Experiences of Accessing Health

STAGE INFLUENCE GROUP BRIEFING

May 2021

This paper has been prepared for the STAGE Influence Group, drawing on learning and exploration within the STAGE project about how women who are experiencing or who have survived sexual exploitation experience health services.

It is understood by the STAGE project that equitable access to health services is essential to reducing the health inequalities faced by women who are supported by the project. STAGE therefore make recommendations to improve access to health services and reduce health inequalities, as part of a wider aspiration to create a new National Framework for Adult Survivors of Sexual Exploitation.

The briefing is based on learning from the STAGE project, supported by the Department for Digital, Culture, Media & Sport (DCMS) Tampon Tax Fund to explore and highlight the nature and extent of sexual exploitation of adult women across our communities.

The STAGE Project brings together charities Changing Lives, GROW, A WAY OUT, Together Women, Basis and WomenCentre (Kirklees and Calderdale) to provide trauma-informed support for women who have been groomed for sexual exploitation across the North East and Yorkshire[1].

Background

The STAGE partnership held a series of workshops with project staff and partner leadership, to share the health experiences of the women who are supported by the project. This briefing, based on these conversations, describes a variety of experiences of how women have accessed health care services during or after their exploitation and makes recommendations for improvement.

The majority of women supported by the STAGE project are at risk of poor health outcomes. Women's health needs can be complex, stemming from adverse childhood experiences, the impact of complex trauma on brain and bodily functioning and both physical and mental harm directly caused by their exploitation. The crimes carried out against women during their exploitation can include multiple rapes, gang rape, sexual assault by penetration (which can involve the use of weapons, for example), physical assault of varying severity and the use of substances as a means of control and coercion. These crimes have wide-ranging impacts on women, directly resulting in poor health for women. The impact of exploitation and trauma can become further linked to social determinants of health such as living, community and social conditions, resulting in further risk of long-term health inequalities.

Women can be alienated from health services to the point at which they experience vast health inequalities when compared to the general population. Some women who are supported by the project, for example, first accessed healthcare only when in prison or on probation. Women's health is often neglected, and in the worst cases, women are at risk of premature death. Across the

[1] Partners deliver services in eight areas where there are recent or live sexual exploitation investigations: Bradford, Huddersfield, Leeds, Newcastle, Rotherham, Sheffield, Stockton and Sunderland.

partnership's projects, the average age of women who die in receipt of service is 39.2 years compared with a UK average of 82.7 years for women[2].

Alienation from services can be due to the interaction of the above factors and the inflexibility of mainstream ways of working in healthcare settings. Specific barriers include short appointments that do not allow a holistic understanding of women's needs and/or do not allow sufficient time to gauge women's understanding of the medicalised language used, long waiting lists and tier systems that can be difficult to navigate. These complexities and barriers have only been exacerbated by covid-19, in which care for long term conditions has been delayed and appointments have been offered remotely, for example, all while women have been at increased risk of mental ill health.

This briefing is structured around:

- Primary healthcare
- Physical health
- Mental health
- Additional factors for consideration for women with protected characteristics.

STAGE recognise, however, that these distinctions can miss the interaction between the different elements of health and women's identities. Additionally, when similar distinctions are made in healthcare settings, opportunities to address women's holistic needs can be missed.

Where health services are meeting the needs of women who access STAGE, they are trauma informed. They listen to individual women and are responsive to their needs. This can include working in integrated models of care and partnering with voluntary sector specialist services. The adoption of trauma informed approaches to health is therefore crucial in respecting the dignity of women and in aiding their healing and recovery. Where this works particularly well, it is systemic rather than reliant on pockets of good practice amongst practitioners or NHS Trust departments.

