

Official Event Report

Showcasing the Power of Women in Childhood NCD Community Development

69th Session of UN Women Commission on
the Status of Women Forum for NGOs

19 March 2025



Acknowledgements

CLAN (Caring & Living As Neighbours) acknowledges the traditional custodians of Country throughout Australia and the connections of Aboriginal and Torres Strait Islander peoples to land, sea and community. In particular, CLAN acknowledges the Wallumedegal Peoples of the Eora Nation, on whose land CLAN is headquartered. CLAN pays its respects to Elders past and present and extends that respect to all First Nations peoples around the world.

CLAN thanks the many individuals involved in organising and presenting at this event, with especial thanks to our United Nations Youth Representatives from Lehigh University, Nikki Pasterczyk, Katie Blomkvist, Samiha Islam and Tara Chelvam,

Further, CLAN thanks the many organisations who have generously contributed to the @MATES4Kids (Maximising Access to Essential Medicines for Children) movement and helped to make this event a success.

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Executive Summary

CLAN (Caring & Living as Neighbours) was proud to host a side event at the 69th Session of the Commission on the Status of Women in March, 2025.

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 used this opportunity to highlight the relevance of gender equity to reducing the preventable mortality and morbidity associated with childhood non-communicable diseases.

Of note, the Beijing Declaration highlighted the necessity of elevating women's voices to driving change and implementation of the Platform for Action. This event showcases 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.

Thank you to everyone who made this event possible!



Click [this link](#) to read our entire written statement for CSW69!

Agenda

Content	Speaker
Introduction and Housekeeping	Nikki Pasterczyk
Welcome and Introduction to @MATES4Kids - Celebrating 20x30x40 on the road to 2030	Kate Armstrong
@MATES4Kids 2023-2024 Activity Report Launch	Katie Blomkvist
The power of mothers and community- Striving for equity in Zimbabwe	Heriet Mhondiwa
Scaling NBS in challenging circumstances- Training Health Professionals in Uganda	Esther Kobel
The power of mothers and community- The story of CARES Foundation	Dina Matos & Alyssa Leight
Driving change for all- Achievements for the CAH community of Colombia	Paola Duran
The importance of allies- CAHSAPI and Intersex Asia working together	Jeff Cagandahan & Eli Rubashkyn
Protecting future generations- Creating change through NBS in Indonesia	Astrid Larasati
Closing discussion- Reflections and recommendations for next steps	Kate Armstrong

List of Abbreviations

<u>Abbreviation</u>	<u>Full Text</u>
CAH	Congenital Adrenal Hyperplasia
CLAN	Caring & Living As Neighbours
@MATES4Kids	Maximising Access To Essential Supplies for Children
NBS	Newborn Screening
SDGs	Sustainable Development Goals
NCDs	Non-communicable diseases
CSW69	69th Commission on. the Status of Women

Introduction to CLAN, @MATES4Kids, and Lehigh University's CSW69 Parallel Event



Nikki Pasterczyk
United Nations Youth Representative

CLAN and @MATES4Kids presented at the 69th NGO Commission on the Status of Women on 19 March 2025. The parallel event hosted was titled “Showcasing the Power of Women in Childhood NCD Community Development.”

The priority theme of CSW69 is to focus on current challenges that affect the implementation of the Beijing Declaration and Platform for Action, the achievement of gender equality and the empowerment of women, and its contribution towards the full realization of the 2030 Agenda for Sustainable Development.

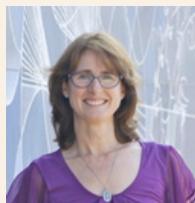
The Beijing Declaration was adopted in 1995 at the 4th World Conference on Women in Beijing. The Beijing Declaration identified 12 critical areas where urgent action is needed to advance women's rights, including:

- Women and poverty
- Education and training
- Women and health
- Violence against women
- Women and armed conflict
- Women and the economy
- Women in power and decision-making
- Institutional mechanisms for the advancement of women
- Human rights of women
- Women and the media
- Women and the environment
- The girl child



Our event addressed several of these critical areas, including women and health, women in power and decision-making, human rights of women, and the girl child.

