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**Follow-up to the Fourth World Conference on Women and
to the twenty-third special session of the General Assembly
entitled “Women 2000: gender equality, development and
peace for the twenty-first century”**

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-fifth session of the Commission on the Status of Women and recognizes the imperative need to advance gender equality as outlined in the Beijing Declaration and Platform for Action (1995). CLAN would like to acknowledge the Wallumetjegal peoples of the Eora Nation, the Traditional Owners of the land on which we are headquartered. CLAN also acknowledges that the present statement is written and submitted on the traditional lands of the Lenape people, on which the United Nations is headquartered in New York City. CLAN pays its respects to Elders past, present, and emerging.

CLAN, founded in 2004, is an Australian non-governmental organization (NGO) dedicated to maximizing quality of life for children and their families who are living with chronic health conditions in resource-poor settings of the world. As stated in the United Nations Convention on the Rights of the Child (UNCRC), all children with special health requirements have a right to the care needed to enable them to live the healthiest and most fulfilling life possible (Articles 3, 6, 24; 1990).

Since first engaging in the international non-communicable disease (NCD) discourse in 2010, CLAN has become increasingly concerned about the lack of focus on Indigenous Peoples. There are an estimated 370 million Indigenous Peoples living in 90 countries across the world, and the evidence indicates Indigenous Communities are inequitably burdened by NCDs. In 2018, CLAN founded Indigenous NCDs, a global coalition committed to Indigenous control and advocacy to promote the voices and perspectives of Indigenous peoples on issues relating to the prevention and management of NCDs.

CLAN operates under a rights-based strategic framework for action that promotes a community development approach to redressing inequities experienced by children living with chronic health conditions in resource-poor countries. CLAN's model seeks to focus multisectoral collaborative efforts on five pillars considered essential to achieving the highest possible quality of life for these communities. The five pillars focus action on:

- Access to medicines and equipment;
- Access to education, research and advocacy;
- Optimisation of medical management;
- Encouragement of family support groups;
- Actions to reduce financial burdens and promote financial independence.

An exemplary utilization of CLAN's strategic framework was most recently observed in Pakistan, where collective action advanced access to essential medicines for treatment of Congenital Adrenal Hyperplasia (CAH). In 2020, local production of hydrocortisone tablets in Pakistan at an extremely low cost (Rs2.2/tablet; AUD 0.018/tablet) commenced after years of advocacy, ensuring this life-saving medication was affordably available for all persons living with CAH in Pakistan. This achievement led to a CLAN pilot project run by the National Institute of Child Health (NICH) in Karachi, which had a one-hundred percent success rate during the COVID-19 pandemic, and it is reasonable to assume all of these children would otherwise have suffered enormously had the project not been running.

CLAN will focus on the following critical areas of concern in 2021, based on the Beijing Platform for Action. Our call to action is dedicated to improving the lives of the poorest families and children suffering from non-communicable diseases and

other chronic health conditions all over the world. CLAN acknowledges how these issues particularly affect women, especially Indigenous Women throughout the world.

(Women and Health): CLAN is committed to the Beijing Platform for Action through our five pillars that promote women and health through affordable access to medication and equipment, education, optimisation of medical management, encouragement of family support networks, and reducing financial burdens on families. There needs to be a particular focus on the unique cultural needs of Indigenous women. What also needs to be recognised is the ongoing impacts of colonisation and racism. Indigenous women are often some of the most marginalized within their own countries. With communities engaged in the design and delivery of relevant services.

According to the Beijing Platform for Action paragraph 90, women have different and unequal access to, and use of, basic health resources, including primary health services for the prevention and treatment of childhood diseases, malnutrition, anaemia, diarrhoeal diseases, communicable diseases, malaria and other tropical diseases and tuberculosis, among others.

This aligns with CLAN's first pillar of promoting access to medication and equipment. This can be achieved where there is political will, and collaborative action by medical device manufacturers and policy makers to make drugs, therapeutics, and medical equipment more affordable and accessible. This is especially important for families with girls who may not get equal access to medical treatments.

Additionally, this portion of Beijing Platform for Action touches on pillar five of CLAN's framework for action, which aims to reduce financial burdens and promote financial independence. We also note that too often mothers are left to care for children with severe and chronic health conditions in resource poor settings.

Beijing Platform for Action paragraph 107 discusses creating and supporting programmes in the educational system, in the workplace and in the community so that opportunities to participate in physical activity and recreation is equally available to girls and women of all ages.

This goal of the Beijing Platform for Action directly aligns with CLAN's second pillar of improving access to education with a community focused approach. CLAN approaches access to education by empowering families and communities to get the resources they need so that children will not only be able to attend school but also complete to their full potential.

Finally, one of the main goals stated in the Beijing Platform for Action in paragraph 106, is to support non-governmental organizations working on women's health and help develop networks aimed at improving coordination and collaboration between all sectors that affect health.

This holistic approach directly aligns with the third and fourth pillars of CLAN. Pillar three focuses on the optimisation of medical management so those living in the most vulnerable circumstances can access multidisciplinary care. Pillar four focuses on strengthening NCD Community networks and partnerships to reduce social isolation and empower families. For women and girls these networks are especially important as many times women with chronic illnesses may be overlooked by traditional health care systems.

Conclusion

CLAN is 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 NCDs in resource-poor countries of the world will enjoy a quality of life on par with that of their neighbours in wealthier countries.

CLAN calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to acknowledge women as mothers and primary caregivers of children living with NCDs. This puts women in a powerful position to be active partners in driving change, and CLAN advocates for recognition of their invaluable contributions to maintaining the health of their children. See: *We All Have a Role to Play: Redressing Inequities for Children Living with CAH and Other Chronic Health Conditions of Childhood in Resource-Poor Settings* in the *International Journal of Neonatal Screening*, published by CLAN and partners (2020).

CLAN calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to recognize the vast potential of the WHO's plan to establish a Youth Council and the critical nature of being inclusive of Indigenous Youth. Although Indigenous Peoples make up only five percent of the global population, they account for about fifteen percent of the extreme poor. Indigenous Youth face unique cultural, social, political, and commercial determinants of health, underscoring the vital need to meaningfully engage Indigenous Youth in the global NCD discourse, and ensure their voices are heard.

CLAN calls upon the Commission on the Status of Women, UN-Women, and other relevant United Nations entities to carefully consider resourcing required for an inclusive Youth Council. It is essential for WHO's Youth Council to not only include young people living with NCDs from high income countries and families, but also young people living with NCDs in resource poor settings.

CLAN reaffirms its commitment to eliminate gender equality in accordance with the sixty-fifth session of 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.
