

IDPA congress 2023 report

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Introduction

I was fortunate enough to have my 21-year scoping review on cerebral palsy in African paediatric populations selected for oral presentation at the 2023 International Developmental Paediatrics Association Congress, which was held from 28 November to 1 December 2023 at the Indaba Hotel and Conference Centre in Johannesburg, South Africa. My attendance was supported by a travel award from the Department of Paediatrics and Child Health at the University of Cape Town, and a grant by PANDA for which I assisted with logistics of the conference on a day-to-day basis.

Pre-Congress Workshops – Tuesday 28 November

The first day of the congress involved six parallel workshops that involved skills development and training in various aspects of development for early childhood. Participants benefited from training from a diverse and international faculty that brought a range of experience and perspectives on child development from various settings around the world. The formal programme ran from 08:00 to 17:00 and the following topics were offered:

1. Global Scales of Early Development
2. WHO/UNICEF Care for Child Development
3. International Guide for Monitoring Child Development
4. Parent-mediated interventions – focus on the WHO-caregiver skills training programme
5. Gender and sexuality
6. New to wheelchair seating and positioning

I attended the workshop on the international GMCD, which is a unique package that pioneers an individualized, comprehensive approach to monitor and support children's development. Based on bioecological, family-centered, strengths-based theories, the GMCD acknowledges families as experts of their children's development and supports service providers in strengthening a compassionate, trusting, working partnership with the family around supporting child development. The GMCD uses an open-ended interview technique and strengths-based, individualized, culturally adaptable interventions. The National Institute of Health (NIH) funded international GMCD study has standardized and validated the GMCD in diverse countries (Argentina, India, South Africa and Turkey) eliminating the need for re-standardization or re-validation. To date, the GMCD training has included service providers from many countries. The intention of this one-day course was to provide participants with information, skills and attitudes to use the GMCD and a roadmap on how to incorporate the GMCD in their communities and countries.

On completion of the workshop, participants were issued with certificates confirming their newly-acquired skillset and were encouraged to implement these tools and extend the training to other professionals in their place of work.

Day One – Wednesday 29 November

Opening ceremony

The first day of the congress started with a welcome from IDPA Congress President Prof K Donald and IDPA President Dr Ghassan Issa, followed by a speech on the importance of child health and development by South Africa's First Lady Dr Tshepo Motsepe. She highlighted the long-reaching impact of adverse childhood experiences and the need for multisectoral collaboration in order to optimise early childhood development, especially in low-resource settings. Citing various metrics, she outlined where the shortfall was in meeting the Sustainable Development Goals, the impact of the COVID-19 pandemic on child health globally and the effect of violent conflict as currently playing out in Sudan and Gaza. Christine Muhigana from UNICEF, South Africa then addressed the congress on the rights of children as enshrined in the United Nations Convention on the Rights of the Child, again touching on the challenges faced globally in meeting global targets. She also reminded the congress on the recent celebration on World Children's Day in November and the need to keep children central to any health or development agenda. The speeches were followed by a musical performance by South African artists to end the opening ceremony.

Keynote lecture: Lessons from the Birth-30 study: Setting the Scene for a Healthy Life – Prof Linda Richter

