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**INAUGURAL ISSUE**

# **Indian Journal of Developmental & Behavioral Pediatrics**

Official Journal of IAP Chapter of Neurodevelopmental Pediatrics

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## **Aims and Scope of Indian Journal of Developmental and Behavioural Pediatrics (IJDBP)**

IJDBP is a specialty journal in Developmental and Behavioural pediatrics published by Indian Academy of Pediatrics Chapter of Neurodevelopmental Paediatrics

The Journal welcomes Original papers, Review articles, Case reports and other articles relevant to child development & Behaviour including :

- Neuro developmental disorders,
- Developmental delays,
- Behavioural issues,
- Autism,
- Attention deficit hyperactivity disorder,
- Learning difficulties,
- Intellectual disabilities,
- Evidence based role of early intervention,
- Family centred multidisciplinary intervention,
- Neurogenetic disorders affecting child development,
- Neuroimaging & Neurological issues affecting child development,
- Corrective and assistive surgeries
- Home environmental and environmental issues affecting child development,
- Medical conditions
- Low birth weight and High-risk neonate requiring neonatal intensive care & its outcome,
- Preventive aspects in adolescents and pregnancy.
- Management of conditions covered in Rights of Persons with Disability Act,2016 of GOI.

It aim to promote advances in research in the field of child development and Behavioural issues so that latest evidenced based information is shared to enhance the quality of care and improve lives of children with special needs and their families.

The journal will be National Double Blind Peer review Open access journal published Quarterly. We will accept for publication manuscripts that were not published earlier in any form. The journal is devoted to publishing quality papers based on original innovative and most advance research in the field of developmental behavioural pediatrics.

The Journal aims to have the highest possible ethical and publication standards by scrutinizing the papers, through peer review assisted by eminent experts from prestigious teaching institutes from the country. For all Manuscripts submitted the journal will employ a plagiarism detection system for detecting plagiarism against previously published work.

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## INVITED GUEST EDITOR

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Indian Journal of Development and Behavioral Pediatric (IJDBP) is a natural progression from developing the Neurodevelopment chapter, introduction of IAP Fellowship program, Developmental Nurse Counsellor Program, all denoting the academic temper of the chapter. The Editorial Board need special appreciation for planning the academic contents of the journal in a systematic manner. This is in tune with the academic objectives of the chapter – Clinical Child Development and Behaviour aspects in general. With the approval of the consensus statement of the chapter by the Executive Board of IAP, our special focus from now on would be;

- o First 1000 days of babies’ life from the moment he/she is conceived until they have reached at least 2 years of age.
- o Habilitation - ‘Prevention of Impairment leading on to Disability’, as against traditional rehabilitation which is prevention of disability going on to handicap.
- o Developmental delay/deviation and language delay, as it forms over 75% of problems in the community with proven efficacy of intervention.
- o Developmental therapy that specifically looks at how a child is developing during the most significant period, the formative first 6 years of life.
- o Right of every baby particularly “LBW/Preterm/NICU or SNCU graduates” to get developmental stimulation, early screening including metabolic screening.

I am sure that IJDBP, a novel venture of the chapter, that has been built over the last few years by stalwarts in the field of Developmental Pediatrics in India would go a long-way in achieving the objectives of the ND chapter, caring for the children needing special attention and their parents in a humane manner.

**Prof (Dr.) M.K.C.Nair, D.Sc.**

Patron in Chief - IJDBP

Director, NIMS-Spectrum-CDRC, Thiruvananthapuram

Founder Director, CDC Kerala & Formerly Vice Chancellor, KUHS

## EDITORIAL

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I am thankful to the distinguished Editorial Board who honoured me with the responsibility of becoming the 1st Editor in chief of the Indian Journal of Developmental & Behavioural paediatrics (IJDBP). As this is the official Journal of The Indian Academy of Pediatrics Chapter of Neurodevelopmental Paediatrics, I also thank the office bearers of IAPNDP Chapter who reposed faith in me. In two decades of working exclusive in developmental paediatrics, I have seen the specility progress from lack of acceptance; to awareness building; to risk stratification; to early detection; multidisciplinary intervention; capacity building; to empowerment of families and planning maximum potential with individual intervention programs.

The Indian academy of paediatrics with its visionary office bearers with the full backing of Neurodevelopmental paediatric chapter under the watchful guidance of our seniors have helped in this noble Mission. The Government of India on it's part passed the Rights of Persons with Disability Act, 2016. With greater awareness and acceptance about Neurodevelopmental & mental health issues, it also exposed fissures of lack of evidence-based management plans, lack of National data of various NDD, which is needed for proper prioritization of resources and uniform management protocols.

It is in this backdrop after much deliberations, guidance of mentors and inputs from young enthusiastic developmental paediatricians that the idea of South Asia's first index double-blind peer reviewed journal was conceived. The Journal will welcome Guidelines, Original papers, Review articles, Case reports and other articles relevant to child development & Behaviour.

We aim to promote advances in research in the field of child development and Behavioural issues so that latest evidenced based information is shared among paediatricians and other stakeholders. It will enhance the quality of care and improve lives of children with special needs and their families.

The Journal aims to have the highest possible ethical and publication standards by scrutinizing the papers, through double blind peer review and we have in plcae a 3-layer screening for this purpose. Every volume Will have one of the Advisors as invited Guest Editor & 3 Associate Editors as Co Editors. The invited Guest editor along with Editor in Chief and the 3 Co Editors will be the first screen to check suitability of topic & it's relevance. Any promotional therapy or funded article will be screened out at this stage. Next screen will be by a statistician and finally the article will be reviewed by 2 anonymous reviewers who are eminent experts from prestigious teaching institutes from the country.

The aims are high but the purpose is noble. I feel fortunate to have such a learned distinguished Editorial Board. By grace of Almighty, guidance of seniors and support of colleagues, I hope this journey will be successfull and fruitful.

Best Regards

**Dr Zafar Mahmood Meenai**

Editor in Chief IJDBP

## **PRESIDENT IAP 2022**

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The IAP Chapter of Neuro Developmental Pediatrics is known for innovation and landmark initiatives in the field of Developmental and Behavioural Pediatrics. After the IAP Fellowships, Consensus Guidelines and many other initiatives, the Chapter has now achieved another academic milestone in the form of its Journal to be called The Indian Journal of Developmental and Behavioural Pediatrics (IJDBP).

The Chapter has many members who are engaged with medical colleges and research institutions and they are in a unique position to set up clinical studies on Indian Children. Many of the members of this Chapter are practising in the private sector and they may miss the scaffolding of an institutionalised structure to conduct engage in clinical research. The Journal can be an excellent forum for them to publish their academic work as well. Going ahead, I see this Journal being the source of inspiration to all pediatricians and medical students all over India and South east Asia to develop a love for developmental and behavioural paediatrics and this will surely be a revolution in offering ethical and quality based services to children with neurodevelopmental and behavioural conditions as well as quality data in this field from the developing world.

This journal is a step forward in chapters mission to continuously enlarge its scope to cover the entire spectrum of child neurodevelopment and I congratulate the Office Bearers of the Chapter. A special thanks to Dr Zafar Meenai who is the Editor In Chief of the Journal and the Editorial Board and wish them all the best in their venture in future. They have taken pains to produce an authoritative high quality publication which is worthy of the reader's attention. I wish them success in this venture and hope that the reader response will motivate them to continue updating this journal with further inputs in the years to come.

### **Dr Remesh Kumar**

President 2022  
Indian Academy of Pediatrics (IAP)

## PRESIDENT ELECT IAP 2022

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Dear All,

It's extremely heartening to know that the IAP Neuro development chapter has planned to start a specialty journal "Indian Journal of Developmental & Behavioral Pediatrics" a peer reviewed indexed journal of international standards. More importantly it is starting an E journal keeping in mind the Go Green policy of IAP and keeping our responsibility towards environment in mind.

Though the field of Growth, Developmental and Behavioral Pediatrics constitutes a relatively new pediatric subspecialty as compared to infectious diseases, vaccinology or respiratory disorders, I'm sure the journal is going to focus on the understanding of functional changes in all domains of child and adolescent development, including cognitive function, social-emotional development, language, behavior etc. Prematurity, fetal growth restriction, and prenatal influences, genetic conditions as well as epigenetics are all directly related to neurodevelopmental outcomes and surely the journal will support the original research in these areas.

The general pediatrician needs proper and evidence-based guidance on the assessment of children with, or at risk of, neurodevelopmental and behavioral difficulties. The journal must provide such easy to implement tools for HC Providers practicing not only in the cities but also in smaller villages. We are getting increasingly aware of the fact that psychosocial aspects of health, adversity in the form of abuse/neglect/deprivation, and parenting styles, Sleep, feeding, and sensory issues are also important factors that influence child behavior. The journal can consider to publish one issue each which is focused on such important developmental domains.

If the journal highlights the importance of monitoring and supporting child development, especially during the critical periods of life, helps to raise awareness of the identification of high-risk conditions in developmental and behavioral pediatrics, as well as to enhance the understanding of neuro psychobiological aspects of children with neurodevelopmental disorders, I'm sure the purpose of the journal is served.

I wish Dr.Zafar Mahmood Meenai, Editor in Chief. IJDBP and the entire editorial team a grand success in this academic venture

Best Regards

**Dr Upendra Kinjawadekar**

President Elect 22

Indian Academy of Pediatrics

## HONOURARY SECRETARY GENERAL IAP 2022-23

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It gives me immense pleasure to introduce the 'Indian Journal of Developmental & Behavioral Pediatrics' - the official journal of the IAP Chapter of Neurodevelopmental Pediatrics. This pioneering Journal of Neurodevelopmental Disorders has evolved after years of hard work by the members of the IAP Chapter of Neurodevelopmental Pediatrics. This is their maiden initiative to showcase the work of those who pioneered neurodevelopmental pediatrics in India, as well as the work of the young researchers in this subspeciality.

Growth, Development & Behavioral Pediatrics is the most intriguing, interesting & unique aspect of our Specialty which sets it apart from Medicine. It starts right from the time of conception and continues till a newborn baby grows into a mature human being, passing through various milestones one after the other. Over the past 50 years, studies have documented an increasing prevalence of NDD and mental health issues, and a UK study shows a 20% increase in the past decade. There is a lack of quality data in this area from the Indian subcontinent. Understanding that the incidence of NDD is increasing amidst India's child population of 472 million, it is imperative to explore the reasons thereof. Our huge population strength itself gives a robust database, subsequently a big clinical load, and thereby material for good original research work. This should uncover in detail the understanding of the unique etiological factors, conditions per se and the management in the backdrop of a diverse culture and ethnicity of India. These are coupled by the disparate socio-economic conditions, literacy, transport bottlenecks, and the lack of easy availability of professional help. Ironically, in the 2017 study 'Status Report on Children with Developmental Delay and Neurodevelopmental Disorders in South-East Asia', under the section on shortage of manpower, there is no mention of pediatricians, who have a major role to play in the early detection and prevention.

Given the expertise of the Editorial Team and contributors, it will serve to be an indispensable tool for Practicing Pediatricians and Postgraduates. A special thanks to Dr Zafar Meenai who is the Editor In Chief of the Journal and the Editorial Board and wish them all the best in their venture in future.

Best Regards

**Dr Vineet Saxena**

HSG-IAP 2022-23

## PATRON IJDBP

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This pioneering Journal of Neurodevelopmental Disorders has evolved over years of work by the members of the Neurodevelopmental Pediatric Chapter of IAP. This is our maiden initiative to showcase the work of those who pioneered neurodevelopmental pediatrics in India, as well as the work of the young researchers in this subspecialty. This need was emphasised by the changing focus of pediatricians towards neurodevelopmental problems. Over the past 50 years, studies have documented an increasing prevalence of NDD and mental health issues, and a UK study shows a 20% increase in the past decade. This pattern is being seen globally too.

Understanding that the incidence of NDD is increasing amidst India's child population of 472m, it is imperative to explore the reasons thereof. Our huge population strength itself gives a robust database, subsequently a big clinical load, and thereby material for good original research work. This should uncover in detail the understanding of the unique etiological factors, conditions per se and the management in the backdrop of a diverse culture and ethnicity of India. These are coupled by the disparate socio-economic conditions, literacy, transport bottlenecks, and the lack of easy availability of professional help. Ironically, in the 2017 study 'Status Report on Children with Developmental Delay and Neurodevelopmental Disorders in South-East Asia', under the section on shortage of manpower, there is no mention of pediatricians, who have a major role to play in the early detection and prevention.

The focus of this journal is to serve as a leading resource for clinicians, researchers and all stakeholders in child care. It will be a peer-reviewed journal, with a high impact factor, and in time fulfil the criteria to be an indexed journal. Our plan is to incorporate video abstracts for a quick review of summaries. Our plans to categorise in different sections, have case reports and get guest editors and supplements on specific issues. This is relevant in standardising nomenclatures and upgrading approach to neurodevelopmental care in India

We are making efforts to standardise pediatric care in India and in the field of NDD. I feel we are ready to put forward our work. This journal should encourage clinically translatable work for wider application in the community. We have in Dr Zafar Mahmood Meenai, as the first Chief Editor, a person of long-standing experience in pediatric neurodisability to carry forward this vision.

Best Regards

**Dr Shabina Ahmed, MD., FIAP**

Patron IJDBP

Chairperson

Neurodevelopmental Pediatric Chapter of IAP

## **ADVISOR IJDBP**

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The IAP Chapter of Neuro Developmental Pediatrics is known for innovation and landmark initiatives in the field of Developmental and Behavioural Pediatrics. After the IAP Fellowships, Consensus Guidelines and many other initiatives, the Chapter has now achieved another academic milestone in the form of its Journal to be called The Indian Journal of Developmental and Behavioural Pediatrics.

The Chapter has many members who are engaged with medical colleges and institutions as well as those doing their Fellowships and they would be in a position to set up clinical studies and to publish them. Many of the members of this Chapter are practising in the private sector and they may miss the scaffolding of an institutionalised structure to conduct academic activities or engage in clinical research. The Journal can be an excellent forum for them to publish their academic work as well.

Going ahead, I see this Journal being the source of inspiration to all pediatricians and medical students to develop a love for developmental and behavioural paediatrics and this will surely be a revolution in offering ethical and quality based services to children with neurodevelopmental and behavioural conditions.

I congratulate the Office Bearers of the Chapter. A special thanks to Dr Zafar Meenai who is the Editor In Chief of the Journal and the Editorial Board and wish them all the best.

