



Early intervention and diagnosis in paediatric neurodevelopmental disorders in Brazil

Workshop report

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Opinions expressed in this report do not necessarily represent the views of all participants at the event, the Academy of Medical Sciences, Brazilian Academy of Sciences, National Academy of Medicine or its Fellows.

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Executive summary

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>

Introduction

Current estimated rates of childhood disability are high, with up to 93 million children suffering with a disability.² Alongside this, the spectrum of disabilities is shifting to include more neurodevelopmental and behavioural disorders. Although long-term trends in paediatric neurodevelopmental disorders have been difficult to track, it is widely believed that the prevalence of children with neurodevelopmental disorders, particularly autism and ADHD, is increasing.³ Particularly in LMICs the burden of neurological disorders in children is probably underestimated due to the limited reach of diagnostic centres high childhood mortality rates in this population and stigmatisation.⁴

Neurodevelopment is a complex process and disorders arise from a multitude of genetic, environmental and sociocultural factors. Thus, diagnostics and interventions are likely to vary between countries where demographics, health services and social culture all differ. Additionally, research and medical progression in the field of paediatric disability are lagging with services and resources are disproportionately scarce, particularly in the public health systems of LMICs such as Brazil.

Against this backdrop, a two-day workshop of key stakeholders from Brazil, the UK and other countries was held on 29–30 November 2017, jointly organised by the UK Academy of Medical Sciences, the Brazilian Academy of Sciences and the Brazilian National Academy of Medicine.

This report provides a summary of the key themes that emerged during the workshop discussions. It reflects the views expressed by participants at the meeting and does not necessarily represent the views of all participants or of the UK Academy of Medical Sciences, the Brazilian Academy of Sciences or the Brazilian National Academy of Medicine.

The workshop was funded by the UK Government's Global Challenges Research Fund (GCRF) and was one of a series of policy workshops co-organised by the UK Academy of Medical Sciences that aim to:

- Enable partners (primarily National Academies) in Official Development Assistance (ODA) eligible countries to consider how scientific evidence can help address key global health challenges.
- Build capacity in ODA countries for the provision of scientific advice.

Further information and reports from the programme of workshops can be found at www.acmedsci.ac.uk/GCRF

2. UNICEF (2013). *Children and Young People with Disabilities Fact Sheet*.

3. United States Environmental Protection Agency (2013). *America's Children and the Environment*, Third Edition. Washington, D.C.

4. World Health Organization (2006). *Neurological Disorders: Public Health Challenges*. Geneva.

Understanding the epidemiology

Child mortality has been reducing at a significant rate over the past two decades. In 1990, 12.6 million children under the age of five died whereas in 2016 this number decreased to 5.6 million.⁵ Whilst this represents a significant success, newborn deaths are still high with 2.6 million deaths per year worldwide. In addition, most deaths are due to readily treatable conditions, and infections and newborn conditions are responsible for the vast majority of deaths.

The Global Strategy for Women's, Children's and Adolescents' Health (2016–2030) supports the need for all children to 'survive and thrive'.⁶ In the era of Sustainable Development Goals,⁷ there is a renewed emphasis on early child development and the need to maximise the developmental potential for all children.⁸ It is estimated that there are 250 million children with developmental delay or disability across the world.⁹ However, at present there is no reliable and representative estimate of the contribution of neurodevelopmental disorders within this population.¹⁰

Workshop participants discussed how the environment that a child is born into determines firstly their chances of survival but also their risk of disability. Current understanding the full burden of neurodevelopmental disorders is reliant on cross-sectional data often only with prevalence rates available in single settings. With high mortality rates in these populations, this often leads to an underestimation of rates. Furthermore, stigma and lack of inclusion in low- and middle-income countries adds to children not always being identified as easily as we would wish. Whilst some of these figures can be estimated through two phase community surveys where screening follows formal assessments, there are challenges to screening and surveillance in settings where public health infrastructure and systems to provide quality coverage and measurement of child development are limited. There is work currently taking place on global metrics for child development but this is not yet at a stage where it is being implemented in country settings and presently is not being used at an individual level for screening.

