



@MATES4Kids Consensus Statement on Newborn Screening

28 June 2024

Commending the World Health Organization (WHO) Resolution A77/A/CONF./5 (*Accelerate progress towards reducing maternal, newborn and child mortality in order to achieve Sustainable Development Goal targets 3.1 and 3.2*) call to “to consider implementing a universal newborn screening programme... including specific needs and considerations for diagnosis, management and long-term care” approved at the Seventy-Seventh World Health Assembly on 28 May 2024;

Respecting the WHO Regional Office for South-East Asia’s *Universal newborn screening: Implementation guidance* (published in April 2024)

Emphasising the *WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions* (2023).

Noting the specific references to Newborn Screening in the WHO *Pocket book of primary health care for children and adolescents: guidelines for health promotion, disease prevention and management from the newborn period to adolescence* (published in 2022);

Acknowledging the WHO Resolution promoting primary prevention and improving the health of children with Birth Defects (Resolution 63.17) passed at the Sixty-Third World Health Assembly in 2010; and

Recognising insights shared by participants at side events co-hosted by @MATES4Kids at the:

- United Nations’ 62nd Session of the Commission for Social Development (CSocD62) on 6 February 2024;
- 77th World Health Assembly (WHA77) on 26 May; and
- 4th Conference for Small Island Developing States (SIDS4) held on 30 May 2024,

this **@MATES4Kids Consensus Statement on Newborn Screening** (hereafter referred to as the ‘**Consensus Statement**’) is launched as part of celebrations for International Neonatal Screening Day (#INSD) on 28 June 2024, and in support of collaborative efforts to achieve the United Nations’ Sustainable Development Goals (SDGs) by 2030. The Consensus Statement will be housed and disseminated on the [@MATES4Kids Community of Practice \(CoP\)](#), which is hosted on the World Health Organization’s Global Coordinating Mechanism on Non-Communicable Disease Knowledge Action Portal (WHO GCM/NCD KAP), and will be included in the [@MATES4Kids Toolkit](#).



**@MATES4Kids (Maximising Access To Essential Supplies for Children)
Consensus Statement on the need to urgently scale universal access
to Newborn Screening to achieve the SDGs**

This Consensus Statement seeks to:

- (a) support advocacy and awareness relevant to the importance of scaling equitable and universal access to Newborn Screening (NBS);
- (b) highlight strategies that have been demonstrated to effectively support NBS Program delivery in resource poor settings;
- (c) emphasise the importance of a comprehensive, health system strengthening, community development approach to implementing NBS Programs so that children with diagnosable and treatable congenital conditions survive and thrive;
- (d) synthesise the key challenges, concerns and limitations relating to equitable and universal access to NBS for #EVERYnewborn;
- (e) identify principles to inform multisectoral collaborative efforts; and
- (f) provide recommendations of actions urgently needed to rapidly scale universal access to NBS, to contribute to efforts to achieve the SDGs by 2030.

We, the participants of the @MATES4Kids Community of Practice, acknowledge:

1. Congenital anomalies are a leading cause of death under 20 years of age, contributing to 10% of all neonatal deaths and 8% of all deaths in children younger than 5 years. Other non-communicable diseases (NCDs) contribute to 14.2% of all deaths in children and adolescents aged 5-19 years.
2. Effective Newborn Screening (NBS) Programs help babies survive and thrive. Comprehensive NBS Programs promote the early diagnosis of a broad range of congenital anomalies (such as cleft palate, clubfoot, hip dysplasia, hearing loss and congenital heart disease) and childhood NCDs (such as congenital hypothyroidism, sickle cell disease, phenylketonuria, congenital adrenal hyperplasia and glucose-6-phosphate dehydrogenase deficiency), leading to timely referral and initiation of medical, surgical or other management which is vital to promote and protect the rights of all children to flourish in life and health to their full potential.
3. Heelprick NBS was first used to screen newborns for phenylketonuria using bloodspots in the United States in 1963, and shortly after expanded to include screening for congenital hypothyroidism (CH). Since then, NBS has expanded to encompass comprehensive programs that have saved and transformed millions of lives and are now considered a vital public health initiative in every high-income country of the world.