**Dr Samir Hasan Dalwai,**

MD, DCH, DNB, FCPS, LLB.

Developmental Behavioural Pediatrician,

Treasurer, IAP, 2022-23,

Chairperson, IAP Chapter of Neuro Developmental Pediatrics, 2014-17.

## **ADVISOR IJDBP**

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Indian Journal of Developmental and Behavioral Pediatrics should be a collaborative endeavour of the IAP Chapter of Neuro Development Pediatrics.

The publications should aim at driving forward research in the field of neurodevelopmental and behavioural disorders in children and adolescents by providing high-quality peer-reviewed research papers for academics, researchers and policy decision-makers.

The journal must endeavour to influence the academics as well as the public and private health services the world over, with focus on India and other developing countries, to provide quality care for children with special needs.

The scientific deliberations need to create opportunities for discussion and exchange of ideas across a wide spectrum of scholarly opinions to promote practical, evidence-based tools for screening, confirming diagnosis and management of differently abled children. The range of topics to include the mundane to some of the most challenging issues affecting child development and behavior.

The Journal should offer ideas with impact; should have readers who eagerly wait for the next issue and refer to it often. This demands pursuit of excellence by a committed and dedicated team that values editorial independence while executing ethical strategies to achieve a top-bracket impact factor.

Priority will be to ensure that the Indian Journal of Developmental and Behavioral Pediatrics develops into a leading resource for clinicians, teachers, and researchers involved in pediatric healthcare and child development.

### **Dr Jeesson C Unni**

Advisor IJDBP

Chief Editor-IAP Drug Formulary

## **ADVISOR IJDBP**

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The Indian journal of Developmental and Behavioral Pediatrics is a long awaited leap in research related to this field in our country. It will open the gates to unveiling and publishing genuine and locally relevant data in neurodevelopmental and behavioral aspects of child care from our own country and beyond.

My best wishes to IAP, the IAP Neurodevelopmental Pediatrics chapter and the entire editorial team for this endeavor and looking forward to academic excellence and enrichment through this venture.

**Dr.S.S. Kamath**

National President IAP 2015

Advisor IJDBP

## ADVISOR IJDBP

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Through a rigorous process of evaluation and peer review, “Indian Journal of Developmental and behavioral pediatrics will strive to publish pediatric research of the highest value for a diverse audience of pediatric healthcare professionals: subspecialty physicians and clinicians, researchers, educators, practicing and general pediatricians, nurse practitioners/physician assistants, residents, fellows, and others.

The Journal seeks to inform immediate care decisions, deepen knowledge, and advance further scientific discovery to improve the quality of care and the health of infants, children, and adolescents.

The IJDBP should be a peer-reviewed quarterly journal that advances pediatric research and serves as a practical guide for pediatricians who manage health and diagnose and treat Developmental and Behavioural disorders in infants, children, and adolescents.

The IJDBP should publish original work based on standards of excellence and expert review. The Journal should seek to publish high-quality original articles that are immediately applicable to practice (basic science, translational research, evidence-based medicine), brief clinical and laboratory case reports, medical progress, expert commentary, grand rounds, insightful editorials, “classic” physical examinations, and novel insights into clinical and academic pediatric medicine related to every aspect of child health.

The Journal IJDBP should continue to promote the latest developments in the field of Development & Behavior pediatric medicine, child health, policy, & advocacy.

The editorial board and IAP NDP chapter is well acquainted with the expertise and exemplary services in the field of developmental pediatrics to do justice to the publication of “Indian Journal of Developmental and behavioral pediatrics”.

Special compliments and thanks to Dr.Zafar Mahmood Meenai, Chief Editor, IJDBP

For the great initiative in this academic venture and look forward to its grand success under the able guidance of Respected Prof M.K.C. Nair

### **Dr. Uday Bodhankar**

Executive Director COMHAD -

Deputy Chairperson of CHPA - UK

Adjunct Associate Professor Pediatrics -Sydney

International Council Member - ASPR-Japan

Nodal Officer -RCPCH -DCH -UK

## **ADVISOR IJDBP**

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First of all let me congratulate the Neurodevelopmental Chapter for bringing out a much needed publication 'Indian Journal of Developmental and Behavioural Pediatrics'.

The scope of Developmental Pediatrics has tremendously increased in the current times especially with survival of more and more high risk babies. So there is a need for more and more developmental pediatricians to take a lead role.

Through Developmental - Behavioral Pediatrics, many learn and approach to the so called new morbidities, which continue to evolve with shifting demographic trends. Through these experiences residence also learn and approach to the care of children with disabilities and special healthcare needs.

With above said facts, it is essential to have an official publication of the subspecialty to update the members, residents and general pediatricians. I take this opportunity to congratulate the office bearers on this very positive initiative.

Wishing the endeavour all success.

**Dr. Abraham .K. Paul**

Senior Consultant Pediatrician & HOD  
Indira Gandhi Co-operative Hospital  
Kochi - 682020

## ADVISOR IJDBP

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According to a study published in medical journal 'The Lancet' on August 29, 2022 India has the maximum number of children —around 1.15 crore — who have development disabilities. The study which surveyed 195 countries and six development disabilities — epilepsy, intellectual disability, hearing loss, vision loss, autism spectrum disorder and Attention Deficit Hyperactivity Disorder (ADHD) — found that India had maximum number of cases of the first five disabilities while ADHD was the most prevalent among children in China, with 40.36 lakh cases recorded, Nigeria (24.58 lakh), Pakistan (18.48 lakh), Indonesia (17.07 lakh) and Ethiopia (13.20 lakh) are the other countries besides India and China who have a large number of their child population afflicted with these disabilities, as per the study.

Developmental paediatrics is perhaps the most recently added sub-speciality of the IAP. In the last few years the chapter has made great endeavour to bring awareness of developmental problems to both the public and professionals working in this field,

With better neonatal care and medical management the survival of children with developmental problems and their comorbidities are further enhancing in numbers. Today a child with Down's syndrome can live till 55 to 60 years and so have the life span increased in children with ASD, Cerebral palsy and other conditions. On the other hand there is paucity of professionals to help in the management of problems these children face.

With the advent of fellowship program in Developmental paediatrics the proposed journal can play a great role not just in publishing case report, research articles but also in better understanding the needs in community care evidence based intervention programs.

In other words, it will serve a great resource to bridge the knowledge gap and focus on research and review articles, to the need of the concerned population not just in India but also the south Asian countries.

### **Dr Nandini Mundur M.D**

Director centre for child development and disabilities  
Bengaluru

# How to Write a Case Report

Jeeson Unni<sup>1</sup>, MKC Nair<sup>2</sup>, Zafar Meenai<sup>2</sup>, Samir Dalwai<sup>2</sup>, Shabina Ahmed<sup>2</sup>, Abraham Paul<sup>2</sup>, S.S.Kamath<sup>2</sup>, Kawaljit Multani<sup>2</sup>, S.Sitaraman<sup>2</sup>, Leena Shrivastav<sup>2</sup>, Dr. Anjan Bhattacharya<sup>2</sup>, Leena Deshpande<sup>2</sup>, Shambhavi Seth<sup>2</sup>, Monica Juneja<sup>3</sup>.

From: 1. Dept. of child & Adolescent health, Aster medicity, Kochi; 2. Indian Academy of Pediatrics, Neurodevelopment Paediatric Chapter; 3. Department of Pediatrics, Maulana Azad Medical College and associated Lok Nayak Hospital, New Delhi;

Correspondence: Dr. Zafar Mahmood Meenai, Editor in chief IJDBP

Indian Journal of Developmental and Behavioural Paediatrics (IJDBP) will accept for peer review case reports that highlight:

- Uncommon or unusual presentations of a disorder - Single case reports not preferred, unless it represents a hitherto unknown or rarely reported aspect of a disorder.
- Genetic syndromes with a major phenotypic reporting
- Major or clinically significant variations of rare but well-known disorders; rarity of a condition by itself may not be a criterion for acceptance
- An unusual or unexpected association between signs and symptoms of a disorder
- An unexpected event during management course of a patient
- Unreported or unusual side effects or adverse interactions involving medications used in children with special needs
- New findings on pathogenesis of a disorder.
- Unusual presentation of a common condition which presented a diagnostic, treatment related or ethical challenge.
- Cases which highlight pitfalls in diagnosis or management will also be considered.

Case reports submitted to the IJDBP should be of educational value and/or suggest changes in the approach to clinical practice

The covering letter submitted by the authors along with case report must highlight its publication-worthiness including its educational and scientific merits.

For case reports, IJDBP will follow International Committee of Medical Journal Editors (ICMJE) Recommendations for the conduct, reporting, editing and publication of scholarly work in medical journals. IJDBP utilizes an online manuscript management and processing system for manuscripts that is accessible from a dedicated website. No hard copies of the manuscripts will be entertained.

The case report can be authored by a maximum of 4 authors from a single department and 5 if more than one department is involved.

Authors should seek written and signed consent to publish the information from the patients or their guardians prior to submission. The submitted manuscript must include a statement to this effect in the consent section. The editorial office may request copies of the informed consent documentation upon submission of the manuscript.

Images should protect the child/adolescent's anonymity as far as possible. Photos or medical imaging should not show the name, medical record number, or date of birth. Images should be cropped only to show the key feature. If an image of a face must be published, this should be cropped so that only the affected area is shown. Number of tables/figures should be limited to 2.

Photographs should be in black and white only.

### **Manuscript preparation:**

The text should not exceed 1000 words

Details of section headings and expected contents in each are detailed below –‘

Title page

- An appropriate title
- Full names with designation and email addresses of all authors
- Name of corresponding author

#### ➤ **Abstract**

The Abstract should not exceed 50 words. Please minimize the use of abbreviations and do not cite references in the abstract. The abstract must include the following separate sections:

- Background: why the case should be reported and its novelty
- Case presentation: a brief description of the patient’s clinical and demographic details, the diagnosis, any interventions and the outcomes
- Conclusions: a brief summary of the clinical impact or potential implications of the case report

#### ➤ **Keywords**

Three to Ten keywords representing the main content of the article.

#### ➤ **Introduction**

Attempt to explain the background to the case report, its aims, a summary of the existing literature.

#### ➤ **Case presentation**

This section should include a description of the patient’s relevant demographic details, medical history, symptoms and signs, treatment or intervention, outcomes and any other significant details.

#### ➤ **Discussion and Conclusions**

This should discuss the relevant existing literature

and should state clearly the main conclusions, including an explanation of their relevance or importance to the field.

#### ➤ **References**

References should be numbered consecutively in the order in which they are first mentioned in the text. The Vancouver reference style is to be followed.

#### **List of abbreviations**

➤ Abbreviations, if used, should be defined in the text at first use, and a list of abbreviations should be provided.

#### ➤ **Declarations**

All manuscripts must contain the following sections under the heading ‘Declarations’:

- Ethics committee approval - include a statement on ethics approval and consent with name of the ethics committee
- Consent for publication must be obtained from the adolescent, or in the case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.
- Competing interests - Financial and non-financial competing interests of all authors must be declared. If there are none, a statement saying “The authors declare that they have no competing interests” should be documented
- Funding if received should be mentioned.
- Authors’ contributions - The individual contributions of authors to the manuscript should be specified
- Acknowledgements - Anyone who contributed towards the article who does not meet the criteria for authorship including anyone who provided professional writing services or materials

If any of the sections are not relevant to the manuscript, please include the heading and write ‘Not applicable’ for that section.

# Self Counseling for Mother of Children with Autism Spectrum Disorder

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Someone rightly said that the biggest tragedy a mother can have is diagnosis of Autism Spectrum Disorder (ASD) in her child. You may not totally agree with this statement, but would not contest if I say that in spite of all supportive services we may boast of, ultimately, she is alone to 'face the music'. On one side her whole dream about her child come to a standstill; she doesn't know how to handle the erratic behaviors of the child; how to face unwanted criticism of people around; worried about the future of the child and so on .....

As professionals working in this field we do know that as per DSM-5 criteria ASD involves; (i) Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays and (ii) Restricted, repetitive patterns of behavior, interests, or activities(1). Doesn't it sound so simple to us?. Do we think of the implication of the same on the hapless mother, who has to face it 24 x 365 days, often without the support of the husband, in the background of needling by in-laws at least in some cases. Surely she is likely to go through the five stages of grief namely – Denial, Anger, Bargaining, Depression and the final stage of Acceptance may be unduly delayed(2), unless she has received appropriate and timely counseling to manage her frustration, anger and helplessness.

My forty two years of counseling experience have convinced me that counseling is effective only if the counselee is an active partner in the counseling process, that has led me to consider 'Self Counselling' as more and more appropriate for the parents of ASD children. In general, the major approaches to counselling include; (i) Psychoanalytic approach, (ii) Behaviour approach, (iii) Humanistic approach(3). Self-counselling is the process of examining one's own behaviour, using psychoanalytical methods of free-thinking and free association. Self-counselling can help one take more effective control of everyday situations and enable to make continued progress (personal growth). For me self counselling involves preparing the mother/father to imbibe and assimilate the following basic principles;

Do not bluff to yourself, even though you may have to bluff to others at times, meaning that you listen to your inner soul always; Understand that we are not God and hence likely to make mistakes - take precautions at all times and appreciate the help and support of therapists/caregivers.

Try to build Self – Love and do not think that others have to like you always or appreciate your efforts or struggle managing an ASD child; You might have suspected that your partner loves you, but managing an ASD child together may bring

out the best 'Caring' from your partner, if you are fortunate.

When there is a conflict situation regarding management of your ASD child, do not blurt out your disagreement- think of what he/she has done for you always; Do not think that others are lesser than you; Think of other person's point of view and try to be a third party and then making adjustments may be easy for you.

As partners, parents should try not to hurt each other, and not to hurt yourself at all by refusing to take insult; The initial hurt feeling should not last more than 30 seconds and switch over to cognitive/thinking pathway.

Self-counselling strategies for mothers of ASD children

Self-counselling takes you on a journey of self-discovery, working at your own pace and in the directions you most feel comfortable with. Some problems may be too deep-seated for self-counselling, and these may require additional forms of Psychotherapy.

Simple techniques to initiate Self Counselling

Try to sit separate/away from the rush area. This will help you to be calm with your own thoughts. Try to ensure comfortable seating.

Just close your eyes if necessary and begin to focus to your own mind and thoughts. If you are interested you can play some melody soothing songs in the background.

Imagine that you are another person (Eg: You the real person, can be represented as 'A'; The reflection that came within you can be represented as 'B', the third person). Remember that this 'A' & 'B' have no relation to each other.