The risk factors for neurodevelopmental delay and disability were also raised during the workshop. There was agreement that factors from preconception through to infancy and childhood were all important, and these ranged from genetics to nutrition to access to healthcare. The significant contribution of neonatal conditions, most prominently premature birth and perinatal asphyxia, was also discussed, with more deaths than disability occurring in low-income settings but increasing rates of disability in middle-income settings. There is a two-fold risk of disability in low-income compared to high-income countries.¹¹

Whilst data were presented at the workshop on the epidemiological situation in South America, there was agreement amongst participants that difficulties remain in providing reliable epidemiological data of neurodevelopmental disorders in Brazil. Much remains unknown about the burden of neurodevelopmental disability. Participants discussed the need for population-based surveillance for neurodevelopmental delay and disability, better metrics for countries, research across different contexts (aetiology, risk factors, burden and trends), better understanding for what works for early detection and intervention, implementation research and a collaborative and interdisciplinary approach inclusive of health and education sectors.

5. UNICEF (2017). *Levels and Trends in Child Mortality*. <https://data.unicef.org/resources/levels-trends-child-mortality>

6. <http://www.who.int/life-course/partners/global-strategy/global-strategy-2016-2030/en/>

7. <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>

8. <http://apps.who.int/iris/bitstream/handle/10665/272603/9789241514064-eng.pdf?ua=1>

9. Black MM, et al. (2016). *Early childhood development coming of age: science through the life course*. The Lancet.

10. Bitta M, et al. *Burden of neurodevelopmental disorders in low and middle-income countries: A systematic review and meta-analysis*. <https://wellcomeopenresearch.org/articles/2-121/v1>

11. Lawn JE, et al. (2014). *Every Newborn: progress, priorities, and potential beyond survival*. The Lancet **384(9938)**, 189-205.

Response to Zika: Lessons and opportunities

International coordination

In 2016, WHO and partners set out the strategic response to Zika, which placed a greater focus on preventing and managing medical complications caused by the Zika virus infection.¹² The first action was to declare the outbreak a public health emergency of international concern.¹³

Workshop participants heard that these actions stimulated an international collective effort, scientific research, and funding that helped stabilise the crisis. In addition, it strengthened integrated surveillance of mosquito-borne viruses, and accelerated understanding of the modes of transmission and the abnormalities associated with congenital Zika virus syndrome.^{14,15,16} This international research is a useful platform for wider research on paediatric neurodevelopmental disorders. It highlighted the need for further research using animal models to enable scientists to elucidate the physiopathology of disorders. Furthermore it highlighted the need to develop new diagnosis tools and treatments.

The coordination and resource generation that occurred between international and national authorities and health professionals, especially in Latin American countries, to detect, diagnose, and characterise cases of microcephaly is noteworthy. At the federal level, one of the main gaps in Brazil is the lack of funding. According to the World Health Statistics 2014, Brazilian per-capita government health expenditure in 2014 was US \$1,318.¹⁷ Brazil ranks below the Organisation for Economic Co-operation and Development (OECD) average in terms of health expenditure per capita (OECD average is US \$3,484).¹⁸ Finding new sources of funding from federal and international organisations will be important in facilitating the changes required.

Invisible children and improving screening

Participants agreed that one of the key positive aspects of the response to the Zika outbreak has been the inclusion of 'invisible children' in the public health system. These children were either not previously known to the system or simply went undetected. The response to Zika allowed a spotlight to be shone on children suffering from associated and unrelated neurodevelopmental disorders.¹⁹

A less fortunate consequence of the response to Zika is a growing disparity of resources between different regions in Brazil, particularly between Zika and non-Zika affected areas. Examples provided during the workshop included an unequal awareness of the conditions and the need for more specialist training in some regions. In particular, training of paediatric neurologists and paediatricians specialising in neurodevelopmental disorders would enable specialist treatments, such as paediatric ophthalmology evaluations and early stimulation to be promoted and provided. There was agreement that in order to most effectively tackle paediatric neurodevelopmental disorders, there needs to be universal and equitable resources and training for paediatricians and other related cadres of workers across all regions of Brazil.

