



# INDIAN ACADEMY OF CEREBRAL PALSY

Central Office: 403. X Block, Tower 1, Adarsh Palm Retreat, Devarabisanahalli  
Outer Ring Road, Bengaluru-560103, Karnataka, India

Official Newsletter for Members of IACP

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## Are we committed enough for our community Awareness Program?

When we started our National cerebral palsy program in October 2010, we all shared an infective enthusiasm & fine celebrations were held all over the country & as general secretary, I was pleased to compile the flowing reports & put them up in the newsletter. Just after 5 yrs, we seem to have lost steam & there were hardly any reports in 2014. I am wondering if IACP members are so busy as not to have any time for creating community awareness or they find the effort involved not worth the results!

Cerebral palsy & disabilities in general are invisible public health burdens. For every child we see in our clinic, there are 3 more adults in the community unseen & probably with no health cover & the only way we all can work at various ICF levels is to make inroads into community consciousness & aim at creating more participatory roles for our children & young people with disabilities. The global perspectives on epidemiology of cerebral palsies recently published puts India in such poor light. A country with about 15,000 pediatricians, 6000 orthopedic surgeons & near about 2000 neuro science specialists [ I do not know the no of the therapists & educators we have amidst us!]- is not strong enough to impress upon MCI the need for change in our disability curriculum nor are we research minded enough to do multicentre epidemiological studies. We have the ever present defeatism of clinical workload but are we not good enough to educate public also? Is public health education only to pass an exam & forget it for the rest of our lives? I raised the issue at our Mumbai meeting when I saw an auto driver educating public not to spit on roads to prevent the spread of MDR tuberculosis in chembur by lane! Are we professionals not even on par with the not so common, common man like him [I wish I had the punch power of Late R.K.Lakshman] to practice community social responsibility?

This I consider as a challenge for IACP Executive body members at least to respond to. There is a great need to move from our clinics to community if we have to fulfill the much publicized health for all Slogan. Can we at least have this Commitment from our office bearers that they will be different in 2015 & see that they celebrate the CP day in as small a way as Possible. Otherwise, I do not see any way for IACP moving forward in realizing our vision. Let me remind all of you what every child with cerebral palsy teaches us- brilliantly hidden in these words of Martin Luther King-Junior:

If you can't fly, then RUN,  
If you can't run, then WALK,  
If you can't walk, then CRAWL,  
But whatever you do, you have to keep moving forward.

In the service of academy,

Dr. G. Shashikala

Ref: A global Perspective-Maureen S Durkin-63-71.Cerebral palsy-Science & clinical practice, Clinics in Developmental Medicine-Ed by-Bernard Dan, Margaret Mayston, Nigel Paneth & Lewis Rosenbloom, Published by Mac Keith press-2014

Newsletter Editors

**K.D.Mallikarjuna, Dr. Madhavi Kelapure, PT  
Dr. G. Shashikala & Dr. Asha Chitnis, PT**

# IACPCON 2014

## First International and IXth Annual Conference of IACP

9th to 13th October 2014, Shanti Sarovar, Hyderabad



## From Secretary's Desk

Dear Members

I take this opportunity to introduce myself as IACP Secretary, It is a great honour to have been selected to serve in this capacity, and I will endeavour to do justice to this very important position. As I step into this role, I see a great parallel between the challenges faced by people with CP and the challenges faced by IACP today: keeping a steady gaze on the horizon and maintaining balance in a changing environment & communicating as a team will go a long way We welcome 2015 with much anticipation & hope that we all evolve as a team working towards new horizons.

**"A good plan for today is better than great plan for Tomorrow .  
Look back with satisfaction & move forward with confidence"**

God bless  
**Asha Chitnis**  
General Secretary

## IACP Consensus Statement on Stemcell Therapy



This is a consensus statement from the scientific & research committee group of IACP. AS per the national guidelines issued by ICMR on stem cell research & the general international consensus, Stem cell therapy in cerebral palsy is an unproven but promising translational research intervention which is still considered to be a clinical trial methodology. Translational research is the process used to turn scientific knowledge into real world treatments. It has lot more questions to answer than what it has answered till now & ongoing studies are underway. Till such time that we have an accepted evidence based medicine pronouncements, it is unethical to offer it as therapy. As per the latest national guidelines for stem cell research published by ICMR and DBT "any stem cell

use in patients must only be done within the purview of an approved and monitored clinical trial with the intent to advance science and medicine, and not offering it as therapy. In accordance with this stringent definition, every use of stem cells in patients outside an approved clinical trial shall be considered as malpractice." Parents undergoing this form of intervention need to ask questions to those offering this intervention. Science has lot more obstacles before it becomes medicine. They can subject their children at their own risk, discretion & option. IACP also declares that we are not part of any organisation & institution offering this therapy & our scientific platform has been misused by vested interests without official approval. We distance ourselves from all such spurious statements & offer no credibility to such claims as & when they are quoted by any one at any place. This notice is issued in the interest of parents & children with cerebral palsy whose welfare is the guiding spirit of Indian Academy of cerebral palsy with approval from competent authorities.

For more details, log on to following websites • [icmr.nic.in/About\\_Us/Guidelines.html](http://icmr.nic.in/About_Us/Guidelines.html) • [Vib.nic.in/newsite/PrintRelease.aspx?relid=104095](http://Vib.nic.in/newsite/PrintRelease.aspx?relid=104095) • Department of Health Research (DHR), Government of India, [www.dhr.gov.in/](http://www.dhr.gov.in/) • [stemcells.nih.gov/](http://stemcells.nih.gov/) • [www.eurostemcell.org](http://www.eurostemcell.org) > [ucp.org/resources/from-the-medical-director-s.../stem-cell-therapy/](http://ucp.org/resources/from-the-medical-director-s.../stem-cell-therapy/) • Stem Cell Treatments for Cerebral Palsy, Factsheet for patients and families, Crystal Ruff, \* Jared Wilcox, \* Michael Feelings-Childhood disability LINK • <http://www.isscr.org/public> • [http://www.ninds.nih.gov/disorders/cerebral\\_palsy/detail\\_cerebral\\_palsy.htm](http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm) Stem cell therapy • [isscr-Patient Handbook on Stem Cell Therapies](http://www.isscr.org/Patient_Handbook_on_Stem_Cell_Therapies), Appendix I of the Guidelines for the Clinical Translation of Stem Cells December 3, 2008 • [http://www.closerlookatstemcells.org/How\\_Science\\_Becomes\\_Medicine.html](http://www.closerlookatstemcells.org/How_Science_Becomes_Medicine.html)

## NATIONAL CEREBRAL PALSY DAY by SANVEDANA CP Rehabilitation Centre, Latur



Sanvedana, CP Rehabilitation Centre, Latur, Maharashtra celebrated National CP day, in the auspices of Jankalyan residential school, involving their students and staff. All the parents also participated in the function. The main objective of the programme was to sensitize and orient the students and teachers on management of Cerebral Palsy and the Schemes of National Trust. The children with CP performed a dance programme 'thare jamin per' which thrilled the audience. Smt. Deepa Patil, HM of the Sanvedana, explained about National CP day & Dr Perin's life. Sri Suresh Patil interacted with normal children and motivated to do survey and to interact with parents of mentally challenged children in their villages during DIWALI holidays. Dr. Devashish Ruikar, only neurophysician in Latur graced the function, overwhelmed with the "students performance, told that working for this children is nothing but 'Eeswar sewa'.