'A' (me) can try to speak about my problems or what I am suffering from to 'B' (reflection of me) without any restrictions. The 'B' should be impartial while taking decisions / giving suggestions.

After each self counseling sessions you can practice meditation to ease your mind/soul.

Partner relationship Assessment and Counselling

The travails of managing an autistic child is likely to seriously affect marital relationship, but on the other hand it may also be an opportunity to cement your marital relations, if both of you can work as a single unit. First of all, we need to understand types of love relationships in a marriage that include; (i) Liking (intimacy), (ii) Infatuation (passion), (iii) Empty love (commitment without intimacy or passion), (iv) Romantic love (passion + intimacy), (v) Fatuous love (commitment + passion), (vi) Companionate love (intimacy + commitment), (vii) Consummate love (passion + intimacy + commitment). To continue to have a successful marital relationship is possible, only if the mother/father receive timely anticipatory counselling based on items of Partner-relationship Assessment Scale Trivandrum(5) by Developmental Pediatrician/ Developmental Therapist/Developmental Nurse Counselor.

**Seven domains of PAST**

*Reality:* With all the good & bad in marriage overall real life rating

*Fantasy:* Whether fit in as a fantasy husband / wife.

*Family Support:* Whether family of both/either would come to help in crisis.

*Attitude towards Marriage:* Whether taking the concept of marriage seriously

*Sexuality:* As a satisfying sexual partner-overall assessment

*Giving Type Personality:* Enjoy more by giving pleasure to partner

*Conflict Resolving Strategies:* Problems are resolved amicably, not getting unduly upset

(Note: Scoring <50%-poor satisfaction or >50%-good satisfaction)

**PAST – Reality Vs Fantasy:** We need to keep on teaching ourselves that fantasy is a beautiful but eluding mirage, that keep on changing with age and maturity, whereas reality is what we have at hand and the day we learn to be satisfied with the reality, our life become beautiful in the true sense. For example, parents dreamt that they will get a healthy normal baby – indeed it was normal till 18 months, but now the reality of ASD stare at you and you tend to become helpless. If we could reduce the duration of grief stages and come to the stage of acceptance in a month's time and get on with the therapy process – self counselling is successful.

### **Guided Counselling for the couple**

Counselling being a collaborative effort between the counselor and client, aims at identifying goals and potential solution to problems which causes emotional conflicts. A husband-wife relationship follows certain laws- 'laws of attraction, difference and self-image'. In this context, relationship counseling not only aims at identifying the problems but also provides insight into the type of relationship. Based on this knowledge, one can seek to improve communication and coping skills, strengthen self-esteem and promote behavioural changes and strong interpersonal relationships(6).

The four common factors shown to determine the effectiveness of counseling in the field of marriage and family therapy with each factor attributed to a percentage of the improvement include; (i) client and extra-therapeutic factors (40%), (ii) counsellor-client relationship factors (30%); (iii) specific techniques or model factors (15%) and (iv) expectancy, placebo, and hope factors (15%), all together contributing to the clients' (parents) feeling that there is hope and chance of improvement(7).

### **Understanding and optimizing parenting skills**

A diagnosis of ASD is often traumatic for the parents. It dampens the physical and mental

well-being of parents, often more of mother's than fathers. During the process, parents are typically faced with myriad feelings, including anxiousness, guilt, excessive worry, hope, and fear about the future. However, often the grief associated with it is real and an understanding of the grief stages helps them adapt and adjust in a better way. Everyone reacts differently to grief, and how one reacts has a great deal to do with what happened and whether they have dealt with it appropriately, so that you can focus on home therapy options.

**Psycho-education:** Very often than not, mothers of children with ASD are left with a lot of questions to deal with, which includes medical interventions, therapeutic decisions, safety concerns, educational decisions and other associated co-morbidities. A prior knowledge of what to be prepared for and a confident approach often helps.

### **Socialisation through ASD Group therapy:**

Lack of social acceptance-real or perceived, of your ASD bothers every mother. NIMS-Spectrum-CDRC model group therapy offers some solace to these parents(8). It is an opportunity for a small group of 3 or more individuals to come together and simultaneously learn social behavior. Advantages of Group therapy include; peers in close proximity, great deal of observational learning, scientifically proven approach, effective and efficient method and for assessment of school readiness. Short term ASD specific add on group based therapy program has shown post intervention efficacy with regard to parent rated social responsiveness in children with ASD(9).

### **Managing stress and Healing of the soul**

Stress can not only just affect the management but also bring about significant derogatory changes in the health of the mother. In order to stay healthy, one needs to learn to manage stress efficiently. The daily stress of an ASD parent is tremendous and constant. Self-Counseling can

help by offering a conscious, caring, supportive, parenting effort and encourage self-care skills. Self-Counseling can help someone through a rough patch or be used on an ongoing basis throughout the parent's journey.

Spiritual psychology is concerned with the health of the individual's soul. This soul-centered approach believes that "when love is applied to hurt we heal." Practically applied, it helps a person become aware of a recent upset, ride the emotion back in time to the root of the matter (its core), communicate with that portion inside that is fixated, and apply love to it(10).

## Conclusion

The mothers of ASD children can practice "self-counselling" skills by listening with an open heart, asking for clarification, and probing around options that can help most mothers to cope better. The Developmental Pediatrician/Developmental Therapist/Developmental Nurse Counselor managing the ASD child can help the parents learn how to work with emotional conflicts and master the art of healing. After all, all it takes is human compassion to heal even deeply seated wounds that may have been there for years.

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# Is Sensory Integration & Praxis Test Useful in India? Single Parameter Index Analysis in an Indian Set Up

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## Abstract

**Introduction:** Integration of various senses is a function of childhood development. Subtle problems in these areas of development leads to many problems in children and adult life including learning and emotional problems. Currently, these can be measured reliably and thus, remedied; leading to satisfactory resolution, if intervened early. Sensory Integration & Praxis Test (SIPT) is one such tool.

**Aim:** Study utility of SIPT in Indian setting to consider its widespread applicability.

**Objective:** Analyse one Indian set up having certified SIPT professionals using single parameter as index of utility for a defined period.

**Methods:** Retrospective analysis of SIPT tests in 2019 calendar year was conducted from one Child Development Centre at Kolkata. All Sensory Skill sub-sets of SIPT that were deficient beyond two Standard Deviations (SD) on the test were collated. This was analysed to see, if the data for significant deficiencies were useful in planning remediation for Sensory Dysfunctions identified.

**Results:** 17 areas of Sensory Functions were deficient in this cohort of 314 children with complaints suggestive of NDDs (below 2 SDs). 11 out of 17 sub-scales of SIPT scored, demonstrated deviation below 2SDs in more than half (>50%) subjects studied.

**Conclusion:** SIPT seems to be useful in Indian setting to plan multidisciplinary management for children with special needs. Larger studies involving other centres and involving deeper analysis of the SIPT scores can guide professionals to target their intervention better using upcoming precise tools like SIPT.

**Keywords:** Sensory Integration; Sensory Processing; Sensory Dysfunction; Special Needs; Learning Problems; Neurodevelopmental Disorders; Child Development Centre

## Introduction

Learning<sup>1,2</sup>, behavioural and emotional disorders<sup>3,4</sup> are 3-10% in India. In a study conducted in Chandigarh in 2017, it was found that 1.58 per cent of 12 to 18 year old school students, were specific learning disability<sup>5</sup>. Considering India's population of 1.38 billion in 2015 with about 0.65 billion under 14 years of age<sup>6</sup>, we are looking at 20 to 65 million affected children at least, who can benefit from the latest technologies to help them.

One of the underlying causes of their suffering remains their Sensory Processing difficulties<sup>7</sup>. Sensory Processing Skill Set is a set of childhood developmental functions, which like most other developmental skill sets, is amenable to accurate and targeted intervention<sup>8</sup>.

Sensory Integration & Praxis Test [SIPT] is a standardized<sup>9</sup> tool of measurement of Sensory

difficulties<sup>10</sup>, leading to secondary difficulties like learning or emotional difficulties.

Since the training and accreditation of SIPT has become available in India, healthcare units like Child Developmental Centres now have trained and accredited professionals, who are in a position to unearth such maladies, which can easily escape the naked eye.

A retrospective analysis of available records from 2019 at one Indian Child Development Centre at Kolkata, that has three SIPT trained and accredited professionals, was conducted to see, if SIPT has utility in Indian setting, so that it can be widely applicable for more accurate pick-ups for remediation.

**Aim**

Aim is to conduct a short and retrospective study with the available SIPT reports to see, if SIPT is picking up Sensory Processing Disorders in children in India, using one Child Development Centre [CDC], where SIPT assessment is part of routine assessments in children presenting with suspected neurodevelopmental disorders [NDD], who are thought to have Sensory Dysfunction.

**Objectives**

SIPT identifies Sensory Processing Disorders by measuring 17 sub-scales of Sensory Processing development in a standardized manner. Two standard deviations below each sub-scale is considered to be Disorder in that area of Sensory Processing Skill.

This study identified, where in children living in India, presenting to CDC with diverse complaints with probable underlying NDD(s), these sub-scales are disordered viz. below 2SDs.

This is considered as an index of utility of SIPT in India, which could call for more widespread studies using similar and more diverse criteria to establish any need for its applicability. The postulate is that, if we know where SIPT helps children of India, we can refine and standardize

an useful tool for more precise pick-ups and thereby improving opportunities of improved and better targeted interventions.

**Methods**

Available SIPT reports from the calendar year 2019 were collated and anonymised. Areas of deviations below 2SDs in each of the 17 subscales were identified. Data thus obtained, were then analysed to identify any pattern that has clinical utility for targeting remediation. Analysis was done by a qualified Developmental Paediatrician of Good Standing. SIPT evaluations were conducted and reports were generated by qualified (meeting SIPT qualifications standard C) and accredited consultant therapist. Assessor and Analysts did not confer to avoid one influencing the other.



**Sensory Integration and Praxis Tests (SIPT)**  
By A. Ann-Steve, Ph.D.  
A WISC TEST REPORT by Western Psychological Services  
1201 Wilshire Boulevard, Los Angeles, California 90025-1211  
Copyright © 1976, 1998 by Western Psychological Services  
Version 4.1.12

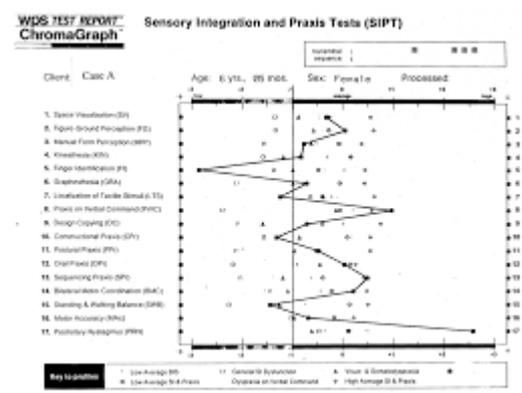
Client's Name: Ben E.  
Testing Date: 07/20/21  
Age: 7; 7 mos.  
Grade: 2  
Gender: Male  
Working Hand: Right

Processing Date: 07/29/21  
Number of Tests Administered: 17  
Number of Tests Scored: 17  
Normative Age Group: 7 yrs. 6 mos. to 7 yrs. 11 mos.

Test	Number of Subtests	SIPT Score	Major Scale (SIPT)
CV	6	102	Verbal Comprehension
PPVT	10	100	Block Design
WISC-III	17	100	Full Scale IQ
SIPT	17	100	Sensory Integration and Praxis
SIPT-1	17	100	Sensory Integration
SIPT-2	17	100	Praxis
SIPT-3	17	100	Sensory Integration and Praxis
SIPT-4	17	100	Sensory Integration and Praxis
SIPT-5	17	100	Sensory Integration and Praxis
SIPT-6	17	100	Sensory Integration and Praxis
SIPT-7	17	100	Sensory Integration and Praxis
SIPT-8	17	100	Sensory Integration and Praxis
SIPT-9	17	100	Sensory Integration and Praxis
SIPT-10	17	100	Sensory Integration and Praxis
SIPT-11	17	100	Sensory Integration and Praxis
SIPT-12	17	100	Sensory Integration and Praxis
SIPT-13	17	100	Sensory Integration and Praxis
SIPT-14	17	100	Sensory Integration and Praxis
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SIPT-16	17	100	Sensory Integration and Praxis
SIPT-17	17	100	Sensory Integration and Praxis

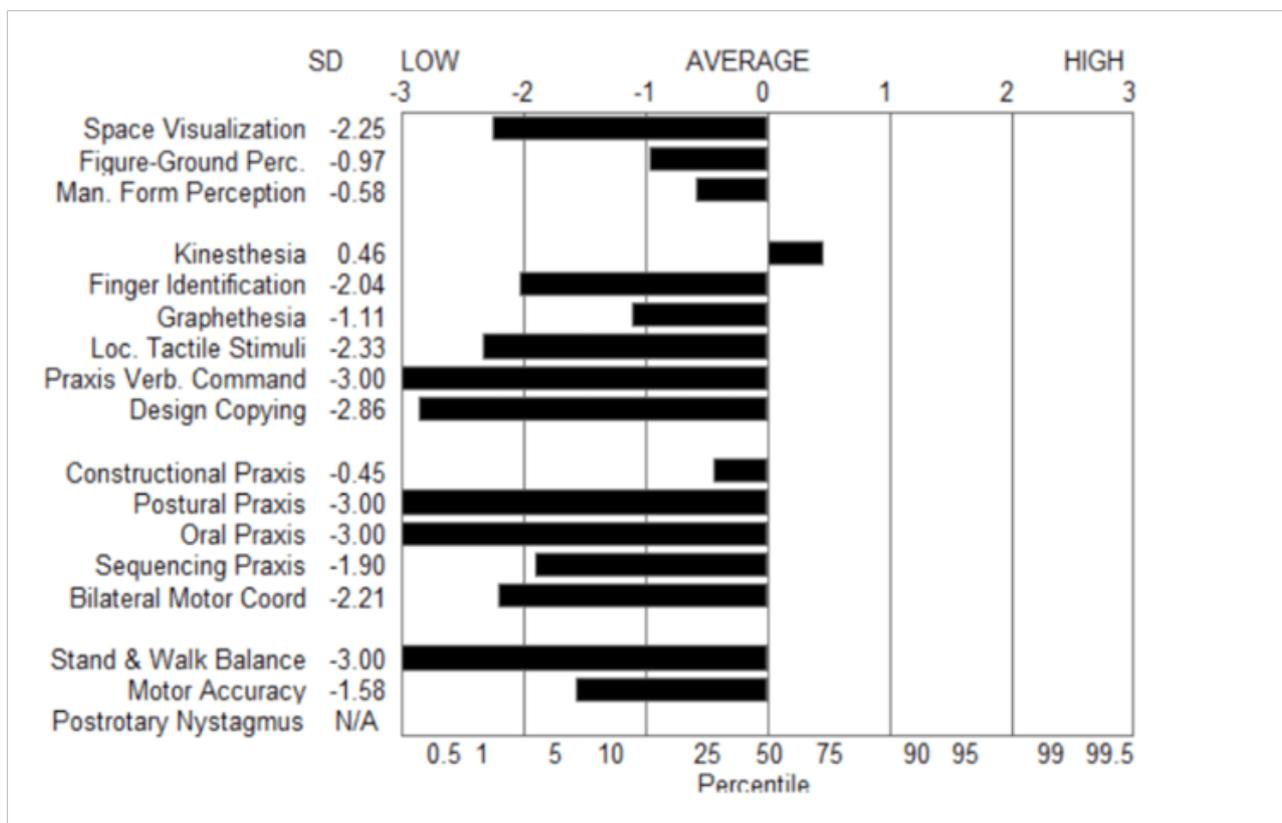
The SIPT TEST REPORT for the SIPT system includes information on Test's sensory processing and praxis abilities. It consists of a summary of SIPT tests and scores, normative scores for Test is provided below. Page 2 of this report presents a graph of these scores, and Page 3 shows the estimated raw scores. The complete listing of SIPT scores appears in Page 4. Following the listing are two checklists: "You may want to consider the profiles of the six groups described in the SIPT Manual. The upper checklists are the clinical standard list."

