NHS England

Developing the 'Forensic Mental Health Community Service Model'

Background Information Resource (2 of 5):

Service User Perspectives

Background

About this document

This document provides an overview of more than 100 peoples' lived experience of secure in-patient care. This information forms a critical part of the evidence used to envision and design the new 'Forensic Mental Health Community Service Model' and should be used by those seeking to implement the model on the ground.

This document is part of a series of supporting 'Background Information Resources' related to the Forensic Mental Health Community Service Model. Other documents in the series include:

1. **Background Information: *the data***
2. **Background Information: *service user perspectives***
3. **Background Information: *literature review***
4. **Background Information: *core components of the model and the Specialist Community Forensic Team***
5. **Background Information: *the values, knowledge and skills of the Specialist Community Forensic Team***

Please contact england.sc.mh@nhs.net if you would like to receive the full series.

About the research

The NHS England Mental Health Secure Care Programme is committed to embedding the principles of coproduction throughout its activities where it is possible and appropriate. With that in mind, and to support the NHS Benchmarking Network data (*see* ***'Background Information Resource: the data'***), we asked people currently in secure care services to share their experiences, helping us to better understand the routes into secure care and identify what is, or will be, important for their recovery on discharge from secure in-patient care.

With the support of the national Recovery and Outcomes Network of Secure Care Groups (***see Box 1***), facilitated discussions were held with 90 people. This document summarises the experiences, issues, concerns and points made through these discussions.

BOX 1: Recovery and Outcomes Network
Recovery and Outcomes is a network of regional service user groups that meet across England, organised and facilitated by ***Rethink Mental Illness***. Each region meets quarterly to bring together service users, staff and commissioners to share best practice and improve the recovery focus of secure mental health services.

The NHS Benchmarking Network data established that there is an over-representation of Black and Black British men in mental health secure care but did little to help us understand why this might be. With the support of the Equalities Advisor to the Programme, Jacqui Dyer, we led additional targeted conversations with 40 Black and Black British men currently detained in secure care settings, to understand what might be particular to their journeys into and out of secure in-patient care. These discussions are summarised in Section 2.

Service user perspectives

1. Recovery & Outcomes Network narratives

Early years and experiences of trauma:

- Participants described experiences around first onset of mental health difficulties, often describing early experiences of trauma, including violence or other abuse in the home or in institutional care, or bullying by peers.
- Participants felt these traumas led directly to them adopting risky behaviours as coping mechanisms, in particular problematic use of drugs and alcohol and self-harm.
- Some participants reported that experiences of violence in early years taught them that violence was the answer to disagreements and led them to use violence themselves.
- Those who had grown up in care said they had not had opportunities to develop life skills or social skills, leaving them with poor social networks.
- Many felt they didn't receive adequate support or weren't believed by those in authority, services or family who they told, leading to a loss of trust in authorities that would reduce their help-seeking behaviours in later life.

Stigma:

- For various participants, the stigma experienced around mental health was compounded by stigma around both thoughts about and engagement in criminal behaviour, particularly sexual offences, which meant they did not feel they could ask for support because they would be judged.
- Many reported knowing something was 'wrong' but not where to go for help, as well as a lack of understanding from family, friends and schools.
- Participants described either losing contact with mental health services or avoiding it deliberately.

Social networks:

- Participants reported their social networks as a vital influence on risky behaviours (including taking drugs) and help seeking.
- Being part of a 'criminal network' for some participants meant they adopted attitudes of not trusting authority and not asking for help.
- Others found social connections through places in the community, such as church, or the pub, though these were not described as effective sources of support.
- Others described withdrawing from social contact due to not feeling understood or supported.
- Help seeking was also sometimes hindered by cultural and family attitudes such as 'keeping it in the family'.
- Unhealthy relationships, particularly for participants who were vulnerable, had very negative impacts on their trajectory and some felt prevented from access to services by those exerting control over them.

Seeking help and support:

- Participants often described engaging in

criminal or extreme behaviours in desperation or frustration in the hope of receiving some form of help.

- Some participants were able to describe the support they would like to have been able to access, which might have prevented admission to secure care, including:

Discharge:

- On considering discharge from hospital, the primary concern was that there would be some continuity between hospital and community services.
- Being able to access services quickly when needed was an important safety net for most participants.
- Some felt services were removed too quickly when people were well, meaning they went to the back of the queue when needing to access them again.
- When this happens, relationships became even more crucial because people feared that practitioners or services might overreact if they went to them with difficulties, perceiving them to be high risk because of their history and sending them back to hospital. As a result, some people felt it would not be in their interests to approach services they did not know after moving back into the community.

Risk of relapse:

- It was acknowledged that risk of relapse is an ongoing issue, particularly around substance misuse. This was another area where people feared the reaction of services in the community and were unsure how openly they would be able to talk about these risks with practitioners.

Stepped transitions:

- Stepped transitions were also seen as very important, though the pace and number of steps available varies according to local resources.

Box 1: What is helpful but not widely available:

- **Short term respite** and admissions, including crisis/recovery houses;
- **Community drop in** as a safe space and to access immediate assessment;
- **Community based peer groups:** many mentioned peer support groups as the most helpful aspect of hospital. Those who were anti-authority said they may have listened to peers;
- **Specialist psychological therapies** provided in the community to manage emotions and problems. This was described as transformative support which is not available until admission. This was described as transformative support that is not currently available;
- **Stable and appropriate accommodation:** some people had been forced to sleep on the street due to the risks posed to them in the accommodation they were offered;
- **Outreach** including daily check in and advice. Reluctance to receive support might have been mitigated by practical help such as sleeping bags, showers, food, and help with finances and accommodation.