The keynote address was delivered by Prof Linda Richter, distinguished professor at University of Witwatersrand on the *Birth-to-30 study*. Biological, psychosocial and socioeconomic data collected on >3000 people and first generation of the cohort born in 1990, living in Gauteng with reviews occurring twice a year over this 33-year period. Staff and infrastructure based at Chris Hani Baragwanath Hospital with an expanding base and growing mobile visit capacity. Cohort has been colloquially called Mandela's children as his release from prison preceded the birth of the first child in the cohort by 6 weeks. The motivation for this birth cohort came from the anticipation of the repeal of apartheid laws and the expected shift in the sociodemographic landscape of urban areas and the growing need for better infrastructure for health and education to meet the changing needs and rights of the population. One unique aspect of the cohort was the standard collection of cord blood lead levels which showed significant associations with increased aggression in male adolescents and delayed puberty in female adolescents. Part of an international consortium of birth cohorts in transitioning economies with India, the Philippines, Brazil and Guatemala. The phrase "First 1000 days of life" likely first mentioned by Hillary Clinton in a public speech around the launch of the Lancet series on Maternal and Child Nutrition and the establishment of a foundation addressing these issues, and has helped enhance the public profile of this important and vulnerable period of growth and development. She expanded on many of the factors in childhood around anthropometry and growth parameters that impact schooling, wealth, BMI, IQ height, BMI, BP and off-spring birth weight as adults. Height, weight and BMI at age 2 years seemed to have high sensitivity and specificity in predicting these adult outcomes – catch up in growth after this period impacted final anthropometry but did not seem to improve cognitive outcomes. In Jamaica, effects of nutrition alone washed out by age 7 years but when combined with a stimulation intervention were seen to have impact on human capital e.g. income as an adult i.e. optimising adult cognitive function cannot be improved by nutrition alone. Poorest and most deprived children received the greatest benefit from maternal stimulation and responsiveness in terms of cognitive outcomes, even though cognitive performance in childhood remained the strongest predictor of adult cognitive outcome. Nurturing care was associated with increases in IQ even taking adversities into account in

the Birth-to-30 study. While there are material gains in this cohort, in terms of home amenities, half still are unemployed and dependent on their families. The Birth-to-30 study shows clear evidence that the first 1000 days from conception to age two years, is the period that offers the greatest benefit from intervention and support.

Prof Richter was then presented with the IDPA mentorship award by Dr Wiedaad Slemming.

Keynote panel discussion: WHO global report on children with developmental disabilities

Vanessa Cavallero gave an overview of the WHO global report on children with developmental disabilities focusing on inequalities in health and opportunities to thrive. Frameworks from which the report has stemmed includes the Conventions on the Rights of People with Disabilities and of Children. It provides principles for organising and delivery care including a twin-track approach. The full report can be found here: <https://www.who.int/publications/i/item/9789240080232>.

Raoul Berméjo from UNICEF then spoke about action areas based on the report findings. The report maps out ten action specific action areas, but a few were highlighted in this session. Participation of children and families is important to make any work sustainable and relevant and to maximise impact of the changes, and they should be involved in the development and implementation of all services for children with developmental disabilities.

There were three self-advocates who then spoke on the lived experiences of children and families dealing with navigating health and school systems that are not equipped to adequately care and support developmental disabilities. They shared their personal experiences and commented on the work remaining to be done to make the needs of these children core to the agenda of these government sectors, with reference to key actions from the global report. "Autism is an invisible condition, but our needs are not invisible".

Keynote lecture: Family-based interventions for autism spectrum disorder – Prof Petrus de Vries

Prof de Vries spoke about the continuing role of family in the life of people with ASD from early childhood through to adulthood. He explained the concept of Naturalistic Developmental Behavioural Interventions (NDBIs) and how it can be used to move the setting of interventions to the community and specifically the family environment: for example, how can routine daily activities be used as learning opportunities and how can interventions be embedded into these. In order for ASD interventions to be family-based, the following need to be considered: family priorities, definitions of success, context, intervention partners and recipients and co-developer of interventions. However, family-based interventions are a complex construct and not easy to implement everywhere.

Prof de Vries spoke about the larger construct of neurodiversity and then progressively narrowed to individual's with ASDs and how their primary concern may be related to an associated co-morbidity rather than the ASD itself, which affects the intervention choice. He spoke repeatedly on the importance of context in designing research and implementing interventions, which was particularly pertinent to world majority countries that are also often resource-constrained.