Welcome and introduction to @MATES4Kids 30 years after Beijing Celebrating 20x30x40 on the road to 2030



Kate Armstrong
President of CLAN
Founding Chair of NCD Child
Co-Founder of @MATES4Kids

Australian Public Health Physician
Fellow of the Australasian Faculty
of Public Health Medicine

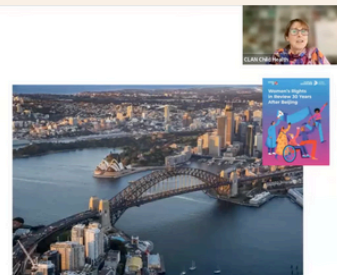
Kate began her presentation by reflecting on the Beijing Declaration identified five priorities to make faster gains and prepare for an uncertain future. Those priorities include:

1. Close the accountability gap
2. **Elevate women's voices**
3. Close the financing gap
4. Harness technology
5. Shock-proof services and infrastructure

FIVE PRIORITIES TO MAKE FASTER GAINS AND PREPARE FOR AN UNCERTAIN FUTURE

The global progress review defined five cross-cutting recommendations fundamental to achieving the Beijing Declaration and Platform for Action for all women and girls:

1. CLOSE THE ACCOUNTABILITY GAP
2. **ELEVATE WOMEN'S VOICES**
3. CLOSE THE FINANCING GAP
4. HARNESS TECHNOLOGY
5. SHOCK-PROOF SERVICES AND INFRASTRUCTURE



Introducing @MATES4Kids

Kate also spoke to the work of @MATES4Kids (Maximising Access To Essential Supplies for Children), a global movement of individuals and organisations committed to reducing the preventable mortality associated with CAH by 30% by 2030. To achieve this goal, @MATES4Kids facilitates collaborative, international action focused on three objectives:

1. Improving access to essential medicines and equipment
2. Strengthening CAH community development
3. Scaling newborn screening (NBS)

As we approach 2030, @MATES4Kids promotes a focus on the Sustainable Development Goals (SDGs), specifically SDG 3.2 (end all preventable deaths under 5 years of age) and SDG 3.4 (reduce mortality from non-communicable diseases and promote mental health).

@MATES4Kids is committed to awarding 40 grants by 2030 to CAH communities in low- and middle-income countries. So far, we have awarded 11 grants to 8 countries. Stay connected to learn about future grant opportunities.

Launch of the @MATES4Kids 2023-2024 Activity Report



Katie Blomkvist

United Nations Youth Representative

@MATES4Kids Project Officer



The @MATES4Kids 2023-24 Activity Report is both a celebration of our collective progress and a call to action. The report underscores the importance of collaboration, the power of community-driven solutions, and the urgent need to redress healthcare inequities for children living with CAH and other chronic conditions.

@MATES4Kids officially launched the 2023-2024 Activity Report at CSW69. The report showcases the incredible progress of the @MATES4Kids Network from July 2023 to December 2024, as well as the challenges we continue to face in our mission to reduce the preventable mortality associated with CAH by 30% by 2030. The report highlights the incredible work of our network of champions across all six WHO regions; there are so many people working tirelessly to improve access to life-saving treatments, strengthen community development, and scale newborn screening programs worldwide.

Inside the report you'll find:

- Key achievements from our global Community of Practice.
- Inspiring success stories from local champions in the Philippines, Colombia, and Pakistan.
- The strategic frameworks guiding our work in improving access to medicines, strengthening communities, and scaling newborn screening.
- Tools to track progress as we work toward our 2030 goals.
- Updates on the impactful work of our Community Development Grant recipients

The power of mothers & community – striving for equity in Zimbabwe



Heriet Mhondiwa

Managing Partner of JIDE CONSULTANTS

Founder of Endocrine Southern Africa Trust (ESAT)

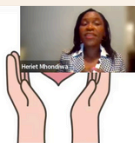
In Zimbabwe, women are the primary caregivers. Heriet's fourth child was born with ambiguous genitalia and diagnosed with CAH. Heriet did not know much about CAH before the diagnosis but was determined to become an expert. The CARES Foundation introduced her to young girls and grown women who have CAH and also provided her with a sense of community to discuss the challenges she was facing.