12. http://www.who.int/mental_health/neurology/zika_toolkit/en/

13. <http://www.who.int/mediacentre/news/statements/2016/1st-emergency-committee-zika/en/>

14. [http://www.thelancet.com/journals/laninf/article/PIIS1473-3099\(16\)00138-9/fulltext](http://www.thelancet.com/journals/laninf/article/PIIS1473-3099(16)00138-9/fulltext)

15. <https://www.frontiersin.org/articles/10.3389/fcimb.2016.00206/full>

16. [https://www.cell.com/cell/fulltext/S0092-8674\(16\)30505-0](https://www.cell.com/cell/fulltext/S0092-8674(16)30505-0)

17. http://www.who.int/gho/publications/world_health_statistics/2014/en/

18. <http://www.who.int/countries/bra/en/>

19. http://www.who.int/mental_health/neurology/zika_toolkit/en/

Participants identified that regional disparity also exists in terms of screening, with there being a large variability in the capacity across Brazil to diagnose and make referrals. Theoretically, babies are seen every month for a health check, though more often it is every three months for the first year and then three times a year in their second year. These check-ups are key points of contact where primary care physicians or allied community health staff could be trained to support neurodevelopmental surveillance with specialists only being required for further assessment of cases that are concerning. This would require better training and programmes for supporting these processes within the Brazilian primary care systems but would enable less need for highly trained specialists in doing these more routine tasks.

Improving long-term tracking and evaluation

Workshop participants agreed that, in general, research evidence supporting specific interventions for children with neurodevelopmental disorders is often inadequate. This has meant that there is a lack of knowledge about which interventions are efficacious in supporting children and families in the right way – particularly when some interventions can be labour intensive and expensive to provide. This hinders the ability to efficiently target the most cost-effective and efficacious interventions. In addition, this has led to a lack of validation on what is currently taking place, how universal these interventions are and whether they can be promoted more widely.

The collaborative workshop highlighted a current gap in implementation science in Brazil, linking this to the lack of evaluations at both implementation and outcome level. In order to address this gap, participants suggested building up a skills base for conducting better implementation research for screening, surveillance and programmatic work for managing and supporting children and families. It was highlighted that alongside this, improvements in digital data acquisition of identified children with neurodevelopmental disorders in Brazil would benefit this process.

Workshop participants also heard that the full spectrum of Zika-caused congenital disorders remains uncertain; there are many apparently unaffected children whose mothers had the Zika virus infection in pregnancy, but as yet we do not know whether these children will develop normally in the longer term. Further research is needed to look at whether these children may have long-term cognitive or neurobehavioural difficulties which may only become evident years later. Participants agreed that fully supported research to understand, track, and address the long-term congenital, perinatal, and paediatric sequelae of the Zika virus infection on children's development must be prioritised.

Evaluating centralised responses: Strengths and weaknesses

Brazilian National Immunization Program

A number of positive centralised responses were noted during the workshop as having been successful in addressing certain health issues in Brazil. One example was the Brazilian National Immunization Program (PNI) that has registered a 95% rate of national vaccination coverage, similar to the rates observed in high-income countries.²⁰ Although there are areas that could be improved within this programme, particularly with regards to national data collection processes, participants agreed that it is a platform that could be built on.

Empowered parents, IT and apps

Workshop participants agreed that the empowerment of parents to support their children in some small pilot studies led by non-governmental organisations and parent-led groups has been a success. Strong movements have built up gradually in some areas with and by parents and these are a recipe for success. These social organisations enable better and more targeted care and the networks that are created can be used as a platform for reaching families as well as for research. They rely on motivated parents and are presently not at a national scale, have no specific frameworks and no structure for all parents to be supported in the same way throughout Brazil. It remains to be demonstrated whether these projects are scalable.

There was also acknowledgment of the power of innovative technology, IT and apps in these efforts, particularly with regards to social media. This could be a way that future programmes may continue to support families and expand in their efforts to link parents and families. It may also be a platform for ethical data collection. These systems could not only empower parents but also provide a network and platform on which to build other efforts to address neurodevelopmental disorders in Brazil.

