Health and Social Care Alliance Scotland (the ALLIANCE)

Response: Engender call for evidence on the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)

4 April 2018

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to help inform Engender's CEDAW shadow report. Set out below are some general comments in respect to women's rights and health and social care in Scotland.

Representation on Public Boards

Whilst Health Boards and Special Health Boards are subject to the Gender Representation on Public Boards (Scotland) Act 2018, Integrated Joint Boards (IJBs) – the decision making bodies at the heart of Health and Social Care Partnerships across Scotland – are not. Although women represent over 77% of the NHS workforce and 86% of the social care workforce, information collected by the ALLIANCE[1] suggests that only 20% of IJB Chairs identify as women.

The ALLIANCE believes that better gender representation should be established across IJBs and that attention should be placed on this issue as the law is implemented. Further consideration should also be given to assessing the impact that gender balanced boards have on the decision making process in health and social care integration.

Self-directed Support

Self-directed support (SDS) is "the support individuals and families have after making an informed choice on how their Individual Budget is used to meet the outcomes they have agreed"[2]. It aims to shift the balance of power from people who provide social care services towards those who access them, including disabled people and people living with long term conditions. SDS is enshrined in legislation that came into force in April 2014. It is administered by local authorities, who are legally required to offer those eligible a choice of four different options over how their SDS budgets and social care services will be managed. There is also a 10-year

[1] https://www.alliance-scotland.org.uk/health-and-social-care-support-and-services/wp-content/uploads/sites/4/2017/11/4-Board-Information-version-1-16.11.17-2.xlsx

[2] Self-Directed Support: A National Strategy for Scotland, Scottish Government, 2010 http://www.gov.scot/Resource/Doc/329971/0106962.pdf

national SDS strategy, which is underpinned by the fundamental principles of choice and control and the human rights principles of equality, non-discrimination, participation and inclusion.

The ALLIANCE is concerned that SDS is not being implemented according to its rights-based values and principles. As such we believe there is a risk it will not achieve transformational change in social care culture and services or help improve women's lives as intended. The ALLIANCE carried out research into people's personal experiences of SDS. We extrapolated data relating specifically to women's experiences[3], and amongst these findings conclude that:

- There appears to be a very low uptake of SDS by women.
- Very little official evidence has been gathered into women's experiences of SDS, their perceptions of its impact on their personal outcomes or whether it is helping them have more choice and control over their support.
- Women appear to have exercised less autonomous decision-making in choosing an SDS option than men.
- Women are substantially less likely than men to indicate they feel "very informed" about SDS.

A better picture of women's experiences of SDS across Scotland is needed. The ALLIANCE recommends that the Scottish Government, Health and Social Care Partnerships and local authorities work together to ensure robust qualitative data is regularly gathered on how women engage with SDS and their views on how it is helping to achieve their personal outcomes and improve their lives.

Social care

The ALLIANCE has long recognised that care and support is undervalued in Scotland, despite being essential to the lives of many disabled women and women who live with long term conditions. Paid care can support women to exercise their right to independent living and live the way they choose – to socialise, to work, to get an education and to be a member of their community.

As Engender have noted however, "care continues to be a profoundly gendered issue, resounding along women's lives in Scotland. Women take on the major share of responsibility for caring as either unpaid or paid carers, caring formally or informally."[4] The social care workforce is comprised of 86% women[5] and the Scottish Parliament's Economy, Jobs and Fair Work Committee recently

[3] Women's experiences of Self Directed Support, the ALLIANCE, 2017 https://www.alliance-scotland.org.uk/wp-content/uploads/2017/10/ALLIANCE-SDS-Womens-Experiences-of-SDS-2017.pdf

[4] https://gendermatters.engender.org.uk/content/care/

[5] http://www.parliament.scot/S5_EconomyJobsFairWork/Reports/EJFWS052017R06.pdf

recommended that care should become a Scottish Government priority sector with a monetary value put on the sector. The ALLIANCE believes that this could have the impact of raising the profile of paid care and the potential to reduce the gender pay gap.

Unpaid carers

Women comprise 59% of unpaid carers and provide 70% of Scotland's unpaid care[6]. Unpaid carers play a critical role in supporting disabled people and people living with long term conditions across Scotland to live independently with support in their own homes and communities, a role often carried out with little support or assistance. As key partners in care, they contribute significantly to society and it is estimated that the cost of replacing the care currently provided by carers would be more than £10 billion each year[7].

The contribution of unpaid carers must be central to supporting the preventative and anticipatory approach to health and social care that current policy and law call for. It is therefore vital that effective ongoing support for unpaid carers, preventing future need for increased local authority support, is in place to support this shift in the balance of care without a negative impact on carers' health and wellbeing, or that of the person they care for.

