IAPCDG
Newsletter
INDIAN ACADEMY OF PEDIATRICS CHILDHOOD DISABILITY GROUP

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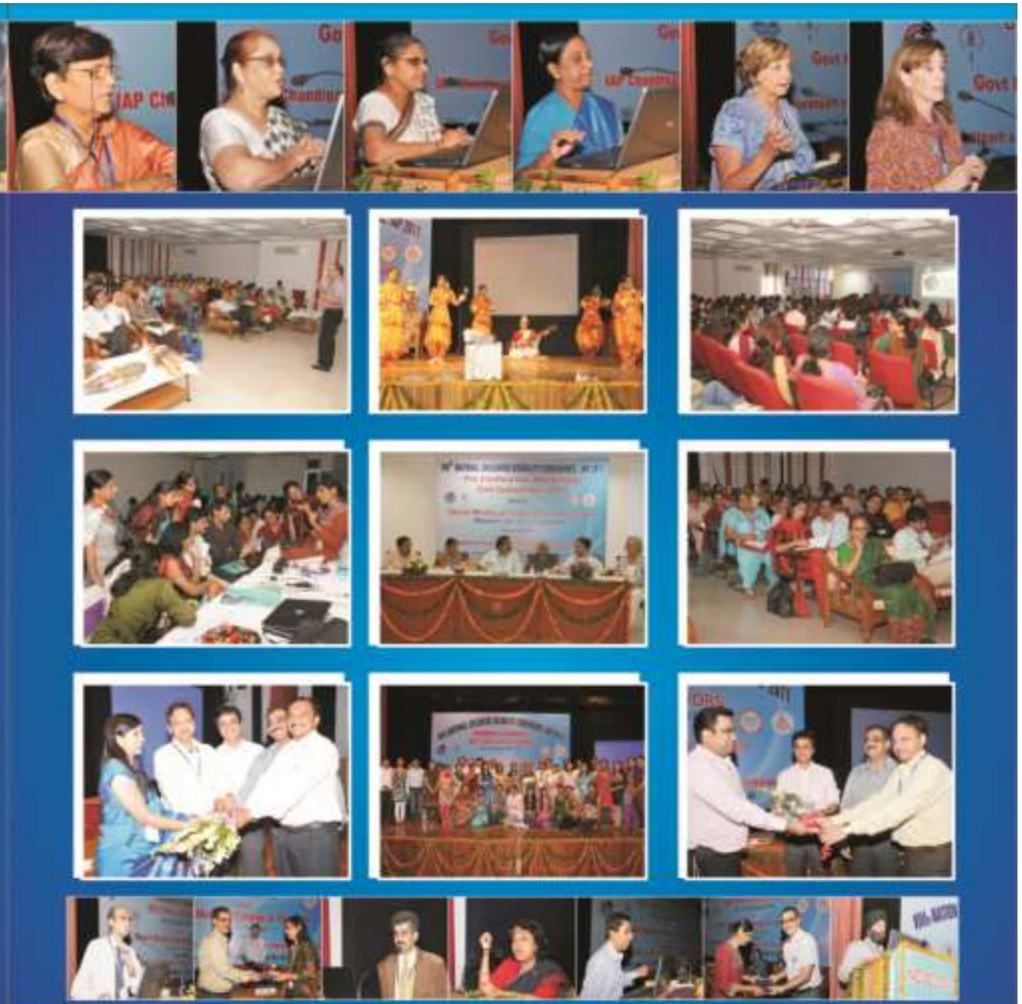
8th ANNUAL NATIONAL CONFERENCE
2- 4th SEPTEMBER 2012, CHANDIGARH



Prasoon Joshi, Shahnawaz Hussain, Hon Prime Minister,
Madhu Yasky, Hon Minister Krishna Tirath, Dr Samir Dalwai,
Hon Minister Sachin Pilot with the HUNGAMA Survey Report

Mr Baijayant Jay Panda, The Honorable President Mrs. Pratibha Patil,
Mr Prasoon Joshi, Mr Shyam Benegal, Dr Samir Dalwai,
Mr Sachin Pilot, Mrs Harsimrat Kaur Badal, Mr Neeraj Chandra Shekhar

open arms, read it through, offer your comments and suggestions and most importantly, make it useful in your day-to-day practise as well as recommend it to other Pediatricians and para-medical professionals.

We have also had a very successful annual conference National Childhood Disability Conference (NCDC) 2011 organised by our dynamic Joint Secretary, Dr Chhaya Prasad hosted at Chandigarh. The conference offered excellent discourse delivered by eminent National as well as International Faculty like Dr Waheeda Pagarkar, NHS, UK, Dr Jane McGrath, Dr Catherine McClain and Dr Patricia Osbourn, Centre for Development and Disability, New Mexico, USA.

The Poor Scholastic Performance Programme, under the aegis of the Presidential Action Plan for 2011, was held at Chandigarh, New Delhi, Cochin, Coimbatoore, Trichi, and Kolkata covering all zones well. The PSPP is very compellingly coordinated and managed Nationwide by the ever hard working and smiling Dr Jeeson Unni! We invite you to conduct the PSPP in your Zone, State, City or Village. The CDG is happy to provide all the scientific and academic logistics and support.

