Colours of Spring

A colourful canvas painted by the students of IICP in celebration of Holi
A CSR initiative of Akzo Nobel and United Way, Kolkata
From the Editors ...

Visitors to India are always fascinated by the centuries-old traditions and festivals celebrated in different regions of this vast country. No month passes during the year without the occurrence of some attractive event. And April is the time when one is spoilt for choice! Whether it is the magnificent Tulip festival in Srinagar or the Bihu festival in Assam, the Music festival in Varanasi or the Food and Cultural festival in Goa, the enthusiasm is infectious. April also heralds the harvest season, which is observed in many States with music and dance.

Students and young adults in IICP celebrate many of these events with verve and excitement. After praying to Saraswati, the Goddess of Knowledge in February, they revel in the joyous colours of spring during Holi in March. April also ushers in the Bengali New Year, and what Poila Baisakh means to them is shared in their words and drawings in this issue of Deepshikha. New clothes, gastronomic delicacies, family get-togethers and, most exciting, looking forward to the summer holidays!

April this year is also a time for discussion and anticipation not only for the young and not so young adults in IICP but for voters in the entire country. The 17th Lok Sabha elections scheduled to be held in seven phases started on 1 April. Polls will be held across West Bengal on specified dates through April and May. Two members of IICP’s Ankur Advocacy Group share their thoughts on what the elections mean to persons with disabilities.

Full-page advertisements in newspapers have become a common sight nowadays. But what grabbed my attention was one in the Times of India last month, featuring a differently-abled girl on a wheelchair looking happy with her shopping experience. Through this ad, the brand claimed that more than 140 Big Bazaar stores in metros and smaller cities offered not only wheelchair-accessible ramps and trial rooms but other facilities such as shopping assistance, priority checkout counters and free home delivery. This revolutionary initiative should certainly encourage other retail chains to follow suit. After all, “Little drops of water... Make the mighty ocean.”

In Ode to the West Wind, P B Shelley asked “if Winter comes, can Spring be far behind?”... thus after an only too brief winter and a short colourful burst of spring, Kolkattans are getting ready for a long and gruelling summer. Heat, humidity and dust aside, summer brings with it its own colour, flowers and bird song and the vibrant hues of fruit and vegetables...and thus continues the cycle of seasons and life.

In an altogether different context, the funding by our partners ABP of this five-year cycle of the project ABC: Aiming for Better Communication comes to an end with this issue of Deepshikha. I am very grateful to ABP for its continuing support, our readers and contributors, and the editorial team - Anjana Jha, Subhra Chatterjee and Sumita Roy (Mita) who deserves special mention as the person who has done all the ‘spade work’ for Deepshikha after Subhra and I retired from our regular posts in IICP last March.

I am confident Deepshikha will return – in a new form and format, with topical and thought provoking content and different modes of presentation – with Sumita Roy as the Editor, supported by the IICP team.
Major Breakthrough
A voice output device reaches children with complex communication needs in the Sunderbans

A report by Swati Chakraborty, Head, ICT

Speech is the most natural form of human communication and very often people with complex communication needs (CCN) who cannot speak due to various reasons such as cerebral palsy, autism or physical and cognitive challenges are left out. A large section of the population who can’t verbally express their needs, feelings, emotions or opinions are bypassed or ignored. IICP, a pioneering organisation in the disability sector has worked for the past four decades to rectify this glaring omission and break the shackles of silence for people with CCN. Extensive work has been done to provide Augmentative and Alternative Communication (AAC). Kathamala is a portable, electronic voice output device where 1-16 messages, depending on the need and abilities of the user, can be pre-recorded and stored.

The successful outcome of the collaborative research by IICP, Micro Solutions and IIT Kharagpur was a device with clear audio output easily understood by the communication partners that costs 75% less than any imported device. The project was sponsored by ONGC under their CSR initiative.

The gift of the Kathamala to children sans speech in rural Sunderbans was a major breakthrough to facilitate their inclusion in society. It was the first time in India, rural children were being provided with an electronic device for communication for better participation in school and at home.