The Chief Executive officer, Latur ZP, expressed that Sanvedana doing great service and idea of conduction of survey by jankalyan students is excellent and we also will co-operate for the same. Dr. Ashok Modak ex-MLC also graced the function. All the children of Sanvedana were warmly welcomed by jankalyan students and honoured, Sri Basaveswar Pike, who was awarded by ministry of SJ & E recently. Suresh Patil, Karyavah, Sanvedana Cerebral Palsy Vikasan Kendra, (School For Multiple Disabled) Plot No P-55 M.I.D.C. Latur, M:9422072517. Visit: [www.sanvedana.org.in](http://www.sanvedana.org.in).

# Minutes - 9th I A C P Annual General Body Meeting

## MINUTES OF 9<sup>th</sup> GENERAL BODY MEETING OF IACP

DATE: 11th October 2014; VENUE: Shanti Sarovar, Hyderabad

**Participants:** Dr.M.A. Mahadeviah, Dr. G. Shashikala, Dr.Ashok Johari, Dr. A. K. Purohit, Dr.Dhruv Mehta, Mr.K.D.Mallikarjuna, Dr.Asha Chitnis, Dr.Vipul Shah, Dr.S.Das, Dr.Taral Nagda, Dr.S.Rangwala, Dr.F.Jetpurwala, Dr.S.Samanta, Dr.S.Singh, Dr.R.Kumar, Dr.Mansoor Alam, Dr.S.Gawande, Dr.N.Pandey, Dr.G.Kitnasamy, Dr.P.Khatri, Dr.N.Patil, Dr.T.Nikharge, Dr.K.Shah, Dr.M.Kelapure, Dr.J.Singh, Dr.N.Hariharan, Dr.H.Badiger, Dr.A.Varma, Dr.G.V.Subbarayalu, Dr.S.S.Shelke, Dr.S.Ramaguru, Dr.G.Bhalerao and Dr.S.Khadilkar.

**Duration of meeting:** Two hours

### Agenda:

1. President Address / Report of last year 2013
2. General Secretary's report
3. Statement of account
4. Membership Status
5. IJCP journal status
6. Official Website status
7. Next IACP Conference, Odisha and Pune
8. New Resolutions
9. New Executive Committee for next term
10. IACP Film
11. Protocol Development Status
12. Collaboration of IACP with Medical Council of India

#	Topic	Discussion
1 2	<b>Address from the President / Report of last year</b>	<ul style="list-style-type: none"> <li>· President Dr. A.K. Purohit gave a run through of events in last year. He said, the graph of progress of IACP has been growing steadily with two highlights being increased awareness about the CP day and the publication of Indian Journal of Cerebral Palsy (IJCP)</li> <li>· He briefed about the 9<sup>th</sup> Conference saying the spirit of delegates was good and so was the response. There were number of paper presentations. However, he agreed that the time schedule of the sessions was not followed diligently.</li> <li>· Dr. Chitnis and Dr. Bhalerao stated that the quality of research papers presented in the conference was not really correct to be accepted by research norms. Dr. Asha said that this has been the condition for last three years' conferences. Dr. Shashikala suggested that we need to train the professionals for conducting research.</li> <li>· Dr. Dhruv Mehta talked about two conferences of year 2013, first being the Conference at Lucknow, on the 8<sup>th</sup> 9<sup>th</sup> 10<sup>th</sup> of March and second being the 8<sup>th</sup> Conference of IACP which was conducted by Polio Foundation of Gujarat on 20<sup>th</sup> 21<sup>st</sup> and 22<sup>nd</sup> December 2013. These conferences had eminent faculty but were not very well attended.</li> <li>· Dr. Mehta also accepted that they were not able to conduct CMEs by IACP in 2013 after the last one held at Rajkot in September 2012, which wall very well attended and appreciated.</li> <li>· He said that CP day was celebrated very well in different parts of the country.</li> </ul>
3	<b>General Secretary's Report Annual Accounts</b>	<ul style="list-style-type: none"> <li>· Mr. Mallikarjuna read out the statement of accounts for the year 2013- 2014, which was passed by the GB.</li> <li>· It was also agreed that this statement should be presented as a hard copy or a power point in the next GB meetings.</li> </ul>

- 4 Membership Status / Fees / Certificates**
- The number of members of IACP has crossed 450
  - It still comprises of a large number of therapists with a very poor representation of Pediatricians
  - It was agreed that certificates should be issued to all those who are members since two years and have attended two conferences
  - Members passed a resolution of keeping the membership fees 'status quo' i.e. Rs. 1500/-
- 5 Official Website Status**
- The general body amicably decided that Mr. Mallikarjuna assisted by Dr. Harish and Dr. Sanket will be the web master and will share the responsibility of Website functioning.
  - New President to formally inform the old web master, Dr. Vipul Shah, about the same.
- 6 Indian Journal of Cerebral Palsy**
- Dr. Purohit expressed that seniors should encourage professionals to conduct studies and produce research papers so that IJCP can be made as an indexed journal.
  - Dr. Johari was of opinion that it is quite premature to come out with a research journal at this stage. Till we develop the climate of research and generate papers, in order to survive, we should have multidisciplinary review articles on specific topics on CP. Eminent experts in the field can be invited to write on these topics. Converting this education journal into research journal is going to take time.
  - Dr. Shashikala also said that the mission of IACP is to improve the services and in absence of good quality services, it is premature to expect research to come out. Instead it becomes essential to organize and attend Research Methodology Workshops in each conference to teach the professionals how to collect, analyze data and write papers.
- 7 Next IACP Conference**
- Dr. Das proposed that the 10<sup>th</sup> IACP conference will be held at Cuttack, NIRTAR, on 18<sup>th</sup>, 19<sup>th</sup> and 20<sup>th</sup> December 2015
  - 11<sup>th</sup> IACP conference will be held at Pune
  - Following new guidelines were drawn for conference conduct
  - Scientific content should be strictly theme specific
  - Parents should not be allowed to attend any scientific session- Family forum should never be called as a workshop, and should be held in the evenings after the end of scientific sessions. Family forum should consist of two way interaction between professionals and parents.
  - Conference should not facilitate any private consultation at the venue
  - The Executive Committee should be informed about any co-host or collaborator of the conference from the beginning. Co-host should necessarily be an academic body only.
  - Conference should be 3 day long.
  - No conference org team shall transfer any post conference financial liabilities to IACP & will contribute 50% of the profits to IACP after compulsory submission of accounts.
- 8 New Resolutions**
- Formation of **Board of Directors** was proposed, seconded and passed by the GB. Previous presidents, with their consents, will be the members of this advisory board.
  - Advisory board will supervise, guide, strategize and look into the role of EC.
  - EC will be answerable to Advisory Board.
  - There will be one EC meeting prior to GB meeting during every conference, on the first day.
- 9 New Executive Committee**
- New EC was elected as follows
  - President: Dr. G. Shashikala
  - Vice president 1: Mr. K.D. Mallikarjuna
  - Vice President 2 : Dr. Dhruv Mehta
  - General Secretary: Dr. Asha Chitnis
  - Treasurer: Dr. Shakti Das
  - EC members
  - Surgery: Dr. Shankar Shelke

Non Surgery: Dr. Sandeep Samanta  
 Physiotherapy: Dr. Madhavi Kelapure  
 Occupational Therapy: Dr. Anita Suresh  
 Psychosocial / Education: Shobha Sundar

- 10 IACP film**
- It was suggested that the body should come up with films in two phases
  - Phase one: Small film about CP day
  - Phase two: A documentary to increase awareness about CP.
  - A committee consisting of Dr. Sanket and Dr. Gajanan will work for the same.
- 11 Incomplete Agenda**
- Protocol review and collaboration with MCI could not be discussed due to time limitations.