Regarding the extremely important issue of Advocacy, our founders Dr SS Kamath, Dr Abraham Paul and Dr Jeeson Unni continue to offer yeoman services in the field of Newborn care, Hearing Screening and Rehabilitation and Adolescent Inclusion.

As your Secretary, I have had the honour to be very closely associated with two National Movements- the Young Parliamentarians' Citizens' Alliance Against Malnutrition and the Save the Girl Child-Movement against Female Foeticide.

As part of the Citizens' Alliance Against Malnutrition, we had the opportunity to advocate the issue of Malnutrition with resultant catastrophic effects on Growth and Development to the Honourable Prime Minister on 2 December 2010 and the Honourable President of India, on 8th August 2011. The year began on a high note for advocacy with the Prime Minister releasing the HUNGaMa (Hunger And Malnutrition) report on 10th January 2012. We need to reiterate the devastating consequences of malnutrition on the developmental status of children, especially those below 3 years of age.

All our members continue to offer their untiring services vide the Right to Education Act throughout the country. The Persons with Disabilities Bill is soon to be considered and will offer substantial benefits to the community. Many States continue to recognise the Rights of Children with Learning Disabilities; many more need to join the fold. To this end, Dr Jeeson Unni and Dr Chhaya Prasad have launched a National Campaign. We need to strengthen their hands as well as those of the many who continue to serve CSN without any support or encouragement.

We, as the CDG, are the voice of those nameless hundreds. We derive our strength from our members who continue to guide and mentor this movement across India.

New ideas and ventures for services for CSN continue to be sought after. It is proposed to set up an online forum (google groups/yahoo groups) which will provide a platform for this interaction. We request you to write to us at cdgiap@gmail.com with your current email and geographical address. Please share the subject or issue in the field of Disability or CSN that interests you. It would be a pleasure to have coordinated efforts between members of the CDG.

Last but not the least, I thank all the office bearers of the CDG for their excellent team spirit, cooperation and encouragement. But most of all, I thank all of you for your continued untiring efforts in the service of Childhood Disability.

In Academy Service.
Sincerely.
Samir Dalwai
Secretary,
Childhood Disability Group,
IAP
cdgiap@gmail.com
samyrdalwai@enablemychild.org

8th ANNUAL NATIONAL CONFERENCE OF THE CHILDHOOD DISABILITY GROUP IAP

The month of September 2011 at Chandigarh witnessed a huge event for the first time for a cause as righteous as childhood disabilities. IAP Chandigarh along with the Govt Regional Institute for Mentally Handicapped, Chandigarh co hosted the VIIIth Annual National Conference of the IAP Childhood Disability Group, NCDC 2011 on the 2nd, 3rd and 4th Sep 2011 at the Govt Medical College,Sec – 32, Chandigarh. It was a moment of pride to host the National Conference with the Theme - "Disability to Ability - Beyond Endeavors" which received an applaud from all.

The stalwarts and members of the Childhood Disability Group have been striving hard for past many years to generate awareness and create an impetus amongst the general pediatricians for early identification, early diagnosis and early intervention of children with developmental disorders in view of decreasing their future degree of disability. This conference was another opportunity to take the cause a step ahead. It was also an effort to bridging the huge gap between the medical and social aspects of Disability.

Renowned International and National faculty deliberated during the 3 day conference shelling out guidelines and recommendations on childhood developmental disorders.

The three pre conference workshops held on 2nd Sep 2011 saw a huge attendance of more than 60 participants per workshop. The pre conference workshop was inaugurated by the Member Secretary, Rehabilitation Council Of India, Dr J.P Singh.

A) Newborn Hearing Screening: A Sound Strategy

Dr Waheeda Pagarkar, Pediatric Audiovestibular Consultant at the Royal National Throat, Nose & Ear Hospital, London, U.K along with Dr Abraham Paul and Dr Samir Dalwai created a gateway for the 3 day scientific forum by proficiently introducing the concepts of hearing in newborns and the importance of induction of newborn hearing screening programmes for early detection of hearing impairments with aims of early interventions. The participants moved through 5 workstations effectively conducted by a team of experts such as Dr Arjun Dass, H.O.D, Dept of Ent, GMCH, Dr Renu, and a team of speech and language therapists and audiologists Mr Ravi Kapoor, Mrs Gurvinder Kaur, Mrs Ritu Chaudhary. It was a pleasure to see the Member Secretary, RCI Dr JP Singh personallyattend and participate in the hearing workshop. He was delighted to see the enthusiasm amongst the faculty as well as the huge number of delegates.

B) Strategies for Teaching Children with Autism Spectrum Disorder using principles of Applied Behavior Analysis

A four hour workshop was adroitly conducted by Dr Catherine Mc Clain, Prof of Pediatrics, Director, Center for Development & Disability and Dr Patricia Osbourn, Deputy Director, Speech & Language Pathologist at the center at University of New Mexico. The session concluded with case discussionsand the faculty was delighted to answer the scores of questions put up by the avid audience of more than 80 in number.

