

# CHILDREN ARE THE FUTURE - THEIR DEVELOPMENT MATTERS REPORT

• *first international developmental pediatrics congress* •

*Olaf Andres Kraus de Camargo\**

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Autor correspondente: Olaf Andres Kraus de Camargo - krausdc@mcmaster.ca

\* Dr. Olaf Kraus de Camargo is an Associate Professor in the Department of Pediatrics at McMaster University. He completed his medical education and pediatric training in Brazil, followed by a residency in Germany where he received training in developmental-behavioural pediatrics and child neurology.

## Summary

A brief report about the First International Developmental Pediatrics Congress with reflections on the role of the discipline for Low and Middle-Income, highlighting the need for developmental monitoring, a bio-psycho-social approach and interprofessional collaboration.

*Keywords:* ICF (International Classification of Functioning, Disability and Health); Developmental Monitoring; Developmental Pediatrics, LMIC

Child development is the foundation of pediatrics. Physicians decided to specialize in children after charities started to take care of orphaned and poor children and the doctors observed that children were not “little adults” and required special skills for diagnosis and treatment. Since the beginning of the discipline, poverty, social determinants of health and adequate stimulation have been recognized as important factors for a healthy child development<sup>(1)</sup>. With such a long history of caring for this fundamental aspect of children’s health it was about time for an international exchange of ideas. From December 2-5 of 2015 participants from all over the world convened for the First International Developmental Pediatrics Congress in Istanbul, Turkey (<http://www.idpcongress.org>). Over 500 attendees from over 50 countries, many from Low- and Middle-Income Countries (LMIC) gathered in the modern Sabanci Center in Istanbul to discuss their strategies for monitoring child development, provide early intervention and train a new generation of specialists in a field that in many countries is not yet recognized as such. This is a selection of take-home messages:

## “MONITORING” VERSUS “SCREENING”

The recent identification of Zika virus infections in Brazil initiated a discussion about screening for microcephaly among newborns<sup>(2)(3)</sup>. Screening is supposed to identify potential congenital infections and initiate further diagnostic workup for these children. With regards to child development, screening is often misunderstood. Assessing parameters related to development at any stage, being them head circumference, weight, or a developmental milestone, tells us very little about the future developmental trajectory of a child. This happens for various reasons: Child development is variable and changeable; it is like a moving target and having assessed it once (especially at a young age) does not have a high predictive value for future development and needs. A child's development depends as much on its biology as it depends on the environment where the child is growing up. The chance of having a developmental delay increases to 90-100% when a child is exposed to a number of 6 - 7 risk factors like poverty, caregiver mental illness, child maltreatment, single parent and low maternal education<sup>(4)</sup> cited in<sup>(5)</sup>. Therefore, passing a developmental screening test does not have the same significance as for example screening negative for hypothyroidism or phenylketonuria or not having microcephaly. What is the solution? A group of researchers around Ilgi Ertem from Ankara University in Turkey has been developing a monitoring tool over the last 20 years called the “Guide for Monitoring Child Development”<sup>(6)</sup>. It is based on some important ground rules: Establishing a relationship with the family of the child to be monitored (it is not a screening test), asking open questions to avoid response bias and stigmatization, applying repeated measures and providing intervention and counseling while monitoring. The tool has been developed and validated in culturally diverse countries with the aim to be utilized in LMICs. It can be applied by a diverse range of professionals from health care, education and community services and is free-of-charge. Training workshops were held in Turkish, English

and Russian languages during the congress. Several Brazilian specialists obtained training and are now qualified to further disseminate this tool.