Users of this WISC TEST REPORT should be familiar with the information including interpretation guidelines, psychometric properties, and Reliability presented in the SIPT Manual published by Western Psychological Services, 1201 Wilshire Blvd., Los Angeles, CA 90025. This WISC TEST REPORT should be used only in conjunction with that Manual.



**Results**

One example of SIPT report shows sub-scales in one page for appreciation



The following table shows the data collated from available reports of SIPT during 2019 at Kolkata CDC:

Total available SIPT reports at CDC, Kolkata in the calendar year 2019	314
Number of SIPT sub-scales <2SDs	
Space visualization	256 (81.5%)
Figure-Ground Perception	104 (33%)
Recognition of forms held in hands: Stereognosis (Manual Form Perception)	66 (21%)
Somatic Perception of Arm Position and Movement: Kinesthesia	111 (35%)
Tactile Perception of Individual Fingers: Finger Identification	132 (42%)

Tactile Perception of Single Designs: Praxis (Graphesthesia)	221 (70%)
Identification of Place on Arm or Hand Touched: Local Tactile Stimuli	183 (58%)
Translation of Verbal Directions into Actions: Praxis on Verbal Command	304 (97%)
Design Copying: Visual Praxis	299 (95%)
Three-Dimensional Visual Space Management: Constructional Praxis	52 (16.5%)
Planning and Executing Bodily Movements: Postural Praxis	287 (91.5%)
Imitating tongue/lip/jaw movements: Somatopraxis (Oral Praxis)	307 (97.7%)
Sequencing Praxis: Bilateral Integration to sequence movements	213 (68%)

Bilateral Motor Coordination	256 (81.5%)
Standing and Walking Balance	270 (86%)
Motor Accuracy	301 (95.8%)
Post-rotatory Nystagmus (CNS processing of vestibular input)	Separately done

### Discussions

SIPT unearths many reasons behind a child's failure. Although the test was originally designed for children aged 4 to 9 years (8 year 11 months), SIPT is used beyond that age range worldwide now (albeit non-standard) even in adults (16 March, 2018) since it is increasingly felt that many people have missed out this ability to pinpoint real origin of a person's failures in life to target remediation, as far as possible.

Simply looking at one index in one centre in India, where children thought to have Special Needs (often Neurodevelopmental Disorders) largely present, it is obvious that so many of them actually have difficulties in their Sensory Development.

11 out of 17 sub-scales of SIPT scored, demonstrated deviation below 2SDs in more than half (>50%) subjects studied.

Number of SIPT sub-scales <2SDs	
Space visualization	256 (81.5%)
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Three-Dimensional Visual Space Management: Constructional Praxis	52 (16.5%)

First Table showing items where >50% caseloads show disorders, whereas the Second Table shows <50% affected.

It can therefore, be concluded that SIPT unearths significant under-recognized maladies in children with Special Needs and NDDs. Moreover, if this is the state of affairs identified in a single centre in India, how many children might be going either unrecognized or sub-optimally appreciated about their extent of primary biological issues. There are however, major limitations of this study that should be borne in mind before generalizing the results.

Some of the limitation of this study involves (a) single centre, (b) only 2SD below data were utilized, (c) clinical correlates were missing, (d)

2SD above abnormalities (?Savants) were ignored (e) post-rotatory nystagmus is not measured as part of SIPT assessment in this centre (although, it is measured separately in Visuo-perceptual Assessments at this centre quite regularly) (f) absence of reference for using 50% cases as something of significance etc.

Nonetheless, this study unambiguously highlights the possibilities that closer and more scientific look at the underlying causes of functional failures in children of India in their life, particularly learning, behaviour and their emotions, definitely

have potential to improved understanding of scientific fact behind their origins.

Since accurate targeting of therapeutic plans show to improve the subject's life chances multifold (topic of another study), it can be argued that precision standardized detection tools ought to be used more universally in evaluation of children of India with Special Needs.

### Conclusions

SIPT is a useful tool in evaluation of children with Special Needs/NDDs

#### *What is already known on the subject?*

SIPT is a useful tool to measure Sensory Integration and Praxis related difficulties in children

#### *What does this study add?*

1. SIPT is useful in Indian setting
2. There is potential to use it more widely for improved outcome

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# Music Therapy in Childhood Neurodevelopmental Disorders

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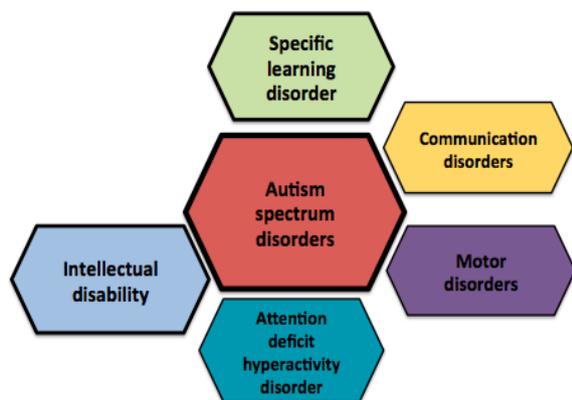
## Abstract

The global prevalence of neurodevelopmental disorders (NDDs) has been on a rising trend in the past decade. Currently, no definitive treatment exists and the prime focus stays on rehabilitation strategies when it comes to managing children with developmental disabilities. Alternative interventions, therefore, have gained considerable interest among researchers. One such form of intervention utilizes music therapeutically to target diverse neural networks pertaining to cognitive, sensorimotor and language functions. Although various studies have reported conflicting results regarding the therapeutic value of use of music therapy in children with NDDs, the existing body of evidence is encouraging. Largely, children with autism spectrum disorders, cerebral palsy and specific learning disability (dyslexia) have demonstrated a favorable response to some extent. However, no uniform consensus exists among the published studies with respect to acoustic features, type of musical instrument employed, and duration of intervention and outcome measures. Neurophysiological correlates of music training explored by the limited available imaging studies have provided further insight into this complementary treatment

approach. In this article, we aimed to provide a comprehensive review of the effect of music in the modulation of various developmental processes and evidence from literature regarding the role of music therapy in the rehabilitation of common neurodevelopmental disorders.

## Background

Neurodevelopmental disorders (NDDs) are a group of heterogeneous conditions characterized by delay or disturbance in the acquisition of skills in a variety of developmental domains, including motor, social, language and cognition<sup>[1]</sup>. Although etiology remains unidentified in many cases, various factors such as perinatal complications (asphyxia, infections, hypoglycemic injury), genetic causes, metabolic errors, exposure to environmental toxins and socio-economic factors can lead to an aberrant development trajectory. Very often, the chronic disabling course of NDDs are complicated by multiple behavioral and medical comorbidities. Rehabilitation in the form of sensorimotor training and tailored behavioral interventions form the standard of care for the majority of the developmental disabilities. None of the approaches offer a definitive cure and hence complementary alternative therapies and novel therapeutic approaches are worth exploring.



**Figure 1:** Classification of NDDs as per DSM-5, 2013<sup>[1]</sup>

Increased survival and thus an increased prevalence of NDD's has been observed in the recent years. A multicentric study by Arora et al. (2018) assessed the prevalence of NDDs in children aged 2-9 years.<sup>[2]</sup> These included neuromotor impairments including cerebral palsy, ASD, ID, hearing impairment, language disorders, vision impairment and epilepsy. All-site-pooled estimates for NDDs were 9.2% and 13.6% in children of 2-5 and 6-9 year age categories, respectively. Nearly one-fifth of these children had more than one NDD.

According to a systematic review by Zeidan J et al. (2022), one in 100 children worldwide has autism.<sup>[3]</sup> One in 44 children aged 8 years in the United States was estimated to have ASD as per CDC's Autism and Developmental Disabilities Monitoring (ADDM) network, 2018.<sup>[4]</sup> The global prevalence rate of SLD ranges from 17.5 percent to 21 percent.<sup>[5]</sup> Of children with specific learning disorders, 80% present with dyslexia. INCLEN data in 2011 revealed 1.8 million children aged 2-9 years old suffer from learning disorders.<sup>[6]</sup> Cerebral palsy is the leading cause of childhood disabilities with an estimated pooled prevalence of 2.95 cases per 1000 children in India.<sup>[7]</sup>

The upsurge in the number of children with developmental disabilities is confounded by

multiple factors; such as increased public awareness, standardized universal screening for developmental delay at well-child visits and increased availability of early intervention programs.

The diversified needs of people living with NDDs are reflected in the fact that some of the affected children manifest specific deficits, such as ADHD and specific learning difficulties, which enables them for a self-sustaining life. Others such as children with ASD, ID however may need lifelong assistance even with basic living skills depending on the degree of disability.

### Can music benefit children with NDDs?

NDDs have multiple associated co-morbidities apart from the core features, which prohibit optimal performance by these children. Traditional therapy in these children is generally not curative and the focus is on improving quality of life via training and limiting associated co-morbidities. The chronic disabling nature of NDDs poses a significant health and economic burden on families and society, raising the demand for the need of more effective and efficient rehabilitation strategies. Evidence from the literature suggests that music therapy could offer a platform for neuro-rehabilitation.

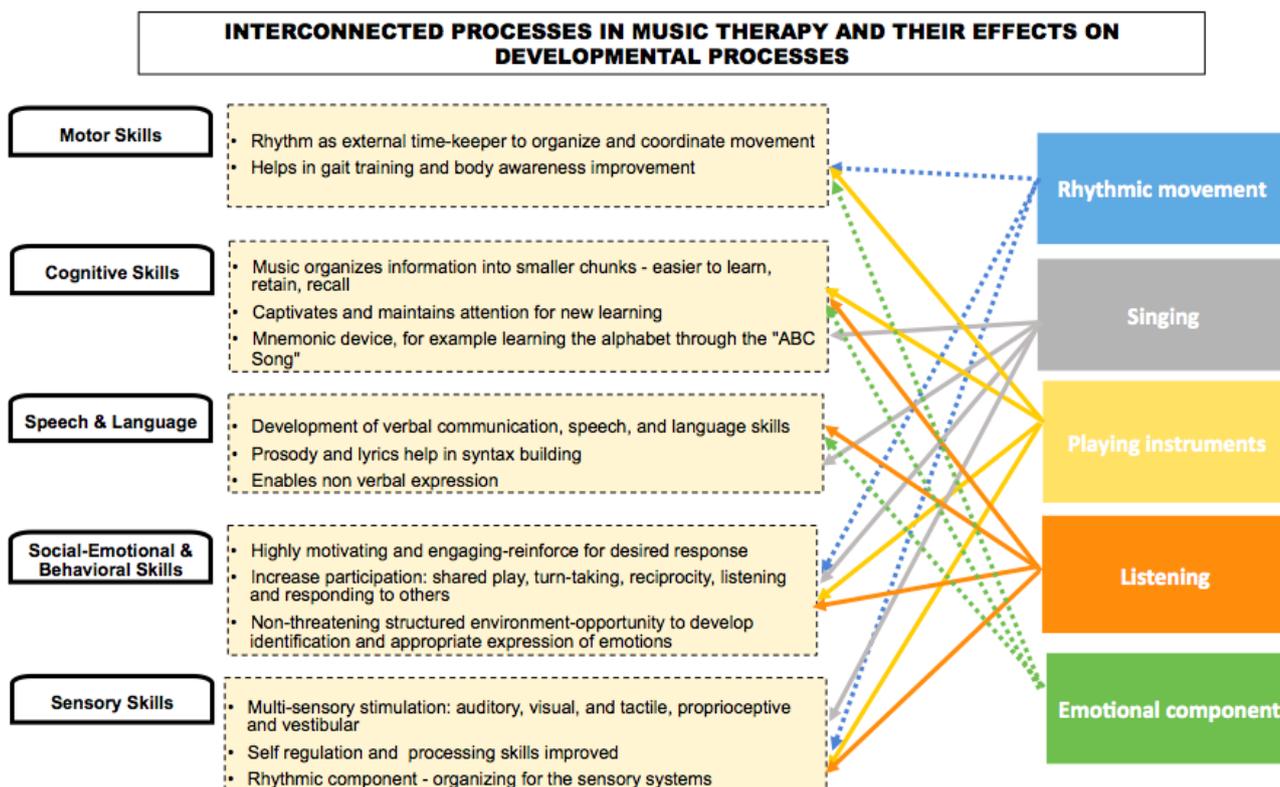
The networks and processes involved in understanding, producing and appreciating music<sup>[8]</sup>, can be used therapeutically to engage and shape non-musical perceptual, cognitive, language, social<sup>[9]</sup> and sensorimotor functions in these children. (Refer to Figure 2 for a detailed illustration of the effects of music on developmental<sup>[10]</sup> processes).<sup>[11]</sup> Animal studies have shown that a music-rich environment induces long-term changes in neurotransmitters and neuroplasticity.<sup>[12]</sup> Considerable research in musicians and instrumentalists has demonstrated the long-term effect of music therapy in enhancing sensory integration with increased volume and density in the cortex especially