## Minutes of EC Meeting

DATE: 12th October 2014; VENUE: Shanti Sarovar, Hyderabad

**Participants:** Dr. G. Shashikala, Mr. K.D. Mallikarjuna, Dr. Dhruv Mehta, Dr. Asha Chitnis, Dr. Shankar Shelke , Dr. Sandip Samanta and Dr. Madhavi Kelapure

**Duration of meeting:** Three hours

### Agenda:

1. Contribution of EC members for CP day
2. Midterm EC meeting in
3. News letter
4. New Memorandum
5. Selection of further presidents
6. A doc committee

#	Topic	Discussion
1	<b>CP day</b>	It is mandatory for each and every EC member to celebrate CP day on the 3 <sup>rd</sup> of October and send reports to the general secretary. Celebration should involve the local Government. Guidelines to celebrate CP day must be sent to new EC members.
2	<b>Midterm EC meeting</b>	It was decided that the midterm EC meeting will be held in February 2015. Venue: Bhubaneswar or Mumbai
3	<b>News letter</b>	All members of EC felt that the news letter should have 2 or 3 articles through which the members will understand how to use disability language. E.g. ' <i>mind your language</i> '. This language should also reflect the case symposia, lectures at scientific sessions of the annual conference.
4	<b>New Memorandum</b>	In an event of misconduct of any EC member of the IACP, the President and General Secretary will issue a memo to that member and he/she is supposed to respond in a stipulated time with the explanation of same. This memorandum was passed by the EC. This should be informed to the advisory board / board of directors
5	<b>Selection of further Presidents</b>	Board of directors is empowered with the selection of President after the term of EC members is over. Any member from EC does not have the power to interfere or suggest any change in the administrative matter of the IACP. Such members are liable to be excluded from holding any place in the Academy. This does not mean that there is no freedom of expression. However, it should go through right channels. Ratification of this resolution should be kept as one of the agenda of the next GB meeting.
6	<b>Adhoc committee</b>	EC can have Adhoc committees which will include professionals from all disciplines who will be willing to serve the academy in some way. One of the Adhoc committee members will be Dr. S. Ramaguru, MS Ortho, from Chennai as per discussion with Dr. Asha Chitnis, Dr. Sunanda Reddy is ready to be a part of Adhoc committee. She is also willing to be the editor of IJCP.

## NATIONAL CEREBRAL PALSY DAY CELEBRATIONS – BENGALURU, KARNATAKA, INDIA. 29<sup>th</sup> OCTOBER 2014



This year, the National Cerebral Palsy Day, was conducted under the aegis of the Indian Academy of Cerebral Palsy. This day was commemorated on 29<sup>th</sup> October 2014, by a group

of organizations working in this area at Bangalore.

Spastics Society of Karnataka, led this initiative under the leadership of Dr. M. S. Mahadeviah, Hon. Medical Director and Dr. Shashikala Gopaldaswamy, Hon. Additional Medical Director. The theme for this year was **parent professional partnership**.

The day was commemorated by a Candle Light March and Interaction with Medical professionals at Bangalore Medical College Auditorium.

The Candle Light March was flagged off by Dr. M. S. Mahadeviah, from Bangalore City Institute, at sharp 6.00 pm. A large number of parents and children from all the institutions walked and finally reached the Bangalore Medical College, where we were received by the Director cum Dean of BMC, Dr. P. K. Devadass and Dr. Gangadhar Belavadi, HOD, Department of Pediatrics, Vani Vilas Hospital.

The children carried many colourful placards with meaningful messages about Cerebral Palsy.

The program at the Bangalore Medical College began with an invocation by Mrs. Vani Prasannam, mother of Ananth, ex-student SSK and a person with Cerebral Palsy. Vani is a special educator at SSK and also a recipient of best parent award from the National Trust of India, 2009-2010.

Director of Spastics Society of Karnataka, Mrs. Rukmini Krishnaswamy then welcomed the gathering.

Dr. M. S. Mahadeviah, first introduced the concept of the Indian Academy of Cerebral Palsy and also spoke of the work done by the Spastics Society of Karnataka.

This was followed by a talk by the chief guest Dr. Devadass, who was highly appreciative of the initiative to spread



awareness about Cerebral Palsy and extended an invitation to Spastics Society of Karnataka to set up early intervention program at their hospital.

Dr. Gangadhar Belavadi, of Vani Vilas Hospital also appreciated the activities and wished the work all success.

Following this, Mr. Sonnad, parent of a person with Cerebral Palsy shared with everyone, his sense of joy, about his son's achievements. He was happy to share that his son was a BCA graduate, despite being severely handicapped and that this was because of all the interventions he had received, as a child and as a family.

Mr. Manjunath Ram Reddy, who works at Mindtree and is an engineer by



qualification, and is an ex student of Spastics Society of Karnataka, spoke next. He shared that his journey so far was the reward of the efforts of the rehabilitation team and his family. He stated that as an adult, the most important thing that one looks forward to is friendship.

This was followed by children tying friendship bows to the chief guest and the doctors who were participating in the program. The chief guest also tied a friendship bow to Mr. Manjunath, ex-student of Spastics Society of Karnataka.

Dr. Shashikala, President IACP, and Hon. Medical Director, Spastics Society of Karnataka, then gave the Vote of Thanks.

The Association of People with Disabilities (APD); Foundation for Action, Motivation and Empowerment (FAME) India; Shristi Special Academy; Academy for Severe Handicaps and Autism (ASHA) participated in the event.

The highlight of the day was that Orthotics Specialists and also Orthopedicians, Obstreticians, PG students from Pediatrics department & several undergraduates saw the theme-Parent professional partnership-realised & exemplified by persons with cerebral palsy becoming productive members of society. They were happy to interact with the children and

to hear their success stories. The theme will be deliberated upon all through the year to see how we can take it forward to strengthen it as an effective strategy in management of cerebral palsy & other developmental disabilities.

## CEREBRAL PALSY DAY - GOOD TOUCH AND BAD TOUCH



How many of us like hugs and kisses and touches from people we know, love and trust? So are those considered as GOOD TOUCH? YES

How about those same kind of touch from people we don't know or don't like or don't trust? Could those be considered as bad touches? YES

So its very important for us to understand and differentiate between the two different types of touches , sometimes it does make a difference as to who is the person touching us.