Day Two: 30 November 2023

Keynote lecture: African Innovation – daring to deliver more than just hope – Ms Shona McDonald

Shona McDonald started her lecture by sharing her personal journey from diagnosis of her first daughter with cerebral palsy while living in a remote part of South Africa and their journey to get her appropriate support and inclusion. Her concern was that even when appropriate support and assistive devices is available in South Africa, the majority of children with motor disabilities still did not have access to any wheelchairs or else were forced to use incorrectly sized or worn or broken equipment. Shonaquip CC was then started in 1992 with the purpose of providing properly fitted wheelchairs to children with motor disabilities and investing all profits into training and advocacy work for children with disabilities. Shonaquip CC subsequently evolved into Shonaquip Social Enterprise with a range of collaborations that enabled them to expand their reach and goals. She described the activities she and her team have been involved in, with advocacy aimed at changing the narrative from pity and charity in providing this support to children with disabilities to one of human rights and inclusion. A particular aim was to provide a consistent supply of wheelchairs that were designed for the needs and terrain of African countries rather than Europe where the majority were previously being made. Their team also works on inclusive play in early childhood education with training for parents and those working in ECD using the “Ndinogona I Can Programme”. Another pillar of their work is capacitating a parent network across Southern Africa which addresses the severe disconnect and lack of access to quality information experienced by families of children with disabilities. This network comprises an advisory committee, network parents and parent champions and communicates via a Whatsapp group with rules that allow the space to be a welcoming and respectful arena for communication and information-sharing. Shonaquip also collects data to track their progress and expanding network across the four main pillars of their work. Currently, they are building a regional hub linking centres in other parts of Africa to government and international resources and upskilling people involved in care of children with motor disabilities to establish a similar model of care and service provision as seen in South Africa.

“With an appropriate assistive device, knowledge to make informed choices and agency to action them, a family of a child with a disability will no longer experience their child as less valued.”

Keynote lecture: Levelling the tilt: Research in Majority World Countries – Prof Thirusha Naidu

Prof Naidu addressed 5 main questions in her talk. On “What is the problem with our research in the Global South?”, research is dominated by the global north and the voices of the global south are suppressed. Research is skewed in favour of the global north in terms of knowledge but also methods, practices and agendas. The disease burden is lowest in countries in the highest income bracket, but they publish more. The composition of editorial leadership teams in medical education journals is skewed heavily towards HICs. On “How did this problem originate?”, Prof Naidu summarised the problem with the word “colonisation”. Our systems are based on colonial systems of research where the power rests with others and our work is dependent on and informed by their agenda. The colonial matrix of power rests on the tripod of colonialism, racism and patriarchy, which permeates authority, economy, gender and sexuality, knowledge and subjectivity. There are

enduring effects of colonialism on contemporary research in the global south with imbalance and exploitative research practices, and a legacy of knowledge extraction. There is limited research capacity building in LMICs, which can hinder the development of local expertise. She highlighted many of the tensions global south authors experience in conducting and publishing research. On “How is the problem story told?”, the main issues are research and publication bias, unequal partnerships and language and editorial bias. There is coloniality of voice, epistemic violence and northern ventriloquism, but to move away from this, we need epistemic disobedience in order to tell our stories. This applies to funding, authorship, scholarship, choice of publication language, publication options, citation choices, emerging researcher training and scholarly activism. Ultimately, one needs to think about researcher positionality and identity.

Keynote lecture: Bridging the gap: a global perspective on harmonised child development – Dr Vanessa Cavallera

Dr Cavallera started by recapping the major global policies relating to early childhood development and the measurement tools to monitor interventions. Issues to consider include properties of the indicator and implementation considerations including modality of administration, cost and copyright issues, training and capacity, language and cultural difference and materials needed. Different situations and age ranges also call for different tools, as children age and their needs and skills change. The D-score has been developed by colleagues in the Netherlands where every change in a unit is equivalent across the scale. It is not tied to a specific measurement instrument or population. The WHO Global Scales of Early Development was launched in February 2023 to try to provide a single, standardised instrument for measuring and monitoring ECD. Harmonising instruments is crucial to monitoring progress towards the Sustainable Development Goals. GSED online tool does require necessary hardware and access to software with complicated calculations at backend but is a user-friendly tool that is scalable, gives immediate feedback and can be used in multiple settings. The utility of the results in terms of how they can be packaged for use for policy versus clinical practice is still in development. One aspect that still needs to be addressed is also language, which can impact multiple functional domains and is a critical issue in many current instruments used to monitor ECD.