Challenges Heriet faced as a mother to a child with CAH:

- Cultural beliefs- discrimination and having to keep the illness a secret
- Difficult diagnosis- when her daughter was first born, they were not sure about the presence of ovaries
- Doctors who are not able to attend to adrenal crisis
- Scarce medication, and if available, it is expensive

ESAT was founded to help children with endocrine disorders. With CLAN's support through a community development grant, ESAT received its first donation to build a website and create material for distribution. They are collaborating with doctors to put up posters and fliers at hospitals to make endocrine disorders easier to diagnose, as well as seeking cheaper access to medicine for patients in Zimbabwe.

Hope and Help



- Collaboration with Government – Ministry of Health
- Advocacy – schools, rural Areas using various channels (e.g. community radios)
- Disseminating information through varied channels (e.g. Whatsapp etc.)



From struggles to strengths: Empowering families of children living with NCDs



Esther Kobel

Head of Programs at CLAN Child Health Africa
Doctor, Pediatrician, Child Health Advocate

Esther Kobel is a pediatrician and child health advocate leading programs at CLAN Child Health. Her experiences as a doctor revealed the emotional, social, and economic challenges families face when caring for children with non-communicable diseases (NCDs). This motivated her to advocate for long-term change in the NCD community.

Esther's inspirations include:

- Her medical background highlights the struggles families endure.
- The resilience of families navigating the healthcare system amid stigma.
- She believes that every child deserves to thrive, not just survive.

In Uganda, where 37% of the population suffers from NCDs, Esther initiated projects to:

- Provide financial support for mothers to establish businesses while caring for their children.
- Create family support groups for emotional and informational assistance.
- Train healthcare workers to identify NCDs early for better treatment outcomes.

She shared impactful stories from mothers:

- One mother found a second opinion that improved her child's treatment.
- Another, who had to leave her job, now sees hope and support in starting a business that will help her afford food and medication for her child.

Esther underscored the importance of family support, community education, and recognizing the potential of children with NCDs beyond their diagnoses.



Success stories and lessons learned



The power of mothers & community - the story of the CARES foundation



Alyssa Leight

Daughter of Kelly Leight,
Founder of CARES Foundation
Advocate & Person Living With
CAH



Dina Matos

CARES Foundation Director
since 2009
Founding Member of CAH
International

Alyssa Leight has non-classical congenital adrenal hyperplasia. She shared her story and the story behind her mother Kelly Leight's motivation to create the CARES foundation.

When Alyssa was 4, her mother noticed that something wasn't quite right with her and discussed it with her pediatrician. For years and years, she was repeatedly told by doctors that everything was normal, but like many mothers, she had an instinct that something wasn't quite right. When Alyssa was 7, after years of persistence, doctors finally decided to do her blood work. Results revealed high androgen levels and irregular hormone patterns, clearly abnormal for a child her age. She then got her diagnosis at Weill Cornell, and the doctor there connected Kelly with other families in the CAH community in 1999. Kelly went on to create a website to bring together people of the CAH community in a time when technology wasn't as common. In 2012, she launched the CARES foundation.

Dina Matos highlighted CARES Foundation's contributions to the CAH community over the past 25 years, including:

- Catalyzing the addition of CAH to newborn screening panels in all U.S. states since 2008.
- Funding the National Institutes of Health's CAH program.
- Developing 9 CAH Care Centers nationwide.
- Supporting clinical trials that led to the first new CAH treatment approved in over 70 years.
- Advocating for improved emergency care for those with CAH.

Services available at CARES:

- Podcast CAH pulse to educate people inside and outside the CAH community about CAH
- 40 support groups across the US
- "Ask the expert" online service available on website
- Preventing Adrenal Crisis Events(PACE) app that teaches people life saving strategies

Growing Community



What started in a small state called New Jersey represented by the small yellow dot on the map, has reverberated throughout the globe. CARES now serves patients all across the United States and in more than 80 countries and territories.



Driving change for all - Achievements for the CAH community of Colombia



Paola Duran

Chief of pediatric Endocrinology Service at Fundación Cardio Infantil
Director of Fundación SiEndo
Professor of Pediatric Endocrinology

In Paola's presentation, she focused on some of the achievements been made in developing the CAH community in Colombia.