The distribution in the assembly constituencies of Basanti and Gosaba blocks was done in two phases. In mid-February, the distribution camp in Basanti was inaugurated by Pratima Mandol, Member of Parliament from the Jaynagar Loksabha constituency. Seventy-four children and young adults with CCN enrolled under the Sarva Shiksha Abhiyan were given the Kathamala free of cost after due screening.

In the second phase, the programme was inaugurated by the Joint Block Development Officer of Gosaba after the local MP expressed her inability to attend due to work commitments. Sixty two school-going children with special needs were screened and 55 with complex communication needs received the voice output device.

Training for resource teachers and Shiksha Bondhus at both Basanti and Gosaba was conducted by the IICP team of Madhumita Dasgupta, Krishnarupa Choudhury and Swati Chakraborty. All training material and the screening and assessment forms are developed by IICP. Each special educator was provided with an assessment kit containing a device, objects and pictorial resource materials to continue working with parents and children. This will be of immense help particularly in the case of Gosaba, where some of the users live in extremely remote areas only accessible by boat.

Pratima Mandol, Member of Parliament from the Jaynagar constituency inaugurates the Distribution Camp at Basanti

Swati Chakraborty supervises the use of ‘Kathamala’
A group of 22 professionals comprising physiotherapists, occupational therapists and speech and language pathologists from IICP, Apollo Hospital and BR Singh Railway Hospital attended a one-day workshop conducted by Dr Susan Balandin in March this year.

The topic of the certification workshop was Dysphagia Disorder Survey (DDS) and Dysphagia Management Staging Scale (Revised edition 2013) which is a standardised screening and clinical examination of swallowing and feeding disorders in children and adults with disability.

Dr Balandin spoke about the causes and assessment of swallowing and feeding disorders in developmental disability. Using a power point presentation, she described the tool explaining how it was developed and validated. The tool detects difficulties in eating originating from:

- behavioural problems such as disruptive mealtime behaviours; food selection; rapid eating and food phobias
- developmental disorders such as poorly developed biting and chewing skills; drinking from a cup and straw
- physiological disorders such as choking (gagging and coughing); dribbling of food and drink; inability to clear the mouth; deficient oral movement

The tool comprises two parts: the first part describes posture of the patient/person, texture of food, adaptive utensils used and independence of eating. The second part deals with orientation, reception, containment, oral transport, chewing, swallowing and gastroesophageal functions. It takes 10-15 minutes to employ the tool which can be used to screen for risk of dysphagia, describe the functional disorder and for research purposes. Participants filled forms while watching videos of mealtime during the practical session and were assessed. They were guided by Dr Balandin who recommended using the DDS tool with at least six persons with dysphagia. The workshop ended with an interactive session for clarification of relevant queries.
In Conversation with Susan Balandin

_During her visit to Kolkata, Sumita Roy chats with Dr Balandin about her long association with IICP_

**How long have you been associated with IICP?**

SB: I have been coming regularly for the past seventeen years.

**What are the changes you have seen in IICP?**

SB: There has been an expansion in the range of services over the years. The Tea Packaging and Jugnu, the inclusive play school have been introduced. There is a greater focus on advocacy and more interestingly old people, as is the case all over the world. The degree of disabilities seen in children who now come to IICP are definitely more severe than before. This could be due to availability of better medical facilities. Alternatively children with minor disabilities are being managed in regular schools with support of therapists and special educators.

**What are the primary clinical problems that you observe in persons with cerebral palsy, here?**

SB: Cerebral palsy is a motor disability which makes chewing and swallowing difficult. It makes the child prone to chest infections and is also the cause of very slow development. In India, my observation is mothers spend too much time at mealtimes. The notion of a healthy baby is equated with being chubby and plump. A skinny child with low appetite is considered a problem. So mealtimes management become difficult for families who have children with neuromotor disabilities.

**What are the changes you see in Kolkata?**

SB: It is certainly much cleaner now with less garbage around. However the volume of vehicular traffic has increased by leaps and bounds. The traffic snarls are quite bad. Another significant change is the way women dress now. Earlier the majority of them only wore sarees but now I notice most women across generations have opted for more modern trends in apparel.
Craig Carsadden, CEO of Cerebral Palsy International Sports and Recreation Association (CPISRA) visits IICP

Power of sports for disabled children

CHANDREYEE GHOSH

Taratala: A former Paralympian athlete on Friday shared with students and teachers of the Indian Institute of Cerebral Palsy (IICP) the benefits of sports for children with disability.

