Experiences of accessing healthcare amongst women who have experienced sexual exploitation

A briefing from the STAGE project

July 2022

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Introduction

This briefing is based on learning from the STAGE project, supported by the National Lottery Community Fund, to explore and highlight the nature and extent of sexual exploitation of adult women across our communities. STAGE brings together charities Changing Lives, The Angelou Centre, Ashiana, GROW, A Way Out, Together Women, Basis and WomenCentre to provide trauma-informed support for women who have been groomed for sexual exploitation across the North East and Yorkshire. Since STAGE began in 2019, we have supported over 300 women affected by sexual exploitation.

Sexual exploitation of adults is a form of sexual abuse that is poorly understood and rarely recognised across many sectors, including healthcare. Whereas understanding and responses to child sexual exploitation (CSE) have improved, particularly since the statutory definition of CSE was published in 2017, women whose vulnerabilities have been exploited for the advantage of others are still often described as 'prostitutes' or 'making poor choices', rather than people who have been subject to horrific forms of sexual abuse and do not receive the support that they deserve.

Evidence from STAGE shows that women who have experienced sexual exploitation are more likely to experience poor health outcomes and often struggle to access healthcare services because of this lack of understanding or recognition of their needs. While this report contains examples of women's individual circumstances, in our experience these are not isolated occurrences but indicative of wider systemic issues across the health sector that fail to address the needs of women who have experienced significant trauma and exploitation.

This briefing is based on learning gained from a series of workshops with project staff and leadership, to share the health experiences of over 300 women who are supported by STAGE.

Primary Healthcare

86.5% registered with a GP
82.4% made a GP appointment within the last year
7.7% had accommodations made for a GP appointment (e.g. female practitioner)

The majority of women supported by the STAGE project are registered with a GP and have attended an appointment within the last year. However, many have had to overcome substantial barriers to do so and many report negative experiences. These negative experiences make them less likely to engage with healthcare in future, and inability to access GPs often means that women are unable to access longer term care (e.g. mental health support).

Registering with a GP often requires identification and a fixed abode, which many of the women we support do not have. Further, women who are registered often then move so are not located near enough to the GP to easily access services. This is particularly challenging for women who have fled from their perpetrator, as well as Black and minoritised women with no recourse to public funds (NRPF) who are not only likely to lack identification and may be experiencing street homelessness but are also often expected to pay for healthcare which they cannot afford. Those with insecure immigration status are also reluctant to register with a GP or attend appointments due to fear that their information may be passed onto the Home Office and they may face detention and/or deportation.

Many of the women supported by STAGE also have very poor dental hygiene linked to both violence and irregular care. This is not only a health issue but can have a significant impact on self-esteem. Most dental practices are not accepting new NHS patients, and there is a 2-year waiting list for ones who are, therefore women are not able to access support. On the current caseload, only 27% of women are registered with a dental practice.

Restrictions introduced during Covid-19 lockdowns and the subsequent backlog in cases has made booking a GP appointment difficult for anyone, but the women we support face additional barriers:

- Many surgeries still rely on patients calling first thing in the morning and remaining on hold, often for up to an hour, and do not allow people to enter the surgery unless they have an appointment. Some women supported by STAGE do not have a phone, and many rely on pay-as-you-go phones and do not have the credit to remain on hold for a long time.

- Appointments are often booked up very quickly so women will be told to try again tomorrow after a long wait. It will have often taken a lot of support and courage for women to even reach out in the first place, so they will not always try again.
- Online appointments cannot be accessed by women who lack digital competence or confidence, mobile data or devices that connect to the internet.
- Women who we support have multiple, complex issues, often due to not being able or willing to access healthcare in the past, that cannot be covered in a 10-minute appointment.

Women have reported negative experiences both when making appointments and at the appointments themselves. Initial triage is often conducted by receptionists to prioritise patients. Women often do not feel comfortable disclosing details of their condition or do not understand why they are being asked.