Primary healthcare

STAGE partners regularly encourage and support women to engage with primary healthcare, yet problems with access remain. On one worker's caseload, for example, there were 2 women registered with a GP, out of a possible 17. Lower numbers still are registered with dentists and opticians and women experience anxieties around these types of care, due to feeling loss of control and triggers apparent from sexual exploitation. Additional reasons for low levels of engagement with primary care, include:

- Women's prioritisation of immediate and survival needs over their engagement with health services
- Women having no fixed abode and/or frequently moving between areas
- Digital exclusion when registration (and more recently, appointments) must be done online,
- A preference for engagement with female practitioners, due to fear of being touched by males
- A fear of the questions that may be asked and treatments that might take place. These fears are often based on past experiences where the practices of health services are not flexible and when women must see new GPs or dentists on each visit to a surgery. Women additionally fear that health disclosures will result in child protection proceedings

[2] Taken from '[Life Expectancy in England 2020]'.

- Short appointments in which women do not have time to fully express themselves in a way that is well received by professionals. This has, in the extreme, led to one woman, after almost 20 years of trying to communicate with health professionals about pain at the site of repeated historic head trauma, only recently being referred to a specialist team
- A perception that GPs aren't sufficiently able to recognise and respond to complex trauma and will act as gatekeepers to secondary tiers of the healthcare system
- Fears that medication(s) will be reviewed or stopped by new GPs
- The increasingly common practice that appointments must be arranged by repeated calls made first thing in the morning, which does not meet the needs of women whose mental health results in problems with sleep. This practice causes additional barriers for those with limited phone credit, who cannot afford to use this on voicemail messages

Good practice was also shared, that has helped women overcome these barriers. These include the allocation of one consistent doctor or dentist who can build professional relationships with women; allowing a support worker to communicate with healthcare providers and attend appointments; and systemic flexibility in the appointment making process. Some partners have additional arrangements with specialist primary health providers, whose practices recognise and respond to trauma. These provisions include women's only clinics, outreach clinics to or special allocations for women who are experiencing exploitation, engaged in sex work or who have no-fixed abode, as occurs in Leeds.

Physical health

- Women are fearful of accessing treatment for long-term conditions as well as emergency settings (though frequent attendance in accessing emergency services is also prevalent). Fear can be compounded by past experiences where healthcare professionals do not appear to be trauma-informed in their practices. One woman, for example, whose hospital passport explicitly mentioned a preference for female only care woke up in a hospital bed after treatment, with two males stood over her, causing significant distress.

- Many women feel unable to access gynaecological, colorectal, urology and sexual health treatment due to the interaction between these areas of health and sexual exploitation and the lack of understanding offered by medical professionals. One 16-year-old, for example, was told by a receptionist, on request of sexual health screening that, "you shouldn't be having sex during the (covid-19) pandemic", without concern over why this young person might need screening. It appears to STAGE that there are no standard questions asked to assess whether women have experienced sexual violence, which is at odds with the prevalence of this experience in society.

- Many other women do not access cervical screening, as they find it too traumatic. One woman had difficulties being taken seriously and told "you've had sex and had children, so why are you bothered about this". The neglect of this area of health is of particular to concern to STAGE, bearing in mind the increased risk of cervical cancer for women who were introduced to sex/sexual violence at a younger age with multiple partners/perpetrators and skin to skin contact[3].

[3] Louie, K.S, de Sanjose, S et al (2008) Early age at first sexual intercourse and early pregnancy are risk factors for cervical cancer in developing countries. British Journal of Cancer. 100(7): 1191–1197. Available from

- There are concerns amongst STAGE that long term physical damage is being caused by violent crimes associated with sexual exploitation, without women feeling able to access treatment, even if experiencing pain. Additionally, when adult women present with long-term injuries potentially caused by sexual violence, this is not being accounted for on a forensic basis, as it would be in paediatric care.

- When women who access STAGE become pregnant or suspect pregnancy, they usually tell caseworkers before health services. This is due to both the trusting relationships with caseworkers but also fears of the reaction of statutory services. One woman was told by her social worker, "you should have an abortion". Another was told by social services at 23.5 weeks pregnant, that it had been decided that she would lose the care of her child upon birth. This resulted in a short notice, late-term abortion, which was additionally traumatic for the woman.