Access to health services by women from refugee and asylum seeking communities

"What do you mean, I have a right to health?", a participatory action research project on health and human rights supported by a range of partners including the ALLIANCE, highlighted the experiences of women from refugee and asylum seeking communities in accessing health services[8].

The peer-led research found that:

- Many participants felt that they were listened to by their GP and they felt confident and comfortable in seeking medical attention from GPs and hospitals, however some noted that this was dependent on the GP's attitude.
- Among the critiques of health services, lack of continuity of care and racism within services were cited as overarching concerns.

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[6] https://www.engender.org.uk/content/securing-womens-futures-report/

7 'Valuing Carers', Carers UK, 2011, http://www.carersuk.org/media/k2/attachments/Valuing_carers_2011___Carers_UK.pdf

[8] What do you mean, I have a right to health? A participatory action research on health and human rights, Strathclyde University, 2016 https://strathprints.strath.ac.uk/58209/1/Abdulkadir_etal_IPPI_2016_What_do_you_mean_I_have_a_right_to_health.pdf

- Stigma, racism and Islamophobia had caused some participants distress and they said it greatly affected their mental health.
- Language presents a barrier for many women, with access to and quality of interpreters varied.
- Although most participants knew about the concept of human rights, there was a degree of uncertainty about human rights in the UK.
- Not knowing how to complain when experiencing discrimination or insufficient services was a common theme among the participants.

Several key recommendations emerge from the findings of this study that have implications for policy makers and service providers. These recommendations largely focus on challenging racism and religious prejudice within NHS services as well as strengthen complaint processes and learning from other programmes about reducing stigma. Culturally sensitive training was also recommended by women from asylum seeking and refugee communities.

Reproductive health

The ALLIANCE is concerned that women's health rights are being compromised in Scotland: two examples include the diagnosis of endometriosis and the use of transvaginal tapes and meshes.

Endometriosis is a chronic and long term condition that affects approximately one in ten women of reproductive age in Scotland. Despite being a common gynaecological condition, it takes an average of 7.5 years for diagnosis after first consulting a doctor[9]. This lack of access to timely health care means many women experience prolonged periods of pain and distress and allows the condition to progress and become more difficult to treat. New guidelines published in September 2017 by the UK's National Institute for Health and Care Excellence (NICE)[10] aim to improve diagnosis. The ALLIANCE recommends that the Scottish Government and Health Boards ensure robust tools are in place to monitor the use and effectiveness of the NICE guidelines on endometriosis and take all necessary measures to drastically reduce unacceptable delays in diagnosis and treatment.

After years of campaigning by women affected by painful and crippling complications[11], the use of transvaginal tapes and meshes[12] was suspended in Scotland in 2014. In March 2017, an independent review commissioned by the Scottish Government recommended that the procedure be reinstated, albeit not

[9] https://www.endometriosis-uk.org/news/nice-call-improved-diagnosis-and-management-endometriosis-37516#.Wr4iTC7wbIU

[10] https://www.nice.org.uk/news/article/suspect-endometriosis-in-women-with-chronic-pelvic-pain-says-nice

[1111] http://www.scottishmeshsurvivors.com/

[12] Medical devices used by surgeons to treat pelvic organ prolapse and incontinence in women which can occur after childbirth.

routinely[13]. However, following the resignation from the review group of two affected women and a clinical member[14] - and claims that the final review report was watered down[15] - doubt surrounds the review's independence and recommendations. In May 2017, the Scottish Government commissioned a further independent examination by Professor Alison Britton of the original review process[16], which has yet to report. The procedure has been banned in Australia and New Zealand, and major class action suits are pending in these countries, the USA and UK, including around 400 women in Scotland who are taking legal action against Health Boards and manufacturers[17]. The ALLIANCE recommends that Professor Britton's review is promptly published and a fresh independent inquiry into the use of transvaginal mesh implants is established that ensures fully transparency and accountability.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. The ALLIANCE's vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has over 2,200 members including large, national support providers as well as small, local volunteer-led groups and people who are disabled, living with long term conditions or providing unpaid care. Many NHS Boards are associate members and many health and social care professionals are Professional Associates. Commercial organisations may also become Corporate Associates.

For More Information

Contact:

Lucy Mulvagh, Director of Policy and Communications
E: lucy.mulvagh@alliance-scotland.org.uk

Andrew Strong, Assistant Director (Policy and Communications)
E: andrew.strong@alliance-scotland.org.uk

T: 0141 404 0231
W: http://www.alliance-scotland.org.uk/

[13] http://www.gov.scot/About/Review/Transvaginal-Mesh-Implants
[1414] http://www.bbc.co.uk/news/uk-scotland-39408064
[15] https://www.holyrood.com/articles/news/cross-party-calls-scottish-government-review-mesh-scandal
[16] http://www.bbc.co.uk/news/uk-scotland-39964844
[17] http://www.bbc.co.uk/news/uk-scotland-39279028