



Early intervention and diagnosis in paediatric neurodevelopmental disorders in Brazil

Executive Summary

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Rio de Janeiro, Brazil

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Key context

Global trends suggest that the prevalence of children with neurodevelopmental disorders is increasing. This is of particular relevance in low- and middle-income countries (LMICs) like Brazil, in which the burden of these conditions is poorly understood.

The 2015/16 outbreak of the Zika virus in Brazil brought the issue to international attention and garnered action worldwide. The response to this crisis provided an excellent illustration of the challenges presently posed for integrating the identification and management of children with neurodevelopmental disorders into the present health care systems.

However, large gaps still remain in our understanding of the epidemiology and etiology of these disorders. In discussions and breakout sessions during this workshop, participants discussed the current state of research into paediatric neurodevelopmental disorders and what actions are needed to address the shortfalls.

The scope of the issue

It is estimated that there are 250 million children with neurodevelopmental delay or disability across the world. Participants discussed the scale and nature of the issue, noting the following:

- Current epidemiological understanding of neurodevelopmental disorders in Brazil is imperfect, often based on cross-sectional data providing prevalence rates only in single settings.
- High mortality rates and a lack of inclusion in the system due to stigma in LMICs often lead to underestimations of prevalence figures.
- A wide range of risk factors exist across all developmental stages of childhood, including genetics, nutrition, sociodemographic status and access to healthcare.
- Improvements in understanding the epidemiological data may be feasible by two-phase screening programmes, but this is currently limited by inconsistent health infrastructure.
- There is a need for population-based surveillance for neurodevelopmental delay and disability, better metrics for countries, and research across different contexts.

Lessons from Zika

The outbreak of the Zika virus garnered an international response that produced some important lessons. Participants noted:

- The World Health Organization's (WHO) response to the Zika outbreak, declaring it a public health emergency of international concern, stimulated an international collective effort, scientific research, and funding that helped stabilise the crisis.
- Key coordination and resource generation occurred between international and national authorities and health professionals, especially in Latin American countries, to detect, diagnose, and characterise cases of microcephaly.
- The identification and inclusion of 'invisible children' into the public health system has been an important consequence of the crisis.
- The increase in the disparity of care that pre-dated the Zika crisis, and how this was exaggerated in Zika and non-Zika affected areas. This included differences in local screening and access to specialist clinicians and treatments.
- Evidence for interventions for children with neurodevelopmental disorders has been inadequate to date. Particularly, there is a lack of evaluation of interventions, implementation packages and limited measurement of relevant outcomes.

Evaluating centralised responses

Brazil has a distinguished record of successful centralised initiatives, including the Brazilian National Immunization Programme which achieves a 95% vaccination coverage rate. In the light of this record participants critically evaluated existing centralised responses to Zika, childhood disability and neurodevelopmental disorders:

- The Ministry of Health recently introduced a booklet for monitoring child development for community-based health care systems. There is an opportunity for building on this initiative to increase awareness and identify children with neurodevelopmental disorders.
- Empowerment of parents in smaller pilot studies to support children with neurodevelopmental disorders and improve targeted care was successful but not run on a national scale. Presently there is no framework for integrating studies or interventions.
- There is a lack of coordination between different regions within Brazil. This ranged from no standardised tools and clinical definitions, access to laboratory support, and provision within healthcare.
- There is a disparity in response between tertiary research in sciences and public health activities.
- Multidisciplinary treatments are critical for the best clinical outcomes of neurodevelopmental conditions. This includes the use of future new technologies but requires co-ordination to prevent overlapping innovations.

Proposed next steps

- A situational analysis is needed in order to gain a true understanding of the resources available. This would result in the identification of key gaps in the system and prioritization of most important next steps.
- Engagement with internal and external funding bodies is required to address a shortfall in health research expenditure.
- Specific funding avenues such as the UK Global Challenges Research Fund (GCRF) Networking Grants¹ should be taken advantage of to engage researchers with key issues in neurodevelopmental research.
- A centralised evidence base needs to be developed, built on existing centralised systems, to determine the efficacy and cost-benefit of interventions.
- Clinical data should be integrated at a local level (e.g. family medicine groups) as an initial action towards developing a national database for paediatric neurodevelopmental disorders, such as the cerebral palsy registry in Brazil.
- Improvements in the identification and assessment of children with neurodevelopmental disorders are needed. Specifically, there is a need to also consider outcomes important to families and children which might include; their quality of life, the participation and mental health of families and children.
- Increased specialist skills training is required, particularly for paediatricians with an interest in neurodevelopment.
- Additional training of non-specialists in the care pathway is also required, focused on different providers and skill-mixes through task-shifting mechanisms in order to prevent a reliance on physicians.
- Combined interventions at community level which can be integrated into the existing systems (aka nurturing care framework). Evidence presently demonstrates that programmes that have the greatest impact combine interventions to improve nutrition, mother-child interaction, developmental stimulation and child health.
- The education system should be used as an engagement platform to meet the holistic needs of young children, particularly as political prioritisation is needed to scale-up this approach.

1. <https://acmedsci.ac.uk/grants-and-schemes/grant-schemes/gcrf-networking-grants>



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