Keynote panel: Scalable technologies to understand child development

Niall Bourke spoke about the development of accessible neuroimaging methods. UNITY (ultra-low imaging in the young) requires scalable tools, access to this modality and the global health agenda. He compared the requirements for the hyperfine MRI machine in terms of cost, power etc against the standard 3T MRI machine, which show that the hyperfine MRI is a much more reasonable and accessible option for most resource-constrained settings. Basic requirements for additional hardware beyond the MRI machine need to be factored in, such as the various units for storage of data, which also have their own requirements such as a stable power supply and internet connection.

Emma Margolis spoke about EEG as a scalable tool to index the developing brain. She ran through recent advancements to improve scalability such as adapting electrodes to different hair types. Ms Margolis then explained the use of visual evoked potentials as a tool to measure visual impairment and how was used to look at visual processing in a study of children with prenatal alcohol exposure. Using latency, children had VEPs done at 6 months of life which showed prolonged latency suggesting

adverse effects on visual processing, which held for both documented significant alcohol exposure throughout pregnancy and being drinking alone.

Jessica Ringshaw spoke on the role of neuroimaging in monitoring brain health among children where there was documented maternal antenatal anaemia. Her work looks at the influence of anaemia on brain maturation during a particularly vulnerable period. Antenatal maternal Hb concentration was found to have an impact on corpus callosum and caudate nucleus which were 5-8% smaller when measured at age 2-3 years and again at age 6-7 years. This indicates that the effects of maternal anaemia are consistent and persist with age, highlighting the need to optimise maternal antenatal health. A cross-validation study showed that both the high and low-field MRI machines were able to detect these differences in brain volume, suggesting that the low-field system is equally useful in looking at the effect of antenatal anaemia on brain structure.

Keynote lecture: International voices on child-onset disabilities – Prof Rainer Blank

Prof Blank spoke on the qualitative work he is doing with parents/caregiver of children with NDDs in multiple regions of the world and across different settings, although South America has not yet been included. Video recordings of these stories collected will be available from January 2024 on www.eacd-iaacd2025.org.

Parallel symposium: Genetic landscape of developmental conditions

Prof Karen Fieggen gave an overview of various genetic sequencing techniques depending on the gene identified via clinical suspicion. She elucidated the various genetic sequencing techniques and the strengths and limitations of each depending on the clinical question being asked. She also spoke about the resources required for each technique. She covered the difficulties around interpreting variants within genes and brought it back to the final “boxing” of results into a spectrum from benign to pathogenic. African populations are hugely underrepresented in the global stage when it comes to genetic registries and even in capturing phenotypic variability, which is dominated by people of European ancestry. She finished by reminding us that all assessments start and end with the child, and what information you can yield by a thorough history and clinical review. Quite a few of the CNVs found are reduced penetrance alleles which is the case with many NDDs. Detection rate of single-gene variants 20-40% in DEEs and recent publication 2021 shows that children with “unexplained” cerebral palsy had a higher number of relevant pathogenic variants than anticipated.

Ms Patricia Kipkemoi reported on the genotyping and phenotyping results of the NeuroDEV study. She highlighted how less than 1% of the world research on NDDs, ASD for example, come from Africa. Only 2% of GWAS consortia databases include African ancestry. Background on the study and these specific results are available at <https://doi.org/10.1016/j.neuron.2023.06.010>.