- Some women have discovered injuries/the extent of injuries sustained during incidents of sexual violence in labour. Despite the re-traumatising nature of this, maternity staff have not always been empathetic in the moment, with one woman told by a male doctor, "what do you want me to do about it". Another woman was laughed at by a midwife and told "I can't understand how you can engage in sexual activities yet can't let me check how far dilated you are", resulting in increased feelings of being exposed at a moment that is already vulnerable for women.

- Women who have had their children removed at birth have reported being treated poorly on wards with a lack of statutory provision for their ongoing care. This is especially prevalent when there is a dispute over whether this care is the responsibility of health or social care. Some women have felt pressured to immediately access long-term contraception after birth when professionals have sought to physically mitigate additional pregnancies, without due attention to women's emotional needs. Where these women have felt their wishes would not be respected by professionals, they have resorted to removing the contraception themselves, cutting implants out of their arms, for example.

- Positive experiences include professional recognition and responsiveness to the impact of trauma, where women are treated with dignity and services adapt to meet the needs of individual women. Specific examples included the provision of self-testing sexual health kits, outreach clinics to women's services, the provision of female only clinics and when clinical staff appear trained to work with women with complex needs. When services appear to be trauma-informed, they take time to listen and explain procedures to women, providing longer appointments where assessment has enabled an understanding of a women's individual needs. Specialised women's health units, such as in the Royal Victoria Infirmary in Newcastle-upon-Tyne and Maternity Voices Partnerships were noted as areas where women and specialist voluntary sector services are taken seriously.

Mental health

- The length of time it can take to access appropriate mental health treatment is a barrier to recovery. STAGE staff shared experiences of women being on waiting lists for psychiatric diagnosis or therapeutic intervention for years, often without knowing which waiting list

they're on and whether they're still on it. During this time, STAGE partners are often the main source of support, providing psychoeducation and self-soothing techniques to women. On occasion, mental health services have referred women into STAGE for this support, when they are unable to work with women due to long waiting lists.

- During this waiting time, women may be attending regular GP appointments and being prescribed medication that is presumed to be correct for the pending diagnosis.

- It is recognised that GPs might be trying to do the right thing in this instance and for some women, this can help to shape the therapeutic interventions sought out. Presuming diagnosis is not always positive, however. This is particularly apparent for those presumed to have personality disorders. Women's self-esteem can be negatively impacted by this label, which can result in women feeling that there is something inherently wrong with themselves, rather than that their mental health has been negatively affected by crimes perpetrated against them. The label of personality disorder can result in further judgement from services, limiting access to support and influencing outcomes in the criminal justice system. This can further lead to an internalisation of the stigma and behaviours associated with personality disorders, particularly if the cause and effect of, or effective therapy for, personality disorders has not been explained to women. Once explained, women might disagree with this label, and other types of presumed diagnosis. Despite this, they feel unable to challenge medical professionals or ask for a second opinion due to stigmas associated with disorders and power imbalances. STAGE welcomes recent progression in mental health services that recognises the common misdiagnosis of borderline personality disorder.

- When women do reach the top of waiting lists, presumed diagnoses can be withdrawn and thresholds for intervention seem to have changed. One woman had been presumed to have borderline personality disorder from age 17-29, which impacted on her access to services and justice. On review by a psychiatrist, it was found that she is more likely to have autism, cognitive impairment due to substance misuse and disorder(s) related to trauma. This woman feels like a weight has been lifted and she can now move on with her life.

- The removal of diagnoses and associated medication can further impact on the receipt of the personal independence payment (PIP), despite no material changes to women's lives or ability to live independently. To receive PIP, women are likely to have had to undergo an overwhelming process in which forms are difficult to complete without professional support and assessments can be both impersonal and intrusive. One woman, for example, was asked by a PIP assessor why she did not report her rape to police and was later denied the benefit, despite her mental health causing significant disruption to her everyday life.

- Access to services becomes very difficult or impossible should women have coexisting mental ill health and substance dependence. Each service can say that the other's problem should be dealt with before their specialist treatment can begin, impacting women's ability to access long term care and crisis team intervention.