- Some expressed frustration at long delays in discharge despite a feeling amongst their care team that they no longer needed to be in hospital. They felt that the longer their discharge was delayed the more difficult transition was going to be.

Purposeful activity:

- A key concern was developing a purpose and structure to fill people's time once they have been discharged.
- Hospital provided a routine and structure and without this some people feared an increased risk of relapse.
- Access to work and employment was the most common activity people mentioned but others talked about re-engaging with hobbies and interests.
- Participants expressed worries about having a narrative around their past, to build new identities in the community and explain large gaps in CVs to employers.
- A common fear was people in the community judging them or being hostile because of their history, or difficulty getting a job.
- Having a status and role in society was an ambition of many, often after years of feeling like an outcast.
- Some people expressed a desire to give something back directly to secure services, for instance by being a peer supporter for other people going through the system.

Everyday activities:

- Many participants lacked confidence in managing daily life such as carrying out housework, managing benefits, paying bills and using the internet, particularly for those who had spent many years in hospital.
- Some participants had previously transitioned into the community and been re-admitted, citing these issues as a major cause of their relapse.

Family / friend trauma:

- A barrier that some mentioned to moving on was that while the individual may feel their previous behaviours are in the past, their loved ones are still dealing with the trauma caused by their illness and actions and were not ready to support them because they had not benefitted from the therapy the individual has had.
- Participants felt that family therapy prior to discharge could be beneficial.

2. Black African and Caribbean narratives

Early years and racism:

- Many participants described similar aspects of early experiences as the Recovery & Outcomes Network participants, including:
  - socio-economic disadvantage
  - encountering violence
  - substance use in adolescence
  - an absence of meaningful relationships in their lives

- a lack of trust in services or agencies.

- However, participants also described experiencing racism and exclusion in society, reflected in areas such as housing, education and employment, contributing significantly to social disadvantage throughout their lives.
- Along with these, participants described feeling the impact of racial stereotypes which meant they were more likely to be suspected of being criminals.
- Participants also talked about struggling against internalising these negative social expectations and the impact of this on their wellbeing.

Lack of awareness and understanding:

- When mental health problems first began, participants spoke particularly of having no recognition or language for the mental health challenges they had experienced.
- Participants spoke often of being in denial, becoming withdrawn from family and friends and turning to substances, most often cannabis.
- Whilst some imagined at the time that their experiences, including hallucinations, might be spiritual in nature, none had any idea that their experience might be related to mental health.
- According to participants, families often lacked awareness and saw the change in them as behavioural and within their control.
- The point was also made that certain 'Black cultures' may be more likely to want to support the person within the family rather than turn to statutory services.

Contact with services:

- Most participants only realised they were experiencing a mental health problem following contact with statutory services, their index offence, and subsequent contact with criminal justice or statutory health services.
- The contact participants had with services generally involved abrupt, quickly escalating confrontation.
- Participants described being labelled as 'violent' in police reports which were used to inform later assessments and a perception of them which was, in their view inaccurate.
- Their initial encounters with services were described as marked by strong and over-riding fear and that they needed time to process this experience.

Lack of cultural understanding:

- Participants described a lack of understanding by decision makers and staff about the experiences of multiple disadvantage and discrimination which had contributed to their eventual admission to secure care.
- They mentioned that they needed someone to talk to who could empathise, acknowledge and understand their specific experiences as Black African and Caribbean men, such as a peer worker or advocate.
- Some described a difficulty in engaging with conventional advocacy services, as they were not confident that these services were

sufficiently aware or sensitive to their needs as Black men.

Barriers to recovery:

Participants were keen to discuss experiences within secure care settings which they felt were particular to them as Black men, and detrimental to their chances of recovery:

- Participants detailed their perception that diagnosis, treatment and the way they are handled may be influenced by racial stereotypes; that they are viewed as higher risk than non-Black patients.
- Participants felt that the combined lack of trust and stereotyping resulted in Black people being required to *"jump through more hoops"* when, for example, their risk for unescorted leave was being assessed.
- Participants described staff relying on cultural stereotypes and a lack of meaningful acknowledgement of their particular life experiences.
- Participants reported that their negative experiences of therapeutic relationships were further exacerbated by racially abusive language used by other patients being tolerated in secure services.

Preparing for discharge:

- Participants talked about the importance of being supported to develop skills before leaving hospital, such as staying calm in hostile situations, maintaining stable and hygienic accommodation and working towards vocational training opportunities.
- Participants expressed an interest in accessing a positive recovery environment in the community which would have facilities for activities such as cooking, learning relaxing techniques and expressing themselves through music.

Supporting recovery in the community:

- Once in the community participants expressed a strong desire to be able to go to a place where efforts are made to understand their background so that they can feel accepted.
- Participants talked about a type of resource that would support recovery, build up their skills, and provide legal, medical, housing advice.
- Participants described the beneficial impact of outreach schemes and community buddy schemes where a regular group of individuals would oversee their recovery and integration into the community.
- Housing was an important part of recovery and resettling into the community.
- For some it was the central issue, being housed in an area where they were the only black person made them feel vulnerable but they did not necessarily want to be housed in a location they were familiar with if this brought them into contact with negative influences.

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