AIMS For a better birth...

Putting a spotlight on women's health

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By Charlotte Edun

In September 2023, AIMS was invited to speak on a panel titled, 'Health inequalities and different groups of women', at The King's Fund's 'Putting a spotlight on women's health' event. The Kings Fund was established as a charity in 1897, and has a mission to ensure the best possible health and care is available to everyone in the UK. The conference was an opportunity to discuss the causes and experiences of women's health inequalities, bringing together speakers and delegates from Government and policy, from NHS Trusts, third sector organisations and service users.

Setting the scene – an equal picture

Inequalities – or perhaps variations – in women's health were clearly described by Professor Dame Lesley Regan (Professor of Obstetrics and Gynaecology at Imperial College London and appointed the Government's Women's Health Ambassador in 2022) in the plenary session. Women's health needs are predictable, so it may be anticipated that women could prepare appropriately, yet 45% of pregnancies are unplanned or ambivalent, one in three women over 60 years of age suffer urinary incontinence, and fewer than 10% of women say they have enough information about gynaecological conditions, the menopause and specialist women's health conditions. However, the point was made that while women's reproductive health forms a generally predictable rhythm through our lives, these specific issues are not the only ones that mark health inequalities between men and women. Symptoms of cardiovascular

disease (CVD) present differently in men and women, and women wait longer for diagnosis. Osteoporosis is a major cause of women's morbidity and mortality in later life. Twice as many women as men live with Alzheimer's disease. While women's life expectancy is higher than men's, the years they live healthily is lower (ONS 2022). (Of course, there are issues which disproportionately affect men, including suicide and alcohol related death, cancer and COVID-19[1]. A question mooted in the plenary session was: should The King's Fund put a spotlight on men's health too?)

Health inequalities and different groups of women

AIMS was invited to join the panel reflecting on how health inequalities affect different groups of women in relation to maternity care. This was an opportunity for AIMS to draw attention to continued failure to implement a universal offer of midwifery continuity of carer (CoC). CoC was recommended in Better Births (2016) and is consistently identified by mothers as an important factor in their care. This model - which provides a named midwife for every mother - has been shown to improve outcomes for mothers and babies, especially those from disadvantaged groups. CoC facilitates a dynamic in which women can confidently and safely disclose information about their pregnancy and circumstances, and midwives can tailor their practice to provide truly personalised care. The absence of CoC, in favour of the continuing bureaucratic, fragmented, institutionalised model, marks a significant structural health inequality for all women, and particularly those who already face intersecting health inequalities. Intersecting health inequalities include: poor health literacy (4 in 10 UK adults struggle to understand health information[2]); geographical variations in services (for example, whether your local NHS Trust provides antenatal education or not, and whether it is practically accessible to you); and institutional bias[3]. Matrescence, the period of time during which we transform into mothers, has a significant and long-lasting effect in women's lives, so the quality, accessibility and appropriateness of maternity services matter. Despite strategic ambitions for 'woman-centred care', it remains true that maternity and post-natal services grow from the existing form and function of the institutions that are delivering those services and are not truly designed with the needs and preferences of mothers and new families at their centre. This is evident at every stage of women's motherhood journeys, from fertility services, through booking-in and scheduled antenatal appointments, to postnatal care and support.

In preparation for this event I asked for feedback from my AIMS colleagues, from third sector organisations including Baby Umbrella, my independent birth worker colleagues, and those working in the NHS . They were generous in their feedback and keen that their observations on the issues women face in accessing high quality, appropriate maternity care were represented. The AIMS Helpline[4] regularly hear from women who are not given the adequate and unbiased information they need to make informed decisions, who are not supported in those decisions and who are not listened to when they raise concerns or make complaints. These are all issues that impact safety and well-being, and that we at AIMS believe CoC could address. We already know that having a relationship with your midwife, and being able to continue a conversation about your options and preferences through your pregnancy, leads to better outcomes[5] than the current fragmented system, where it's 'pot-luck' whether you see the same midwife or not, and appointments are focused on managing risk and the completion of scheduled

observations and tests.

In addition to the absence of this important condition of continuity in NHS maternity care, colleagues noted that new mothers often face practical and physical challenges that inhibit their access to services. Invitations to postnatal appointments held in clinics, rather than at home, often within days of giving birth, and sometimes with older siblings in tow, makes those appointments stressful and challenging, rather than easy to access, welcoming and positive in these important and often overwhelming early days. For those reliant on public transport this can make travel costly, difficult and time-consuming - sometimes impossibly so. Colleagues also identified that the referral system is unwieldy and opaque, so new mothers often are not clear on what role the health professional they have been invited to see has, what the intended outcome of their appointment is, or how to follow up. New mothers regularly face long waiting lists for early-days interventions and support for issues including breastfeeding, post-natal recovery and birth trauma. This often means that women rely heavily on either peer-to-peer support, or on charitably funded or private services (if they know that they are available and are able to afford them). These community and charity groups are, in effect, mopping up what the NHS cannot cope with. It is notable that these groups are facilitated and staffed largely by volunteers, and are subject to the twin threats of increasing costs-to-serve and decreasing funding. Much of the weight of women's health services is carried by 'mothers supporting mothers', investing their own time, drawing little income and managing this work amidst the demands of their own families. As one charity Trustee noted "Imagine we lost funding tomorrow. I wonder how the system would cope?"

