



# Economic and Social Council

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## Commission for Social Development

Sixty-first session

5–14 February 2024

**Follow-up to the World Summit for Social Development and the twenty-fourth special session of the General Assembly:**

**Priority Theme: “Fostering social development and social justice through social policies to accelerate progress on the implementation of the 2030 Agenda for Sustainable Development and to achieve the overarching goal of poverty eradication”**

### **Statement submitted by CLAN (Caring & Living as Neighbours) Incorporated, a non-governmental organization in consultative status with the Economic and Social Council\***

The Secretary-General has received the following statement, which is being circulated in accordance with paragraphs 36 and 37 of Economic and Social Council resolution 1996/31.

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\* The present statement is issued without formal editing.



## Statement

Caring & Living as Neighbours (CLAN) supports the sixty-second session on the Commission for Social Development and its mission to improve social development to follow up the World Summit for Social Development and twenty-fourth special session of the General Assembly. CLAN would like to acknowledge the Wallumedegal peoples of the Eora Nation, the Traditional Owners of the land on which we are headquartered. CLAN also acknowledges the Lenape people, on whose Land the UN is headquartered in New York City, and we pay our respects to Elders past, present, and emerging.

CLAN is an Australian non-governmental organisation (NGO) founded in 2004. CLAN's mission is to maximise quality of life for children living with non-communicable diseases and other chronic health conditions in resource-poor settings. According to the World Health Organization, a non-communicable disease is a long-term, non-transmittable disease that results from genetic, physiological, environmental and behavioural factors. Non-communicable diseases cause 24.8% of disability-affected life years and 14.6% of deaths among children and adolescents. In addition, the Centres for Disease Control and Prevention states that non-communicable diseases account for 41 million deaths each year with about 85% occurring in low- and middle-income countries. With vulnerability of age and socioeconomic factors combined, these children face disadvantaged abilities to live with their conditions.

CLAN operates under a rights-based, strategic framework for action that promotes a community development approach to redressing inequities for children living with non-communicable disease in resource poor settings through multisectoral collaborative efforts focused on five pillars considered essential to achieving the highest possible quality of life. CLAN's five pillars focus multisectoral action on:

1. Access to essential medicines and equipment
2. Education, research and advocacy
3. Optimisation of medical management
4. Encouragement of family support groups
5. Reducing financial burdens and promoting financial independence.

Children living with non-communicable diseases in low- and middle-income countries experience inequitable health outcomes due to delayed diagnosis, limited access to affordable medicines, quality healthcare, social services and support. Early diagnosis and treatment of childhood non-communicable diseases has a major impact on improving health outcomes and quality of life. Universal access to Newborn Screening plays a vitally important role in diagnosing many childhood non-communicable diseases at an early stage and can include simple heel-prick tests (as used for Congenital Adrenal Hyperplasia, Congenital Hypothyroidism, Phenylketonuria and Cystic Fibrosis), hearing tests and pulse oximetry (for Critical Congenital Heart Disease). Whilst available in all high-income countries, Newborn Screening is rarely available in lower income countries.

Newborn screening is a vital public health innovation that was first made available in the 1960s. Undertaken in all high-income countries of the world, these tests have the potential to diagnose conditions requiring urgent (yet affordable) treatment to prevent profound developmental delay, disability and even death, thereby helping to redress preventable childhood mortality and morbidity. For instance, according to the National Institute of Health, in a cohort of infants diagnosed with Congenital Adrenal Hyperplasia, the cost of care was \$33,770 per case in unscreened

vs \$17,726 in screened newborns. Infants screened for the condition were less likely to require medical transport and longer hospital stays, and thus lower hospitalisation costs.

It is unacceptable that newborn screening is not uniformly available to all. Children born with these same non-communicable diseases in low- and middle-income countries are at increased risk of preventable morbidity and mortality. Newborn screening overcomes economic and social inequities. Universal newborn screening programs do not discriminate against girl babies nor babies born in resource poor settings. Newborn screening must be scaled and made available to all – and most particularly to those living in the most vulnerable circumstances. Newborn screening meets World Health Organization screening criteria; it is cost-effective, acceptable, available, and safe. The technology is already developed, and has only to be scaled appropriately to cover more disadvantaged populations.