A) The Poor Scholastic Performance Programme

Dr Sacchidanad Kamath, Chairperson, CDG IAP, Dr Jeeson Unni, National Convener PSPP, and Dr Samir Dalwai, Hon Secretary CDG IAP enthralled the audience nearly 80 participants with their

powerful talks on issues related to poor scholastic performance in children and provided handy tips on management of the same, in the home environment as well as the community. The audience consisted of pediatricians, psychiatrists, special educators, psychologists, principals and school teachers, and other therapists and rehab professionals. The PSPP was being conducted for the first

time in Chandigarh, North Zone.

The Day 1 of the National Conference began with symposium on Learning Disorders with power packed talks delivered efficiently by Dr Samir Dalwai, Dr Jeeson Unni and Prof Priti Arun.

The session was followed by a panel discussion on "Inclusion and Beyond: Empowering the Children with Special needs" with eminent personalities such as Mr T.D Dhariyal, Deputy Chief CommissionerDisability, New Delhi, Dr J.P Singh Member Secretary RCI, New Delhi and other prominentinternational and national faculty . The session focused on issues related to legislation inimplementing inclusive education, impact of UNCRPD, status of Inclusive education in India andbarriers to inclusion. The concept of Least Restrictive Environment was beautifully discussed by Dr Catherine. Prof BS Chavan gave his suggestions on how empowering the families and persons with disabilities can help improve the current scenario. The panel discussion was very successfully moderated by none other than Dr Jeeson Unni.

The panel discussion was followed by a short presentation by Dr BS Chavan, Prof & Head, Dept of Psychiatry and Jt Director RIMH and his team on how the Institute for the intellectually disabled faced years of challenges and has now emerged as one of the pioneers in providing all kind of services under one roof such as medical care, education, training and human resource development. The Inaugural ceremony was held at the Auditorium of the Govt Medical College & Hospital, Sec–32, Chandigarh. The beautiful dance performance "sarwasti vandana" by the intellectually disabled children from RIMH created magic on the stage marking the inauguration of the conference.

Amongst the eminent stalwarts seen off the dias were Dr Abraham Paul, Dr O.N Bhakoo, Dr Anil Narang, and others. Prof B.N.S Walia could not attend but conveyed his message for all the professionals working with children with developmental disorders to work with dedication towards helping the children achieve their best potential. Shri. D.K. Tiwari, (IAS) Special Secretary, UT Administration, inaugurated the conference and in his address he congratulated the organizers and expressed his concern about the rise in the percentage of children/adults with disability. He emphasized on barrier free environment to facilitate the functioning of persons with disability stressing on need to sensitize the community. He also expressed that the recommendations of this national conference would be of great importance for children with disabilities.

The welcome address was delivered by Prof Raj Bahadur, Director Principal, GMCH & Director RIMH, Chandigarh. He welcomed the chief guest, and other dignitaries and faculty from abroad andthe delegates. In his address he highlighted the activities of RIMH and Medical College towards

rehabilitation of children with disability, shared his vast experience in the field of disability andexpressed his hope that soon it will be an institute of national repute. Prof BS Chavan, the organizing chairperson presented the overview of the conference and conveyed his warm heartfelt gratitude to the IAP Childhood Disability Group and

the IAP Chandigarh Chapter for providing this great opportunity. Dr RP Bansal, President IAP Chandigarh chapter expressed that this was a moment of pride for IAP Chandigarh to host the event.

Dr Samir Dalwai, Hon Secretary CDG IAP, Convener NCDC 2011, Director NHCDC Mumbai introduced the theme of the conference and spoke about the need of institutes like RIMH to take lead in the country for defining the roles as well as upgrading the roles of corporate social responsibility in disability rehabilitation. Dr Sacchidanand Kamath, Chairperson CDG IAP introduced the activities of the group to the audience and thanked the organizers for their team effort in putting up a successful show.

The Guest of Honor, Dr. J.P. Singh, Member Secretary of Rehabilitation Council Of India, New Delhi in his address congratulated RIMH for the wonderful infrastructure for human resource development and rehabilitation of children with intellectual disability. He also expressed hope if Chandigarh could develop an effective training module for children below six years and this could be replicated in other parts of the country. He congratulated the IAP CDG group for conducting effective scientific forums across the country. Our special guest for the day, Shri D.K. Dhariyal, Deputy Chief Commissioner, GOI, New Delhi in his address highlighted on inclusion of children with disability in order to empower persons with intellectual disability. He also urged to give them opportunity so that they can demonstrate their ability. Prof MKC Nair, Director, CDC, University of Kerala, Trivandrum, deliver the Key Note Address – 'Prevention of Disabilities under 6 years – A National Strategic Approach". He focused on how neonatal practices can be helpful in prevention of disability at early childhood and talked about early developmental predictors, early stimulation and its effect on the development of children with childhood developmental disorders. He emphasized on the need to train mothers on simple techniques to identify symptoms of developmental delay.