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4. Comprehensive NBS Programs are an integral component of strong health systems and include:
 - a. well-baby checks (systematic visual body screen and physical examination to identify genetic syndromes and congenital anomalies such as orofacial clefts, gastroschisis, atypical genitalia, hip dysplasia and clubfoot);
 - b. hearing testing;
 - c. vision checks;
 - d. heel-prick bloodspot testing (with screening panel selection reflecting local disease burden and robust recall systems facilitating urgent commencement of effective treatment); and,
 - e. pulse oximetry (to screen for critical congenital heart disease).

5. When made universally available to #EveryNewborn, NBS Programs support efforts to redress child health inequities. Despite this, NBS Programs are almost non-existent in many lower-income countries with high annual birth rates, especially in Southeast Asia and sub-Saharan Africa. Inequitable access to NBS contributes to the high and inequitable burden of preventable child morbidity and mortality in these countries.

6. NBS should be fully integrated into the broader health care system, and supported by national strategies, guidelines, programs and resources – similar to the approach taken with immunisation. Effective NBS Programs must address the WHO’s six building blocks for strong health systems at every stage of their design, delivery and evaluation. It is realistic that implementation of NBS Programs in lower-income countries occur in a transitional or phased manner.

7. An estimated 240,000 newborns die worldwide within 28 days of birth every year due to congenital disorders. Urgent scaling of comprehensive NBS Programs has a vital role to play in efforts to deliver the United Nations’ Sustainable Development Goals (SDGs) by 2030, specifically:
 - a. SDG 3.2 – end preventable deaths of newborns and children under 5 years of age:
 - i. SDG 3.2.2 - By 2030, reduce neonatal mortality to **at least as low as 12 deaths per 1,000 live births**;
 - ii. SDG 3.2.1 - By 2030, reduce under-5 mortality to **at least as low as 25 deaths per 1,000 live births**.
 - b. SDG 3.4 – reduce the preventable mortality associated with non-communicable diseases (NCDs) and
 - c. SDG 10 – to reduce inequality within and among countries by empowering and promoting the social economic and political inclusion of all, including persons with disabilities.



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8. For any NBS test offered, effective, sustained and affordable condition management and supportive care should be available to the families of all newborns diagnosed with the relevant childhood NCD. NBS Programs do not cure children of childhood NCDs, but when coupled with access to quality healthcare and effective treatments, they do give those babies diagnosed through screening the best chance of achieving their full potential in life.
9. NBS Programs must take a rights-based, community development approach that addresses the needs and priorities of those most impacted. NBS Programs must empower families with access to the information, resources, support and financial protections required to care for their child, prevent complications and mitigate risks.

We propose the following principles should inform national NBS Programs:

1. **A holistic view of health** —the WHO definition of health promotes a holistic approach, and appreciation of the impact of the social, cultural, economic and commercial determinants of health. A preventive focus is required so that children are optimally supported to survive and thrive across the life-course.
2. **Human rights-based approach** — acknowledging the rights and responsibilities enshrined in the United Nations' Convention on the Rights of the Child (United Nations Treaty Database, 1990) and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, effective 2008).
3. **Equity** — striving for excellence for all, respecting, promoting and protecting the rights of children to the highest quality of life possible, regardless of where they are born. Universal Health Coverage has an important role to play in making NBS Programs affordably available to all. Especial focus is required to scale affordable access to NBS in lower income countries of the world.
4. **Community development** — recognising all children living with the same NCD as members of a national NCD Community, these national NCD Communities - and the healthcare professionals who care for them - must be supported to unite at the national, regional and international levels.
5. **Strengths-based approaches that privilege lived experience** — acknowledging WHO's commitment to meaningful collaboration with people living with NCDs, respecting their expertise and lived experience, it is important childhood NCD Communities are actively engaged and consulted at every stage of the planning, implementation and evaluation of national NBS Programs.



- 6. **Person- and family-centred care** — ensuring the community of children, young people and families diagnosed with NCDs through NBS are maintained as the hub of all collaborative activities, and the needs and priorities of children and families diagnosed with NCDs are comprehensively addressed using the five pillars of the Strategic Framework of CLAN (Caring & Living As Neighbours) to guide proactive initiatives: affordable access to essential medicines and equipment; education, research and advocacy; optimisation of medical management; encouragement of family support groups; and reducing financial burdens on families.
- 7. **A health system strengthening approach** – noting comprehensive approaches to implementing and sustaining universal NBS programs must centre those most affected and address all six of the WHO Building Blocks for health system strengthening: governance and financing; access to medicines, equipment and technology; community and stakeholder engagement; health system delivery; health workforce; data and information systems; and community and stakeholder engagement (see Figure 1). Collaborative and integrated approaches by a broad range of stakeholders are essential. An example would be the integration of NBS programs and childhood NCD management within National Maternal and Child Handbooks and guidelines; supported by national policies, legislation, essential medicines and diagnostics lists, insurance programs, research strategies and funding allocations commensurate with equitably addressing community needs.