Women who do not speak English face additional barriers as interpreters are rarely provided. They may not be able to book an appointment in the first place and struggle to communicate their needs, but GP surgeries often make few accommodations. One woman who spoke broken English tried to explain her needs to the receptionist who responded, "You can't speak English properly so we can't help you". Organisations specialising in supporting Black and minoritised women often have to pick up the pieces, including advocating for women and offering support when they are denied healthcare. This was especially difficult under Covid-19 restrictions as women were not able to bring support workers with them to appointments.

"You don't speak English properly so we can't help you."

Black and minoritised women in particular are also less likely to disclose sexual exploitation for fear and shame that this information will get back to their communities. They are also subject to cultural stereotypes - one woman who was subject to sexual exploitation via her boyfriend disclosed that her GP appeared shocked she was allowed a boyfriend as a Muslim woman, rather than the fact she had been abused.

Whilst we would expect that healthcare staff who are aware of a woman's experiences of sexual exploitation would be able to make appropriate accommodations, in some cases women are treated even more poorly:

- Women describe doctors as dismissive, uncaring, and unapproachable.

- One woman said, "I told my GP about the abuse and her attitude changed". She told her female GP she suspected she had complex post-traumatic stress disorder (PTSD) after experiencing physical and emotional abuse. This affected her physical health however she reported that the doctor began to treat everything as though it was imagined and would dismiss it.
- There is a 'pregnancy focus' where women are continuously asked questions about pregnancy and feel forced into contraception.
- When support workers are present at an appointment, GPs often talk to the support worker rather than the patient, particularly when the patient is older, young, or non-English speaking.

Due to barriers with accessing support from GPs, some women's health has deteriorated to the point they have presented at A&E, where they face similar barriers of healthcare professionals being dismissive and lacking understanding. One woman went to A&E after she suspected she was drugged by her partner on multiple occasions; they listened to the partner who said she had been drinking too much and let her go. This is compounded for Black and minoritised women who may be at risk if the wider community believes that she was using alcohol or drugs due to religion and cultural expectations. Another woman had an ectopic pregnancy suspected but they never did a pregnancy test to confirm, and this was not followed up.

We are concerned that the examples highlighted in this briefing are indicative of wider systemic flaws in healthcare. The system is simply not designed to meet the needs of adult women who have experienced sexual exploitation, or indeed anyone who faces additional barriers to healthcare due to experiences of trauma and discrimination. While more work is being done to ensure better treatment for children who have experienced child sexual exploitation, the quality of care drops off once people move into adult services.

Examples of good practice

Throughout STAGE, we have identified examples of good practice within primary healthcare that we would recommend are replicated more widely:

- One GP surgery in Bradford is well known for supporting people with vulnerabilities, including experiences of homelessness, selling sex, asylum seeking and trafficking and modern slavery. They offer longer appointments and do a full health check with women. Another practice in Leeds provides a healthcare bus which offers outreach to patients in different locations.

- Positive engagement between primary care providers and caseworkers who already have a trusted relationship with the women, including making caseworkers an agreed point of contact to facilitate communication, and allowing caseworkers to attend appointments with women.
- One partner explained how they write letters for GP appointments, detailing what the woman has been through and how she might present; they have seen better engagement because of this, and women describe feeling empowered
- Awareness and understanding of sexual exploitation makes a big difference to staff's treatment of women and their subsequent relationship. In some areas this awareness was often limited to specific police operations that had taken place, so women who had been exploited but not part of these operations may still have been overlooked.
- Some GP surgeries do online triage to keep the phones free for people with vulnerabilities who cannot use the online system, for example because they cannot do so safely or do not possess the digital capabilities necessary to access services online.