Dr Waheeda Pagarkar, Pediatric Audiovestibular Consultant, U.K, on this occasion, donated 300 hearing aids to the Childhood Disability Group. She promised her continued support the group for the cause of childhood disability in India. The Chief Guest felicitated all the International Faculty and expressed his deep gratitude & appreciation for their dedicated participation in the scientific forum.

Dr Chhaya Sambharya Prasad, the organizing secretary delivered the vote of thanks and conveyed a heartfelt thanks to everybody who contributed towards the success of the conference.

The Oration delivered by Dr Pratibha Singhi, Prof of Pediatrics, PGIMER, and Chandigarh on "Rehabilitation under Resource Poor Conditions" was applauded by all.

Dr Jane Mc Grath, Prof of Pediatrics, Director, Envision, University of New Mexico delivered the Guest Lecture which received great appreciation from all. She introduced a new concept of helping people with disabilities in the community while talking on 'Patient Centered Medical Home'.

The latter half of the day revolved around symposiums on High Risk New Born and Recent Advances in Cerebral Palsy. The sessions were chaired by Dr ON Bhakoo, Dr Anil Narang and Dr Pratibha Singhi.

The Day 2 of the Conference began with the round of free paper presentations followed by symposium on 'Understanding Disability in the Community'. Excellent deliberations were delivered by Dr Sandhya Khadse, Dr Dipty Jain and Dr Rashmi Kumar. The symposium on Attentional Disorders enthralled the audience with brilliant talks delivered by Dr Samir Dalwai, Dr Prabjot Malhi and Dr Anjan Bhatt giving clear guidelines on diagnostic and management issues of ADHD.

The pre lunch session on Communication Disorders was made interesting and inter active with brilliant deliberations by Dr Catherine Mc Clain, Dr Patricia Osbourn and Dr Shabina Ahmed. The post lunch mixed bag session was appreciated by all. The last session for the day on 'Neurological Presentations of Developmental Disorders' saw outstanding presentations by Dr Shekhar Patil, Dr Neeta Naik, Dr Murlidhar Mahajan and Dr Kanwaljeet Multani.

The National Conference came to an end on the eve of 4th Sep 2011 with the Valedictory ceremony presided over by Dr Samir Dalwai, Hon Secretary CDG IAP. He acknowledged that CDG IAP is dedicated to bridging the huge gap between the medical and social aspects of Disability. 40 faculty from India and abroad shared their expertise and research. The conference was attended by nearly 300 delegates from different parts of country from various fields working on childhood disability who got an opportunity to interact with expert pediatric faculty from India and abroad. The conference highlighted many important concerns of children with developmental disorders including legislation in implementing inclusive education, impact of UNCRPD, and newer concepts such as Least Restrictive Environment, and Patient centered medical homes were introduced to the Indian audience by the International Faculty. The conference saw great participation of various organizations such as Childhood Disability Group Indian Academy of Pediatrics, Govt of India, Rehabilitation Council of India and the local Administrative Authorities alike, all pledging to work towards a common cause in dedication – Empowering the families and persons with disabilities.

Dr. Chhaya S. Prasad

Org. Secretary, NCDC 2011

Dr. Abraham Paul receiving the Fellowship Award at the NNF National Conference, Chennai on 18th Dec. 2011in appreciation of services for the cause of new born, especially for conceiving and implementing centralized new born hearing screening program in the city of Cochin. The program is being replicated in other parts of the country as a model project.

Dr. Sachidanand Kamath, President IMA Cochin Branch receiving the Award for Best IMA Branch President at the IMA National Conference Banglore on 27th Dec. 2011

National Childhood Disability Conference (NCDC-2010), New Delhi

PEDICON 2012

SUBSPECIALITY CHAPTER SYMPOSIUM CHILDHOOD DISABILITY GROUP

Venue- 9- PEDICON Theme Hall

Theme:

SPECIFIC STRATEGIES AND INTERVENTIONS IN SPECIAL NEEDS

CHAIRPERSON	**Dr Uday Bodhankar**	Dr (to be decided by Org Committee)
Guest Lecture 1	**Dr Abraham Paul**	Integrating Hearing Impaired Children into the mainstream
Guest Lecture 2	**Dr Samir H Dalwai**	Sensory Integration in Special Needs

PANEL DISCUSSION- SPECIFIC STRATEGIES AND INTERVENTIONS
(including Law and Insurance)

Moderator	**Dr Anju Agarwal**	
	Dr S S Kamath	Including Disability in the Insurance Sector
	Dr Jeeson Unni	Inclusion of Adolescents with Special Needs
	Dr Chhaya Prasad	Educational Inclusion of children with Special Needs
	Dr Dipty Jain	Inclusion of Children with Chronic Disability

CHILDHOOD DISABILITY GROUP ANNUAL GENERAL BODY MEETING

8:00 to 9:00 am Saturday, 21st January 2012

Venue- 9- PEDICON Theme Hall

Please note that the Annual General Body Meeting of the Childhood Disability Group will be held from 8:00 am to 9:00 am Saturday, 21st January 2012, at 9- PEDICON Theme Hall (the same venue as the Symposium). All life and associate members are invited to participate in this meeting

Dr Samir Dalwai,
Secretary, CDG

LEARNING DISABILITY

Dr. Samir H. Dalwai, Director New Horizons Child Development Centre

LD Clinic, Hon. Consultant, Sion Hospital Mumbai

Case 1: Sushil, a 10 years old boy in Grade V, was referred to the clinic with complaints of academic problems.