Dr Zandre Bruwer gave an overview of what genetic counselling is, how it involves the family and the importance of confidentiality and pre- as well as post-test counselling. Considerations prior to testing include 1. The motivation for testing, 2. The cause of the condition and 3. Family context. Dr Bruwer then gave several case examples where results were returned to families in Cape Town, giving details on the implications for management and reproductive planning among family members in each case. She highlighted the psychosocial implications of returning a positive genetic result and the support

that is required to do that sensitively and allowing families sufficient time to work through this information.

Keynote lecture: A Future for the World's Children? A Child Centered World as the Basis of the Way Forward for a World on Fire – Prof Mark Tomlinson

Prof Tomlinson gave an engaging and thought-provoking lecture on the way in which children hold the key to moving humanity forward. Drawing parallels between the benefits of emerging AI such as ChatGPT and the unique role that humans can play in addressing crises such as climate change, he spoke about play as key to childhood development, the importance of emotional connections and relationships and the institutionalisation of education which threatens to eliminate individuality and creativity in youth.



Day Three: 1 December 2023

Keynote lecture: HIV exposure and child development, where are we now? – Prof Amina Abubakar

Prof Abubakar started by sharing global trends in HIV epidemiology, noting a reduction in number of new infections and people living with HIV in the sub-Saharan region although the extent of the reduction was below target. Five African countries met the UNAIDS target of 90-90-90 by 2020, but the updated target for 2030 is now 95-95-95. HIV exposure has been shown to increase risk of poorer neurodevelopment especially language and motor domains. Foetal HIV exposure can adversely influence infant immune function, structural brain integrity and growth trajectories, with increased risk of stunting. Prof Abubakar pointed out that effects are not transient and extend beyond childhood into early adulthood and beyond, with good evidence of this from a Kenyan cohort study (ADOLESCENT) which was a longitudinal study of 560 adolescents aged 12-17 years at baseline with a multimodal approach to data collection. Poor neurobehavioural outcomes were seen for HEI adolescents across all domains but HEU performed similarly to community controls. Ongoing high viral loads, due to non-compliance with subsequent development of drug resistance, was an important risk factor for poor outcomes. A qualitative sub-study showed the complexity of the challenges faced by adolescents in obtaining optimal treatment outcomes for HIV. HIV programmes that look at multiple chronic co-morbidities faced by children with HIV infection are needed. Priority areas for action has been identified by the latest UNAIDS report and is publicly available. Treatment remains a priority, as it saves lives, drastically reduces transmission and improves neurodevelopmental outcomes, but adherence remains the biggest challenge.

Keynote lecture: Reflections on Strengthening Infant Child and Adolescent Mental Health in Low Resource Settings – Prof Rene Nassan and Dr Tereza Whittaker

Prof Nassan presented an overview of infant child and adolescent mental health system (ICAMHS) strengthening and transformation in the Western Cape. Children and adolescents often fall through the cracks in terms of mental health services, which are already limited. In order to fill in the cracks, a transformative approach had to be adopted, including addressing harmful social environments, moving away from categorical diagnoses, empowering diverse front-line providers, and including a diversity of stakeholders especially those with lived experience of these conditions. Local leadership is key to all aspects of service delivery including transformation. Passion and commitment support microsystem improvement, along with transparency and ongoing support of front-line workers. A model for this transformation can come from the NHS which has done substantial work looking at how best to transform their CAMHS. The 2021/22 Child Gauge document specifically provided locally applicable guidelines and indicators around child and adolescent mental health. The Western Cape ICAMHS was established in August 2022 and looked at task-shifting the delivery from tertiary to primary care and from clinicians alone to universal care. The overall strategy is to align with provincial government strategy as well as WHO outlined optimal mix of services, to interface with tertiary CAMHS, to capacitate workforce at primary care, and to look at early prevention and intervention services.