Boccia, racetrouting, frame football and cerebral palsy football are some of the sports that children with disability can pursue, not just as therapy but at a competitive level.

“Sports spell empowerment, especially for disabled children on wheelchairs. It improves their motor skills and muscular coordination. A child’s confidence and social skills also get a boost.” Craig Carsadden, the chief executive of Cerebral Palsy International Sports and Recreation Association (CPISRA), the founding organisation of the Paralympics, said at an interactive session at IICP, Taratala, on Friday.

Carsadden, a Scottish national, is on a visit to India to spread awareness about various sporting disciplines that schools can offer as part of their curriculum. He was accompanied by experts from South Asia Cerebral Palsy Sports Federation (SACPSF) and Cerebral Palsy Sports Association India (CPSAI).

“There are around 35 lakh children with cerebral palsy in India. Less than 10 per cent of them play a sport,” said Kavita Suresh, the secretary general of SACPSF. The organisation, along with its Indian unit, plans to build CP (cerebral palsy) sports hubs for children in India, where they can train at a competitive level.

“The infrastructure needed for these sports are often beyond the means of Indian parents. Racerunning is an unheard-of sport in Asia but popular in Europe. The racetrunner, a custom-built tricycle without pedals, is very expensive. Most parents will not want to spend that much on a bike for a child who cannot even walk. But then it is sports that will improve his mobility in the long run,” Suresh said.

Carsadden said sports was also a step towards inclusion. “Imagine a child on a wheelchair taking part in a race and that too on a competitive level. It improves chances of inclusion,” he said, educating teachers about race running, which is a World Para Athletics discipline.

The first racetrunner was built in Denmark in 1991. “Racerunning bikes are expensive. They are mostly manufactured in Sweden and Denmark. But if the sport is popularised in Asia, local manufacturers are likely to come forward to make the three-wheeled bikes at a lesser cost. We are hoping to encourage that,” Carsadden said.

Students of IICP regularly engage in boccia, a recognised paralympic sport. A team game using many balls, it is offered as therapy at the institution, said Somali Nandi, IICP’s chief operating officer and director. “It will be good if our children can be slowy inducted at a competitive level,” she said.

IICP played host to representatives from regional, national and international Cerebral Palsy Sports Associations at an interactive session in March.

The visitors were treated to an exhibition match of Boccia (a ball game like bowls) by the IICP students.

Photo at the back cover
What Elections mean for Persons with Disabilities

Saswati Acharya, Sudipendo Dutta, Dipak Ghosh and Sheba Naaz
of the Ankur Advocacy Group share their thoughts on what elections mean to them

Like any other person with disabilities, I also believe that we have equal rights and opportunities as other citizens of India. Unfortunately that is not always the case and therefore we are constantly fighting to ensure our rights as equals. Participating in the election process is one of our fundamental and constitutional rights. Some years ago, going to cast our vote was not at all easy for us. Most of the booths were not accessible as they didn’t have ramps and barrier-free environment. Very often, names of persons with disabilities did not even get enlisted in the electoral rolls.

I feel we are an undeniable, invincible part of our country’s population and we must enjoy all our democratic rights and play an important role as citizens by casting our valuable votes. So in my opinion, Election Day for persons with disabilities is not just another day to enjoy a holiday anymore but be visibly proactive to exercise our fundamental right. I feel it is our duty to join the election process and encourage others to do the same. By casting our vote, we can create awareness in our own unique way.

Constant awareness programmes by disability activists has made local and state governments realise the importance of including persons with disabilities in the electoral process. This year the election commissioner’s office has taken many positive steps for PWDs. They held special camps for enrolment (of persons with disabilities), issued voter cards, arranged training sessions for the visually impaired on the process of using the Electoral Voting Machines, made access to polling booths user-friendly for persons with disabilities and senior citizens. They have even made provisions for transport facilities to reach polling stations. These are all very encouraging signs or steps to ensure that persons with disabilities can enjoy their voting rights. It is just the beginning. Our struggle will be to ensure all polling booths in different parts of India, even in remote rural areas, become accessible for all. The election commission should train more people with the help of the political parties to make the election process in India barrier-free and accessible for all.

