

EDITORIAL

ETHICS IN DEVELOPMENTAL PAEDIATRICS: BEYOND DIAGNOSIS TO DIGNITY

Developmental paediatrics sits at a unique ethical crossroads where medicine, education, family hopes, and societal values intersect. Unlike acute paediatrics where the pathology is visible and the cure measurable, we deal with evolving brains, uncertain trajectories, and children who cannot always speak for themselves. Our ethical responsibility, therefore, extends beyond prescribing therapy to protecting childhood itself.

The Ethics of Language and Labelling

The first ethical act is in how we name. A label of “Autism” or “Intellectual Disability” is not merely a diagnosis; it is an identity that will follow a child into school, marriage, and employment, especially in India. We must ask: does this label serve the child, or does it serve our need to categorize?

Ethical practice demands we move from deficit-based language “abnormal, retarded, affected” to function-based, family-centred language. We must describe what the child can do, what supports he needs, and what participation is possible, rather than merely what is lacking. The Rights of Persons with Disabilities Act, 2016 reminds us that disability is an interaction between impairment and barriers; we are ethically bound to address the barriers, not just the child.

Autonomy: The Child, The Parent, and The In-Between.

In developmental paediatrics, autonomy is tripartite. The child has developing autonomy, the parents have proxy autonomy, and the state has a duty of protection. The ethical tension is constant.

Do we honour a parent’s request for 6 hours of daily therapy for a 2-year-old because of their anxiety, when evidence suggests it will burn out the family and the child? Do we respect a 14-year-old with autism’s refusal to attend social skills training that his parents desperately want?

The principle of beneficence doing good - must be balanced with not causing harm. Harm in our field is often invisible which include loss of play, loss of childhood, parental debt from unproven stem-cell therapies, or the psychological harm of a child who believes he is “broken” and needs fixing. Family-centred care is ethical care only when the family is empowered, not merely instructed.

Justice and the Inverse Care Law.

The most profound ethical failure is one of justice. Early intervention services are concentrated in private clinics in metros, while 90% of children who need them live in towns and villages which lack the services. When we allow a market where only the wealthy can access the critical 0-5 year window of neuroplasticity, we violate the fundamental principle of distributive justice.

As developmental paediatricians, we cannot be silent bystanders. We have an ethical obligation to advocate for scalable, home-based, parent-mediated models.

The New Frontiers: Commercialization and Artificial Intelligence.

Two new ethical challenges demand vigilance. First, the commercialization of desperation. Families of children with neurodevelopmental disorders are vulnerable to claims of cures like hyperbaric oxygen, chelation, unverified supplements. Our silence, or worse, our collusion for financial gain, is a breach of fiduciary duty. We must base every recommendation on evidence, and when evidence is absent, we must say so clearly.

Second, the rise of AI-assisted screening and intervention. AI can democratize screening, but it can also dehumanize care. An algorithm can flag red flags, but it cannot hold a mother's hand when she cries after hearing the word autism. The ethical use of AI in developmental paediatrics must always be hybrid (Human + Artificial Intelligence) where technology augments, never replaces, human empathy and clinical judgment. Data privacy, especially video data of children, must be protected with HIPAA and DPDP Act, 2023 level stringency.

Conclusion: From Therapist to Ally

Ultimately, ethics in developmental paediatrics is about shifting our role. We are not fixers of broken children. We are allies in a family's journey toward participation, inclusion, and dignity.

The question we must ask at the end of every consultation is not "Did I give the correct diagnosis?" but "Did I leave this family more capable, more hopeful, and more respected than when they entered?"

If the answer is yes, we have practised ethically.

Best Regards

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