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Physical and Sexual Health

Whilst women face barriers to accessing healthcare for any health concerns, there are certain physical health concerns that are seen more commonly amongst women supported by STAGE:

- Self-neglect – lack of self-care, personal hygiene
- Pregnancy
- Gynaecological issues
- Physical injuries – from perpetrators or self-inflicted i.e., self-harm and infected drug sites
- Abscesses
- Scabies
- Lung problems from women who are rough sleeping or using substances
- Seizures and epilepsy
- Fibromyalgia
- ME / chronic fatigue
- Bladder / incontinence issues

Some STAGE partners have seen an increase in women being diagnosed with epilepsy, which can be a result of PTSD and trauma[1]. One woman, who was a victim within Operation Sanctuary, started having seizures following the criminal justice process, and this was determined to be a result of post-traumatic stress. Another woman in our service, who is an ex-veteran, has also just been diagnosed with epilepsy.

Many women experience issues such as fibromyalgia and extreme body pains, which can also be triggered by stress and trauma - this is sometimes described as trauma trapped in the body[2]. While this can be the case, describing the body's response to trauma in this way can lead to women feeling that they are being gaslit and that their physical health issues are not being properly investigated. One woman with severe body pains following her abuse was told by her doctor that it was down to trauma. She began to get red swelling lumps on her wrists, and it was later discovered that she had severe arthritis that had progressed rapidly and had been missed due to lack of investigation.

[1] Mariotti, S., Valentin, D., Ertan, D., Maillard, L., Tarrada, A., Chrusciel, J., Sanchez, S., Schwan, R., Vignal, J., Tyvaert, L., El-Hage, W. and Hingray, C., 2021. Past Trauma Is Associated With a Higher Risk of Experiencing an Epileptic Seizure as Traumatic in Patients With Pharmacoresistant Focal Epilepsy. Frontiers in Neurology, 12.

[2] Nardi, A., Karam, E. and Carta, M., 2020. Fibromyalgia patients should always be screened for post-traumatic stress disorder. *Expert Review of Neurotherapeutics*, 20(9), pp.891-893.

Many professionals fail to see the link between physical health and exploitation, often seeing presenting physical issues as consequences to 'life choices' the woman is making.

Black and minoritised women describe receiving poor medical support in the identification, diagnosis, and treatment of illness for healthcare needs in comparison to white women. Black and minoritized women have disclosed that they are not listened to when they explain their symptoms, and it is often downplayed or ignored by health care professionals. One migrant woman from Nigeria went to her GP on multiple occasions as a result of experiencing severe pain in her stomach. Her GP repeatedly told her that there were no physical concerns and the pain had likely been brought on by stress, despite not conducting any tests. It was not until she was rushed to hospital due to complications with an undiagnosed cancerous tumour, that her health care needs were considered seriously. This woman disclosed a real belief that her treatment would not have been the same if she had been white and with secure status in the UK.

Sexual Health

Gynaecological issues are very common with women supported by STAGE, but often they do not want to or are prevented from accessing support.

Sexual health issues are common amongst women supported by STAGE and only 20.3% have accessed sexual healthcare within the last year. Reasons for not engaging include feeling it is not a priority; fears they will be judged or questioned about their circumstances; and, if they have children, fear of repercussions from statutory agencies. Black and minoritised women are less likely to access sexual healthcare due to it being seen as shameful, which leads to a higher prevalence of untreated sexually transmitted diseases and unwanted pregnancies. For non-English speaking women, describing their symptoms can be affected by the language barrier as many languages do not have a direct translation when discussing sex, rape, STDs etc.

Women have had 'backroom abortions' carried out on them during their exploitation, often by 'doctors' within large grooming gangs, leaving women concerned about fertility issues. This is also prevalent amongst Black and minoritised women; one woman, who had been trafficked and sexually exploited by several perpetrators, had to endure multiple abortions each time she fell pregnant.

Professionals often fail to question why women are presenting with multiple unwanted pregnancies and recurrent STDs from multiple partners, despite these being warning signs for sexual exploitation. Rather than asking explorative questions to determine why a pregnancy is unwanted or if a woman is being forced, they tend to only focus on contraception as a solution (which whilst relevant and important should not be considered the only solution).

Many pregnant women supported by STAGE do not access antenatal care, even with support workers, often due to chaotic lifestyles or feeling disconnected with the baby due to the thought that 'It's going to be removed anyway,' often based on previous experiences. Many women have continued to use drugs throughout pregnancies due to lack of support from services, or alternatively have felt judged by social workers supporting them through the process based on their past.