When someone touches us , it leads to an inculcation of a feeling inside. Good touch gives us good feelings. Bad touch makes us feel bad or uncomfortable.



So we discussed exactly this with our special kids at our Physiotherapy clinic in Dadar on 5<sup>th</sup> October 2014, as a part of IACP undertaking.

We had invited Dr Khyati Gada, a counseling psychologist, who took time off her hectic schedule to spend some time with our kids and did a workshop on GOOD TOUCH, BAD TOUCH to HELP

THE CHILD, HELP HIMSELF in this world.

This included some songs, videos and a lot of information to make them understand the differentiation between a GOOD and a BAD TOUCH and what should be done in case of a bad touch.

Parents and guardians are the primary educators of their own children. They should create an environment where children are free to ask them questions about their life and about their bodies.

This early experience of honesty and trust will then set the stage for each child's life long relationship with significant adults.



### KEY WORDS

- Say NO, tell the person that you don't like it and don't want to be touched.
- GET AWAY FAST! Run away from the person whose touch you don't like.
- CALL FOR HELP, You can scream as loud or make noise as you want no matter where you are.
- Believe in yourself, YOU DID NOTHING WRONG, your body belongs to you.

## IACP WORKING COMMITTEES

### Research

**Chairpersons** - Dr.Ashok Johari & Dr.Shashikala

**Members**-Dr.Gajanan Bhalerao, Dr. Samanta, Dr. Anand Verma

### Medical Education

**Chairperson** - Dr.Shashikala

**Members**-Dr.Sunanda Kolli Reddy, Dr. Anand Verma & Dr.Satendra Singh

### Community Awareness

**Chairperson** - Dr.Dhruv Mehta

**Members**-Dr.Shelke, Mrs.Shobha Sunder, Dr. Ramaguru

### Newsletter & Publications

**Chairperson** - K.D.Mallikarjuna & Dr. Sunanda Kolli Reddy

**Members**-Dr.Samanta, Dr. Madhavi Kelapure, Dr. Kruti Shah

### Assistive Technology

**Chairperson** - Dr.Dhruv Mehta & Dr.Shaktidas

**Members**-Dr.Anand Verma, Dr.Anita Suresh OT, Dr.Trupti Nisarge

### Conference & Protocol Committee

**Chairperson** - Dr.A.Johari & Dr.Shashikala

**Members**-Dr. Asha Chitinis, Dr.Gajanan B. , Dr.Shaktidas

### CP Day Celebration Committee

**Chairperson** - Dr.Shelke & Dr.Vipul Shah

**Members**-Dr.Rujuta Mehta, Dr.Anjali Desphande, Mrs.Shobha Sundar

### Disciplinary Committee

Dr.M.Mahadeviah, Dr.A.Johari, Dr.Anaita Hegde, Dr.Sunanda Kolli Reddy

### National & International Liasoning Committee

**Chairperson**-Dr. Ashok Johari (IOA.POSI & POSNI)

**Members**-Dr.G.Shashikala (Mackeith Press & Canchild), Dr.Anaita Hegde (IAN& IEA), Dr.Samanta (IAP), Dr.Vipul Shah (AACPD & ICNA) Dr.Asha Chitnis (IAP), Dr.Ananda Verma(APMR), Dr. Trupti Nikharge (AIOTA)

### Fund Raising

**Chairperson**-Dr.Anaita Hegde & Dr.A.K.Purohit

**Members**-Jasmit Arora, Asha Sonavane, Dr.Ramguru

### Webmaster, Cyber Space & Media

**Chairperson** - K.D.Mallikarjuna

**Members**-Taral Nagda, Sanket Khadiikar & Harish Badiger

All committees have the President & Gen ,secretary over seeing & they all need to interact among themselves & give us quarterly feedback. Members from one committee are welcome to give relevant suggestions & opinions on other committee inputs.

**BOOK REVIEW**

Empathetic identification with disability.

By Mrs. Rukmini Krishnaswamy-Director, Spastics Society of Karnataka, Indiranagar, Bengaluru.  
p.r.krishnaswamy@gmail.com.

ON

Disability studies in India; Global discourses, local realities. Renu Addlakha, editor. Routledge India; 2013, 441 pp.  
ISBN 978-0415812122 Rs 846.00.

Disability is a subject arousing much professional interest, research effort and analysis and is the focus of expert Perspectives yielding documentation and literature from Scholars, policy makers, people with active engagement in the subject and "subjects" with a vast variety of disabilities. This Book is a remarkable effort to string together contemporary research in India, the conditions of disability on a vast canvas of gender, class, caste, and locational disability (eg rural/urban) and their effect on policies, health issues, culture and family. It is a unique document in terms of content, style, relevance and analytical quality. The collection which features chapters from seventeen authors is superbly edited by Ms Addlakha, a scholar known for her interest and writings on the sociology of medicine, mental health as a facet of public health, ethics, gender, family, disability and society. The volume reflects her broad perspective and deep knowledge of the field, and will serve as a reference source for a wide spectrum of people engaged in disability issues.

Beginning with a chapter on history of disability in India, Shilpa Anand analyses the inhuman handling of the microcephalic by some, and the protection received from others as an example. Thus there is a marginalizing attitude on the one hand and empathy and acceptance on the part of a few, on the other. Contemporary attitudes have a distressing similarity to those in history, showing the marginal impact of technology and associated developments, if any. Jagdish Chander's essay on rights and the emergence of disability studies provides a guideline for both advanced scholars and community based workers on disabilities. His tracing of the evolution of attitudes from Manu's exclusion philosophy to the more recent approach of looking at problems from the social action angle is fascinating and instructive.

Sunderesan tracks disability-related policies and actions through the past five or six decades, with a particular focus on the millennium development goals set in 2000 raising hopes for action, as strategies and goals are thoughtfully developed and plans laid out. This is a positive development indeed!

Prenatal diagnosis is a component of "Family care and wish (!)". This poses grim issues to be dealt with, the most relevant and ethically important being sex selection versus medicalisation of disability, involving deep cultural overtones and ethical issues. An innovative suggestion which can be explored is for the genetic counsellor's role to be played by persons with disabilities as a perspective-facilitating strategy.

Chakravarti's section on comprehensive and long term care has a thoughtful analysis, with sample narratives, of the complex problems, both physical and emotional, faced by care givers.

Clues for deriving coping strategies are indicated here and elsewhere in the book. Mahotra and Shubhangi Vaidya's section on intellectual disability constraints in Delhi and Haryana is illustrative and informative. The influence of the rapid changes in the structural and cultural milieu in society on intellectual disability, whether in terms of definition, severity, or functional consequence cannot be underestimated. The impediments people with disability experience in urban India today are enormous. One has to view them from the human rights angle and seek redress and remedy. Nandini Ghosh poignantly conveys the grim lot of the woman with disability. The young child growing to womanhood faces sexual exploitation, devaluation of her body in the public space, and further inhuman marginalisation, all of which need to be addressed.

The editor's own writing on "Body politics and disabled femininity" - dealing with the perspectives of adolescent girls from Delhi - traces diligently how the concept of medical disability has acquired wider dimensions- the need for self-advocacy, and political action to achieve a more supportive, and understanding environment to ensure dignity. In short, strong advocacy is necessary for women with disability to be heard and honored by the public.