- Risks associated with mental ill health can be underestimated. Women have been told to call case workers when highly distressed, rather than the crisis team, despite STAGE not

operating 24 hours a day. This was particularly apparent during covid-19, where crisis team provision was limited. When case workers have sought input from crisis teams, they have been told not to "underestimate the resilience" of women who are well-known to STAGE partners, not well known to crisis services and who are frequently making serious attempts to take their own lives. Women are hesitant to work with crisis teams due to repeated negative experiences.

- When the risks associated with women's mental health are extremely high, they may need inpatient care (either on a voluntary basis or when detained under the Mental Health Act). Once in hospital, women have experienced a dismissal of their needs. One woman, for example, was restrained by two males and held face down on the bed. This was inappropriate for a known survivor of sexual exploitation. The experience caused an adverse response from the woman, who was then labelled as a violent patient and risk to staff.

- It can appear that the thresholds for inpatient care are increasingly high, resulting in an approach that can seem to STAGE partners to "just keep women alive, rather than aid recovery". Women with complex needs are left frequently attempting to take their own lives, seriously self-harming and resorting to carrying weapons to increase feelings of personal safety. The latter has, in some cases, resulted in women being assessed as too risky to detain and arrested instead of cared for. On one such occasion, a woman was released with no safe address to return to. Instead, she was left to sofa surf and was at further risk of sexual exploitation.

- Voluntary sector advocacy and joint work taking place both with and between statutory services plays a key role in assisting women to access mental health services and manage risk. The Trauma and Resilience Service in Rotherham, for example, have clinicians managing cases alongside the voluntary sector. This model enables the sharing of expertise and advocacy for person-centred care for women experiencing complex trauma, who may be experiencing multiple issues with their health and the wider social determinants of health. Senior leadership buy in and the recognition of the professionalism of the voluntary sector is crucial for the success of this model.

Additional factors for consideration for women with protected characteristics

Though there are limitations in project data collection about protected characteristics, STAGE noted particular challenges for black and minoritised women and women with learning disabilities. Though further work must be done in understanding the perspectives of all women who experience sexual exploitation, project staff noted additional barriers for women with protected characteristics.

- Several British-Asian women supported by the project have asked for their primary health providers to be moved due to concerns around patient confidentiality and community stigma around accessing support for mental ill health. Where risks exist around the unlawful accessing of patient records, STAGE have been able to advocate for records to be locked to everyone but a named individual in a practice, after the sharing of best practice from specialists, Karma Nirvana.

- Women with learning disabilities can be "passed between" services, receiving no long-term statutory support in the interim period. STAGE have experience of women with learning

disabilities only being spoken to about sex in relation to risk. The professionals around them seem to have avoided speaking about sex and relationships as a regular part of life. This can cause confusion and increased risk for women who can believe there's something wrong with them for seeking out sex and who have not been encouraged to understand healthy relationships.

- STAGE also noted good practice from health services when women are listened to and taken seriously, for example LGBT+ women in women's health services in Newcastle-upon-Tyne.

Recommendations

STAGE makes the following recommendations so that health services better meet the health needs of women who have experienced sexual exploitation, at the earliest opportunity. It is our understanding that, should the recommendations be adopted, health services could mitigate against future spend, resulting in cost benefits to the NHS and public health bodies.

As part of our wider aspiration for the creation of a National Framework for Adult Survivors of Sexual Exploitation, led by the Home Office, we therefore recommend that:

- There is a statutory duty to ensure appropriate care for women who have experienced sexual violence.

- The Government's Women's Health Strategy includes resourcing for trauma-informed integrated care systems.

- Structured multi-agency working is adopted in areas affected by sexual exploitation, based on the work of the Trauma and Resilience Service in Rotherham and including opportunities for women who've experienced sexual exploitation to influence service delivery.

- Trauma informed training and practices are integrated into all health care settings, enabling service specific barriers to care to be addressed.

- There is an increase in training delivered to health professionals on screening for sexual exploitation and history of sexual exploitation of adults, including the long term injuries that are potentially related to sexual violence and exploitation.

- Mental health services are adequately resourced to enable specialist care and support for women who have experienced complex trauma.