Some areas of good practice were identified which have aided women to overcome barriers, that we would recommend are replicated more widely:

- Women have praised their local sexual outreach teams and sexual health drop-ins where professionals have taken their time to explain, follow-up issues, build positive relationships and support women to make informed decisions
- Bi-weekly visits to locations more convenient for women for sexual health screenings with information on contraception and consent
- Condom distribution points, for condoms, lubricant and pregnancy tests all free of charge
- Some healthcare services in Leeds offer 'red umbrella' appointments – women can show a red umbrella card or just say 'red umbrella', which discretely identifies them to healthcare staff as someone involved in sex work (which includes both those who are being sexually exploited and those consensually selling sex), allowing them to access fast-tracked appointments with no difficult questions.
- Specialist safeguarding midwives who create trauma-informed birth plans for survivors of sexual exploitation
- Linking in with *Doulas Without Borders* in different localities that provides services to women and childbearing people experiencing multiple disadvantage.

Substance Use

18.9% have substance use issues
57.1% are currently accessing support
28.6% are accessing single-sex provisions

Many of the women are aware of what substance use services are offered, referral processes, pathways, and requirements when in treatment, so those who want to are able to access support independently. However, many do not want to access drug and alcohol services for reasons including:

- They do not want to go through the titration period, where drug use is monitored, and withdrawal is required to understand the correct dosage of methadone.
- Treatment options are more limited for women seeking help with substances such as cannabis or crack cocaine, often focusing more on harm minimisation and healthy coping strategies. Some services offer group work, which is not always appropriate for women especially if single-sex provision is not provided, and many addiction and recovery services lack the time or capacity to deliver psychosocial interventions that really tackle the trauma behind addiction.
- Pain of withdrawal and fear of having to deal with emotions, trauma and deteriorating mental health without alcohol or drugs.
- Lack of cultural sensitivity. One woman who tried to access support for substance use said "When I told my GP I thought I relied too much on alcohol, it didn't feel like they really took me seriously because of my culture. Like it was impossible for anyone Muslim to have an addiction to drink."

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57.1% of women supported by STAGE have a dual diagnosis of substance use and mental ill health, which remains a key barrier to accessing services. Despite guidance to the contrary having been available for a while now, many mental health services still will not support women who experience addiction, so they struggle to get the support they need. Often the root of both the addiction and the poor mental health is unresolved trauma, therefore it is important that women are able to access specific trauma support, whether within specialist sexual exploitation services or within addiction and recovery services. We welcome the increased funding for addiction and recovery services through the 10-year drugs plan which

could be used to increase the availability of psychosocial support in addition to clinical interventions to tackle the trauma behind addiction.

Some positive experiences with accessing support for substance use and dual diagnosis have been shared which has aided women to overcome the above barriers:

- Complex caseworkers who do assertive community outreach – areas surrounding addiction and recovery services can themselves be hotspots for drugs or risk encounters with people women would rather avoid (e.g., abusers, acquaintances who may encourage substance misuse).
- Sex work specific drug and alcohol workers who have accessed specialist training, including around the intersection between sex work and sexual exploitation, as occurs in Leeds.
- Specific dual-diagnosis teams that take a holistic approach.

Mental Health

45.9% have mental health support needs
32.4% are currently accessing support
14.7% are currently on a waiting list

Waiting lists for mental health services remain a problem for women. Women are often left in limbo, without communication or support to manage mental health in the interim while awaiting a diagnosis and more enhanced treatment.

Many women who have experienced sexual exploitation live chaotic lifestyles and, with healthcare services operating a 'three strikes and you're out' policy, many women end up back on a waitlist due to their case being closed for non-engagement. This leaves women confused as to who or what they have in place for support. Furthermore, the stepped care model that is in place means, following a long wait and multiple assessments, women are often told their needs are too complex to receive support and their IAPT service (Improving Access to Psychological Therapies) cannot help them. This can often take up to a year, resulting in women being retraumatised by the assessment process.