Identity provides empowerment. Hearing impairment, a good example, has its own culture, space and location. "The inner world of adolescent girls with hearing impairment: Two case studies" - is an unforgettable part of the narratives in the book. That the blind can see the world with senses other than the visual, and the illustrations given thereof are a poetic illustration of the potential for human creativity beyond what we label as handicaps. There are sections devoted to mental illness, psychiatry in self and identity constructions, with inclusion of choices of women users.

Much of disability literature inevitably assumes a rhetoric complexion. The essay on participation, inclusion and law rightly titled "Beyond the rhetoric", by Jeela Ghosh, boldly and unequivocally argues for legalizing social inclusion, with appropriate illustrations. This essay, in the reviewer's perception, provides relief from the jargon and juggling of phrases and arguments, inevitable in a field such as disability.

The reviewer having spent over five decades of her active life in the field, as a student, teacher, counsellor, Institution builder, advocate and most importantly, connected to hundreds of families and thousands of young people of all description of disability, labels, medical, social and cultural, has not come across a collection of essays such as these. While generic in nature, they are specific to our culture; they are analytical, yet deeply sensitive and empathetic; theoretical, yet practical in giving leads and directions. It is commendable that the editor and the erudite authors have identified so deeply with a human condition from which profound lessons are yet to be learnt.

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## PARENTAL NEGLECT IN DEVELOPMENTAL DISABILITIES. HOW TO DEAL WITH PARENTS WHO DO NOT HEED TO ADVICE IN INDIAN CONTEXT?

**Mrs.Rukmini Krishnaswamy & DR.G.Shashikala**

This tutorial will have two themes which are global issues. The extent of these problems is probably different in different settings but the outcomes as far as children are concerned are the same everywhere.

- Parental Neglect in Developmental disabilities in an ethical framework adapted to the cultural milieu of developing countries would be our first theme. In our country, 60% of population lives in rural setups and they have poor access to neonatal and developmental care. This of course may change with the introduction of early diagnosis and early intervention programs introduced by the National Rural Health mission for creating health initiatives aimed at solving the three Ds [Defects, Deficiencies and Disabilities]. One dominant contextual factor we regularly deal with is strong, culturally influenced family systems and differing dynamics in nuclear, joint and extended family types, with their myriad ways of dealing with the additional responsibility of parenting special children.
- How to deal with parents who do not take professional advice would be our next theme. We share our learning and experience in dealing with this recurring challenge to service providers with an accent on ethical issues & contextual limitations involved.
- Structure of the tutorial will be under the following headings.
  - Defining parental neglect in the context of disability
  - Epidemiology of parental neglect.
  - Dealing with parents who do not take professional advice
  - Rationale behind parental noncompliance
  - Role of communication in parental noncompliance
  - Family centered service- Is it for all?
  - Capacity Building as a solution

### **Defining parental neglect in the context of disability**

#### **Case scenario**

1] An 18 yr old young man was referred by our senior therapist who saw him in a mosque to the transitional care unit for evaluation for prevocational training. Mother accompanied him & the summary of the case was -he was a First born preterm child who needed exchange transfusion on the 3rd day of birth, had a stormy perinatal period , critically ill but survived at a tertiary neonatal care unit with good medical help .Developmental delay was recognised by parents at 9months & was seen in a super speciality centre with the diagnosis of MRCP. Parents were told that he may not survive & were advised to take him home & look after him as long as he would live. Father was a daily wage earner from a nearby village, mother an illiterate housewife but a strong person who would pray four times a day, would put the child in a sand pit for 4-6 hrs as advised by a local CAM practitioner & was happy when he started walking independently at 8 yrs of age in spite of his troublesome abnormal movements.

He did not go to school as other children would tease him for his dyskinetic movements but learnt Koran recital flawlessly, helped his brothers at home as they all went to school, worked in his uncles packaging business which got closed down. Parents were looking for some training for earning his lively hood. When

asked as to, why no treatment was considered, her reply was "this doctor in a big hospital told us no treatment was possible & we did not have money to go around".

The Young man on assessment turned out to be an intelligent Person with GMFCS1, MACS 2, CFCS2 dyskinetic cerebral palsy who had slow, dysarthric speech but was an unhesitant converser, happy & sprightly. In spite of their economic background, they were well adjusted & mother was keen to do her best after seeing our centre. He was put on syndopa, communication & functional training.

3 months later, his happy mother came back to us saying the medicines & training were helping him & he is happy to be in our centre. The mother dazed us by saying , "I wish we had brought our son here 18yrs back!"

Is this a case of parental neglect & what are the reasons?

By definition, parental Neglect implies- "Any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation; or an act or failure to act which presents an imminent risk of serious harm." Consequences could be-physical abuse, emotional abuse, sexual abuse, even death and abandonment from parents. We will concentrate only on the concept of doing serious harm with regard to the developmental outcome for children in this module.

This generalized definition needs a re look with reference to families with developmentally different children as above. Neglect can occur both from acts of omission and commission as implied in the definition. In case 1, this was not intentional, but certainly an act of omission due to a communication of poor prognosis from a big institution doctor. In spite of it, parents did what was possible for them & the mother's traditional belief in her religion was an excellent coping strategy. With good availability of services & adequate communication, this emotionally strong family would have done better. Decision making & prompt action or non action can be due to differing perceptions both from parental settings and professional views. ETHICAL DILEMMA- when is the right time to prognosticate? Was n't it a professional lapse in communication? Was the concerned professional underestimating parental competence on the basis of their economic background? What were the barriers in this scenario?

#### **Case scenario 2**

Mr.P. a 25 yr old acheiver , wheel chair enabled, well educated & employed came for a consultation for increasing fatigue. He was a full term breech delivery with outlet forceps application for a bighead. Spastic Diplegia was recognised early, got early intervention up to 12 yrs .As he was a brilliant child & mobility was not moving beyond crutches, well educated, upper middle class parents decided on concentrating on his education without pursuing any rehabilitation services. He had two fractures in the ensuing 13 yrs prior to consultation. Osteoporosis was obvious on radiological investigation. During history taking, mother came out with the startling history that the young man was never given any milk since birth as he had lactose intolerance. Parents had not informed the EI set up as they thought that it was not their concern & thought his osteoporosis was natural to his movement limitation. He was on to Functional impairment syndrome with contractures & deterioration to GMFCS 1v from 111.

This was a situation of Neglect due to attitudinal barriers of parents, informational barrier & poor communication between parents & professionals.

Ethical issues-The risk factors for neglect are more likely to be characteristics of the parents than specific child characteristics. Harm done was unintended If neglect is defined in terms of harm to the child. There is no longer the need for the subjective interpretation of parental intention (Connell-Carrick, 2003). However, the same behaviour and the same harm done to children may be judged differently depending on how the intentions of the parents are perceived. Some parents are unable to meet their child's basic needs despite good intentions (for example, through poverty-case 1). Others may lack the knowledge to provide a nutritious diet, or lack the understanding of child development [case2]

**Case Scenario 3.**

A 6 yr old was brought for a consultation for post traumatic spastic cerebral palsy. Well educated NRI parents had spent a fortune in a CAM set up on the recommendations of a friend who was a pediatrician. Mother was extremely remorseful for having allowed her child to play unsupervised in a dangerous situation. Child needed a spinal fixation at a very young age because of an associated spinal deformity which made her ADL care more difficult & family was viciously drawn into denial & bargaining for cure & normalcy with plenty of window shopping. They stopped coming to the centre when referred to seek psychosocial counselling for the mother

Minty and Pattinson (1994) incorporate this into their definition of neglect by qualifying that the child's basic needs are not met, 'in spite of the parents having the economic resources to meet these at a basic level'. [ Child neglect-Dr Johanna Watson 2005].