Sushil's teacher had called the parents and told them that Sushil was doing very badly in school. Sushil's answer papers were full of spelling mistakes, half the questions were not even attempted and answers were completely irrelevant. All this in spite of the fact that Sushil studied a lot and had answered all the questions at home when the mother was 'taking up' his studies. She was puzzled as to why did he perform so badly in school. They blamed the teacher, the teacher blamed the tuition teacher and she in turn, blamed everyone else! And poor Sushil continued to suffer, though otherwise he was very smart, had a powerful memory and was a very sweet child.

Case 2: Dina, an 11 year old girl, in Grade VI was referred to the clinic with behavioral problems.

Dina had become very short tempered over the last year or so and would get annoyed and irritated over trivial reasons. She would become very irritable and would fight with her mother over no reason. Screaming loudly, she would even hit the elders in the family and get physically violent and unmanageable. She was getting frustrated in school and etested going to school. Television became the centre of her attraction. In fact, Dina used to perform very well in class till second or third grade. Thereafter, her performance began to dip and she started losing interest in studies and would score around 50 % initially and now just about 35-40%.

How would you help Sushil and Dina?

The common point running through both these cases is the Poor Academic Performance. (Performance as ensured by personally seeing the Report Card. Parents opinion regarding the same may be faulty, as some parents may regard 80% performance as 'Poor' and below their expectations!) About 25-35 % of all children perform poorly in school.

Poor Academic Performance may be caused due to the following or a combination of Physical / Medical Illness, Socio-Economic-Behavioral-Emotional Issues and/or Learning Disability

a) Physical / Medical Illnesses:

Visual Impairment, Auditory Impairment, Subnormal mental functioning (as measured by a low IQ), Malnutrition, Anemia, chronic illnesses (Epilepsy, tuberculosis, malignancy, etc.) Allergies By a combination of impaired functioning and loss of school days / learning time/ loss of continuity at school, these problems contribute to a child doing badly at school.

b) Socio-Economic-Behavioral-Emotional Issues:

1. Attention Deficit / Hyperactivity Disorder
2. Oppositional Defiant Behaviour
3. Conduct Disorder
4. Anxiety Disorder
5. Childhood Depression
6. Loss of parent or a dear one due to death
7. Physical, sexual, emotional abuse or neglect
8. Adverse economic situation
9. Adverse environmental conditions at home like
   a. Non-inclination of family members towards academic pursuits
   b. Crowded homes with no suitable atmosphere for studying
   c. Parental/familial discord with frequent fights
   d. Alcoholism
   e. Chronic illnesses in the family
   f. Noisy households where there are too many distractions
   g. 24-hours media like Television, Computer Games, etc.
10. Gender discrimination

Such adverse environmental situation may distract/prevent the child from studying.

Hence, the initial assessment is directed at ruling out the above issues. Most of the above are obvious when looked for in some detail and can be remedied.

Visual and Hearing handicap are notorious for being missed due to cursory examination or a casual attitude. Often, parents will remark that the child can hear well and they will positively oppose an objective evaluation. It is here that the physician / counselor must insist on a documented audiogram.

Mild Mental Sub Normality can be assessed informally by enquiring about how the child functions in activities other than academics. If the child is generally found to be equally challenged at all tasks and in all situations, one would suspect mild mental sub normality. It can be formally assessed by a qualified Psychologist by a standardized IQ test like WISC (Weschler's Intelligence Scale for Children). A score below 70 would be considered **Sub Normal.** A child with a score between 70 and 85 would be considered a Slow Learner.

c) Learning Disability:

However, 8 – 10 % of children continue to do badly in school in absence of the above problems. It is in these children that we must keep the Diagnosis of Learning Disability in mind. These children are very bright and may do quite well in the early years of their school, often at the top of their class. They may have a good memory for everything and will also remember oral instruction well and will recite all learned material promptly. However, ask them to read and write, and there comes the problem.

Hence, the next step is to determine the area of academics that the child is having trouble with. These areas could be assessed as Reading, Writing, Arithmetic/ Mathematic. (These terms are easily misunderstood in context of vernacular language. for instance, padhana in Hindi, does not specify the act of Studying or Reading. So if a parent says "Padhane main takleef hai" it doesn't tell you if the child has a problem with ACADEMICS overall or with the specific act of READING)

READING

Reading presents its characteristic pattern. These children will hesitate and stutter and their reading will generally be awful without spacing between words, sentences, etc. They will use their finger to stay with a particular line; else they will lose the continuity and go from the first line to the third. Generally, they will make every attempt and use every excuse to avoid reading.