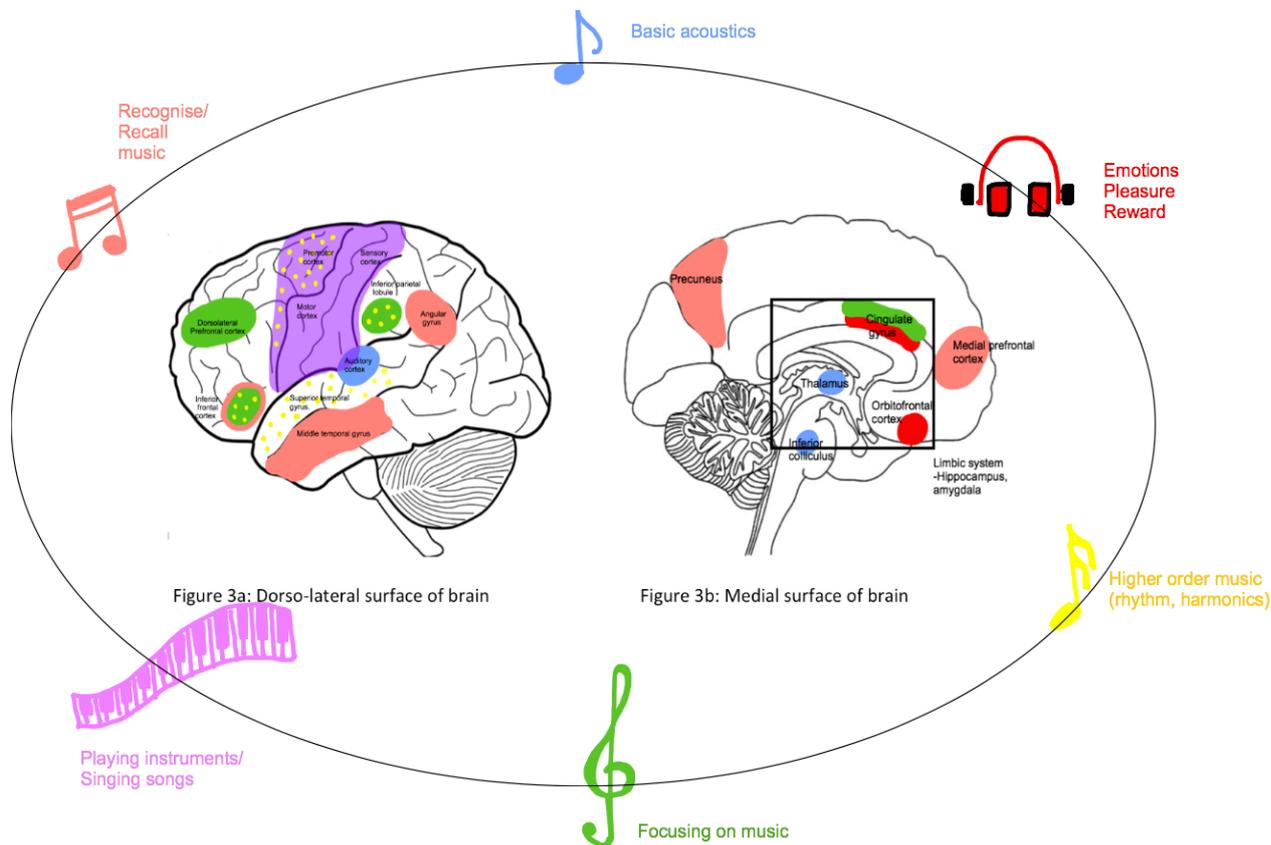
fronto-temporal region and cerebellum as well as improved connectivity [13] of white-matter tracts. [14] Even short-term practice in musical modalities like piano helped improve verbal intelligence and executive function in preschool children. [15] A parallel relationship is also theorized to exist between syntax processing in language [16] and usage of harmonics in music and hence training in music improves speech perception and even pronunciation of non-native languages. [17]

### How is music processed in human brain?

Music is an art or rather a scientific process in which sounds and tones are arranged in combinations or sequenced temporally such that they create unity and continuity. These could be vocal, instrumental, mechanical sounds and tones and this arrangement has a rhythm, melody and harmony (Merriam-Webster et al, 2021).

The processing of these harmonious sounds involves extensive complex brain networks. Figure 3 shows a pictorial representation of the activation of cognitive networks during the processing of music. It starts with sound perception by inner ears carried via auditory nerves largely to inferior colliculi of midbrain where basic acoustic features like intensity and periodicity of music are picked up. There onwards there is a further refinement of this information into sound pitch, temporal and spatial variation of notes, via the thalamus to auditory cortex majorly. Keeping continuous track of music requires attention and working memory. Familiar notes involve episodic memory and recall via the hippocampus and parietal regions. Perception of rhythm and active involvement via movement, singing or playing an instrument also involves the somatosensory cortex, basal ganglia and cerebellar networks.





<b>Basic acoustics:</b> frequency, loudness	Auditory cortex, thalamus, inferior colliculi
<b>Higher order music:</b> rhythm, harmonics	Inferior frontal gyrus, inferior parietal lobule, superior temporal gyrus, premotor cortex
<b>Focusing music</b>	Dorsolateral prefrontal cortex, cingulate gyrus, inferior frontal gyrus, inferior parietal lobule
<b>Recognising and recalling music</b> related memories	Angular gyrus, middle temporal gyrus, hippocampus, precuneus, medial prefrontal cortex
<b>Playing, singing and dancing</b> to music beats	Motor and somatosensory cortices
<b>Music induced emotions</b> and pleasure	Limbic system (hippocampus, amygdala), cingulate gyrus, orbitofrontal cortex

**Figure 3: Pictorial illustration of key cognitive and sensorimotor areas activated during music processing**

[Adapted from Särkämö T et al. Music perception and cognition: development, neural basis, and rehabilitative use of music. Wiley Interdiscip Rev Cogn Sci. 2013 Jul;4 (4):441-451]<sup>[10]</sup>

Music entails more than just a summation of these acoustic features and other connections to limbic areas (amygdala, orbitofrontal cortex) trigger various emotional processes, which make the experience holistic. <sup>[10]</sup>

### **Evidence from literature about music therapy in the rehabilitation of children with neurodevelopmental disorders**

#### ***Autism spectrum disorder***

Autism spectrum disorders are characterized

by core deficits in social communication and interaction associated with repetitive behaviors with restricted interests and activities.<sup>[1]</sup> Children with ASD often can have other debilitating behaviors (ADHD, challenging behaviors, anxiety disorder, etc.) and medical co-morbidities (epilepsy, sleep issues and gastrointestinal problems). The core features as well as the comorbidities have been traditionally targeted using applied behavior analysis (ABA) therapy primarily with pharmacotherapy which may help alleviate associated symptoms. These traditional approaches are tedious and time consuming and are not curative. This nudges caregivers and adults living with ASD towards complementary alternative therapies.<sup>[18]</sup> Among these, music therapy has been shown to be an emerging alternative with a growing body of evidence in its favor.<sup>[19]</sup>

Individuals with ASD have different processing abilities for music as compared to neurotypicals. They show specific interests and talents pertaining to musical modalities with reduced habituation to musical stimuli. They exhibit a strong preference for musical stimuli as compared to verbal stimuli and have superior recognition of pitch.<sup>[20]</sup> There are alternate mechanisms of processing music as evident from imaging studies (MRI), where people with ASD activated temporal networks during perception of sung word similar to controls; but have reduced integrity in language processing networks (fronto-temporal tracts, inferior frontal gyrus, and supramarginal gyrus). In addition to providing an enjoyable, safe outlet for expression it will help other non-musical skills too. Group<sup>[21]</sup> activities and activities with parents<sup>[25]</sup> also help in bonding<sup>[22]</sup> and improve social<sup>[21]</sup> expression in these children.

Many studies have been published recently on the role of musical therapy and musical training in people with autism. Variable improvements in social aspects, parent-child interactions and bonding, attention span, and improved repetitive behaviors have been described, although large randomized controlled trials fail to replicate the same.<sup>[23]</sup> Studies have also shown that there are changes in neural circuitry and improved overall core symptoms of ASD. Even population surveys demonstrate the role of antenatal music in preventing ASD like symptoms, although robust data to back these are not yet available<sup>[24]</sup> A recently published systematic review by Applewhite et al. (2022) has also shown significant heterogeneity in methodologies and outcome variables used in published studies and conclusive evidence for supporting music therapy still is lacking although trend towards beneficial role does exist. The major studies illustrating the effect of music therapy in children with ASD have been tabulated below (Table 1).

Although there have not been any head-to-head trials or designs comparing music therapy with a combination of music and dance therapy, older studies in 2013 by Mateos et al.<sup>[25]</sup> did not demonstrate any significant benefit. The recent noteworthy study by Bergmann et al. (2021)<sup>[26]</sup> subjected ASD children to music and combined music-dance therapies, following which significant improvement was noted in social and emotional behavior scales. Another study by Lakes et al. (2019)<sup>[27]</sup> also reported improved obsessive, compulsive and stereotyped behaviors with the combination of therapies. (Table 2)

**Table 1:** Brief overview of major studies on music therapy in children with ASD

Author	Methodology (Type of study, sample size, diagnosis)	Intervention	Outcome measures	Results
Ghasemtabar et al. (2015) [28]	Longitudinal study design  Children with ASD (n = 27)	MT programs for 45 days in 12 sessions (two sessions of (1-hour/week), whereas the control group received no intervention	SSRS-P: Social Skills Ration System Scale for elementary period	Significant increase in social skills scores post-test (p < 0.001)
Srinivasan et al. (2015) [29]	Randomised controlled trial  Children with ASD (n = 36)	Two novel interventions - rhythm and robotic therapies, vs standard-of-care	SCQ: Social Communication Questionnaire ADOS: Autism Diagnostic Observation Scale-2 VABS: Vineland Adaptive Behaviour Scale RBS-R: Repetitive Behaviour Scale-Revised	With training, the rhythm group showed a reduction in negative affect and an increase in interest affect and positive affect.
Schwartzberg & Silverman (2016) [30]	Randomized control trial  Children with ASD (n = 29)	Cluster randomized to experimental (sung short story) or active control (read aloud short story) groups Daily scheduled music therapy	CC scores: Comprehension check (CC) question scores	Mean CC scores increased from day one to day 3 for both the control and experimental groups. Mean change in CC scores post-intervention: p < 0.05

<p>Bieleninik et al. (2017)<sup>[23]</sup></p>	<p>Randomised controlled trial  Children with ASD (n = 364)</p>	<p>Enhanced standard care vs Enhanced standard care plus improvisational music therapy in a 1:1 ratio</p>	<p>ADOS- social affect domain Parent-rated social responsiveness.</p>	<p>Children with ASD in MT did not result in significant improvement in mean symptom scores compared to enhanced standard care</p>
<p>Crawford et al. (2017)<sup>[31]</sup></p>	<p>Randomised controlled trial  Children with ASD, 4-7 years age (n = 364)</p>	<p>Ratio 1 : 1 : 2  Standard care+ One (low-frequency) session of IMT per week Or Standard care+ Three (high-frequency) sessions of IMT per week, Or Standard alone</p>	<p>Social affect score derived from the Autism Diagnostic Observation Schedule (ADOS) at 5 months.</p>	<p>No significant difference in mean scores of ADOS social effect and parent-rated social responsiveness score.</p>
<p>Lense et al. (2020)<sup>[32]</sup></p>	<p>Mixed design with survey and experimental design  Children with ASD (n = 14)  Neurotypical children (n = 14)</p>	<p>Parent-child integrated music class program  Serenade Program : 10-week program</p>	<p>ADOS-2, 14-item program evaluation survey, semi-structured interview, video recordings</p>	<p>Improved family well-being with enhancing the value of integrated community participation experiences at the level of the family structure.</p>

<p>Cibrian et al. (2020)<sup>[33]</sup></p>	<p>Pilot randomised controlled trial</p> <p>Children with ASD (n = 22)</p>	<p>NMT sessions for 2-month Random allocation to either use an elastic touch-display (experimental group) or tambourines (control group).</p>	<p>DCDQ: Developmental Coordination Disorder Questionnaire PiT: Personality Item Test, timing, synchronisation assessment, the strength control assessment</p>	<p>Significant improvement in coordination with greater control of their movements, p = 0.003</p>
<p>Rabeyron et al. (2020)<sup>[34]</sup></p>	<p>Randomised controlled trial</p> <p>Children with ASD (n = 36)</p>	<p>Comparing music therapy (MT) to music listening (ML) ASD aged 4 to 7 years</p>	<p>CGI: Clinical Global Impression CARS: Childhood Autism Rating Scale (CARS) ABC: Aberrant Behavior Checklist (ABC)</p>	<p>Change in CGI scores: p &lt; 0.001; Change in CARS and ABC scores for both groups: p = 0.001</p>
<p>Pedregal &amp; Heaton (2021)<sup>[35]</sup></p>	<p>Pilot randomised controlled trial</p> <p>Children with ASD (n = 11)</p>	<p>Adolescents with ASD completed 5 music sessions and pre and post-tests of Alexithymia, emotion recognition and language</p>	<p>BPVS-III: British Picture Vocabulary Scale: Third Edition EAQ: Emotion awareness questionnaire ER: Emotion recognition test</p>	<p>Change in vocal and facial emotional recognition scores, p &lt; 0.01 Change in not hiding emotions score, p &lt; 0.01</p>

**Table 2:** Brief overview of major studies on music and dance therapy in children with ASD

Author	Methodology (Type of study, sample size, diagnosis)	Intervention	Outcome measures	Results
Mateos-Moreno &Atencia-Dona (2013) <sup>[25]</sup>	Experimental design  Children with ASD (n = 16)  Neurotypical children (n = 8)	36 sessions of combined MT and DMT	ECA-R: Evaluation of Autistic Behaviour	Positive trend towards a reduction in scores in both control and experimental groups
Lakes et al. (2019) <sup>[27]</sup>	Longitudinal study Design  Children with ASD (n = 12)	4 week intervention of Creatively Able, a music and movement intervention for children with ASD  Given two times per week	RCS: Response to challenge Scale RBS-R: Repetitive Behaviour Scale-Revised; PACES: Physical Activity Enjoyment Scale	Group-level and individual level reduction in stereotypies and compulsive behaviours
Bergmann et al.(2021) <sup>[26]</sup>	Experimental design  Adults with ASD (n = 12)	Autism-Competence-Group (AutCom)-psycho-educative approach with music and dance/movement. 16structured 90-minute sessions	AutCom: Autism-Competence-Group intervention and Questionnaire  Primary outcome variables - social and emotional competence,  Secondary outcome-challenging behavior and quality of life	Significant group differences in AutCom questionnaire, p = 0.024

## ***Cerebral palsy***

Cerebral palsy (CP) is a group of permanent disorders affecting the development of movement and posture, resulting in activity limitation, which is attributed to the non-progressive disturbances that occurred in the developing fetal or infant brain. A child with cerebral palsy faces tremendous lifetime challenges such as physical disabilities, neurobehavioral concerns, sensory impairment, epilepsy and secondary musculoskeletal problems. The management goals in CP are primarily directed toward a multimodality strategy that focuses on improving functionality and capacities in order to achieve independence.