Ethical issue here is how to convince the parents on stopping window shopping & doing greater harm to the child by losing out on time. Lot of parents perceive this kind of prognostication as the lack of expertise cover up by doctors. How do we react to our own colleagues' false promises on possible cure & counsel parents accordingly?

**Case Scenario 4.**

Miss. K. Aged 9, Preterm LSCS delivered for Asphyxia & decreased foetal movements - had GMFCS- 111 bilateral spastic cerebral palsy, received good & appropriate early intervention but had congenital acetabular dysplasia with Migration of more than 40% as early as 7 yrs. Derotational osteotomy was advised. This was a rich well educated , industrialists' grand daughter who had acceptance issues with her grandmother who believed that nothing would happen to her as she was born at an inauspicious time. This constant cribbing at home had affected the child's self esteem so much that she refused to undergo surgery thinking she will never improve. All the family members were given adequate counselling which was of no avail but a chance meeting with an earlier operated child made so much of difference that she underwent the surgery. She did develop transitory learned helplessness as she did not gain independent walking following surgery but recovered completely after evaluation with child apperception tests & continued counselling & group therapies where she received leader's role & peer support & appropriate Functional therapy & continues to do well both mobility & educational wise.

**Discussion:**

Attitudinal barriers & dynamics of joint families are big ethical dilemmas in Indian subcontinent. Till what level of management can parents involve grandparents & how do we help parental decisions without affecting family harmony?

Acts of omission as well as commission may result in this and these issues need to be assessed based on the type of family, their coping skills, services available and the parental ability to utilize the options and address informational barrier of not being aware of the future serious consequences. For ex: Not getting orthopedic surgery at a given age will in long term damage the hips of children with cerebral palsy which may not be realised by parents.

More than innate parenting skills , prognostication given by professionals, information and accessibility of services has a lot to do with the syndrome of parental neglect [the term syndrome is used to convey the myriad behavioral possibilities associated with this phenomenon].They require supports & processes to effectively & emotionally cope with the added demands of parenting special children . These support systems can be-

**External**

- finances, transport,
- professional
- family
- community support

**Internal**

- Emotional .
- Cognitive.
- behavioral.
- [Rita peshawaria etal]

**Epidemiology of Parental neglect.**

Children who suffer a disability, especially boys, are more likely to be neglected. For children who already have a developmental disability, 10 to 25 per cent are likely to experience abuse and neglect. (Trocmé et al., 1998). As many as 11.5 per cent of children with developmental delay suffer neglect compared with only 1.5 per cent of other children (Verdugo, Bermejo & Fuertes, 1995, cited in Brown& Schormans, 2004). According to World bank economic review in 2008, disability is associated with 10% point increase in the probability of falling in the two poorest quintiles of poverty.

**A] Applied child developmental perspectives on causation of parental neglect**

**SCIENCE OF CHILD DEVELOPMENT  
FROM GESSEL TO GERALD EDELMANN**



**URIE- BRONFENBRENNER'S SOCIO ECOLOGICAL MODEL**

**DEVELOPMENT IN CONTEXT**

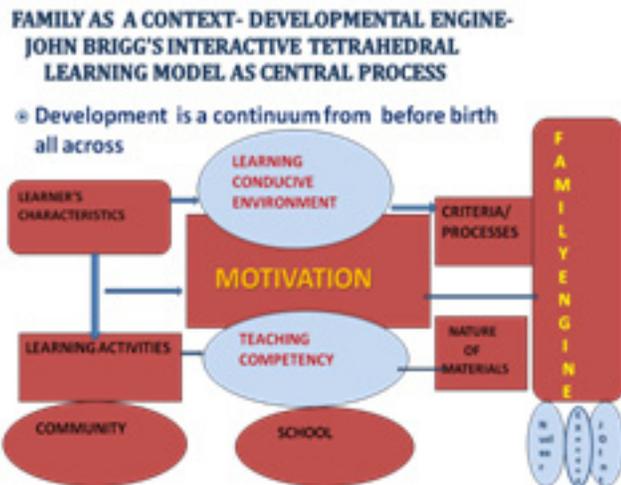
**1] Urie Bronfenbrenner's Socio ecological model**

The child, with a given genetic predisposition, is seen as being at the centre of a series of concentric circles. The family is still conceptualised as the most powerful influence on a child. However, other proximal influences such as the child's extended family, peer group, school and the local neighbourhood are also included. Furthermore, distal influences such as the media, governmental family policies, current cultural beliefs and values are seen as contributing to shaping a child's developmental health. In between the proximal and distal influences are such influences as the parents' work places, parents' informal and formal supports and the interaction between them. There are innate risk factors at each level from micro, meso, exo and macro level barriers.

**2. A pathway approach**

The developmental pathway or trajectory a particular child follows is hypothesised to be a function of multiple proximal and distal factors (Rubin, LeMare & Lollis, 1990; Belsky, 1993). Proximal influences that support or erode parental efforts are many. For example, the level of pre-natal care received, parenting style, family situation and parental mental health can be considered, as well as distal influences such as work/family policies, availability of child care and societal attitudes. Some of these can act as risk factors for abuse or can act for improving child's resilience & protect them as well.

In understanding the family as a singularly important contextual factor in child development, one also needs to superimpose John Brigg's tetrahedral model of interactive learning as a central process at family level also.



**UNDERSTANDING PARENTAL COPING:**

Parental behavior is an outcome of the parental reactions to the disability of their child and resulting coping which is an amalgam of far too many influences. [see the box ]

Parental coping is an individualistic and variable, cognitive, behavioral and emotional effort to Overcome the stress of parenting a special child and generalizations across disabilities do not work although they are very similar across disabilities and at times in particular settings.