WRITING

Writing can be evaluated in three ways:

i. The handwriting, which refers to the visualized matter on the paper

ii. The spelling, which refers to the use of appropriate alphabets to spell a word.

iii. The language, which includes grammar; tense, punctuations, use of capital alphabet to start a new sentence, the

vocabulary used and the representation of ideas, continuity, etc.

This is often the easiest to pick, for these children will show typical Patterns of Errors. Their handwriting is irregular and uneven. Alphabets will be of different sizes and will be all over the place, never within the lines. They will make the simplest spelling mistakes repeatedly. They will often make simple mistakes like " p for q, 6 for 9, b for d, tap for pat, billl for bill, no for know". Their drawing and coloring will be bad; and give them to color and name a Map and they will be all lost. Often the answers they write will be irrelevant to the question and may actually be the answer of another question that they have merely learnt "by heart". These Patterns will be repeated in book after book, year after year.

ARITHMETIC

Arithmetic is a big problem for some children. Simple steps of addition, subtraction, multiplication and division will be confused. And 'word sums' are a nemesis! Errors may occur while copying down figures from one place to another.

Thus, specific types of Learning Disability are :

a) Dyslexia (Difficulty with Reading and Spelling),

b) Dysgraphia (Difficulty with Sizes and Shapes like alphabets, geometric shapes, maps, lines on a page),

c) Dyscalculia (Difficulty with Calculations, arithmetic, mathematics)

These are called Specific Learning Disabilities.

DISCUSSION:

A. Learning Disability is seen in children with normal and above normal intelligence, good vision and hearing and a favorable socio-economic background, who yet, consistently perform badly in academics.

B. Performance worsens as the child goes to higher grades.

C. This is a neurological problem, where some areas of the brain malfunction, though the exact cause is not known.

D. In spite of best efforts, the child is unable to perform up to potential.

E. When these children are unfairly criticized, it completely damages their Self Respect and leads to secondary Behavioral Problems.

INTERVENTION:

If you suspect, refer the child to a Developmental Pediatrician, Psychiatrist or a Psychologist who is trained to deal with this matter. Other causes of difficulty in academics (as mentioned above) have to be ruled out. Appropriate testing like an IQ test along with specific psycho -educational tests will establish the diagnosis. Remedial Education, in addition to their regular schooling, will enable these children to cope with their academic problems. Occupational Therapy will help with Attention, Hyperactivity and Impulsivity issues.

Above all, **Parental Counseling, Behavior Modification** and participation of the School, especially the Classroom Teacher is extremely important in terms of remediation as well as Inclusion, and making the child feel wanted and respected and a part of the class.

Challenges of Disability and UNCRPD

Hemant Singh Keshwal

Coordinator B.Ed & D.Ed (Spl. Edn. MR), RIMH, Chandigarh

Expert Committee Member RCI , hemantkeshwal@gmail.com

Disability has been the key focus area of United Nations since last three decades. It has taken many initiatives for the upliftment of persons with disabilities, and this includes International Year for Disabled Persons 1981, U.N. Resolution - World Programme of Action, U.N. Decade of Disabled Persons 1983-92, Asia Pacific Decade for disabled 1993-2002, Standard Rules on the Equalization of Opportunities for Persons with Disabilities - 1994 Biwako Millennium Frame Work 2003. Recent development in this direction is the United Nations Convention for the Rights of Persons with Disabilities 2006.

UNCRPD & its optional protocol was adopted on 13 December 2006 at the United Nations Headquarters in New York. The convention has 50 Articles. The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with dissabilities, and to promote respect for their inherent dignity. India has been in the forefront in this endeavour and signed the convention on 30th March 2007 and was the first country in the south Asia to ratify this convention on 2nd October 2007. Efforts are on to adopt the recommendations and bring in the legislative framework.

The Convention marks a 'paradigm shift' in attitudes and approaches to persons with disabilities. Persons with disabilities are not viewed as "objects" of charity, medical treatment and social protection; rather as "subjects" with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. The principles of the UNCRPD are:

* Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

* Full and effective participation and inclusion in society;

* Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

* Equality of opportunity & Accessibility; * Equality between men and women; * Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Article 7 of the convention talks of Children with Disabilities which states that all state parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of human rights and fundamental freedoms on an equal basis with other children. Health is one of the another key focus area in article 25 which states that all appropriate measures shall be taken to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation & prohibit discrimination. It highlights early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons. It also lays emphasis on quality health care by the health professionals to the Persons with Disabilities.

As India is a signatory to this convention, efforts are being made to adopt the recommendations in true spirit so that persons with disability can lead a life of dignity without any discrimination from any quarter of the society. They should also get equal opportunities and rights and full participation in the society. For the same, necessary amendments are being made in PWD Act 1995, RCI Act 1992 & National Trust Act 1999.