Black and minoritised women face multiple additional barriers to accessing mental health support. A total of 80% of women accessing support from one of the STAGE partners who specialise in supporting Black and minoritised women stated that, when they had previously accessed external therapeutic services, it did not appropriately address their trauma due to:

- Lack of language support
- Lack of cultural understanding, including failure to see violence through different cultural lenses
- Fear of Home Office informants or that counselling disclosures would impact ongoing court proceedings
- Unconscious and conscious bias
- Healthcare sub-charge for those with no recourse to public funds

Many Black and minoritised women also report not being believed by mental health professionals - which often results in self-harming behaviours and attempted suicides. Some partners have supported South Asian women whose family put their mental health issues down to djinn or other spirits. The barrier of shame within the family and not recognising mental health issues as the trauma they've been through means they do not engage with mental health services.

STAGE partners commonly receive inappropriate referrals from healthcare professionals, often discharging people to our services. Whilst some partners do offer in-house psychotherapy, many do not offer the specialised support women need. Some partners work (or have tried to work) with local mental health teams to raise awareness about appropriate and inappropriate referrals.

Women have also reported negative experiences with medication being stopped or not being reviewed when required. One woman was receiving medication and support for bipolar disorder and suddenly they changed her diagnosis without consulting her. Another 19-year-old woman was prescribed quetiapine whilst on a waiting list, but her prolactin levels increased dangerously to the point at which she risked becoming infertile. Her doctor avoided responsibility and would not explore alternatives as she was on a waitlist for the enhanced team.

41.9% of women supported by STAGE have a mental health diagnosis, and 10.8% have a presumed diagnosis.

The most common diagnosed condition is anxiety (58.1%) followed by personality disorders and PTSD (22.6% each), depressive disorders (19.4%), ADHD and schizophrenia (6.5% each), bipolar and eating disorders (3.2% each).

Nearly a quarter of women supported by STAGE have a diagnosis of personality disorders and PTSD, however there are many other women who self-diagnose. This is often not investigated by healthcare professionals leaving women feeling dismissed.

We are concerned that in many cases trauma responses are being confused with personality disorders. For example, many diagnoses for emotionally unstable personality disorder (EUPD) are given whilst exploitation is ongoing, despite the fact that many indicators of EUPD are similar to trauma responses. Many of the woman supported by STAGE express behaviours that challenge as a result of the trauma they have experienced, not because there is something inherently wrong with them. Women feel that EUPD is often diagnosed to dismiss challenging behaviours, and this label can stick with them. Women feel unable to challenge these diagnoses, with several women supported by STAGE feeling complex PTSD or bipolar disorder is more suited to their presentation.

"You do this because you like the drama."

Women diagnosed with EUPD report feeling dismissed as attention seeking and manipulative. One woman was told when she was being exploited, "you do this because you like the drama" and "this is just what your personality is". Very few women supported by STAGE feel positively about their personality disorder diagnosis due to the stigma of being a 'disordered person' associated with it which can be very dehumanising.

Women also report very poor responses from crisis support and feel very unsupported, let-down and like their time is wasted. One woman felt dismissed by the Crisis Resolution and Intensive Home Treatment service (CRHT) after a suicide attempt where they asked her if she "had done it to get care" because she was on a waiting list. Another woman had an ectopic pregnancy caused by her abuser, and she was asked by a crisis worker if she got pregnant on purpose to get CRHT attention. Many women report such negative experiences with crisis teams that they would rather suffer than going through the ordeal of ringing them. Crisis intervention is not enough for the women supported by STAGE. They require longer-term intervention but, because their behaviours often meet the crisis threshold, they do not get into other services.

Women have had good experiences with eye movement desensitisation and reprocessing (EMDR) therapy; however, this is only accessible to women who have reached a degree of stability in their mental health – therefore it is not appropriate to a lot of the women that present as chaotic.