This is very timely. Brazil is in a high need for such an approach. A recent review article by Zeppone et al. reports that even among trained pediatricians about 60% do not feel adequately prepared to assess specific developmental aspects in children<sup>(7)</sup>. Despite the creation of a booklet for developmental monitoring of children, its utilization is extremely low or incomplete (in some states of Brazil, only 8% of the children have been monitored regarding their development)<sup>(7)</sup>. The recognition of the importance of child development as a national priority is recent: “A major impact [...] was felt in December 2014, when the Brazilian House of Representatives passed *Marco Legal*, a new policy framework for early childhood development. The legislation defines early childhood for the first time in Brazilian history and calls for the creation of a national policy on early childhood that draws on interdisciplinary knowledge”<sup>(8)</sup>.

## “FUNCTIONING” X “FIXING”

One of the keynote lectures was given by the renowned developmental pediatrician, researcher and colleague Peter Rosenbaum. In the talk entitled “Children with Special Needs in the 21st Century” he described the paradigm shift that has occurred since the end of the 20th century. While acknowledging the importance of biomedical research he stressed the importance of providing care and support that is focused on the principles of the International Classification of Functioning, Disability and Health<sup>(9)</sup> and have been well described by him and Jan Willem Gorter in their widely cited article “The F-words in Childhood Disability: I swear this is how we should think”<sup>(10)</sup>. The 6 F-words “Fitness”, “Function”, “Family”, “Friendships”, “Fun” and “Future” can guide us in how we think about patients and their families, plan research and care for children with impairments. Although the ideas of expanding the biomedical model of health have been proposed already in the Seventies

of the last century<sup>(1)</sup>, only with the adoption of the ICF they have been able to be translated into clinical practice<sup>(2)</sup>. Peter Rosenbaum summarized these ideas with the following statements: Think about functioning and development, variation and diversity, the environment and life-course! Stop thinking and talking about “normal” and “fixing”!

## DEVELOPMENTAL PEDIATRICS REQUIRES COLLABORATION

Contrary to countries like the USA, Canada or Turkey, in many countries the subspecialty of developmental pediatrics is not yet recognized. In some countries, pediatricians have been trained in developmental pediatrics abroad and when coming back to their country encounter difficulties in having access to necessary diagnostic and therapeutic services and finding colleagues with the same background and understanding of developmental topics. Various reasons were mentioned for this - the lack of local training opportunities is one and a number of the participants discussed the use of new technologies like tele-consultation and tele-education within collaborative partnerships both in North-South and South-South directions to provide accessible training and adapt the contents of training to the local needs of the countries of origin. Another reason discussed is the tribalism among physicians regarding neighboring subspecialties, e.g. pediatric neurology and child psychiatry. It will require a critical mass of interested colleagues in developmental pediatrics nurturing collaborative exchanges with those from neighboring disciplines and political will to change these positions. On the other hand, it is urgent to provide the supports needed for the children at risk while they are developing and not lose time with political quarrels. In this sense, some countries like India, South Africa and also Turkey demonstrated innovative strategies providing knowledge translation about child development to other workers that have access to families and children. These can be other medical specialists, family doctors, educators, community health care workers etc. This transdisciplinary

approach and competence building allows for a quicker dissemination of knowledge and increases the chance of identifying children and families with needs of support or exposed to risk factors.

## INTERNATIONAL DEVELOPMENTAL PEDIATRICS ASSOCIATION

The congress culminated with the creation of the International Developmental Pediatrics Association (<http://developmentalpediatrics.org>). The founding board reflects the broad representation from diverse LMIC: Ilgi Ertem (Turkey), Ricardo Halpern (Brazil), Ghassan Issa (Lebanon), Vibha Krishnamurthy (India), Mphole Mulaudzi (South Africa), Alexis Reyes (Philippines) and Nenad Rudic (Serbia).

Membership is free and the association welcomes professionals from diverse backgrounds that have a focus on child development. It will organize bi-annual conferences in LMIC. In 2017, the venue will be in Mumbai, India and in 2019 in Porto Alegre, Brazil. The associates envisage that the conferences will stimulate the exchange of knowledge and ideas from an international network of enthusiastic colleagues determined to cross boundaries of dogmas, disciplines, languages and cultures for the benefit of the future of our children.

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