Some achievements mentioned:

- First Colombia CAH club did a Health Needs Assessment Survey where they found valuable results
- Community platform grown to have more than 100+ followers
- GPED survey to find out availability of CAH medication in Colombia

Main Results

- Fludrocortisone IS 100% available - 75% of Ped Endos think it is available to 33% of patients free of charge.
- Oral Hydrocortisone is 97% available - 75% of Ped Endos think it is available to 33% of patients free of charge.
- IV Hydrocortisone is 100% available - 100 % of Ped Endos think it is available to 60% of patients free of charge.
- New born screening: 48% of Ped Endos think it is available for patients free of charge at a national level



She also shared some testimonials from people in Colombia who have been benefited by their HSC community's efforts, which is the first HSC community in Colombia and South America.

Our success stories

Testimonial 1: I feel alone fighting an endless battle. Thanks to this community I am not longer alone!
I greatly appreciate the HSC community for their joining forces, for their immense support and accompaniment throughout my daughter's process, previously I felt alone, fighting an endless battle against the healthcare system. Today, thanks to this community my little girl can receive her medication without delays and receives timely attention.
Sincerely,
Yvoki Esperanza Soto

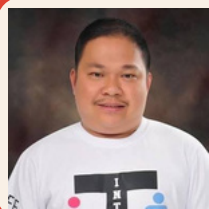
Testimonial 2: I would like to express my sincerest gratitude for your collaboration. Your support means a great deal to me and helps me to move forward. Thank you for your generosity.
With gratitude,
Paola Serrano Ariza

Testimonial 3: The community provided us support when we felt dejected.

Testimonial 4: In a moment of weakness and frustration, I felt the shelter and support of all the members of the community.
It's amazing to be part of this beautiful community in a moment of weakness and frustration. I feel the shelter and support of all its members. I didn't expect so much help from the community, so with we continue to strengthen this bond.
Att Wendy Sandoval

Testimonial 5: I'm one of the caregivers who is part of this beautiful family, which is the Unidos Somos Más Fuerte Foundation. Long type words of gratitude for providing us with support when we feel dejected. I'm Arianna Medina Lander's caregiver. My name is Emelily Londero Guerra.

Life-Affirming Care as a Human Right: Access to Medicine, Life-saving care and Dignity for CAH Communities in the Philippines



Jeff Cagandahan
President & co-founder of
Intersex Philippines
Co-chair of Intersex Asia
First Intersex Filipino legally allowed
to change their sex marker in 2008



Eli Rubashkyn
Cross-Movement Building
Officer at Intersex Asia

Jeff shared a heartfelt speech talking about the reality of living with non-communicable diseases. This is his speech in its entirety:

“
Honored guests, colleagues, and fellow advocates Mabuhay!

I'm beyond grateful to be here with all of you today as the co-founder of Intersex Philippines, a proud board member of Intersex Asia, and a person living with Congenital Adrenal Hyperplasia (CAH).

For too long, children and adults with CAH in the Philippines and across Asia have faced preventable sufferings—suffering that stems not from the condition itself but from systemic barriers to healthcare. Today, I am here not just as an advocate but as someone who has lived this reality. I speak for every parent who has held their child through an adrenal crisis, for every individual, who has struggled to access the life-saving medications that should be a basic right not a privilege.

In the Philippines, and many parts of Asia access to essential medicines like hydrocortisone and fludrocortisone remains inconsistent, unaffordable, or simply unavailable. This is not just an inconvenience; it is a life-or-death issue. Without these medications adrenal crises occur—leading to unnecessary hospitalizations, complications, and in too many cases, premature deaths.

Through our work at Intersex Philippines, Intersex Asia, and CAHSAPI, we have spoken with families who have lost loved ones, because treatment was out of reach. We have seen children's lives apended, due to financial barriers, that should never stand between a person, and the care they need.

Yet, despite these challenges, we also see hope.

Through our current collaboration with CAHSAPI, CLAN, Cancer Warriors Foundation, Philippine Society of Pediatric Metabolism and Endocrinology through Dr. Jedeane Aragon and the broader regional collaboration of Intersex Asia, we are actively working to bridge the gaps between movements and the care our communities desperately need.

This means:

- **Advocating for policy changes** to ensure that hydrocortisone, fludrocortisone, and emergency adrenal crisis kits are included in national health programs, including those associated with New Born Screening.
- **Partnering with orphan disease organizations** to strengthen advocacy for CAH
- **Collaborating with healthcare professionals** to improve medical training and awareness, ensuring that CAH management is accessible and affirming of life.
- **Engaging with affected families** to provide support, raise awareness, and amplify their voices in decision-making spaces.