— Sudipendo Dutta

“Tō vote is my right. A vote is the opportunity given by individual citizens to a political party to come to power. The party that forms the government should provide socio-economic facilities for the common man. I want the government to ensure easy access to polling booths, specially for persons with disability and implement programmes for social awareness.”

— Dipak Ghosh

“It is my right to go and vote. I want a leader who will work for persons with disabilities and improve accessibility for us. Easy access in buses for persons with disabilities and special counters in banks and public sector organisations for wheelchair users should be a priority”.

— Sheba Naaz
Celebrating Bengali New Year

We bring you glimpses of what Poila Baishakh (Bengali New Year) and the advent of summer mean to our children.

Naba Barsho signals the start of the Bengali New Year. On the first (Poila) day of the first month in the Bengali calendar, Baishakh, we bid farewell to the old and welcome the New Year. We ask our seniors to bless us. Bengalees gather for chit-chat (adda) and there are many interesting programmes on television.

— Debjati Ray
Middle & Senior Academy

Naba Barsho is celebrated widely in Bengal. Idols of Ganesh (the God of Prosperity) are worshipped in shops and new ledgers are started. We wear new clothes, there’s good food and everyone is happy.

— Debjani Banerjee

The best part of summer is the month-long summer holidays! I visit my grandparents’ home during my school holidays. I love eating mangoes and watermelon and listening to stories told by my mother on summer afternoons.

— Rubit Sarkar and Sudhovon Mondal
Junior Academics II

Students of Life Skill Training Unit

Sonali Ghosh and Subhankar Das
Junior Academics I
As the sun rises on a new dawn, the conch shells welcome ‘Come, Come Baisakh!’

– Barsha Bhattacharya

Cats and dogs feel just as thirsty as we do during summer. So we should keep bowls of water out for them to slake their thirst.

– Bittu Sen

Junior Academics I

My best wishes for Naba Barsho! There is delicious food at home. We start the New Year by worshipping the gods Ganesha and Lakshmi.

– Sayani Sarkar

Adult Day Centre
Inclusive Community Development for Better Living

Dr MB Chhetri, former Deputy Director, Community Based Rehabilitation (CBR), IICP is presently the Jt Commissioner Disability–Technical, Social Justice & Empowerment and Welfare Department, Government of Sikkim. Dr Chhetri is a medical doctor of Homeopathy and a qualified and experienced physiotherapist.

Working for more than three decades on various aspects of Disability Management, Human Resource and Organisational Development, I realised that there is no age bar for good work no matter where one is and which State or community one is working with. I gained this insight after working with highly qualified and empathetic professionals in IICP, Kolkata. I owe gratitude to all my colleagues at IICP particularly Dr Sudha Kaul, Dr Reena Sen, Tessa Hamblin, Sujata Parekh, Ranu Banerjee and late Anita Varma for their support and guidance.

Though I retired from IICP in 2016, I continued to reside in Bengal and support organisations in the State as a gesture of gratitude for all that I had received over the years.

I returned to Sikkim in January 2018 after 35 years of working outside my State. In September 2018, the Government of Sikkim offered me the post of Jt Commissioner Disability–Technical for one year. I enjoy my job and have found that despite the challenges, there is ample scope for developing services. My life experiences have taught me that challenges can be met and overcome with faith and trust.

The 2011 census reported that Sikkim had 18,000 persons with disabilities. Obviously this figure has gone up by now. People in general and policy makers in particular assume that it is easy to provide services in a small State with less population. The reality is different and that logic does not hold good here. The beauty of the Himalayas notwithstanding, the hilly terrain is in many aspects disadvantageous, especially for people with disabilities. The cost of services is exorbitantly high compared to other non-hilly States. The model of services which are suitable in plain areas of other States, are not going to be effective here. Transport and accessibility is extremely difficult even on the main roads, as regular services have limitations and are costly. Constant efforts are made by the State Government through various concerned departments to ensure easy access of its people-friendly policies for persons with disabilities. More than a thousand students with disabilities are enrolled in mainstream schools Samagra Siksha (Inclusive Education). Those unable to attend school get basic services at home through resource teachers (Home Based Programmes). The Social Justice Empowerment & Welfare Department provides financial subsidies through various schemes as well as supports NGO’s working with persons with disabilities. Assistive devices are distributed through our District Disability Rehabilitation Centre (DDRC) and at camps organised by the concerned departments. Clinic-based services are provided by all districts hospitals.