Lack of coordination between different regions

Participants noted that the inequality of resources between different regions highlighted in the previous section is mirrored by inadequate coordination between the different localities. Examples provided during the workshop included a lack of standardised tools and definitions across different regions and inadequate links to laboratory support (currently missing in many regions). This disjointed approach is common and although there are many examples of small-scale and local efforts, these are not joined-up nationally and remain isolated.

Disparity of response between tertiary sciences (clinical and basic) and public health activities

Brazil's revamped public health system has brought quality healthcare to millions in poorer populations who were previously denied even basic care. However, although the healthcare system is reasonably comprehensive in more developed areas in Brazil, workshop participants noted that the provision of healthcare is predominantly uneven. For instance, Magnetic Resonance Imaging (MRI), which contributes enormously in detailing the structural and functional alterations found in patients with neurodevelopment disorders, is not available in many regions of Brazil. In addition to this, there is a disparity of response between tertiary sciences and public health activities.

20. Bordinhão R (2018). *The Brazilian National Immunization Program and Its Challenges for Modernization and Improvement*. Journal of Clinical Immunology & Research.

There was consensus that multidisciplinary treatments, as early developmental interventions,^{21,22} are critical for the best clinical outcomes of neurodevelopmental conditions. Participants cited models that have been used in other countries and that can be implemented in Brazil to ameliorate the approach of these disorders.²³

Monitoring child development

The Ministry of Health has recently introduced an easily comprehensible booklet for monitoring child development which can be used by families in community-based primary healthcare systems.²⁴ Until recently, only growth, nutrition and vaccines were prioritised in this child health booklet. At present there is still a need for staff in the community-based primary healthcare systems to be well trained in how best to use this child monitoring instrument. Furthermore, they may need to be supported to understand how to provide some basic advice on developmental stimulation and family support, and when to refer children with neurodevelopmental disorders to units that have specific expertise in supporting children with more complex needs.

21. Carlo WA, Goudar SS, Pasha O, Chomba E, Wallander JL, Biasini FJ, McClure EM, Thorsten V, Chakraborty H, Wallace D, Shearer DL, Wright LL; Brain Research to Ameliorate Impaired Neurodevelopment-Home-Based Intervention Trial Committee and the National Institute of Child Health and Human Development Global Network for Women's and Children's Health Research Investigators. Randomized trial of early developmental intervention on outcomes in children after birth asphyxia in developing countries. *J Pediatr.* 2013 Apr;162(4):705-712.e3.
22. Bann CM, Wallander JL, Do B, Thorsten V, Pasha O, Biasini FJ, Bellad R, Goudar S, Chomba E, McClure E, Carlo WA. Home-Based Early Intervention and the Influence of Family Resources on Cognitive Development. *Pediatrics.* 2016 Apr;137(4)
23. Getting to know cerebral palsy available in <http://disabilitycentre.lshtm.ac.uk/getting-to-know-cerebral-palsy/>
24. http://bvsm.sau.gov.br/bvs/publicacoes/caderneta_saude_crianca_menino.pdf

Proposed next steps

1. Situational analysis of existing resources

The workshop discussions focused on the capacity of the health system to address neurodevelopmental disorders in Brazil, including infrastructure, human resources and equipment. There was agreement amongst participants that 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 a prioritisation of where resources could be committed to address neurodevelopmental disorders in Brazil.

2. Involving the Brazilian funding bodies

At the federal level, one of the main gaps is the lack of funding. According to the World Health Statistics 2014 published by WHO, Brazilian per-capita government health expenditure in 2014 was US \$1,318.²⁵ Brazil ranks below the OECD average in terms of health expenditure per capita (OECD average is US \$3,484).²⁶ A critical next step would be to engage with both internal and external funding bodies to address this financial shortfall. Participants also noted that it is critical to ensure that funds available are spent efficiently at all levels (federal, state and individual prizes) and that cost-effective mechanisms are encouraged.