Sensorimotor training forms an essential building block in the rehabilitation of cerebral palsy. Growing evidence indicates that music-based interventions can accomplish the same by recruiting multiple brain areas that are involved in coordination of extremity function with audio-visual-tactile feedback mechanism during active music playing. Imaging studies have delineated various anatomical, functional, and neuroplastic correlates of aberrant developmental trajectories after brain injury in children with cerebral palsy. These changes affect corticospinal tracts and sensorimotor networks as well. Long-term music practice has been demonstrated to cause structural differences (increased thickness/volume in motor cortex, auditory tracts, corpus callosum, cerebellum), increased white matter connectivity and enhanced functional networking

among various sensory modalities, particularly between auditory and somatosensory systems.<sup>[36]</sup>

Music-supported motor training can be used to achieve a more functional and balanced gait pattern while simultaneously motivating children for active participation in physical therapy sessions. There has been a surge of interest in the functional restoration of the upper extremity in individuals with stroke, cerebral palsy, and Parkinson's disease through musical instrument training.<sup>[37]</sup> Acoustic musical instruments such as piano, guitar, and percussive instruments have been most commonly used for such rehabilitation purposes.<sup>[37]</sup> With a focus on hand function, Alves Pinto et al. were the first to employ task-based functional MRI to study the neural correlates of rehabilitation following musical training in CP children (n=10). Increased functional connectivity between the left primary motor cortex and right cerebellum was observed during a finger-tapping test after 18 months of supervised piano training, signifying the neuroplastic effect of music on the neural networks.<sup>[38]</sup> Recently digital musical devices, such as electronic keyboards, drum pads, and tablets/iPads with commercial music software, paved the way for the development of innovative rehabilitation techniques.<sup>[39]</sup> Schaffert and colleagues developed and evaluated a novel music-based therapeutic device (SONATA) for upper limb movement training in 21 healthy subjects.<sup>[37]</sup> This device proved to be feasible and hence opened up novel opportunities for use in restoring motor function.

**Table 3:** Brief overview of major studies on music therapy in children with cerebral palsy

Author	Methodology (Type of study, sample size, diagnosis)	Intervention	Outcome measures	Results
Alves Pinto et al.(2016) <sup>[38]</sup>	RCT N=16 (6-16 years) Neuromotor impairments affecting hand function	Individualized and supervised piano lessons twice weekly for 18 months (cases = 10)	Task based functional MRI (finger tapping task) Variability in keystroke of piano	Increased functional connectivity between the left primary motor strip and right cerebellum in patients who received piano training
Caballero E et al. (2018) <sup>[40]</sup>	RCT N=27 (4-16 years) Severe bilateral cerebral palsy	Neurologic music program of therapeutic instrumental music (TMT) for 16 weeks in addition to its regular physiotherapy (cases = 18)	Overall and specific “Chailey levels of Ability” Locomotor stages	Significant improvement in functionality: overall and specific “arm and hand position”, activities from the “Chailey Levels of Ability” and the locomotor stages were observed in the intervention group, persisting for more than 4 months.
Santonja-Medina CS et al. (2022) <sup>[41]</sup>	Analytic quasi-experimental study N=17 Severe cerebral palsy	Motor learning through therapeutic instrumental music performance (TIMP), using percussion instruments Once weekly for 4 months(total 13 sessions)	Hoisan software video recording for quantifying participation in creating music	Significant improvements: “visual contact”, “motor participation”, “motor participation repetition”. Significant differences were also observed in the subcategories: “reaching and stroke,” “hitting with the hand” and “grasping and hitting.”

**Specific learning disability**

Dyslexia is defined as an unexpected difficulty in reading in an individual who has the intelligence to be a much better reader; dyslexia reflects a difficulty in getting to the individual sounds of spoken language which typically impacts speaking (word retrieval), reading (accuracy and fluency), spelling, and often, learning a second language.<sup>[42]</sup>Dyslexia is, at its core a problem with phonological processing: that is getting to the elemental sounds of spoken language (phonemes), affecting both spoken and written language. Interestingly this phonological deficit has been attributed to faulty temporal processing skills by many researchers. Children with developmental dyslexia may benefit from music based on the hypothesis of a positive correlation between musical perceptual abilities and phonological awareness and reading skills.

The majority of the evidence regarding the role of educational music therapy as a remedial tool for children with learning difficulties came from two randomized controlled trials that evaluated. Register and colleagues showed that short-term instructional program incorporated with music for 4 weeks improved reading abilities, particularly reading comprehension, word vocabulary and word knowledge in 8 students with dyslexia.<sup>[43]</sup>Children with dyslexia showed enhanced phonological awareness and reading abilities (pseudoword accuracy, working memory, auditory attention) after participating in school-based music therapy group sessions for 30 weeks (Flaugnacco et al. 2016).<sup>[44]</sup>A favorable response in the blending subset of phonological awareness showed a positive correlation with rhythmic skills.

**Table 4:** Brief overview of major studies on music therapy in children with specific learning disability (dyslexia)

Author	Methodology (Type of study, sample size, diagnosis)	Intervention	Outcome measures	Results
Register et al.(2007) <sup>[43]</sup>	RCT N=33 (8-dyslexia, rest 2 <sup>nd</sup> grade students) SLD	Musical program thrice weekly for 4 weeks (cases)  Traditional program (controls)	Vocabulary and reading comprehension tests	Significant improvement in reading comprehension in SLD group

Flaugnacco et al.(2016) <sup>[44]</sup>	RCT N=48 (8-11 years) Dyslexia	Music (percussive instruments) & sensorimotor training (cases): twice weekly for 30 weeks  Painting (controls)	Phonological awareness (phonemic blending/segmentation)  Reading abilities (reading loud: text/single words/pseudowords)	Better improvement in text reading, pseudowords accuracy, working memory, auditory attention and phonological abilities in cases as compared to controls.
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**Attention deficit and hyperactivity disorder**

The core deficit in ADHD is related to a primary deficit in behavioral inhibition and executive control. Children with ADHD who struggle with impulsivity and inattentiveness can benefit from the rhythmic, emotional, and motivational elements of music therapy. The results of a survey of 268 music therapists regarding the role of the use of music in the treatment of ADHD in preschool and school-aged children

demonstrated a favorable response.<sup>[45]</sup> In a study by Montello and Coons (1998), educational rhythm-based music interventions reduced hostility and inattention in school children with problem behavior as per teacher reports.<sup>[46]</sup> Rothman et al. (2014) showed similar results of increased attention span and better quality of life in ADHD children who received music sessions with percussion instruments and musical games for 18 weeks.<sup>[47]</sup>

**Table 5:** Brief overview of major studies on music therapy in children with ADHD

Author	Methodology (Type of study, sample size, diagnosis)	Intervention	Outcome measures	Results
Montello and Coons (1998) <sup>[46]</sup>	Pre-post evaluation N=16 (11-14 boys)  Attention deficit disorder, learning disability, emotional issues	Rhythm based music intervention once weekly for 12 weeks (cases)	Teachers report: inattention, hostility and motivation	Significant improvement in rhythm based intervention group
Jackson et al. (2003) <sup>[45]</sup>	Survey (questionnaire based) among 268 music therapists	Several types of music interventions	Perceived effectiveness of music in ADHD	Music therapy was effective in ADHD in the majority of cases

Rothman et al. (2014) <sup>[47]</sup>	Case control study N=101 (5-10 years)  ADHD	Music exercises using percussion instruments and musical games <sup>[11]</sup> once a week for 18 weeks (cases)	Attention  Quality of life ratings  ADHD/conduct disorder symptom checklist	Significant improvement in attention and quality of life
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**Intellectual Disability**

Intellectually disabled children have significant impairment both in intellectual functioning and in adaptive behavior domains as reflected in personal, social-adaptive and academic/occupational skills. Similar to other NDDs, no curative treatment exists.

A handful of studies, mainly pre-post and observational studies are available in the literature, which assessed the effect of music therapy in children with developmental delay

or intellectual disability. Williams et al. (2012) reported an improvement in social skills and parent-child interactions but with persistent child problem behavior following a 10-week music therapy session.<sup>[48]</sup> Educational music therapy improved social communication skills when applied in a classroom setting for 15 weeks in a study by Mendelson et al. (2016).<sup>[49]</sup> On the contrary, observational studies (Aldridge et al. 1995, Duffy and Fuller et al.2001) failed to show any positive effect of music in children with developmental disabilities.

**Table 6:** Brief overview of major studies on music therapy in children with intellectual disability

Author	Methodology (Type of study, sample size, diagnosis)	Intervention	Outcome measures	Results
Williams et al. (2012) <sup>[48]</sup>	Pre-post evaluation, N=201 (3-60 months)  Global delay/ASD/ Specific language impairment	Singing songs, playing instruments: weekly for 10 weeks	Parent reported assessments: child parent interactions, social play skills, receptive communication skills, parenting	Improvement in child social engagement and child-parent bonding

Mendelson et al.(2016) [49]	Pre-post evaluation N=33 ID	Interactive music therapy (songs), weekly for 7 weeks or 15 weeks	Teachers' ratings: Social Skills Improvement System-Rating Scale (SSIS-RS) Behavioral observations	SSIS-RS: no significant results. Social/communicative responses improved during long-term therapy
Duffy and Fuller et al. (2001) [50]	Case control study, N=32, ID	Group music therapy twice weekly for 8 weeks (cases) Non-music therapy (controls)	Social skills evaluation by analysis of videotaped sessions	No significant difference between cases and controls

### Scope for future

There has been a surge of interest in this field of alternative therapy and exploratory evidence does suggest some improvement. However, there is a major lacuna of well-powered studies with meticulous design to conclusively recommend or refute the use of music in NDDs. Largely no major harms have been reported in any of the studies.

Music therapy to a large extent is individualized but good practice guidelines for planning of therapy, structured recommendations for the type of therapy to be used, type of music, music combined with movement therapy, use of artificial intelligence vs. therapists role in music therapy is still unclear at this point of time. These are a few of the many variables, which require further exploration.

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# Utility of the Wechsler Intelligence Scale for Children (IVth Edition) in the assessment of Children with Neurodevelopmental Disorders – A Case Series.

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## ABSTRACT

Neurodevelopmental disorders (NDD) are characterized by early-onset deficits of variable severity in personal, social, academic, or occupational functioning. Although the spectrum of NDD is heterogeneous, intellectual impairment is an important component of most children with NDD. Comprehensive psychological assessments using standardized intelligence tests are required to assess intelligence. This paper describes the profile of four children with different neurodevelopmental disorders and the utility of the Wechsler Intelligence Scale for Children (4<sup>th</sup> edition) in their evaluation. Understanding the profile of children with NDD is important in providing the optimal learning and behaviour interventions required for these children.

**Key words:** Neurodevelopmental disorders, Wechsler Intelligence Scales for children, profile of intelligence

## INTRODUCTION:

Neurodevelopmental disorders, according to the Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> edition (DSM-5) (1),

are characterized by early-onset deficits of variable severity in personal, social, academic, or occupational functioning. The neurodevelopmental disorders include intellectual disability, communication disorders, autism spectrum disorder, attention-deficit/hyperactivity disorder, neurodevelopmental motor disorders and specific learning disorder (2)

Intelligence integrates cognitive functions such as perception, attention, memory, language and planning (3). On the basis of this definition, intelligence can be reliably measured by standardized tests. Since impairment in intellectual functioning is often an important component of neurodevelopmental disorders, formal assessment of intelligence is warranted in these children.

The commonly used intelligence tests in Indian children include the Binet Kamat Intelligence test, Stanford-Binet Intelligence Scale, Wechsler Intelligence Scale for Children (WISC), Malin's Intelligence Scale for Indian Children and the Wechsler Preschool and Primary Scale of Intelligence (WPPSI).

The Wechsler Intelligence Scale – Fourth edition

(WISC-IV) provides an overall measure of general cognitive ability (known as Full Scale Intelligence Quotient – FSIQ), and also measures intellectual functioning in Verbal Comprehension (VC), Perceptual Reasoning (PR), Working Memory (WM) and Processing Speed (PS). The VC, PR, WM, and PS subscales provide scores for the Verbal Comprehension Index (VCI), the Perceptual Reasoning Index (PRI), the Working Memory Index (WMI), and the Processing Speed Index (PSI) respectively. Together, the VCI, PRI, WMI, and PSI provide the overall level of intelligence, or Full Scale IQ (4). The Fourth edition of the WISC (WISC-IV) has norms of Indian children and is culturally appropriate.

This article describes how assessment using the WISC-IV complemented diagnosis and therapeutic planning in four children with neurodevelopmental disorders

### Case History 1:

Master Adil (name changed), 9-year-old boy, was one of twins and was born with a birth weight of 2.5 kg. He was referred with complaints that he was slow in reading and writing, had frequent omissions while reading, missed punctuation marks and disorganized in that he could not write between lines. He underwent a detailed psychological assessment. The Full scale IQ on the WISC-IV was 60. But significant difference was observed between verbal comprehension index (72) and perceptual reasoning index (49) (Figure 1A).

Because of the lower perceptual reasoning index (PRI), visual impairment was suspected. The detailed visual assessment showed that although the vision was 6/6 with spectacles, he had difficulties in crowded spaces, locating objects in a clutter and reading and copying from the blackboard. Lower visual field inattention was also suspected. With these clinical findings Cerebral Visual Impairment was considered (5). His neurologic examination was normal.