**B] Parental Neglect as a subset behavior in negative coping.**

The first year of life is a particularly vulnerable period for children—they are not only at risk of infectious diseases and other health conditions, but also at risk of violence, abuse, exploitation and neglect. The United Nations Study on Violence Against Children highlights that in some OECD (Organisation for Economic Co-operation and Development) countries, infants under one year of age are at around three times the risk of

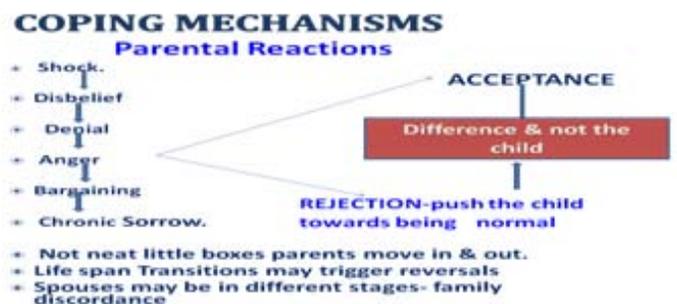
homicide than children aged one to four, and at twice the risk of those aged five to 14. However, the true extent of violence during the early childhood period is unknown given that it mainly occurs in private settings such as homes and institutional environments, and that social and cultural norms may influence the hiding and/or condoning of certain violent behaviours. Children with disabilities are more vulnerable to physical, sexual and psychological abuse and exploitation than non-disabled children. Social isolation, powerlessness and stigma faced by children with disabilities make them vulnerable to violence and exploitation in their own homes and in other environments such as care centres or institutions. Research shows that children with disabilities are three to four times more likely to experience violence than their non-disabled peers. Data for 15 countries showed that in seven countries parents of children with disabilities were significantly more likely to report hitting them. Children with disabilities are a distinct high-risk group for abuse and neglect and are on average two to three times more likely to be maltreated than are children without disabilities in their homes and in institutions (Sullivan & Knutson, 2000a).

An estimated 175,000 to 300,000 children with disabilities are maltreated each year (Westat, 1993)-[World Health Organization 2012]. Children with disabilities are at an increased risk of violence for a number of reasons including cultural prejudices and the increased demands that disability may place on their families. Children with disabilities are often perceived to be easy targets: powerlessness and social isolation may make it difficult for them to defend themselves and report abuse. Exposure to violence, neglect or abuse can lead to developmental delays and behaviour problems in childhood and later life which are additive to the already existing impairments.

**c] Parental reactions- road map for adjustment & coping**

Parental reactions after the disclosure of diagnosis are a series of behavioral sets starting from Shock- Disbelief - Denial-anger- bargaining- Chronic sorrow and then result in either acceptance or rejection of the diagnosis over a period of time [Flowchart below].

The perception of serious harm also changes temporally as the child grows up particularly when parents realise that the child will not out grow the limitations with age and begin to face the reality. Far too many parents come back to us with frustrations and projected anger which may get directed to the child- for ex- post surgery outcome may be attributed to the child's non cooperation than to the inconsistency of parents to attend therapy sessions and may breed a resenting attitude- "nothing works with him" and a vicious circle of neglect may ensue.



*Continued in next issue...*

*Full text is available on [www.iacp.co.in](http://www.iacp.co.in)*

## Workshop for Therapists a report on Management Challenges in Cerebral Palsy Across Life Span - Drawing A Roadmap Through Knowledge Translation & Prevention As Per ICFDH-WHO-2001

Conducted by : Foundation for the Prevention of Disability And  
Department of Human Resource Development and Training, Spastics Society of Karnataka  
on 31<sup>st</sup>. January 2015 (Saturday) and 1<sup>st</sup>. February 2015 (Sunday)  
at Conference Hall, Spastics Society of Karnataka,  
No.31, V Cross, off V Main, I Stage, Indira Nagar, Bangalore - 38. Phone: 080-40745931/11

A workshop for therapists was conducted by Foundation for the Prevention of Disability and Department of Human Resource Development and Training, Spastics Society of Karnataka On 31<sup>st</sup>. January 2015 and 1<sup>st</sup>. February 2015 at Bangalore. The title of workshop was ' Management



Challenges In Cerebral Palsy Across Life Span - Drawing A Roadmap Through Knowledge Translation & Prevention As Per ICFDH-WHO-2001'

The program began with Invocation by Dr. Shashikala Gopaldaswamy, and then by our student Rakshit. The lamp was lit by Dr. M. S. Mahadeviah, Dr. Shashikala, Dr. Gautam Kodikal, Dr. Puja Dhande, Dr. Asha Chitnis and Rakshit. Dr. Shashikala Gopaldaswamy welcomed all the faculty & participants.

Dr. Puja Dhande and Dr. Shashikala then conducted an ice breaking session with the participants, instilling in them the sense that they were going to lead the parents who may be completely uninformed about the disability, therapy goals and about expected outcomes and the options that exist beyond the diagnosis of disability. The role of therapist as a guide, philosopher, Friend & bridge in negotiating the unknown terrain with barriers at each level in parenting the challenged children who need nurturing from bud to bloom was highlighted.

Following this Dr. M. S. Mahadeviah, spoke about the Models of Therapy in the Indian Context. He highlighted the importance of multidisciplinary approach. He emphasised that every family wants to elicit information from the more accessible therapists and how it could be counterproductive for therapists to offer prognostic statements without adequate interdisciplinary interaction.

Following this Dr. Asha Chitnis, presented about Goal Setting and Priorities and the Gross Motor Functional Classification System as a means to that end in the management of CP. She presented actual goals articulated and written by her for the children she worked with and demonstrated videos of the children which helped in seeing the steps being executed.

Dr. Gautam Kodikal then spoke about the Principles of Orthopedic surgery in Management of CP. He highlighted the need for careful consideration of the functional outcomes and for a detailed discussion in this regard with the therapists and the family, before undertaking surgery. He also provided guidelines for the therapists' role in deciding surgery and in post operative care. His advice to temper the parental expectations of normal walking & stress on single event multilevel approach avoiding birthday syndrome & rural parents being more understanding & accepting the outcomes was very educative.

Mr. Saravanan Sundarakrishnan, then elaborated the biomechanics of gait cycle for planning an appropriate intervention for gait management in cerebral palsy particularly in prescribing orthotics which are in line with the biomechanical needs individualised to the child's functional needs & these facts were very informative..All the recent types of orthotics were circulated among the participants.

Dr. Puja Dhande went on to explain the necessity of a detailed report and clear diagnosis, as a cornerstone for the treatment plan of the therapist. She highlighted that many times, the lack of this kind of clear and precise communication created a huge demand on the therapists from the parents, who expect complete cure and sometimes the therapists has to guess at the diagnosis when they do not get clear diagnosis & expectations from clinicians.

Post lunch, Ms. Dipti Bhatia, a person with visual impairment, from Chennai, Vidya Sagar, who has taught children with CP, spoke about the perspectives of the disabled person as a stakeholder. She pointed out the need to ask for and understand the priorities of the stakeholder in setting goals, and in asking the child about his or her comfort with the intervention choices being made.

Dr. Satish Girimaji, Professor and Head, Dept. Of Child and Adolescent Psychiatry highlighted that the Government worked by set rules and sought clear grouping of conditions to implement actions. He mentioned that all government processes worked faster, if there was a precedent and that it was necessary to show the government a previous instance

Dr. Shashikala Gopaldaswamy then spoke about prognostication using ICF framework. She highlighted the necessity for realistic & hopeful prognostication and also about the necessity for doctors to say "I don't know" appropriately. She brought forth that change is a developmental constant and taught the therapists about SPCCBEM, which are part of the new definition of CP. She pointed out that the Gestalt Approach was the best, as it reflected the concept of "functionality" and looked at the needs of the person as a whole, rather than just a set of description as per the perceived perspectives of different professionals using the analogy of elephant & the 10 blind persons. She explained the ICF system and the motor growth curves & also age band wise management & prognostication as a continually changing, time related process across life span & the new creative approach of 6F'S advocated by DR.Gorter & Prof . Peter Rosenbaum-Function, Family, Future. Fitness, Friendship & FUN as the guidelines at all ages

#### Day 2

The day began with Dr. Asha Chitnis, speaking about the Sensory Issues in CP. She began by first asking the therapist to identify which was primary, sensory issues or motor issues & how they need to be treated keeping activity & participation goals. Some easily available sensory stimulation apparatus were shown. She again stressed on moving from methods approach to SMART goals- Specific, Measurable, Achievable, Reachable, Time limited goals as advocated by DR.Margaret Mayston.