Free Distribution of Hearing Aids to Children
'Project SWARAM'
at Govt General Hospital, Ernakulam on 14th November 2011

Child Care Centre a Project of Indian Academy of Pediatrics, Cochin Branch distributed 75 Free Hearing Aids to Children of Poor Socio Economic Strata. Under the able guidance of Dr. Abraham Paul, the function was inaugurated by Sri. K.V. Thomas, Central Minister for Food & Civil Supplies. Sri. K. Babu, Minister for Excise & Port, Sri. Hibi Eden, MLA, Sri. Dominic Presenatation, MLA, Sri. Benny Behanan, MLA, Sri. Ludi Luiz, MLA, Sri. Tony Chammany, Mayor Corporation of Kochi, Sri. P.I. Shaik Pareeth IAS, District Collector were attended the function.

The 75 hearing aids which IAP Childhood Disability Group received from Dr. Waheeda Pagarkar, Royal National Throat, Nose & Ear Hospiotal, London was distributed to needy children at a function organized by Child Care Centre at Kochi on 14th November 2011.

Welcome New Members

Life Members

CDL 325	Dr. Prasanna	CDL 332	Dr. Badur Manohar	CDL 339	Dr Kanya Mukhopadhyay
CDL 326	Dr. Pangiakas Anurag	CDL 333	Dr. Anthati Kireeti	CDL 340	Dr Avinash Dayalal Arke
CDL 327	Dr. Prabha	CDL 334	Dr.Dipty Jain	CDL 341	Dr Sachin Gajanan Damke
CDL 328	Dr. Karthikeyan Periyappan	CDL 335	Dr Jaishree Seshan	CDG 342	Dr Santosh Rajagopal
CDL 329	Dr. Lata Bhat	CDL 336	Dr Monika Sharma	CDG 343	Dr Jyoti Bhatia
CDL 330	Dr. Karnik Prachi	CDL 337	Dr. Zafar Meenai	CDG 344	Dr Roosy Alakha
CDL 331	Dr. Wani Khurshid	CDL 338	Dr Ratan Kumar	CDG 345	Dr Rashmi Kumar

Associate Life Members

CDAL 106	Dr.Simran Randhawa	CDAL 111	Pushpa Dahiya
CDAL 107	Dr. Navdeep Singh Saini	CDAL 112	Deepshikha Manocha
CDAL 108	Vikash Aggrawal	CDAL 113	Shyam Sunder Das
CDAL 109	Diana Agnani	CDAL 114	Parineeta Jindal
CDAL 110	Jaisy Ahuja	CDAL 115	Sneh Bansal

Centralized Newborn Hearing Screening Facility – The Cochin Experience.

Dr. Abraham K Paul, MD, DCH, FIAP
Pediatrician, Cochin Hospital
Convener, Newborn Hearing Screening Programme - IAP Kerala
and National President's Action Plan 2011
Cochin – 16, Kerala
abrahamkpaul@gmail.com

In a developing country like India , we need to face a two pronged problem. More number of high risk babies is born here due to socio economic and other barriers of care. On the other hand, access to proliferating neonatal intensive care services and survival of these high risk babies may result in more number of developmental deficits, one of the most important being hearing loss. The city of Cochin has several neonatal intensive care units in the private and government sector. Adequate screening facility was lacking in majority of the units. In that back ground, the idea of a centralized screening facility covering all the hospitals in the city was mooted, and the facility was established by IAP Cochin Branch. The main objectives were -

(i) to have hearing screening of all the babies in the city for at least the high risk group.

(ii) to create awareness in the pediatrician on the need for early identification of hearing loss.

(iii) to institute early identification in needed cases.

Twenty major hospitals in the city with maternity units catering to various socio economic strata are covered. Paediatricians in the concerned hospitals were convinced of the need to screen all newborns, at least the high risk newborns. The machine used at the launch of the programme (January 2003) was ECHOCHEK OAE screener. Later on, OTOPORT Lite (Hatfield, U.K) was installed.

Otoport Lite Machine Hearing Screening Procedure

Now we have 3 screening machines and 3 screeners. The person selected was a graduate girl with basic knowledge in computers and good communicative skills; she was given basic training in hearing screening. She visits a particular hospital on a particular day of the week; each hospital is allotted a particular day when all the babies in NICU, maternity ward and babies attending well baby clinic would be screened. Out of 20 hospitals, two hospitals have level 3 NICU and the rest have level 2 care. All twenty hospitals have maternity units with deliveries ranging from 10 per month to 60 per month. In six hospitals, it is universal screening and in the rest, it is high risk screening. Even though it is universal in ten hospitals, some infants may miss screen since the screener visits the hospitals only once a week. High risk cases are not missed since they are given specific instructions to come for follow up on the screening day allotted the hospital.

To summarise, almost all the high risk newborns undergo screening even though a good number of non-high risk babies might have missed the screening (despite instructions). The screening takes about 3 to 4 minutes if the baby is asleep (natural sleep in the immediate post natal period). Older babies may require sedation.