MRI showed evidence of periventricular leukomalacia (PVL) (Figure 1B). which is a well-known cause of cerebral visual impairment.

The final diagnosis was Cerebral Visual Impairment with Learning Disability. With few simple suggestions which addressed his visual difficulties his scholastic performance improved considerably.

### Case History 2:

Master Benny (name changed) 14 years 6 months old, was brought with difficulties in reading, poor reading comprehension and writing difficulties. On observation, he was hesitant to read out loud and had to read multiple times to comprehend what he read. There were spelling errors, difficulties in writing between lines and poor paragraph delineation. On examination, Benny was a very pleasant and attentive boy, with normal neurological findings

On the WISC-IV, the scores were as follows: Verbal Comprehension Index – 90, Perceptual Reasoning Index -100 Working Memory Index - 98, Processing speed Index -109 and Full-Scale IQ -97. Since all of were within the average range (90-110), his intelligence was normal. Because the predominant academic difficulties an achievement test - the Wechsler Individual Assessment Test – Third edition (WIAT- III) was done.

The main difference between the WISC and the WIAT is that the former assesses intelligence while the latter is used to assess academic performance. The WIAT assesses the individual's abilities in Reading, Written Language, Mathematics, and Oral Language and is useful in planning academic interventions. His scores on the different domains of the WIAT-III were as follows. In Oral Language (OL) he scored 91 which was average, in Basic Reading (BR) he scored 82 (below average), Total Reading (TR) he scored 81 (below average), in Reading Comprehension and Fluency (RC) he scored

### Difference between VCI and PRI in child with Cerebral Visual Impairment

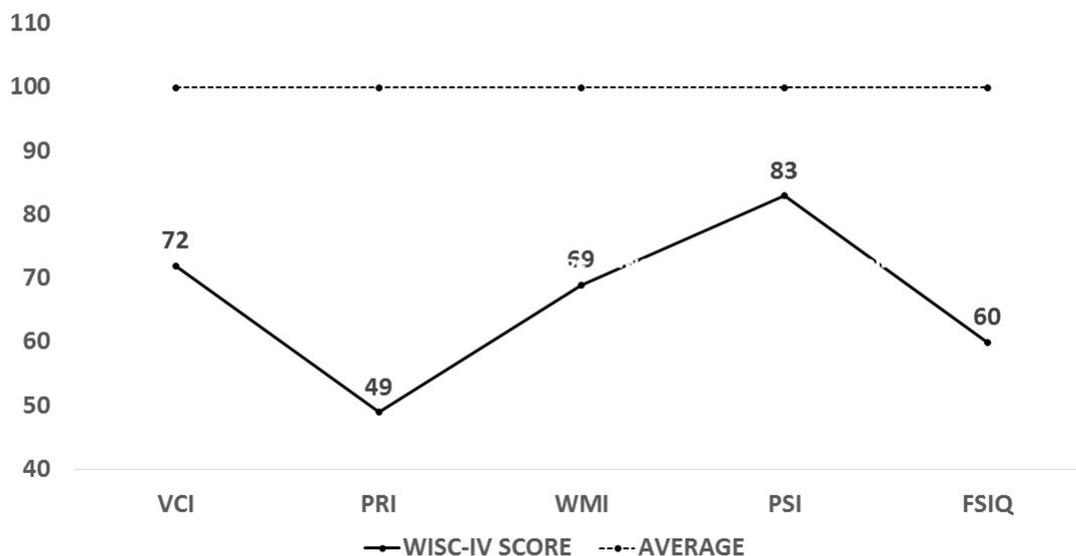


Figure 1A Difference between VCI and PRI in child with Cerebral Visual Impairment

79 (below average) and in Written Expression (WE) he scored 87 (below average). He was above average in his math abilities (102) and in Listening Comprehension (LC) - 105. His profile showed a significant difference between his cognitive ability assessed by the WISC-IV and his reading and writing abilities assessed using the WIAT - III (Figure 2). This discrepancy was indicative of specific learning disability (SLD) in Reading or Dyslexia.

Ability – achievement discrepancy (6) implies that discrepancy between cognitive development usually measured by IQ test (such as the WISC) and academic achievement (assessed using an academic test like the WIAT) is indicative of specific learning disability.

Specific interventions to improve his reading were suggested and he was able to obtain the appropriate concessions required to complete his Board examinations successfully.

#### Case history 3:

Master Chandran (name changed) was diagnosed

to have Autism at four years of age and was on regular developmental monitoring. He was a verbal child, able to converse with strangers,

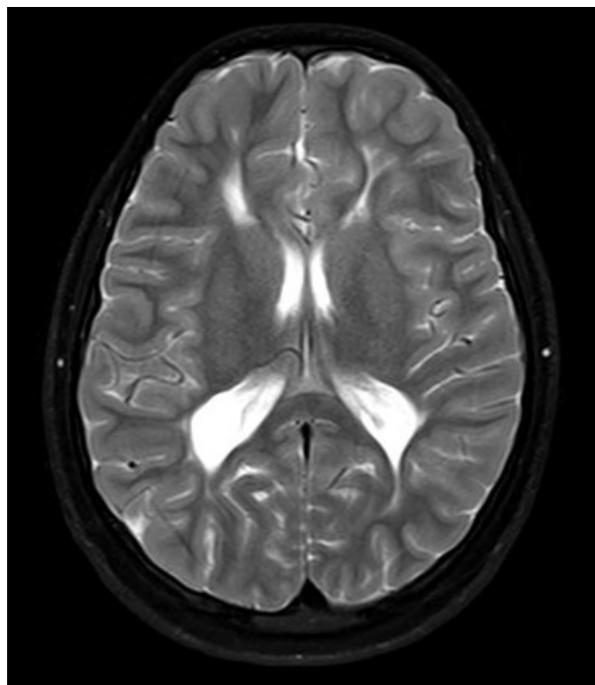


Figure 1B Periventricular leukomalacia - MRI showing posterior ventricular hyperintensities and squaring of ventricles

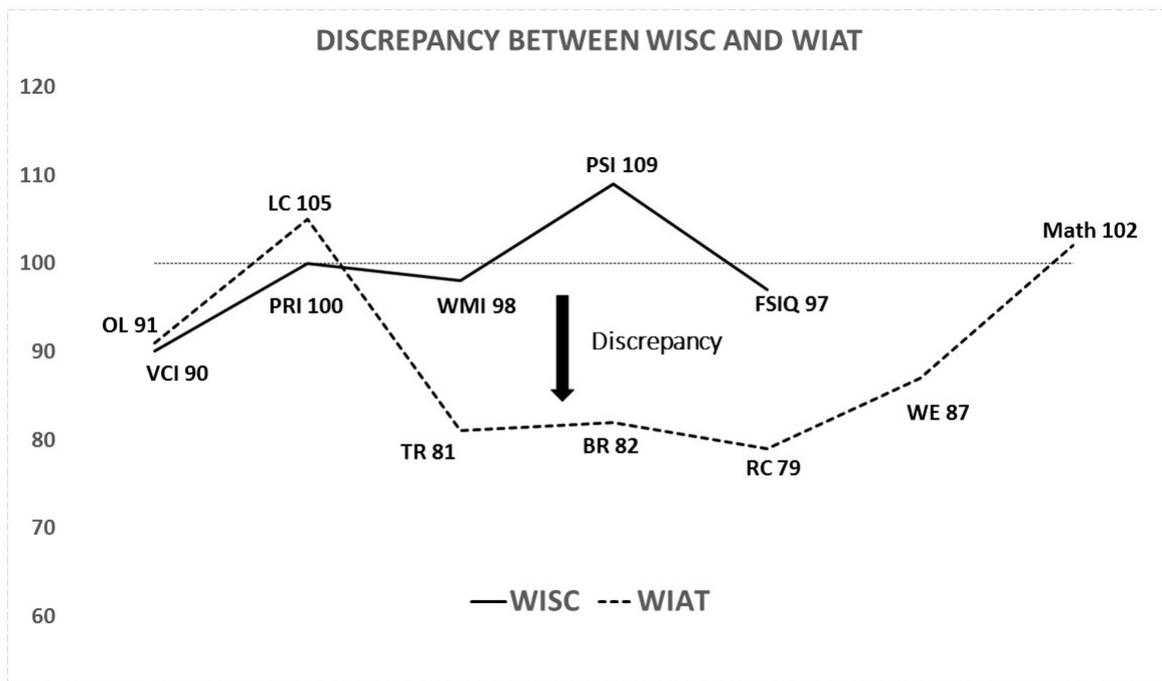


Figure 2 Discrepancy between WISC and WIAT scores in a child with Dyslexia

independent in all his activities of daily living and was attending normal school. He had difficulties with understanding emotions, had repetitive self-talk and struggled with abstract ideas and theory of mind concepts. The diagnosis of autism was confirmed by the Autism Diagnostic Observation Schedule (ADOS-2).

The Wechsler Intelligence Scale for Children IV was done at two time periods (7 years 9 months and 13 years 2 months) to understand his cognitive profile and to plan learning interventions. On both occasions the full scale IQ was in the Average range but there was a significant difference between the Perceptual Reasoning Index (PRI) and Verbal Comprehension Index (VCI) (Figure 3).

Children with ASD are known to have very good visual skills and superior skills in non-verbal concept formation, visual reasoning, visual perception and organization. Expectedly his PRI was high average on both occasions. Children with autism have significant difficulties in verbal abilities and communication, and this

was obvious in the lower VCI. While doing the perceptual and visual tasks on the WISC he had good and sustained attention. But during the tests of vocabulary and comprehension and while in answering questions, he was easily distracted.

Discrepancy between verbal comprehension index (VCI) and perceptual reasoning index (PRI) is a characteristic profile in children with autism (7). With consistent learning intervention his scores improved with time as shown in Figure 3, but the discrepancy between the PRI and VCI have remained.

#### Case History 4:

Master Nithin (name changed), was a boy with mild diplegic cerebral palsy (Gross Motor Functional Classification Scale Level I) because of prematurity and low birth weight. There was some delay in attaining his early developmental milestones. With time he improved significantly and was attending regular school. However, the teachers expressed concerns about his scholastic performance – difficulties in copying from

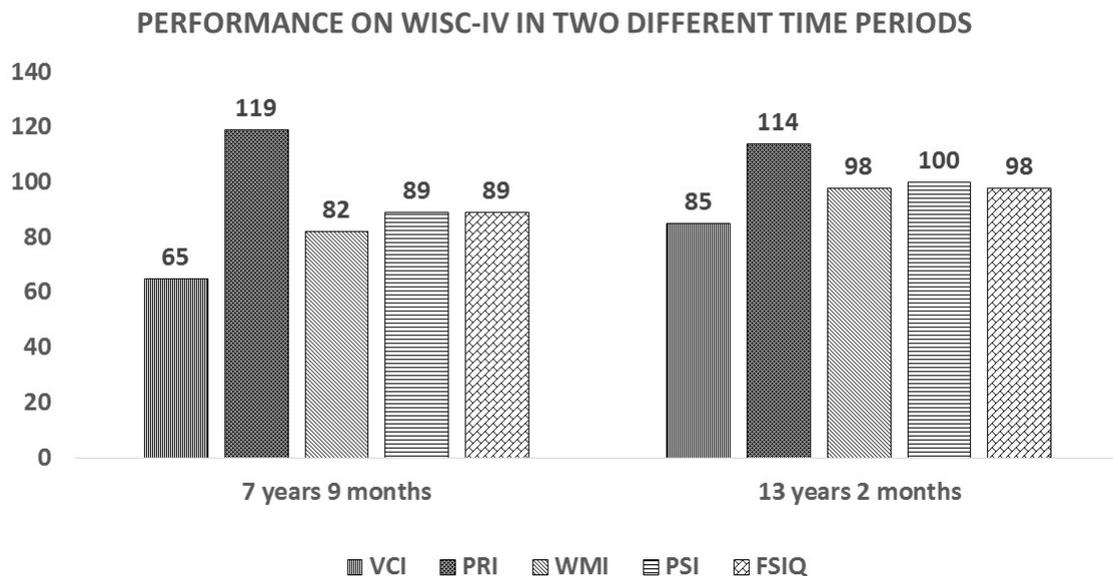


Figure 3 Profile of the child with autism on the WISC at different time periods

the board, slow in writing, poor handwriting and reading difficulties. MRI brain showed periventricular white matter hyperintensities and prominent lateral ventricles with undulated margins suggestive of periventricular leukomalacia (similar to the first child's MRI shown in Figure 1B). Neurologic examination revealed mild spasticity in his lower limbs. He was also detected to have some features of Cerebral visual impairment.

The profiles on the WISC-IV done at two time points (14 years 7 months and 15 years 11 months) (Figure 4) were similar. While doing the WISC-IV it became obvious that he had difficulties in visual-spatial organization, motor coordination, took a long time to identify pictures and symbols and there was a lot of over-writing. His strength was his verbal abilities and the VCI remained consistently higher than the other indices. This profile could be explained by the mildly increased tone of his upper limbs and the mild visual impairments because of his cerebral visual impairment. He was able to obtain concessions from the school for his writing (having a scribe

and extra time for answering) and successfully completed his board examinations. Nithin's profile was consistent with other studies which have shown that the verbal abilities of spastic diplegic children are much better than their performance abilities (8).

#### Discussion:

Assessment of the intelligence using standardized IQ tests is an important component of the overall assessment of a child with neurodevelopmental disorder. Besides evaluating the presence of intellectual disability, the IQ assessment is also used to communicate the patterns of strength and difficulties to parents in order to provide support that is personalized to the child's cognitive ability. Evaluators typically use the Full scale IQ (FSIQ) to report the overall intellectual ability. However, children with neurodevelopmental disorders vary in their profiles and the FSIQ may not give the complete picture of the child's strengths and deficits(9).