Medical experts work for Early Detection and Intervention of new born babies through Rashtriya Bal Swasthya Karyakram (RBSK) scheme. The main focus of this scheme is on the four Ds – Defect at birth, Diseases, Deficiencies and lastly Delayed Development and Disabilities. The fourth D remains an area of need where the doctor’s role is minimised and rehabilitation professionals need to take over. There is a lot of scope for establishing services in these areas.

Door to door surveys have been initiated to gather and analyse current and authentic data to design and develop a model of services suitable to specific disabilities, age groups, gender, community based services, rehabilitation, special education, pre-vocational, vocational, income generation, jobs and employment as well as social security and finally inclusive community development.

Future needs

- Establish systemic linkages for convergence with Social Justice Empowerment & Welfare Department; Health Care, Human Services and Family Welfare Department; Integrated Child Development Scheme (ICDS) Department; Human Resource Development Department (HRDD); and Inclusive Education (Samagra Siksha).
● Enhance knowledge and skills of Special Educators and Resource Teachers who have done Foundation course

● Continue to build and modify infra-structure for accessibility

● Consolidate through awareness programmes the involvement of Panchayats and Rural Development, Police and Law Departments

● Enhance need-based ongoing training for Resource Personnel on disabilities

● Focus on early identification and hospitalisation of infants with disabilities, follow up services including early therapy for those with disabilities. Special Education intervention at home, community centres for 0-3 age group, Aganwadi Centres (3+ to 6 years), referrals to mainstream school after 6 years for inclusive education and need-based support and training

● Constant review and updates of individual profiles and services will be maintained at all levels. Once they finish elementary education, further support for higher studies, vocational skills development training, job creation, income generation, social security and independent living in the community will be provided after review

All the above will perhaps facilitate the establishment of a Department of Persons with Disabilities in Sikkim and lead to a Directorate in future. This will generate recruitment opportunities for educated local youth to qualify as professionals in the fields of comprehensive rehabilitation and special education. It is a unique opportunity for a model of services for persons with disabilities not only in Sikkim but also in all other ‘hill states’.

*Training personnel in Gangtok, Sikkim*
Dr Andrew Curran, Consultant Paediatric Neurologist at Alder Hey Children’s Hospital, UK, conducted an interactive session on understanding seizure disorders in children for parents and professionals at IICP. He was facilitated by Dr Jayanti Bose. Sumita Roy reports

Dr Andrew Curran addressed a number of misconceptions about seizure disorders in children. Patiently answering queries in Bengali that were deftly translated by Dr Jayanti Bose, a paediatric consultant with IICP, he said there was a 50% lifetime risk of epilepsy in children with cerebral palsy. He emphasised the importance of parental inputs and consensus in the management of the child by the medical specialists. Speaking briefly about research and ongoing scientific trials on stem cell therapy and drugs based on cannabis for treatment of cerebral palsy, he mentioned both were a possibility in the distant future. He was happy to state that the team in IICP practiced protocols that are in line with the standards in UK.

Excerpts of some of the views share by Dr Andrew Curran responded to are given below.

**Will frequent seizures damage the brain?**
AC: Convulsions of short durations do not damage the brain. The frequency of episodes can be reduced with medication. Since epileptic drugs are strong, the dosage given should be adjusted for it to be effective without causing side effects.

**What is an appropriate dosage of medicine for seizures?**
AC: Exposing a child to four or five types of medicines at the same time is poor practice. The ideal is one drug per child. Any anti-epileptic drug is to be started in small doses for control and if required, gradually increased till full dose. If that is ineffective and a second drug introduced, again the first one should be withdrawn. The dosage should be increased only if the frequency of fits increase and are more severe and not because the child is older. A major
concern is side effects should not increase. Long-term anti-epilepsy medication can be taken for twenty to thirty years without a problem if there are no side effects.