3. Developing a centralised evidence base

There are many positive, ongoing initiatives which were highlighted during the workshop, including the Brazilian PNI. Participants agreed that there is no need to 'reinvent the wheel' and that using centralised resources is acceptable, but in order to see continued success, resources need to be shared. One suggestion was taking a consortium approach for the different regions in Brazil in order to further develop the evidence base for better practices of child surveillance and support/interventions for children with neurodevelopmental disorders through these platforms.

In addition, participants noted that a centralised evidence base should also demonstrate the cost-benefit of early intervention and which interventions are effective and with what mechanism of provision within the health system. This type of data could provide other regions with recommendations and guidance as to what is most effective so that those regions can target their resources effectively in providing good surveillance, identification and support for families and children with neurodevelopmental disorders across Brazil.

4. Collection and sharing of clinical data at a local level

Although there are many examples of small-scale research at a local level, the data from these are rarely collected or shared between different regions. There is also no database of child disability diagnoses in Brazil. Workshop participants agreed that improvements could be made in this area, however that existing systems should be built on. An example was provided to centre this data collection on the family medicine groups as this is already in place and it could help to develop a national database – such as a cerebral palsy registry or similar for other disorders. It was also suggested that other sectors could play a crucial role in data collection. It is clear that the data collected needs to be relevant for all of Brazil.

25. http://www.who.int/gho/publications/world_health_statistics/2014/en/

26. <http://www.who.int/countries/bra/en/>

Participants also highlighted that the use of an app or other technology could be a solution for recording and disseminating data better. Specialists for each condition could then tailor the app to the condition and identify the type of training and data needed. This approach could work for both making the diagnosis and interventions. Participants noted that there is sizeable work taking place across the world in this area and that Brazil could learn lessons from other countries doing this.

5. Identification and assessment of children

Participants agreed that improvements are needed in the identification and assessment of children with neurodevelopmental disorders in Brazil. They noted the importance of screening and surveillance in targeting interventions to address neurodevelopmental disorders. However, it was recognised that it is currently impossible to screen the whole population, and that it may be better to target high risk populations.

Targeted assessment of children is dependent on three key factors: age of the child, the reason for assessment (aetiology, diagnostic, or intervention related) and context (training and facilities). It is crucial that the assessments chosen are tailored to these conditions and adapted for the circumstances. However, having a battery or tool-kit of well-validated assessments that practitioners and researchers across Brazil can choose from may be very beneficial in the long run – particularly in order to enable comparison across settings. Ideally these tools would cover all areas of the international classification of functioning, disability and health. For example, it is important not just to concentrate on tools that look at outcomes only in terms of child development but also to consider tools that look at quality of life, participation and the mental health of families. In all cases, consideration must be given to the adaptation and validation of tools prior to use and making sure that good procedures are in place for enabling better training for the assessment of children.

6. Collecting and collating resources and research

Throughout the workshop, participants from across Brazil shared their research and resources for tackling paediatric neurodevelopmental disorders. However, there was agreement that improvements need to be made in collecting and collating these resources and the research which is already available in Brazil. This could be addressed by improved networks across different regions and localities or by regular networking meetings of multidisciplinary researchers and practitioners in this field of work. This would help to strengthen the evidence base, improve the lessons learned from different regions in Brazil and support ideas relating to training and the continued professional development of those interested in this area.

7. Better training for family healthcare teams

Participants noted that the training of paediatricians is in decline in Brazil, which is having a knock-on effect on the care of children with neurodevelopmental disorders. In addition, it is also rare to have multidisciplinary teams. The workshop made it clear that the next step should be the improvement of specialist skills training, particularly for paediatricians with an interest in neurodevelopment and neurodisability. This training could also be focused on different providers and skills-mixes through task-shifting mechanisms in order to prevent a reliance on physicians and enable health worker teams to support families and children more broadly. Improved training could bring these different specialist skills together.

8. Working with education

Workshop participants agreed that working across the community is crucial to reach all children with neurodevelopmental disorders and that an individual's functioning is dependent on an interaction between health, environment and personal factors. Although a multi-levelled approach involving the community, schools, medical centres and hospitals is best, in Brazil the education system offers a particularly sound platform to work from in terms of interventions. It provides a platform from which to meet the holistic needs of young children and political prioritisation is to scale-up this approach.