#### Conclusion:

As presented through the above case histories,

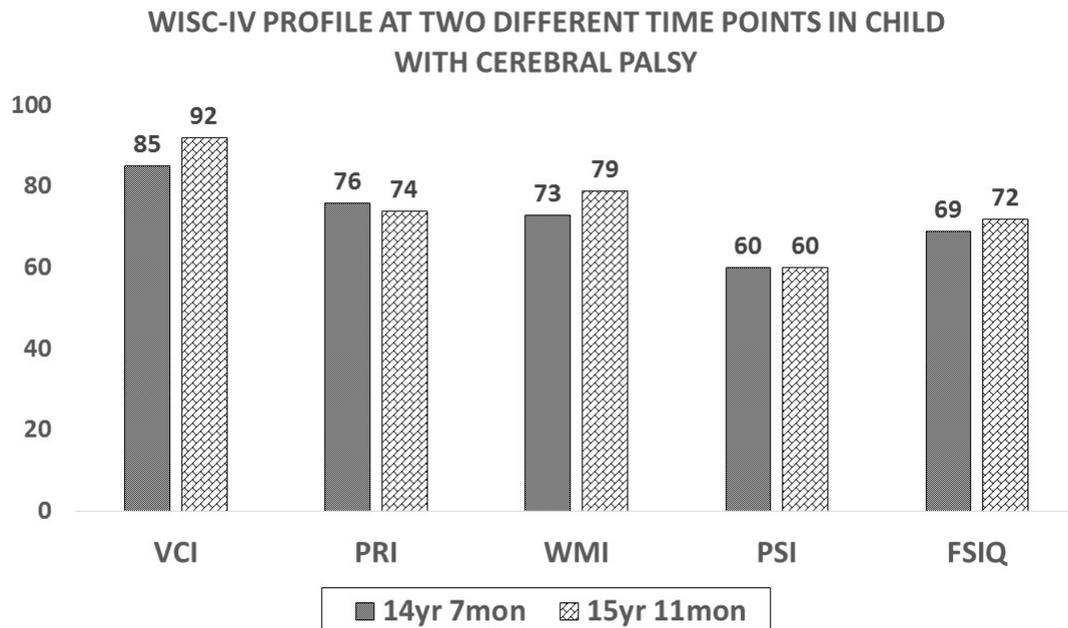


Figure 4: WISC-IV profiles of child with cerebral palsy at two different time points.

detailed assessment of the different subscales of the WISC-I can provide information in establishing the diagnosis in children with neurodevelopmental disorder. This can also help in planning interventions specific to each child’s educational needs.

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# Rett Syndrome in India: demographics, clinical features, and genetic profile of 6 Rett Syndrome cases as part of “Genetics in Autism” research study

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## Abstract:

Rett syndrome is a complex neurodevelopmental disorder, caused by mutations in MECP2 gene. At present, around 900 different variations, both benign and pathogenic of the gene are known. Different mutations can lead to variable levels of severity, different clinical features and may be associated with variable demographic profile. We present here a case study of 6 Rett Syndrome cases, a part of “Genetics in Autism” research study and their genotype-phenotype profile. The study includes two novel variants, c.23\_27del in exon1 and c.538C>T variant (male mosaic) known in females but not in males. Although it is a small sample size, the study highlights the importance of genetic tests and counselling in children with features of autism spectrum disorder.

## Key words:

Rett syndrome, genetics, demographics, clinical features

## Introduction:

Rett syndrome (OMIM#312750) and

susceptibility to X-linked autism-3 (OMIM#300496) are caused by mutations in the MECP2 gene (OMIM\*300005). It is a genetic neurodevelopmental disorder and is seen predominantly in females. The MECP2 gene is a protein coding gene and via the protein MeCP2, modifies chromatin and helps regulate expression of gene activity. Disorders associated with MECP2 gene are Rett syndrome and Intellectual developmental disorder, X-linked syndromic intellectual developmental disorder-13. Most of the cases of Rett syndrome are due to sporadic, de-novo mutation in the sperm<sup>[1,2,3]</sup>. As the inheritance pattern is usually de novo, recurrence risk in subsequent pregnancy is approximately 2%. Genetic counselling is advised for interpretation of the consequences of the variant(s).

Clinically, Rett syndrome is characterized by developmental regression between 6-18 months of age with loss of acquired skills, speech, stereotypical hand movements, microcephaly, seizures and intellectual disability<sup>[4]</sup>. Many of the children also present with symptoms of autism spectrum disorder (ASD) or it is diagnosed

as ASD. We present a case study of 6 children diagnosed as Rett Syndrome as part of “Genetics in Autism” research study.

**Design:**

106 children with features of ASD on DSM-V [5] criteria (social-communication: level-2/3, sensory /repetitive: level-2/3) were enrolled in the study between the period of April 2020 - April 2021. Detailed demographics, clinical features, investigations data was collected. Karyotype, fragile X (for male children) and Whole Exome Sequencing (WES) was done for each child. Validation of the variants and parental segregation analysis was done by Sanger Sequencing.

**Results:**

**Genetic profile: Table-1**

Out of 106 children enrolled in the study, 6 had

MECP2 mutation on WES (5.66% of study population). It was the most common recurring gene with an X-linked inheritance as well as the most common recurring gene in the entire cohort. 5 were female children with X linked de-novo mutation (heterozygous), 1 was male child with X linked post-zygotic de-novo mutation (somatic variant). The variations seen in exon 3 were: c.842dupC, c.491C>G, c.433C>T, c.538C>T, c.952C>T. The variation seen in exon 1 was c.23\_27del.

There were 2 novel variants [6] in the study, c.23\_27del in exon1 (figure-1) and c.538C>T variant (male mosaic) known in females but not in males (figure-2).

**Table-1: Rett syndrome- genetic profile**

No	kar	gene	variant	Zygoty	(omim)	inheritance	F	M
1	XX	MECP2	c.842dupC (p.R282Pfs*61) in exon 3	hetero	Rett	x-linked de novo	N/A	N/A
2	xx	MECP2	c.23_27del (p.A82Efs*32) in exon-1	hetero	Rett	X linked de novo	N/A	N/A
3	xx	MECP2	c.491C>G (p.P164R) in exon 3	hetero	Rett	X linked de novo	N/A	N/A
4	xx	MECP2	c.433C>T (p.R145C) in exon 3	hetero	Rett	X linked de novo	N/A	N/A
5	xy	MECP2	c.538C>T (p.R180*) in exon 3	Somatic variant	Rett	x-linked, post zygotic, de-novo	N/A	N/A
6	xx	MECP2	c.952C>T (p.R318C) in exon 3	hetero	Rett	x- linked de novo	N/A	N/A

Kar-Karyotype, Hetero-heterozygous F-father, M-mother

Figure-1: c.23\_27del variant in exon1

Sanger sequencing electropherograms:

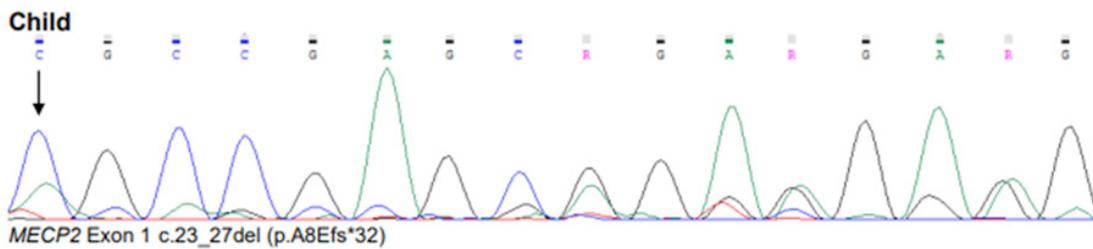
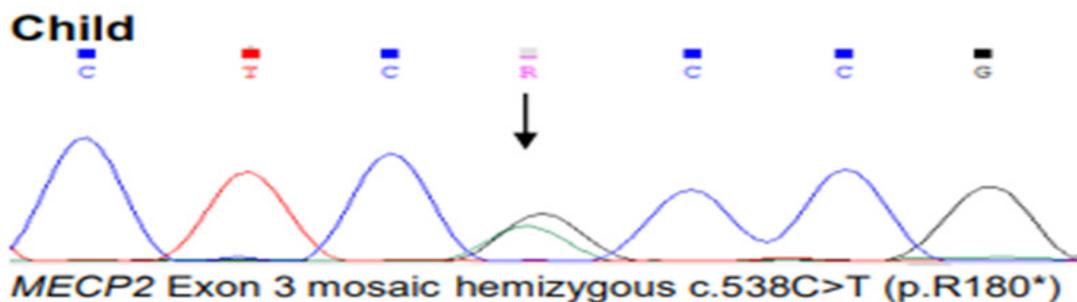


Figure-2: c.538C>T variant (male mosaic)

Sanger sequencing electropherograms:



Demographics & clinical features: Table-2

The female children in the study were between 2-12 years of age, all were full-term born with no maternal or perinatal complications. One parent had 3<sup>rd</sup> degree consanguineous marriage and one had twin pregnancy with miscarriage of one foetus at 4 months of gestation. The mean birth weight was 2.3 kg. MRI scan (done in 5/5), BERA (4/5), eye exam (2/5) was normal.

EEG was abnormal in 2/5 kids with one on antiepileptics. Microcephaly was noticed in 3/5 kids and 2/5 children had bruxism. 4/5 girl's had siblings who were normal.

Male child (2.7 years- born at 32 weeks of gestation), had normal MRI/eye/ear exam/head circumference, abnormal EEG (one episode of convulsions) and right thumb polydactyly<sup>[7]</sup>.

**Table-2: Rett syndrome- demographics and clinical features**

no	Age (years)	sex	term	BW (kg)	seizure	MRI	EEG	BERA/ Eye	Head size	Sib (year)
1	12	F	FT	2.2	none	N	N	N/N	<3 <sup>rd</sup> centile	Bro-7
2	3.1	F	FT	2.5	none	N			<3 <sup>rd</sup> centile	Sis- 5
3	2	F	FT	1.58	1 episode	N	AB	N	<3 <sup>rd</sup> centile	Sis- 6
4	6.4	F	FT	3	ongoing	N	AB	N	In range	Sis-9, bro-7
5	2.7	M	32week	2.1	1 episode	N	AB	N/N	In range	none
6	3	F	FT	2.2	none	N	N	N/N	In range	none

F-female, M-male, FT-full term, BW-birth weight, N-normal, AB-abnormal, Sib-sibling, Bro-brother, S-sister

**Conclusion:**

Rett syndrome is a complex neurodevelopmental disorder which can present with variable clinical findings and demographic [8] profile. As different mutations may lead to variable clinical presentations and severity, it is imperative to study genotype-phenotype association to help in management and to provide counselling support to the parents.

Also, with increase in prevalence of ASD many

of the Rett syndrome cases are diagnosed and treated as ASD especially in developing country like India. It is important to provide access to genetic tests and counselling to parents for long term management and understanding of the prognosis.

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5. Introduction – should state purpose of study & give brief review of pertinent literature. Cite only those references that are essential to justify the purpose of study.
6. Material & Methods should follow the introduction & should provide enough information to permit repetition of experimental work/ project, giving how the study was designed, carried out and data was analyzed. State whether study was approved by ethics committee or not. Describe statistical analysis methods used with required details. Give actual p-values, t-values define statistical terms, symbols and abbreviations.
7. Results should describe the outcome of study giving relevant data. Avoid repeating in the text all the data depicted in tables or illustrations: Tables (numbered in roman numerals) & illustrations (Numbered in Arabic Numerals) should be prepared on separate sheet(s) with headings or legends. Minimum size of illustrations should be 8 x 10 cm. Top of figure should be marked by an arrow on its back as well as figure's number and author's name on left side of photograph. Cite the tables/ figures in the text at appropriate places.
8. Discussion ordinarily should not be more than 1/3 of total length of manuscript. New and possible important findings of the study should be emphasized, as well as any conclusions that can be drawn. The Discussion should compare the present data to existing literature. The implications of the findings and their limitations, including potential for future research should be discussed. New hypotheses and clinical recommendations that are appropriate should be clearly identified.
9. References - In general, the number of references should not exceed 40 for original articles, 50 for review articles and 15 for case reports. The authors are responsible for the accuracy and completeness of the references

and their citations in the text. 1. References should be numbered consecutively in the order in which they are first mentioned in the text. 2. References in text, tables and legends should be identified by superscript numerals in square brackets [] at the end of the sentence outside any punctuation. If several different studies or papers are cited within one sentence, the number should be placed where it will accurately identify the correct study.

- A. Papers published in journals / periodicals: Authors surnames followed by initials of first names; full title of paper; full name of journal; year of publication, volume, issue (in Arabic Numerals), first & last page numbers eg. Rocs DB. Congenital anomalies associated with thoracic outlet syndrome. Am J Surg 1976;132(3):771-778.
  - B. When writing a reference in text, the surname of the author should be given; if there are two authors, the surnames of both the authors should be given & if there are more than two authors, then surname of first author followed by "et al" and name(s) should be followed by year in bracket.
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  - C2. Books: Names of Author(s) of Chapter: Name of the Chapter. In: Name of the book. Names of the editors, Edition, Name & Domicile of Publisher; Year of Publication; PP (first & last Page no.).
10. All figures should be planned to fit within either 1 column width (8.0 cm), 1.5 column widths (13.0 cm) or 2 column widths (17.0 cm), and must be suitable for photocopy reproduction from the printed version of the manuscript.

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit JPEG or TIFF files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programs. Scans (JPEG & TIFF only) should have a resolution of 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size.

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#### **General Writing Format:**

1. The manuscript is prepared in an A4 paper, single-sided, and single line spacing format. A new paragraph should start 5 characters from the left margin, using 10-size, typed in Times New Roman or Arial font type.
2. The manuscript should be written in proper English.
3. The top and bottom margins are 1 inch.
4. The title is written using capital letters only at first word or special name (example: location name), 17 font size, center position.
5. Sub titles are written using capital letters only at first word or special name, 12 font size, starting from the left margin.
6. Sub of a sub of sub titles, if any, are written using capital letters only at the beginning of each word except for connecting words, all in italics. They should be started from the left margin.
7. All references should be preferably of the last ten years publication.

**Tables and Figures :** Tables and figures should be presented as follows:

1. The name of tables and figures should follow a numbering system (Arabic numbering system). The title of the tables and figures are placed at the top and the bottom respectively.
2. The tables and figures should provide the source of information, if any, at the bottom.
3. Each image should be less than 4096 kb(4MB). All the Images/Figures should be submitted in separate files. Do not Zip the file.



# Indian Academy of Pediatrics

## Chapter of Neuro Developmental Pediatrics

### Membership Application Form

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3. Central IAP Membership Number (For Pediatricians Only): \_\_\_\_\_
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7. Mobile Phone Number (1) \_\_\_\_\_ (2) \_\_\_\_\_

8. Present Work Status: Private \_\_\_\_\_ Govt. \_\_\_\_\_ Medical College \_\_\_\_\_ Voluntary Agency \_\_\_\_\_

9.

Qualifications	Name of University	Year of Passing
MBBS		
MD Pediatrics		
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