share it with the class, from the ‘Author’s Chair’.

Stephanie Taymuree runs a programme for children who use AAC and have physical impairments in Oakland, CA in a public school setting. She participated in the creation and implementation of the Technology and Augmentative Communication for Learning Enhancement (TACLE) programme. Trained in speech pathology, her research is centred on narrative writing.

Ms Taymuree referred to Personal Narrative as a tool used to establish connection and social closeness. The starting point of a personal narrative could be a photograph of the child doing an activity/the activity itself, with an emotion attached to it. That makes it an important part of the child’s memory which, in her communication book, can be revisited and shared.

Dr Christine Roman Lantzy is the Director of the Pediatric Vision Information and Evaluation at West Penn Hospital (VIEW) Programme at Western Pennsylvania Hospital in Pittsburgh. The Bridge School has been working with Dr Roman Lantzy to give a fresh perspective to vision, language and learning holistically for better participation of the child in a classroom.

Dr Roman Lantzy’s workshop dealt with Cortical Vision Impairment (CVI), a leading cause of visual impairment in children that is often not identified due to lack of sufficient knowledge and training in service providers. She spoke about the Perkins-Roman CVI Range Endorsement, a programme for training in assessment and intervention for children with CVI.

For more information, visit [http://www.perkinselearning.org/perkins-roman-cvi-range-endorsement](http://www.perkinselearning.org/perkins-roman-cvi-range-endorsement)

Dr Alan Lantzy’s specialisation is in the field of neonatology and perinatology. He is associated with major hospitals in USA including the Forbes Regional Hospital and Western Pennsylvania Hospital. His clinical interest is in Cortical Blindness.

Dr Lantzy introduced the Cooling Protocol and stated that Early Intervention should begin as early as possible, even as soon as six hours after birth.
November 2015
Boccia Competition at IICP

Boccia is a game similar to bowls. It originated in Spain and has been adapted for persons with cerebral palsy as a Paralympic sport. It is a team game in which each team has different coloured balls – red and blue. A white ball is thrown and the idea of the game is for each team member to aim their ball to get as close to the white ball as possible. The team that gets closest is the winner of the round.

Boccia was introduced to IICP in 2014 by Enric Romaguera and colleagues from Rural Development Trust, an NGO in Anantapur, Andhra Pradesh. In November 2015, the first Boccia competition was held in IICP where teams from IICP and RDT fought for the trophy – our guests won. Congratulations RDT!

December 2015
International Day for Persons with Disability

Kolkata Marathon

Nature Camp

Nature Camp: The 25th anniversary of the Himalayan Nature Adventure Foundation (HNAF) Camp was held in North Bengal with great aplomb. The IICP contingent included students and trainees, staff, Ranu Banerjee, Hony Secretary and Renu Sahara, Member of IICP’s Advisory Committee.
Christmas Parties Galore!

Thank You, Joan and Michael Mendosa

Fun and Games at the Adult Day Centre

Thank You Calcutta Cricket and Football Club!

January 2016
Sports Day
Sports Day was held on 22 January on the grounds of the Maritime University, Kolkata. Janet Ahmed, Hony Staff Member of IICP, MK Ghosh, Director, Maritime University and Deepak Atal, Advisor, APPL Foundation and Chairperson, Hope Cup Organising Committee were the Guests of Honour and gave away the prizes.

Caregivers’ Training
Caregivers’ Training for Trainers from Missionaries of Charity.
The Trainers with members of the IICP Faculty
Hope Cup
29 and 30 January 2016

An annual charity golf tournament organised by Tollygunge Club in collaboration with IICP, the Hope Cup is in its fifth year and symbolises a spirit of generosity and compassion. Three hundred golfers participated in the tournament managed by Protouch Sports.

We thank the Tollygunge Club, sponsors, donors, well-wishers and friends for their unstinted support.

Nilanjana Dutta, First Lady, Tollygunge Club hands over the trophies to the eldest Lady Golfer, Kartin Mondal and the Youngest Male Golfer, Ramayush Ray

Deepak Arul, Chairperson, Hope Cup Organising Committee presents the trophy to Col Sajjad PG who had a Hole in One on the 8th Hole

Sudha Kaul, Board Member, Goodricke Group Ltd, Co-Sponsors and Vice Chair, IICP gave away the trophies to the 2nd Runners Up Vivek Mathur, Sujit Sen, Deepak Tandon and Vivek Sahay

Bhaskar Barua, Director, Amalgamated Plantations gave away the trophies to the 1st Runners Up AR Bardian, Kaushik Pyne, Col Sunit Shukla, Wg Cdr JS Negi

Kallol Dutta, President, Tollygunge Club gave away the Rolling Hope Cup and the Winners’ trophies to Mayukh Ray, Indrajit Roy, Amit Basu and Hirak Dasgupta

The Prize Distribution was followed by a performance by ‘Banned’
February 2016
Subhadra Nehru’s visit

We were delighted to welcome Subhadra Nehru, formerly a volunteer and always a well wisher

Saraswati Puja

Saraswati is the Goddess of Knowledge. Hence it is an important festival for students. This puja (worship) is held during the Bengali months of Magh-Phalgun (January-February). Maa Saraswati sits on a swan holding a veena (a stringed instrument) in one hand and a book in the other. Early in the morning, students wear new clothes and give anjali – an offering of flowers. They pray for Her blessings to do well in their studies. This puja is performed in schools and homes.

Milan Mondal

March 2016
Picnic at Bajoria House

Sishu Mela at St Xavier’s College

The Goddess of Knowledge and Music, Devi Saraswati removes our ignorance. Seated on a white swan, She holds a veena. Saraswati puja is performed in every home and school. On the previous day, the place of worship is decorated and the image of Maa Saraswati is installed. The next morning we bathe, wear yellow coloured sarees and offer anjali. On this day, we enjoy songs and dances. Everyone eats khichudi, a gruel of rice and pulses. We have great fun on this day, both at home and in school. The puja ends on the next day and the Goddess is immersed with reverence.

Jui Sardar

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Jui Sardar

Saraswati Puja is celebrated in the month of Magh according to the Bengali calendar. Saraswati is the Goddess of Knowledge. We bathe in the morning before offering anjali. The Goddess is adorned with marigolds. We also celebrate Saraswati Puja in our school. On this day, we eat khichudi and chutney made with a berry called kul.

Soumyadeb Biswas

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Soumyadeb Biswas
Place Mats
@ ₹ 300

Trays
@ ₹ 900

More designs available at CIMA Art Gallery and IICP
Contact Anshu Choudhury at IICP