Some positive experiences with accessing support for mental health include:

- In-house counselling provided by sexual exploitation and women's services, meaning women can access multiple services under one roof
- STAGE caseworkers engage with women through stabilisation and grounding, which allow women to reach a level of stability where they can engage in in-house counselling or more intensive therapy i.e., EMDR.
- Exploring whether diagnoses are appropriate, particularly EUPD. One woman had her diagnosis changed from EUPD to Complex PTST (C-PTSD) and she is now receiving tailored support
- Women accessing survivor-led crisis houses to prevent inpatient hospital admissions have improved mental health support and engagement
- GPs have shown apps to women around mindfulness and relaxation which was a positive coping mechanism to bridge the gap whilst they were waiting for therapeutic intervention

- Referring women into the national referral mechanism (NRM) who pay for counselling and therapy which has been positive for some women who have been sexually exploited

Recommendations

Our fundamental ask of government is that adult sexual exploitation is recognised, understood and included in policy and practice.

The core recommendations of the STAGE project are:

- The establishment of a cross-departmental national strategy for tackling adult sexual exploitation to ensure that understanding of exploitation and its wider impacts are embedded in strategic thinking across relevant government departments, including the Department for Health and Social Care.
- A statutory definition of adult sexual exploitation to ensure a consistent understanding and recognition of the ways that sexual exploitation continues and presents itself in adulthood.
- A statutory duty for specialist support services to be provided to victims of sexual exploitation, either as a specialist role within wider sexual abuse provision or as a separate service.

In addition, we make the following recommendations for policy and practice within healthcare services:

Local practice and commissioning
Wider rollout of codeword schemes such as the 'Red Umbrella' scheme in Leeds or the national 'Ask for ANI' scheme in pharmacies, that discretely identify to healthcare staff that a woman is involved in sex work and/or sexual exploitation and requires appropriate treatment. This should sit alongside regular training of staff to ensure an appropriate response.
Whilst pressures within the NHS may mean not all GP practices can offer fully flexible care, integrated care boards and partnerships should ensure that they have a sufficient number of GP practices accessible for people with no fixed abode and that specialise in supporting people experiencing multiple disadvantage or vulnerabilities (e.g. genuinely trauma-informed, longer appointments, full health check-ups, trained in active listening, asking wider questions.

Integrated care board and partnerships should also ensure that healthcare provision (particularly primary and sexual healthcare) in their area includes assertive outreach, including linking in with women's centres or sexual exploitation services where available.
Healthcare providers to work in partnership with organisations specialising in trauma-informed care and those with lived experience to ensure that being 'trauma-informed' is more than just a buzzword and is reflected not only in individual staff practice but in the systems, procedures and pathways in healthcare.
All GP practices to implement booking and triage systems that are accessible to people with vulnerabilities (e.g. combination of online and telephone booking options) in consultation with women with lived experience and specialist service providers.
Investment in 'by and for' services to deliver specialist therapeutic intervention.

Nationwide system change
Measures should be put in place to ensure that all healthcare staff understand what sexual exploitation is, how it can be identified in adults, and appropriate responses to it within healthcare settings, as has been done for domestic abuse. We recommend that this is done through NICE guidelines on sexual exploitation, training for all staff and ongoing reflective practice and supervision.
Implementation of a 'firewall' within healthcare to ensure that immigration information is not shared with the Home Office.
Equitable healthcare to be made available to all victims of exploitation and abuse, including those with no recourse to public funds.

Strategic oversight
Regular review and scrutiny of addiction and mental health services to ensure that people with dual diagnosis do not continue to fall between the gaps.
The 10-year plan to improve mental health should include a review of access to mental health services for people experiencing multiple disadvantage, including abuse and exploitation, to allow for a more flexible approach to support as opposed to the 'three strikes and you're out' policy.

A review of whether personality disorder diagnoses are being inappropriately given to women with complex trauma and whether appropriate interventions are available across the country.

For more information on this report please contact the STAGE Policy Officer, Jess Creaby-Attwood, at jess.creaby-attwood@changing-lives.org.uk