If an abnormal result is obtained, a repeat test is done after two weeks, or when the baby comes for the next monthly check up (appointment given for the day allotted for screening to the particular hospital).

If the repeat test also is abnormal, the baby is referred for ABR (which is available in many hospitals in the city). Babies with abnormal ABR were referred to National Institute of Speech and Hearing (NISH), Trivandrum, where a comprehensive evaluation is done and are remediated with hearing aids in necessary cases.

The evaluator looks into the medical records of infant / discharge summary to identify the high risk factors which are

recorded. High risk infants who miss screening will be screened on the subsequent follow up and data gathered from the discharge summary.

Preliminary Results

Over the past eight years January 2003 to January 2010 a total of 10165 newborns were screened through this Programme. Out of this, 2031 were high risk and 8134 were from non high risk group. Of the 2031 high risk newborns, 234 failed the first screen. These babies underwent repeat screen after 2 to 6 weeks period. 78 babies failed the second screen. They underwent ABR test and out of them 21 had confirmed hearing loss, ie. an incidence of about 1% in the high risk group. All these babies underwent comprehensive evaluation and are on remediation with hearing aids and supportive care. But for this screening programme, the deafness in the infants would have been missed in the infancy period. The youngest infant to have a hearing aid was a five month old infant, born to deaf mute parents.

DISCUSSION

The definition of early identification of hearing loss has evolved over the years. In the past, early identification was defined as intervention before 18 months. The implementation of UNHSP throughout U.S has caused the issue of identification and intervention to be re examined. Early identification can now be defined as diagnosis as early as 3 months of age, with intervention before 6 months. Children with hearing loss that is identified and remediated by 6 months of age had significantly higher receptive, expressive, and total language quotients than those children identified at 7-12, 13-18 and 19-24 months.

In 1994, the JCIH released a position statement endorsing the goal of universal identification of infants with hearing loss at the earliest, with early identification by 3 months of age and intervention by 6 months.

In 2000, the JCIH modified the high risk register (HRR) to aid the identification of newborns at high risk for permanent hearing loss, particularly those at risk for progressive hearing loss through age 2 years.

The 2007 JCIH position statement includes neonates at risk of having neural hearing loss (auditory neuropathy/auditory dyssynchrony) in the target population to be identified in NICU (18,19,20,21) because there is evidence that neural hearing loss results in adverse communication outcomes. Consequently, the JCIH recommends ABR technology as the only appropriate screening technique for use in NICU. For infants who do not pass ABR in NICU, referral should be made directly to an audiologist for re-screening and further evaluation. Some issues need also to be considered in a two stage protocol as is being practiced.

a. It is critically important to continue to emphasize to families and physicians that passing a hospital based hearing screening test does not eliminate the need to monitor language development systematically and consistently, and to conduct additional hearing screening. Regardless of the results of the infant hearing screening, one must always be vigilant in monitoring language development and hearing status.

b. The relative advantages and disadvantages of a 2 stage (OAE/ABR) protocol for newborn hearing screening need to be considered carefully for individual circumstances. In locations where getting infants to return for out patient screening and testing is very difficult, the substantially lower failure rate that likely will be achieved by using both OAE and ABR at the same sitting has significant advantages. In a setting like ours, this may not be very practical, but has to be considered where-ever possible.

CHILDHOOD DISABILITY GROUP, INDIAN ACADEMY OF PEDIATRICS

Membership Application Form

FOR OFFICE USE ONLY

Membership No. .....

Particulars of receipt : Cheque/D.D. No. ..... Bank .....

Amount ..... Date .....

Name in full .....

(BLOCK LETTERS) SURNAME FIRST NAME MIDDLE NAME

Designation .....

IAP MEmbership No. .....

a) Official/Institutional address .....

..... PIN ..... Tel. .....

b) Residential address .....

..... PIN ..... Tel. .....

Date of Birth .....

Medical Qualification	Name of the University	Qualigication Year
a) M.B.B.S.		
b) D.C.H.		
c) M.D. (Ped)		
d) Others		

Particulars of present work status

Private ☐ Govt. ☐ Medical College ☐ Voluntary Agency ☐

Areas of interest of Childhood Disability

a) Physical b) Visual c) Mental d) Hearing

e) Learning f) Multiple g) Others (specify)

Special Training obtained by you in childhood disability.

Publication /Book/Chapters in books on childhood disability in India/Abroad.

(Please attach the list)

(Please note that membership of IAP is essential. Non pediatricians are eligible for associate membership)

MEMBERSHIP SUBSCRIPTION

Life Membership : Rs. 500/-

Life Associate Membership : Rs. 500/-

D.D. favouring Childhood Disability Group IAP, payabe at Mumbai, send to Dr. Samir Hasan Dalwai, Secretary, IAP Childhood Disability Group, C/o New Horizon Child Development Center Saira Mansion, Pahadi School, Rd-2, Goregaon East, Mumbai, 400063 Ph +91-2265711588, +91-9820026503