This work is not just about access to medicines. It is about affirming that healthcare as a human right should be realized. Access to technologies associated with diagnosis, effective monitoring such as 17OHP tests to name one example, as well as compassionate health care providers aware of this condition and willing to help these communities in times of medical emergencies. Our call is centred in ensuring dignity access to basic life-sustaining treatments, bodily integrity, and access to care that respects the lived experiences of those it serves.

We cannot do this alone. We call on governments, allies, feminist movements, children’ organizations, pharmaceutical sector, and global health bodies to take immediate action and walk with us, in helping us identifying ways, to overcome these systemic barriers by:

1. Make life-saving medications affordable and accessible—no more stock shortages, reimbursement mazes, no more price barriers.
2. Ensure newborn screening and early intervention programs integrate emergency kits in newly diagnosed CAH infants, so that no child is left undiagnosed or improperly treated in case of an adrenal crisis emergency.
3. Recognize CAH medical needs in access to medicines, as urgent public health priorities, integrating them into universal healthcare systems.

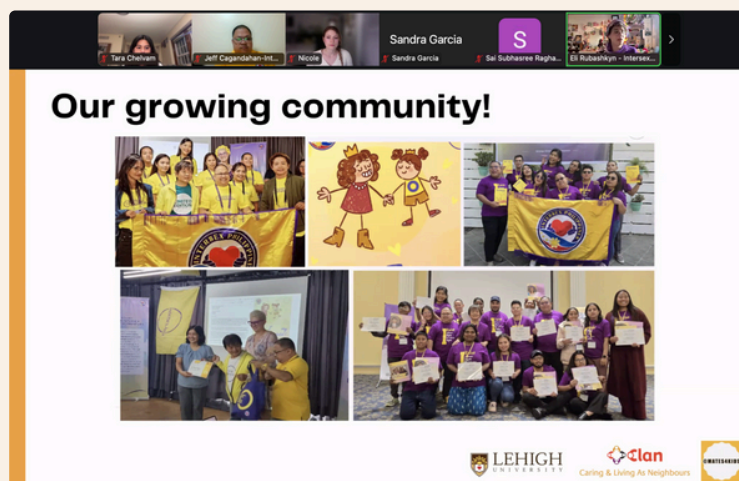
To our allies in the healthcare sector— we hope to work collaboratively to identify ways our communities can see in your efforts a life-affirming partnership in the shared goal of saving CAH children’s lives. While we hope to avoid centering other debates about identity in social issues surrounding gender and bodily anatomy we make a plea for urgent, affirming, and equitable healthcare solutions, for all persons living with CAH including male, female and intersex persons.

To the families here today particularly the voices of mothers—your voices matter. Your advocacy is powerful. Together, we can illuminate the path for the change we so desperately need.

I stand here today because I have been able to access the right care. While I experience daily, the limitations of living with CAH, I have seen what is possible when healthcare is accessible, universal, equitable, and affirming. But too many in our communities are still waiting for that chance.

We cannot afford to wait any longer. Lives are at stake. The time to act is now. Leave no child behind.

Thank you, Maraming Salamat po!



Following Jeff’s speech, Eli shared valuable information about Intersex Asia, including its history, purpose, growing community, and current work. Eli emphasized the importance of regional collaboration in advocating for intersex human rights and highlighted recent initiatives aimed at increasing visibility, education, and solidarity across Asia.



Improving Healthcare Professionals' Awareness: Newborn Screening and Management of CAH



Astrid Larasati, *Universitas Diponegoro, Semarang, Indonesia*

PhD student at Faculty of Medicine

Medical Doctor at Faculty of Medicine

MSc in Genetic Counseling at Faculty of Medicine

Research interests: Congenital adrenal hyperplasia, Disorders of sex development, Genetic diseases, Genetic counseling

In her presentation, Astrid talked about how common CAH is in Indonesia. Despite this, there is a lack of awareness, low CAH detection rates and health insurance coverage issues.

Astrid also talked about her supervisor Agustini Utari, who is a pediatric endocrinologist and Professor Tri Indah Winarni, who is also a geneticist. This team works in one of the biggest CAH Care centers in Indonesia that takes care of more than 162 individuals. Some accomplishments of her team include:

- In 2016, they published a book on introduction to CAH for parents
- In 2017, they created a book in collaboration with CLAN, MATES4KIDS and Sri Lankan endocrinologists. It is available in 4 languages.