Dr. Vishnuvardhan Reddy then spoke about the GMFM administration and also about selection of appropriate goals as per domains identified in gmfm as goal areas.

Dr. Puja Dhande then spoke about MACS (Manual Ability Classification System) and FCS, with vedios which made it very graphic. She also stressed that the FMS needs to be used in conjunction with GMFCS & not as a substitute to it..

Dr. Inayathulla then spoke about the Barry Albrights dystonia scale and Dyskinesia. Impairment scale with appropriate case photoes. He defined terms in usage like dyskinaesia, dystonia & choreoathetosis.. & stressed on the need to differentiate them, measure them to set appropriate management strategies

Dr. Ruby Singh spoke about COGS, how it is based on main events in gait cycle & is helpful for setting therapy goals .in gait training

Dr. Anita Suresh spoke about the EDACS which is the latest in the FCS approach. She highlighted the role of posture & appropriate sitting position, adaptations, textures of foods, physical help & adaptations only to the extent of supporting the child move towards independence as much as possible..

Mrs. Shubhra Shanker Vinay spoke about the CFCS, the micro to macro concept from speech to communication levels along

with the assessment steps used by Speech & auditory pathologists.

Ms. Manisha Gokhale and Ms. Surya Vaz, did a small workshop on communication skills for the therapists. They created activities for the



therapists to reflect on their responses to the clients & how to be mindful & empathetic in their communication styles.

The post lunch session was a hands on session, with children in five different functional levels and the 25 participants were randomised into five groups, each mentored by one of the SSK therapists and Dr. Puja, Dr. Shashikala, and Dr. Asha Chitnis.

After this, everyone assembled and the child seen was discussed, in the presence of Dr. Shashikala, Dr. Gautam, Dr. Mahadeviah, Dr. Asha Chitnis and Dr. Puja Dhande. & Mr.Saravanan. Some parents were part of this session. Many questions on goals and the rationale for these goals were discussed and Dr. Shashikala brought out by demonstration, the importance of MRIs as tool not only for anatomical localisation of the pathology in the brain but also helpful in understanding pathogenesis, prognostication as well as in strategising some interventions & anticipate certain co morbid problems & progression challenges across life span.. The appropriate walking aids & orthotics for each child were discussed & some life span issues were presented & the client's needs were also highlighted. Each group also learnt GMFM administration along with other functional classification systems & interpretation along with anatomical classification which was highlighted in the lecture on prognostication. Functional impairment syndrome & its prevention, importance of Vit.D evaluations & surgical timings & possibilities were also discussed. Rare syndromes of Cerebral palsy due to mitochondrial encephalopathy & an adolescent with tremors & a young man using a powered wheelchair & being mobile enough to enjoy outings were presented & management options including methods to make botulinum therapy more economically feasible by sharing in groups were highlighted. Parental cooperation in evolving parent-professional partnership was highlighted & some parents present in the meeting along with the children were cheered.

The proceedings concluded with a summing up and a Vote of Thanks by both Dr. Mahadeviah and Dr. Shashikala.

# National Cerebral Palsy Day

October 2014

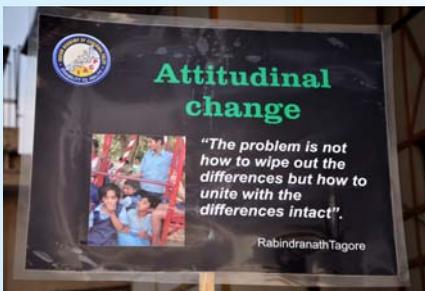
Mumbai



Samvedna, Latur



Spastic Society of Karnataka, Bangalore



# 10th ANNUAL NATIONAL CONFERENCE OF INDIAN ACADEMY OF CEREBRAL PALSY

18th to 20th DECEMBER 2015. Cuttack, Odisha



## Welcome to IACPCON 2015

With great pleasure and enthusiasm, we welcome you to join the 10th Annual National Conference of the Indian Academy of Cerebral Palsy jointly organized by the Indian Academy of Cerebral Palsy, Odisha Chapter and Swamy Vivekanand National Institute of Rehabilitation Training and Research. The conference will be held from 18th to 20th December 2015 in Cuttack, Odisha. Odisha is the land of sand, silver, sculpture and spirituality. The main mission of the Indian Academy of Cerebral Palsy is to contribute to the welfare of children with cerebral palsy and related neuro developmental disabilities and their families by developing, strengthening collaborating and research among all health providers involved on the management of cerebral palsy. The conference theme - "Cerebral palsy: Inter-disciplinary management across the life span" will provide high-quality dissemination of information in the Basic science, Prevention, Diagnosis, Treatment and Technical Advances as applied to persons with cerebral palsy and other childhood-onset disabilities. The objectives will be addressed through plenary session, workshops, oral and poster presentations and much more. The conference will showcase the best in cerebral palsy research and practice and provide excellent opportunities for networking.

### Registration Tariff of the Conference

	Till 31 Oct.15	After 31 Oct	Spot
Member	2500 INR	3000INR	4000 INR
Non-Member	3000 INR	3500 INR	5000 INR
Student	2000 INR	2500 INR	3000 INR
Overseas	120 \$	180 \$	200 \$
SAARC	70 \$	75 \$	100 \$

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**DR SAKTI PRASAD DAS**, ORGANISING SECRETARY, IACPCON2015  
ASST. PROFESSOR & HEAD, PMR DEPT., SVNIRTAR,CUTTACK, ODISHA-754010  
Email: sakti26632@yahoo.com. Mobile-9437016874.

### Programme

- Video Gait Analysis and Gait Abnormalities in CP
- Injection Technique-Phenol and Botox by Nerve
- Stimulator and Ultra Sound Technique
- Understanding of Children with Cerebral Palsy in Functional Way.
- Management of Feet Problem
- Neck and Trunk Control in Cerebral Palsy
- Splinting of C.P. Children
- Application of Sensory Integration Intervention for cerebral Palsy
- Application of NDT Approach for Cerebral Palsy
- Dyskinetic Cerebral Palsy
- Posititonal Assistive Technology for Cerebral Palsy
- Tone Reducing A.F.O.-the Benchmark of Lower Extremity Orthotics for Cerebral Palsy
- Orthotic Therapy for Cerebral Palsy-Do's & Dont's.

### International Faculty

Prof. Freeman Miller-USA  
Prof. Reinald Brunner-Switzerland  
Dr. Ana Presedo-France  
Dr. Abhay Khot-Australia  
Dr. Devanshu Rai-Australia  
Dr. Hyun Woo Kim-Korea  
Prof. Javed Iqbal-Pakistan  
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