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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-ninth session on the Commission on the Status on Women (CSW69) and its mission to improve gender equity as outlined in the Beijing Declaration and Platform for Action at the Fourth World Conference on Women 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, Traditional Owners of the Land on which 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 founded in 2004 with the mission to maximise quality of life for children living with Non-Communicable Diseases and other chronic health conditions in poor resource settings. CLAN operates under a rights-based strategic framework for action that promotes a community development approach to redressing inequities associated with childhood non-communicable diseases through multisectoral collaborative efforts focused on five pillars considered essential to achieving the highest possible quality of life. The five pillars focus action on: access to essential medicines and equipment; education, research and advocacy; optimisation of medical management; encouragement of family support groups; and reducing the financial burdens on families.

CLAN is proud to serve as Secretariat for @MATES4Kids (Maximising Access To Essential Supplies for Children), an international movement committed to collaborative action to reduce the preventable mortality associated with one particular childhood non-communicable disease, congenital adrenal hyperplasia. We believe affordable access to essential medicines, strengthening communities of people living with congenital adrenal hyperplasia and scaling universal access to Newborn Screening are key strategies to reducing the preventable mortality associated with congenital adrenal hyperplasia by 30 per cent by 2030.

In accordance with the CSW69 focus on the review and appraisal of the implementation of the Beijing Declaration and Platform for Action; acknowledging the outcomes of the five- and 20-year reviews of the Beijing Declaration and Platform for Action in 2000 and 2015 respectively; in preparation for the United Nations' High Level Meeting on Non-Communicable Diseases in 2025; and informed by the goals and targets of the 2030 Agenda for Sustainable Development, CLAN seeks to highlight the relevance of gender equity to reducing the preventable mortality and morbidity associated with childhood non-communicable diseases. We acknowledge the importance of empowering women and girl children; the significance of universal health coverage in redressing inequities and protecting and promoting the rights of all children to life and health; and the especial role mothers play in the lives of children living with non-communicable diseases in resource poor settings around the world.

Non-communicable diseases are non-transmittable, long-term health conditions. Children born with these same non-communicable diseases in low and middle income countries are at increased risk of preventable morbidity and mortality. 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 middle and low income countries. With vulnerability of age and socioeconomic factors combined, these children face disadvantaged abilities to live with their conditions.

Impressively, the Beijing Declaration and Platform for Action references non-communicable diseases, a term not commonly used in the 1990s. Specifically,

strategic objective C.4., promote research and disseminate information on women's health states, section D, includes a call to "(i)ncrease financial and other support from all sources for preventive, appropriate biomedical, behavioural, epidemiological and health service research on women's health issues and for research on the social, economic and political causes of women's health problems, and their consequences, including the impact of gender and age inequalities, especially with respect to chronic and non-communicable diseases". The 2015 review went further still, detailing the inequitable burden non-communicable diseases and disability have on women and girl children.

As we approach 2030 and beyond, CLAN calls for specific focus on the inequitable impact childhood non-communicable diseases have on mothers and girl children in lower-income settings. The Beijing Declaration and Platform highlights some of the challenges. For instance, in some cultures, discrimination that results from son preference leaves families less likely to invest limited family funds on chronic care for a girl child. Of all children living with chronic conditions, girls are therefore at increased risks from preventable morbidity and mortality associated with non-communicable diseases. The Beijing Declaration and Platform for Action likewise acknowledges the critical role women play in families. Unfortunately, when a child is diagnosed with a non-communicable disease, the responsibility for their care most usually falls to mothers. Taking care of a child with a serious medical condition results in increased stress and can negatively impact a mother's mental health. Many families break under the stress of caring for a child with special health needs, and it is most usually the father who abandons care of chronically ill children. Increased health supervision requirements lead many mothers to stop working and pivot to full-time caring, thus worsening the economic gap for women. Such compounding pressures are harmful to the mother's health and economic stability. Worse still, the trauma of losing a child lasts a lifetime. There is an urgent need to highlight the significant role mothers play in the care of children with non-communicable diseases and ensure they - and their children - have proper support networks and financial resources to survive and thrive.

One critical public health initiative that reduces the inequitable impact of congenital non-communicable diseases is newborn screening. In every high-income country of the world, quick, affordable and simple heel-prick blood tests from newborn babies are combined with other low-cost initiatives (such as well baby checks conducted by trained health professionals, and hearing, vision and pulse oximetry screening tests on newborns) and universally undertaken on every newborn so steps can be taken to ensure cost-effective treatments are urgently commenced, to prevent profound developmental delay, disability and even death. Phenylketonuria, congenital hypothyroidism, congenital adrenal hyperplasia, sickle cell disease, cystic fibrosis, cleft palate, club foot, hip dysplasia, hearing impairment and congenital heart disease are amongst the many congenital conditions that newborns can be screened for. Early and optimal treatment of these congenital non-communicable diseases during the "golden years" helps children enjoy their rights to life and health and reach their full potential. As noted within the Beijing Declaration and Platform for Action, the girl child of today is the woman of tomorrow. Administrations that choose to cover the costs of screening, diagnosis and early treatment reap the benefits in terms of the longer-term impact of reducing preventable child mortality and disability. Families living in vulnerable situations are less likely to be forced into making painful decisions about how to spend limited resources, and children are best placed to achieve their full potential as productive members of society.

Despite evidence which clearly demonstrates the economic value of newborn screening, its contribution to overcoming gender inequities (universal newborn screening programs do not discriminate against girl babies) and minimising the

impact of barriers to the social and cultural determinants of health, newborn screening remains largely unavailable in lower-income countries. The international community has a tremendous role to play in advocating for equitable and universal access to newborn screening.

Children living with non-communicable diseases in resource-poor countries of the world have a right to a quality of life on par with that of their neighbours' children in wealthier countries.

As we approach the 2025 High Level Meeting on Non-Communicable Diseases and delivery of the Sustainable Development Goals by 2030, CLAN calls upon the Commission on the Status of Women, UN Women, and other relevant United Nations entities to acknowledge the vital role universal health coverage and newborn screening must play in reducing the inequitable burden of childhood non-communicable diseases on women. Urgent efforts must be made to scale newborn screening globally and ensure the essential medicines and therapies required by children diagnosed with non-communicable diseases are affordably available to all. We have a collective responsibility to work together to protect and promote the rights of children living with non-communicable conditions in resource poor settings to life and health.

CLAN believes 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.
