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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.

* The present statement is issued without formal editing.



Statement

Caring & Living as Neighbours (CLAN) supports the sixty-eighth session of the Commission on the Status on Women (CSW) and its mission to improve gender equity as outlined in the Beijing Declaration and Platform for Action (BPfA) in 1995. 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 United Nations 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 per cent of disability-affected life years and 14.6 per cent 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 per cent occurring in low- and middle-income countries. With vulnerability of age and socioeconomic factors combined, children living with non-communicable diseases and other chronic health conditions in resource poor settings are at especial risk of preventable mortality and morbidity.

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. CLAN seeks to facilitate multisectoral, collaborative efforts focused on five pillars that families have told us are essential to achieving the highest possible quality of life for their children:

- Affordable access to essential medicines and equipment
- Education, research and advocacy
- Optimisation of medical management
- Encouragement of family support groups
- Reducing financial burdens and promoting financial independence.

Delays in diagnosis and limited access to affordable medicines, equipment, quality healthcare, social services and support are especial challenges facing children living with non-communicable disease in resource poor settings. Early diagnosis and optimal management of childhood non-communicable diseases dramatically improve health outcomes and quality of life – not just in childhood, but across the life-course.

Universal access to Newborn Screening has a vitally important role to play in diagnosing many childhood non-communicable diseases at an early stage. Newborn Screening is a vital public health innovation that was first made available in the 1960s. Newborn Screening 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. In virtually all high-income countries every newborn child has a simple heel-prick blood test (used to screen for conditions such as Congenital Adrenal Hyperplasia, Congenital Hypothyroidism, Phenylketonuria and Cystic Fibrosis), hearing tests and pulse oximetry (to screen for Critical Congenital Heart Disease), with treatment started as early as possible once a diagnosis is confirmed, thereby optimising health outcomes.

By contrast, Newborn Screening of any description is rarely available in lower income countries. Conditions that are easy and cheap to treat go undiagnosed and preventable mortality and mortality are high. Girl children in these countries are at especial risk. According to the National Institute of Health (NIH), women in lower-income countries suffer from higher levels of economic hardship and gender inequality than in economically advanced countries, which results in poorer health outcomes. The evidence shows women and girls too often have less access to care, and when they do, they often receive less aggressive treatments, thereby increasing their risk of complications and denial of their basic human rights to life and health. Women also are more likely to end up as sole carers for children with special health needs, and this further impacts on their financial wellbeing.

It is unacceptable that Newborn Screening is not universally available to every newborn child. Newborn Screening overcomes gender inequities. Universal Newborn Screening programs do not discriminate against girl babies and have the potential to cut through the social, cultural, and economic determinants of health. Newborn Screening must be scaled and made available to all as a matter of urgency if we are to achieve the United Nations' Sustainable Development Goals (notably SDG 3.2.1, 3.2.2 and 3.4). Newborn Screening meets World Health Organization screening criteria, and is low-cost, effective, acceptable, available, and safe. The technology is proven, and has only to be scaled appropriately to cover those living in the most vulnerable circumstances.

Universal Health Coverage will be key to scaling Newborn Screening, and making it available to 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 equipment, medicines, workforce and structures required to implement Newborn Screening would reap the benefits in terms of reduced mortality, morbidity and disability. With affordable access, families in vulnerable situations will be less likely to experience catastrophic health spends; and will have greater chance of avoiding 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 growth and development would give more children the opportunity to enjoy their 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 per cent 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 inequities for children living with chronic health conditions in partnership with our national and regional communities, the Commission on the Status of Women, UN Women, the WHO, and other relevant United Nations entities. 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' children in wealthier countries. Newborn Screening must be seen as a vital component of a holistic, health-system strengthening approach. A community development approach to the establishment of screening programs will address poverty and gender inequities, and will require countries to ensure the needs of all children diagnosed with chronic conditions can be

met. This includes securing access to essential medicines and equipment; investing in training and education for workforce, families and the broader community; and establishing 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 economic and gender inequities. This mission aligns with the standards established by Beijing Platform for Action and takes account of the sixty-eighth session of the Commission on the Status of Women's priority theme of "accelerating the achievement of gender equality and the empowerment of all women and girls by addressing poverty and strengthening institutions and financing with a gender perspective". CLAN would like to especially underscore the vital role Newborn Screening technology must play as an essential component of any effective health system, noting its capacity for promoting equal, timely and affordable access to treatment for women and girls.

CLAN calls upon the Commission on the Status of Women, UN Women, and other relevant United Nations entities to acknowledge the essential role Newborn Screening must play in providing early diagnosis and treatment for women and girls living with non-communicable diseases. It is essential to increase the span of Newborn Screening globally. The technology already exists and has been proven reliable and cost-effective – now it needs to be made available to all. Innovations such as Newborn Screening and universal health coverage do not discriminate against women and girls and should be made available to #EVERYchild so we #LeaveNoChildBehind.

CLAN reaffirms its commitment to eliminate gender inequality in accordance with the Commission on the Status of Women and Beijing Declaration and Platform for Action. We believe women serve as vital agents of change and recognise the indispensable need for women's empowerment in order to accelerate the UN Sustainable Development Goals and champion the values of UN Women.