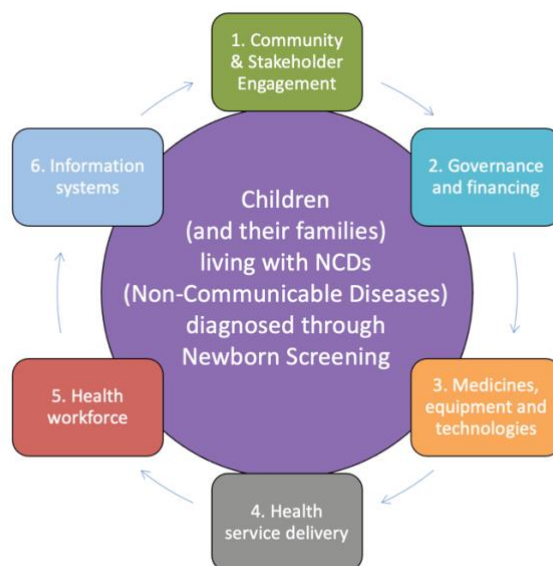


Figure 1 - Health systems plus framework adapted by @MATES4Kids for children living with CAH (congenital adrenal hyperplasia) and other conditions diagnosed through newborn screening.

Note: Figure adapted and used with kind permission of Catherine G Lam MD, MPH; Medical Director, St Jude Global.



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- 8. Valuing a skilled workforce** – a broad range of trained and supported health professionals are required to successfully implement a robust, effective, universal NBS Program.
- 9. Multisectoral collaboration and partnerships** — broad, multidisciplinary and inclusive approaches are key to sustainability and success for NBS Programs;
- 10. Above all do no harm** — overarching guiding principle to inform all actions. Collective efforts are required to reduce stigma, discrimination and misinformation.

We call on policy makers, governments, multilaterals, civil society organisations, professional associations, health and development practitioners, and other key stakeholders to:

1. Clarify, prioritise and respond to high burden conditions for which there are effective treatment options (with pilot programs to establish local incidence rates; patient registers to track prevalence; and shared indicators used to monitor and evaluate efforts to reduce morbidity and mortality);
2. Ensure all national NBS Programs address the WHO's six building blocks and are integrated within the healthcare system, not siloed;
3. Commit to working collaboratively to raise awareness of the urgent need to ensure NBS is available to all children;
4. Combat the misinformation, stigma and apathy associated with many childhood NCDs;
5. High level political support is required to ensure countries actively engage with, support and align national NBS initiatives with WHO frameworks;
6. Routinely integrate NBS within national, regional and WHO policies and frameworks (similar to the approach taken to immunisation), and ensure all neonatal and child health resources (such as National Maternal and Child Health Handbooks) and guidelines include a focus on NBS;
7. Amplify the voices and perspectives of people living with NCDs that can be diagnosed through NBS, to ensure NBS programs address their needs and priorities, noting different conditions will require unique approaches to management and care;