**What are the general side effects?**

AC: The three general side effects of many anti-epileptic medicines are they cause sedation, cause confusion and can increase fits. It is very hard and takes time to find that one medicine in the right dosage for each child to reduce the number of episodes without side effects. We have to try 3 to 4 types before we find the right one.

**Are EEGs and blood tests necessary at regular intervals?**

AC: An EEG is initially done to confirm the diagnosis of epilepsy. Generally this does not have to be repeated as it is the child that is being treated not the EEG. An EEG is done to differentiate between Dystonia (involuntary muscle contractions causing repetitive twisting movements) and epileptic fits. At home, if parents take a video of the episode, it often enables doctors to decide the line of treatment.

According to the guidelines in the International League Against Epilepsy (ILAE), children do not need frequent blood tests. Only those suffering from side effects of medicines need to be monitored. Also those taking ‘Phenytoin’ need to check the levels of the drug to adjust the dose being prescribed.

**What are the pointers for teachers to handle fits related behaviour problems in class?**

AC: Epilepsy is never a behaviour problem. You cannot misbehave if you are having a fit. Behavioural problems can arise due to an imbalance in brain impulses as a side effect of anti-epileptic medicines. It is necessary to first note:

- How many fits the child has on a daily/weekly basis. If it is less than five a week, that is not a problem
- Whether the behaviour problem has arisen after the introduction of any new medicine or change in the dosage. If it has, gradually reduce to stop and observe behaviour. If behaviour improves but fits continue, stop the old and initiate new medicine
- Whether the behaviour of the caregiver is aggravating the situation. Most behaviour is a response/reaction to one’s immediate environment. Hence it is important for behaviour management of the carer/teacher to be appropriate
- If all the above parameters are okay but the problems continue, then safe psychiatric intervention can be initiated. 60% of children respond to positive management strategy, 16% respond to medication and the remaining require additional medicines for behaviour control
- Behavioural problems can take place due to headaches/migraine. When a child exhibits sudden aggression and hits his head repeatedly without any visible trigger and is afterwards very tired, migraine is a probable cause. It is worthwhile for the clinician to try out migraine medicines to deal with this

**Does diet play any role in the occurrence of seizures?**

AC: A key feature of epilepsy is that there is no trigger. There is no evidence to suggest that hyperacidity has any role to play in causing a seizure. A normal diet makes no difference to seizures. Rarely will the omission of dairy and gluten from the diet cause any change. A ketogenic diet (high fat, adequate protein and low carbohydrate), in extremely severe cases, will lower the PH (acidity) level but has to be medically monitored in controlled surroundings. In rare cases of inborn error of metabolism, the correct diet and medication will improve the condition for a short period. Unfortunately these are generally serious cases and these children have a short life span.
Events

Saraswati Pujo, in celebration of Knowledge and Wisdom

Marika Miller, Executive Director, MIBLOU, Switzerland, that has supported IICP’s work in urban slums for 15 years, is the Chief Guest at the Saraswati Pujo

Holi, the festival of colours is celebrated at IICP

Alka Bangur, MD, LN Bangur Group inaugurates the two Smart Classes – Pre Primary and Educational Development Unit (EDU) III in Centre for Special Education (CSE)
A two-part workshop on ‘Project Proposals’ emphasising effective communication of brand and clarity of purpose was conducted by Dipak Kumar Banerjee, Former Joint Treasurer, IICP and Dr Reena Sen, Hony Secretary, IICP

Workshop on Resource Mobilisation

Soumi Banerjee and Mahasweta Roy speak on ‘Enhancing Visibility’

Anindita Chatterjee and Sumedha Khera of Tax Connect share ideas for Income Generation
Sports Day 2019

IICP's bi-annual Sports Day was held on 7 February at the Indian Maritime University grounds, Taratala.

This year the prizes were given by our three Guests of Honour.
1. Kuheli Banerjee, Principal, Behala Balika Vidayapith
2. Dr Arun Jha, Principal, Alipore Tatbhal Vidyapith
3. Saurav Tewari, Secretary, Cerebral Palsy Sports Association, West Bengal
4. The tiny tots of Jugnu play school dressed up for the ‘Go As You Like’ event
5. Senior students race to the finish line
6. ‘Boccia’ match in progress