Women's health needs don't change, but support for them is subject to the tides of politics and economics

There is, of course, the potential for this to be resolved by the putative Women's Health Hubs that Professor Dame Regan championed in the plenary. Intended as 'one-stop-shops' for a variety of health and social care needs, and linked to 'spoke' networks connecting more complex services both in-person and virtually, the ambition is to connect health and social care, education and services in formats and locations that replicate the lives and behaviours of the women and families using them.

The investment in Women's Health Hubs sounds wonderful of course. But it perhaps raises more questions than answers. How different are these Hubs from the now defunct Women's Well-being centres of the early 2000s? Where do these sit in relation to the Family Hubs and Start for Life programme[6] intended to 'join up and enhance' services, and existing primary care networks? Where would we be if 1,416 SureStart centres had not been shut-down since 2010[7]' [8]? How much more budget would we have to invest in women's health?

There's a pattern here. In 1993 *Changing Childbirth*[9] recommended a significant attitudinal change in maternity care, towards 'woman-centred care'. In 2016, Better Births set a target for relational, woman-centred maternity care, in an environment appropriate for the family in question.[10] In 2019 the Royal College of Obstetricians and Gynaecologists *Better for Women* report stated: "When we get healthcare right for girls and women, everyone benefits"[11]. Yet access to appropriate and consistent maternity

care remains an aspiration rather than a reality for the vast majority of women in England, and in many ways seems further away than ever. Why is this? As one of the speakers at this event noted, women in health care are still seen to be "oddly shaped men", and this idea was echoed by one reviewer of the first draft of this article, who commented; "are we simply avoiding reform of core institutions that need to be less male centred and more accommodating of female bodies?"

This merry-go-round of shining spotlights on women's health, generating new initiatives and strategies, appointing new reports and new departments and still, repeatedly missing the mark and failing to give mothers the care and support they need, leaves me feeling frustrated and not a little hopeless. So I am very sorry to say that events like this feel a little hollow. Until the normalcy of female bodies, our physiology and needs, are embedded into the bed-rock of the institutions that provide health and social care, I worry that these events, while an important forum for exchanging ideas and forging new relationships with similarly passionate activists for improvement and change, are essentially toothless.

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[1] Men's Health Forum (2022) Levelling Up Men's Health www.menshealthforum.org.uk/strategy-case

[2] NIHR Evidence: Health information: are you getting your message across?; June 2022; doi: 10.3310/nihrevidence_51109 https://evidence.nihr.ac.uk/collection/health-information-are-you-getting-your-message-across

[3] MBRRACE-UK (2023) Saving Lives Improving Mothers' Care 2023: Lay Summary www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2023/MBRRACE-UK_Maternal_Report_2023_-_Lay_Summary.pdf

[4] helpline@aims.org.uk. AIMS supports all maternity service users to navigate the system as it exists, and campaigns for a system which truly meets the needs of all. The AIMS Helpline volunteers are all experienced in providing information and support on pregnancy and birth issues. We do not give medical advice, but instead we focus on helping those who contact the Helpline to find the information that they need to make informed decisions which are right for them, and support them to have their decision respected by their health care providers. They are also able to provide a listening ear and practical support for women who are unhappy with their experiences.

[5]NHS England (No date) Continuity of carer www.england.nhs.uk/mat-transformation/implementing-better-births/continuity-of-carer/#:~:text=The%20continuity%20of%20carer%20model,midwifery%20team%20throughout%20th

eir%20pregnancy.

[6] Gov.uk (2023) Family Hubs and Start for Life programme www.gov.uk/government/collections/family-hubs-and-start-for-life-programme

[7] The New Statesman (2023) Replacing lost Sure Start centres is a tacit admission of austerity's failure www.newstatesman.com/quickfire/2023/02/replacing-lost-sure-start-centres-is-a-tacit-admission-of-austeritys-failure#:~:text=Since%202010%2C%20the%20policy%20of,sites%20linked%20to%20Sure%20Start

[8] Children & Young People Now (2022) More than 1,000 children's centres closed over last decade www.cypnow.co.uk/news/article/more-than-1-000-children-s-centres-closed-over-last-decade

[9] Department of Health . HMSO; London: 1993. Report of the Expert Maternity Group: Changing Childbirth (Cumberlege Report)

[10] NHS England (2016) *National Maternity Review: Better Births - Improving outcomes of maternity services in England - A Five Year Forward View for maternity care* London: NHS England

[11] RCOG (2019) Better for women: Improving the health and wellbeing of girls and women www.rcog.org.uk/about-us/campaigning-and-opinions/better-for-women