In addition, participants noted that there needs to be an improvement in the communication between healthcare and educational teams, including nursing care and elementary schools. This type of communication between different sectors can help make the system more efficient.

9. A tiered care approach beyond tertiary care

Workshop participants agreed that some of the best approaches are tiered approaches which occur prior to the need for tertiary care. Currently, the response to the management of children with neurodevelopmental disorders between tertiary and public health is uneven. Workshop participants emphasised the importance of providing combined interventions at the community level and integrating them into the existing systems. Programmes that have the greatest impact combine interventions to improve nutrition, mother-child interaction, developmental stimulation and child health. In addition, the most effective programmes scaffold interventions in line with changing needs as the child grows and develops new natural capacities and skills. These types of programmes need to be taken forward universally in Brazil through public and community health services using a tiered approach, with children with increasingly complex needs reaching tertiary services as required.

10. Follow-up through an implementation group

Participants agreed that a follow-up implementation group would be extremely useful to maintain connections made during the workshop, and to drive forwards action on some of the next identified steps. Specifically, facilitating communication between researchers within Brazil and the international community, via schemes such as the GCRF Networking Grants, will help ensure research into paediatric neurodevelopmental disorders is well focused.

Conclusions

The recent scourge of the congenital Zika virus syndrome in Brazil generated a timely interest in the identification, support and management of children with neurodevelopmental disorders. The workshop gathered experts from different disciplines including basic researchers, medical professionals and health professionals (including epidemiologists, ophthalmologists, pathologists, paediatricians and physiotherapists) to collaborate and provide detail on the current understanding of childhood neurodevelopmental disorders in Brazil. It also provided a platform for this multidisciplinary group to come together to identify key barriers to progress in tackling these conditions on a national level and provide recommendations on the next steps needed to address the issues.

Paediatric neurodevelopmental disorders have a variety of infectious, environmental and genetic causes, many of which are still unknown. The workshop enabled new discoveries about the genetic and molecular mechanisms involved in these diseases to be presented, with the data being used to discuss better ways of providing diagnoses for some children in the future. In all cases, it is important that systems, cultures and locations can respond adequately in order to provide the best clinical outcomes for these children. It is also clear that many new discoveries will come at a high cost and that research needs to be carefully aligned with the economic and infrastructure realities faced by Brazil and other LMICs. Critically, they should be implemented within a framework for comprehensive multidisciplinary care.

A key consequence of the Zika outbreak was the identification of 'invisible' children; those outside the reach of the system. The discussion around this led to the identification of ways of bringing these hard-to-reach populations into the healthcare system and that local, parent-driven initiatives can be useful. Equally, there is a need for these groups to communicate and collaborate effectively with larger, national programmes in order to gain a cohesive understanding of the epidemiology of paediatric neurodevelopmental disorders in Brazil. Here, building on existing programmes such as the PNI will be important.

Broadly, the discussions were relevant because they identified many different proposals whilst also recognising actions with unified approval. We expect that this kind of workshop will continue in the coming years to promote a favourable environment for the discussion and generation of new practices that will benefit every person involved in this big issue: the families, the clinical entities, the government, and all the community.

Although many efforts are being made to prevent and treat the consequences of the Zika epidemic as well as other neurodevelopmental disorders, there are many areas of work that could be targeted for future research and programmatic work in order to improve the situation for families and children.

Appendix 1: Workshop steering committee

The organisation of this workshop was overseen by a steering committee based in both Brazil and the UK. The steering committee members are:

Co-chairs:

- Professor Maria Elisabeth Lopes Moreira, Senior Paediatrics Researcher and Professor of Neonatal Growth and Nutrition, Instituto Fernandes Figueira/Fundação Oswaldo Cruz
- Professor David Edwards FMedSci, Chair in Paediatrics and Neonatal Medicine, King's College London

Members:

- Dr Ana Maria Magalhães Costa, Medical Doctor, Instituto Fernandes Figueira/Fundação Oswaldo Cruz
- Dr Melissa Gladstone, Senior Lecturer in Paediatric Neurodisability, University of Liverpool
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