CAH Community Development

Aim

To increase awareness about

- CAH newborn screening
- CAH therapy and its outcomes among healthcare professionals in Indonesia

Educational materials

- Newborn screening for CAH, treatment regularity and adherence, and outcomes of CAH, especially growth
- Online and printed
- For patients and healthcare professionals

Webinars and online training

- Newborn screening for CAH, treatment regularity and adherence, and outcomes of CAH, especially growth
- For healthcare professionals
- In collaboration with a pediatric endocrinologist, a geneticist, and a clinical psychologist.

LEHIGH UNIVERSITY | Clan Caring & Living As Neighbours | MATES4KIDS



Building bridges between Rare Disease & NCD Communities + Updates from RDI on global advocacy efforts



Durhane Wong-Rieger

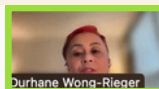
President & CEO of Canadian Organization for Rare Disorders
President of Asia Pacific Alliance of Rare Disease Organizations
Immediate Past-Chair, Rare Diseases International

In Durhane's presentation, she explored how rare and common diseases intersect and diverge in terms of challenges, needs, and emerging trends. She shared the unique yet often overlooked struggles faced by persons living with rare diseases (PLWRD), such as widespread stigma, lack of political recognition, insufficient healthcare infrastructure, and limited access to diagnosis, treatment, and research. These challenges are influenced by country-specific political, socio-economic, and healthcare contexts.

Durhane then highlighted how, despite their differences, common diseases are increasingly being understood through the lens of rare genomic mutations. Tens of thousands of genetic mutations are now being identified in conditions like cancer, cardiovascular diseases, diabetes, and neurodegenerative disorders—revealing a complex genetic landscape that blurs the line between common and rare diseases.

What Makes Rare Unique & Common?

Persons Living With Rare Disease face common barriers due to their rarity. However, the prioritization of these needs varied by country and by rare disease community depending on the unique political, socio-economic situation of each country and clinical needs of each disease.



- Social and cultural stigma, and discrimination against PLWRD
- Lack of coverage and inclusion in health insurance
- Significant health inequalities
- Lack of political awareness and recognition of RD as a priority
- No dedicated policy framework nor dedicated budget for RD
- Huge diverse population, geography, healthcare and resources create unique barriers
- Fragility and fragmentation of healthcare systems
- Small population leads to lack of knowledge and expertise, lack of investment, lack of research
- Lack of specialized services, expert centres and standards
- Lack of available and affordable tests and medicines



Finally, she addressed the growing use of targeted genomic diagnostics in common diseases, especially in oncology. Tools such as single-gene tests, multi-gene panels, and biomarker-specific diagnostics are becoming integral to personalized medicine, showcasing how rare disease research and technology are influencing mainstream healthcare.

Closing discussion – reflections and recommendations for next steps; Grant Reminder



Kate Armstrong

President of CLAN
Founding Chair of NCD Child
Co-Founder of @MATES4Kids

Australian Public Health Physician
Fellow of the Australasian Faculty
of Public Health Medicine

5 Priorities to Make Faster Gains and Prepare for an Uncertain Future

1. Close the Accountability Gap

Fortify institutions to lead and coordinate policy action on gender equality, put gender at the centre of all policies and programmes, and improve **data to measure change**.

2. Elevate Women's Voices

Achieve equal participation and influence in decision-making at all levels, including for marginalized groups of women and girls, and open and protect spaces for women's groups to operate.

3. Close the Financing Gap

Make catalytic investments through national measures, such as budgets aligned with gender equality and progressive taxation, and realign global financial systems based on equity and solidarity.

4. Harness Technology

Close digital gender divides in access and benefits, ensure women and girls can lead the digital and artificial intelligence revolutions, and mitigate the risks of technology-facilitated gender-based violence, privacy violations and bias.

5. Shock-proof Services and Infrastructure

Establish gender-inclusive crisis prevention and response to avoid sudden rollbacks on the rights of women and girls and prioritize gender equality in humanitarian action.

Round 5 @M4K Grants are now open!



If you would like to read more,
please download CLAN's
Written Statement for CSW69.

United Nations

E/CN.6/2025/NGO/8



Economic and Social Council

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Commission on the Status of Women

Sixty-ninth session

10–21 March 2025

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.



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