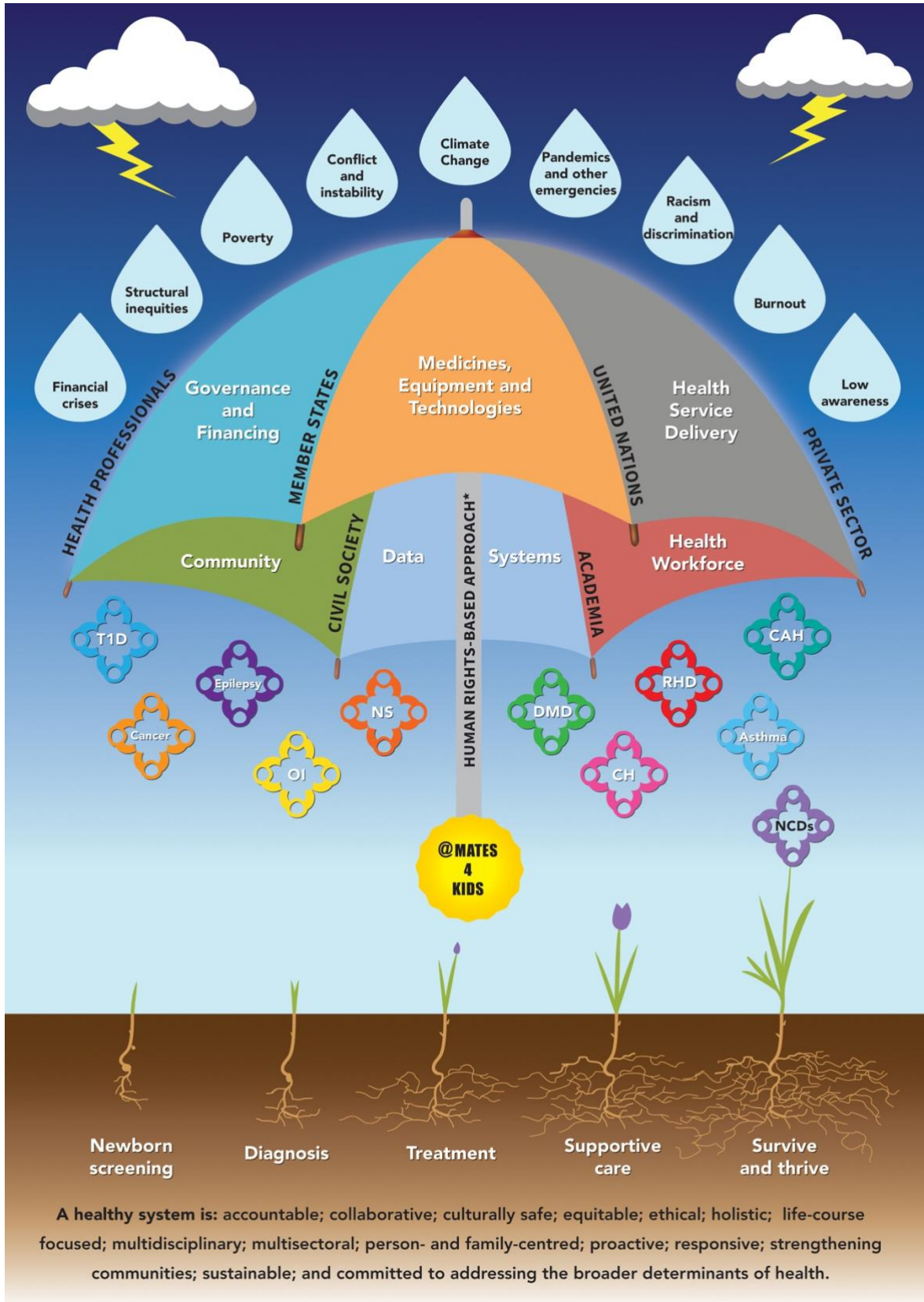


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8. Ensure those essential medicines and equipment required to manage conditions that are screened for, and which are included within the WHO's Essential Medicines List for children (EMLc) and Essential Diagnostics List (EDL), are also included in all National Essential Medicines Lists (NEMs), registered for legal use in-country and made affordably available to all;
 9. Invest in undergraduate education programs and continuing professional development initiatives, so the workforce needed to implement comprehensive NBS Programs and care for the children who are consequently diagnosed with special health needs are suitably skilled and trained;
 10. Commit to Universal Health Coverage, and affordable access to NBS Programs and the quality management of childhood NCDs within national insurance schemes.
 11. Support communities of children diagnosed with NCDs through NBS Programs to come together, with community development initiatives routinely included within national NBS funding allocations;
 12. Invest in community awareness programs, to boost acceptability of and engagement with NBS Programs;
 13. Establish a permanent forum to support inclusive, multisectoral, multidisciplinary and collaborative action (and reduce the destructive impact of siloed ways of working), promote sharing of resources, and prioritise action to ensure those countries with greatest need are urgently supported to scale NBS;
- and
14. Recognise the need for NBS Programs to be integrated within every strong health system in the post-2030 development agenda.

Acknowledgements

@MATES4Kids would like to acknowledge and thank the many individuals and organisations in the development of this Consensus Statement. Especial thanks must go to participants at our side events at the 77th Session of the World Health Assembly (WHA77) and the 4th Small Island Developing States (SIDS4) Conference, as well as the many youth volunteers generously sharing their time and expertise with our Network.



Comprehensive Newborn Screening Programs are an integral component of strong health systems!