Scaling newborn screening will enhance efforts to deliver the Sustainable Development Goals in accordance with the 2030 Agenda. Universal implementation of newborn screening supports efforts across multiple SDGs, by reducing inequalities, promoting health and well-being, eradicating poverty, and strengthening infrastructure.

The applicability of rapid scaling is backed by many previous initiatives. For example, the National Institute of Health (NIH) reports that newborn screening in China, a middle-income country, increased newborn screening rates from 2% in 1995 to 97.5% in 2017. With the rapid advances in technology and communication since then, scaling newborn screening globally is attainable, if prioritised.

Universal Health Coverage will be key to scaling access to newborn screening for all children around the world. Cost benefit analyses have clearly demonstrated the value of newborn screening, and administrations that choose to cover the costs of the essential medicines and equipment required to implement newborn screening would reap the benefits in terms of reduced developmental delay and disability. With affordable access, families living in the most vulnerable situations would be less likely to be forced into making life-and-death decisions about how to spend limited resources. Optimal treatment of childhood non-communicable diseases during the “golden years” of early and rapid human development and growth would give children the opportunity to enjoy their basic human rights to life and health and achieve their full potential.

CLAN is proud to serve as Secretariat for @MATES4Kids, a global coalition seeking to reduce the preventable mortality associated with childhood non-communicable diseases in low- and middle-income countries. Starting with congenital adrenal hyperplasia as a pilot condition, the @MATES4Kids movement is committed to reducing the preventable mortality associated with congenital adrenal hyperplasia by 30% by 2030. It proposes to achieve this through collective and collaborative focus on three objectives: improving affordable access to essential medicines and equipment; strengthening affected communities; and scaling newborn screening.

CLAN and the @MATES4Kids movement are committed to redressing social and economic inequities for children living with chronic health conditions in partnership with national and regional civil society organisations and communities, the Commission of Social Development, the WHO, and other relevant United Nations entities. Newborn screening must be seen as a vital component of a holistic, health-system strengthening approach. The international community has a tremendous role to play in ensuring children living with non-communicable diseases in resource-poor countries of the world enjoy a quality of life on par with that of their neighbours in wealthier countries. A community development approach to the establishment of

screening programs is needed to address poverty and gender inequities in sustainable and holistic ways. Countries must ensure the needs of all children diagnosed with chronic conditions can be met prior to starting screening. This includes affordable access to medicines and equipment; education of families, workforce and the broader community; optimal medical management; strong family support groups; and financial protection mechanisms.

CLAN emphasises the crucial point that all children have a right to health and life and no child or family should ever face the threat of disability or death due to social or economic inequities. This mission aligns with the standards established by Beijing Platform for Action and takes account of the sixty-second session of the Commission for Social Development priority theme of “fostering social development and social justice through social policies to accelerate progress on the implementation of the 2030 Agenda for Sustainable Development and to achieve the overarching goal of poverty eradication.”

CLAN calls upon the Commission for Social Development and other relevant United Nations entities to acknowledge the vital role newborn screening plays in providing early awareness and treatment for young children at risk from the preventable mortality and morbidity too often associated with non-communicable diseases in economically disadvantaged areas. It is essential to increase the span of newborn screening globally; the technology already exists and has been proven reliable and cost-effective. Innovations such as newborn screening and universal health coverage do not discriminate against youth, girls, or lower income families, and should be made available to all.

CLAN reaffirms its commitment to eliminate social inequity and eradication of poverty in accordance with the Commission for Social Development and the twenty-fourth special session of the General Assembly. We believe children living with noncommunicable diseases in low- and middle-income countries deserve equal rights to life and prosperity, and thus recognise the indispensable need for social justice and development in order to accelerate the UN Sustainable Development Goals.

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