Dr Whittaker gave an overview of the pilot project on infant mental health (IMH) run in the Macassar area of Cape Town. She provided statistics on use of antenatal services and antenatal care in South Africa, with 75% of women receiving 4 antenatal visits, 96% delivery in a health facility and 84% of

babies receiving a postnatal check in the first two weeks of life. She spoke of the 5 P's of IMH: Planned parenthood; perinatal support; partners present; personhood of infants; parenting skills and priority groups. Using links to the importance of the work already being done by staff and reminding them of the impact of that single delivery amongst hundreds of others to the mother and child as individuals, may be an entry point to additional training in IMH. Making sure involved staff are validated and feel valuable is also important to sustainability and investment in these programmes.

Parallel symposium: Advocacy, policy and research for children and youth

Dr Lesley Bamford gave an overview of the Side-by-side campaign which fosters the relationship between caregiver and child. The new Road to Health Book is integral to this campaign, but the emphasis is on the caregiver with the healthcare worker playing a supportive role. Five themes in the RTHB are nutrition, love, protection, healthcare and extra care (for those who need special care or support). The campaign is expanding its reach via an implementers' toolkit accessible on www.sidebyside.co.za and a weekly drama and discussion show on 11 radio stations in 9 languages. Side-by-side is also trying to redefine the role of community healthcare workers using the same principles. Lessons learned are to keep it simple, use children's needs as a starting point, focus on approaches that can be up scaled immediately and integration and changing behaviour of HCWs are difficult. Future plans include closer links with colleagues responsible for ECD with more emphasis on children with NDDs.

Prof Catherine Draper spoke about *Bukhali*, which is a lifecourse intervention spanning 4 countries and sites (Soweto in South Africa), starting in preconception, as part of the *Healthy Life Trajectories Initiative*. It is developed iteratively and pragmatically and is delivered by HCWs trained in Healthy Conversation Skills and intervention phases. Intervention is delivered by monthly contact, mostly telephonic. Draws on components of Side-by-side campaign and WHO Nurturing Care Framework. Protocol and report on work so far has been published and is freely available. Uses simple and fun low-resource activities at home to encourage nurturing interaction. The trial is undergoing a continuous process of evaluation.

Dr Given Hapunda spoke about AfECN – the African Early Childhood Network, which is based in Kenya and established in 2015. AfECN is involved in advocacy, influencing policy, strengthening partnerships and knowledge generation and dissemination. Their work includes high-level advocacy at the African Union to support embedding the nurturing care framework into continental work and technical assistance to support AU Development Agency Nutrition Unit. AfECN also fosters ECD networks in various African countries, using global data and to produce landscape analyses and region-specific profiles and documenting the status of the ECD workforce. Priorities include workforce development, supporting advocacy efforts by lobby groups and multisectoral collaboration to develop national advocacy strategies.

Dr Muneera Rasheed spoke on child-centric policy, advocacy and research. She touched on the issues that affect what is considered majority versus minority and the discussion around resources which is influenced by so many factors that in turn affect priorities. She questioned academic incentives and pointed out that children deserve care beyond incentives, which requires cross-learning between community and healthcare systems. She cited a paper that describes developmental paediatrics as operating in silos which actually limits impact. Making the most of opportunities means innovation despite resource constraints, asking the right questions and encouraging a shift perspective.

Keynote lecture: Nurturing care framework update 2018-2023 – Dr Sheila Manji

Dr Manji recapped the launch of the Nurturing Care Framework at the 71st World Health Assembly in 2018. The framework covers what the child's body and mind expects and needs but also enabling environments for nurturing care. The framework requires a universal progressive approach for meeting all children's needs. To create enabling environments, we need enabling policies, supportive services, empowered communities and caregiver capabilities, which requires a whole of society and whole of government approach. Over 30 resources have been developed to support operationalisation of the Framework and are available through the WHO e.g. thematic briefs. A progress report has now been published in 2023 <https://nurturing-care.org/progress-report-2023/>.





