

The beginnings of the International Community of Women living with HIV/AIDS (ICW)

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Courageous women living with HIV started to organize themselves through peer support from very early on in the pandemic. In the UK, they started Positively [Women](#) (now known as Positively UK) in 1987. Positively Women became a trailblazing organisation providing a safe, non-judgemental space for women to come together and talk about what mattered most to them and express their fears around illness, death, sexual relationships, having children, not having children, disclosing HIV status to children and partners, employment, housing, disability and much more. Peer support was, and remains, a crucial part of coping with an HIV diagnosis.

In July 1992, 57 women living with HIV, from 24 countries, came together for a five-day transformational workshop in the Netherlands. They shared their stories and personal experiences, rejection by friends and family, loss of homes and jobs, having children taken away from them, lack of access to basic medical care, forced abortions and sterilisations. They received little support, faced widespread stigma and discrimination, illness and death. But they were determined, in whatever time they had, to work together, to make a difference. After lengthy discussion they drafted the Twelve Statements which became the foundations of a new umbrella network, the International Community of Women living with HIV (ICW).

These founding ICW members, determined that women living with HIV should never again be invisible, voiceless or ignored, stood on the stage during the 8th International AIDS Conference in Amsterdam and read out their Twelve Statements.

ICW continued to organise pre-conferences and workshops for women living with HIV which brought together women from all over the world to discuss and strategise around the issues they identified as important to their lives, including sexual and reproductive health and rights. ICW also facilitated regional meetings of Positive Women in Asia and the Pacific, Africa and Latin America. These workshops brought together women living with HIV to build skills, develop regional advocacy strategies and form regional networks¹.

Between 1994 and 1996, ICW conducted the first assessment of women living with HIV in Europe: “Women living with HIV and AIDS in Europe. Needs, services and policies – assessing provision and strengthening networks • In 1997, the Voices and Choices project used a participatory research approach in Zimbabwe and elsewhere to identify issues facing women living with HIV in relation to fertility desires and pregnancy.² In 1997, ICW News

¹ Archived ICW website (Archive.org)

² <http://www.icw.org/icw/files/VoicesChoices.pdf> Archived ICW website (archive.org)

was launched and sent bi-monthly to ICW members all over the world³ and in 1999, ICW created a Positive Woman's Survival Kit.⁴

ICW 12 statements

To improve the situation of women living with HIV and AIDS throughout the world:

1 WE NEED encouragement and support for the development of self-help groups and networks.

2 WE NEED the media to portray us realistically and not stigmatise us.

3 WE NEED accessible and affordable health care (conventional and complementary) and research into how the virus affects women.

4 WE NEED funding for services to lessen our isolation and meet our needs. All funds directed to us need to be supervised to make sure we get it.

5 WE NEED the right to be respected and supported in our choices about reproduction. This includes the right to have children and the right not to have children.

6 WE NEED recognition of the right of our children and orphans to be cared for and of the importance of our role as parents.

7 WE NEED education and training of health care providers and the community at large about women's risk and our needs. Up-to-date, accurate information concerning all issues about women living with HIV/AIDS should be easily and freely available.

8 WE NEED recognition of the fundamental human rights of all women living with HIV/AIDS, particularly women in prisons, drug users and sex workers. These fundamental rights should include the right to housing, employment and travel without restrictions.

9 WE NEED research into female infectivity including woman to woman transmission, recognition of and support for lesbians living with HIV/AIDS.

10 WE NEED decision making power and consultation on all levels of policy and programmes affecting us.

11 WE NEED economic support for women living with HIV/AIDS in developing countries to enable them to be self-sufficient and independent.

³ [Archived ICW website \(Archive.org\)](#)

⁴ [Archived ICW website \(archive.org\)](#)

12 WE NEED any definition of AIDS to include symptoms and clinical manifestations specific to women.

(The last statement 12 was demanded for women from the USA where at the time an AIDS diagnosis was a requirement to access free Medicare. Women often had different symptoms than those seen in men and many died before receiving an AIDS diagnosis. Without health insurance or treatment women were dying faster than men hence the slogan at the time *It's a disaster, women die faster*).

The language now seems dated but many of the 12 statements remain as relevant today as in 1992.

In the years that have followed, women living with HIV in all their magnificent global diversity became agents for incredible change, highlighting the intersections between gender, rights and HIV.

ICW members created support groups where none existed. They became champions for legal and policy change in their countries. They fought hard alongside other community leaders for access to affordable anti-retroviral therapy for everyone, no matter where in the world they lived. They cared for dying friends and loved ones. They advocated for the creation of UNAIDS and the Global Fund to Fight AIDS, TB and Malaria. They influenced multiple sectors. They raised and supported families and mentored new generations of activists across the globe. They challenged stigma and gave HIV a new face and a powerful voice.

The current ICW website is [here](#).

If you have further information about the early years of ICW that you would like to add, please contact us through this website. We would be glad to hear from you.