

APPENDIX 16: DESCRIPTION OF RESULTS BY THEMES FOR RQ2.2: VIEWS AND EXPERIENCES OF SERVICE USERS, THEIR FAMILY AND CARERS

This appendix reports direct quotes coded as barriers or facilitators under relevant themes and sub themes for each included study. The section numbering and heading mirrors the headings in section 6 of the main report.

Brooks et al. (2007) [+]

6.5 Continuity of care and smooth transitions

6.5.1 Fragmented care

Barriers

"Clients also reported diminished trust with their case managers due to high turnover rates. Thus, given the long term treatment needs of this population, revolving case managers are unlikely to establish the much needed rapport with these patients."

"I ain't got nothing to talk about when I ain't going to see them next month. When they're going to be gone and I'm going to be assigned another case manager."

Facilitators

None reported

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

"Negative interactions with staff (...) had a deleterious impact on the therapeutic environment."

"I had a counsellor once that I was talking to and she started crying. And that wasn't particularly helpful."

Facilitators

None reported

6.6.2 Integrated approach to care

Barriers

"I think getting the help with the mental health is harder (...), they say 'well do you drink or use drugs? (...)' Well, yeah, ok, you're a drug addict, and that's where they put you."

"An additional need that surfaced for clients who are triply diagnosed is consideration and treatment of their medical conditions."

"Everyone through the system has understood that in addition to my mental disability I have a physical disability and have worked with me. You need to see more of that, the people need to understand a lot of times that it's not dual sometimes it's triple."

Facilitators

None reported

6.8 Fast access to reliable health advice

6.8.1 Service structure

Barriers

"Another barrier mentioned is the lack of co-ordination of services across agencies."

"They say, well you should go to hospital for this and you should go over there for that (...). They don't co-ordinate, they don't work together."

Facilitators

None reported

6.9 Involvement in decisions and respect for preferences

6.9.1 Service user-focused approach

Barriers

"Most often mentioned, though, was the desire for client-centred services."

"If they walked in my shoes they could probably get a better insight of what's me and what is good for me."

Facilitators

None reported

Cruce, Öjehagen & Nordström (2012) [+]

6.3 Attention to physical and environmental needs

6.3.1 Housing issues

Barriers

None reported

Facilitators

"Three participants had current or previous experiences from living in a special housing scheme, and described its pros and cons. One participant greatly appreciated this form of housing, stating that it made him feel independent, i.e. not like a patient (...). Living in a special housing scheme was like living in an asylum that offered a feeling of safety through having enough to eat every day and ensuring correct medication (...) the alternative—living alone— could involve chaotic circumstances and probably homelessness."

Mixed

Three participants had current or previous experiences from living in a special housing scheme, and described its pros and cons. [Some participants] thought it was much better to live alone and take care of themselves. (...) When other residents were sometimes under the influence of drugs, this form of living was experienced as being turbulent and exerting a negative influence on the recovery process.

6.4 Clear, comprehensible information and support for self-care

6.4.1 The provision of information/training

Barriers

None reported

Facilitators

"The participants valued treatment that promoted autonomy. Training in self-help skills was regarded as an essential part of the recovery process. Examples of such

training could be housework, road safety or occupational rehabilitation. Self-knowledge acquired by participants gaining a better insight into their strengths and weaknesses was described as a necessary condition for improvement. An ability to recognise and understand early signs of a threatening relapse in psychosis or misuse was requested as a way of preventing impairment. Self-determination was regarded as supporting the recovery process. The participants aimed to gradually limit contacts with treatment units and felt that they also were developing through doing things by themselves."

6.5 Continuity of care and smooth transitions

6.5.1 Fragmented care

Barriers

None reported

Facilitators

"Continuity of contact with key workers and the psychiatrist, which could need to be on a daily basis for certain periods, was found to enhance feelings of safety. Continuity of contact also meant that staff became familiar with the person "behind the symptoms", something which was seen as providing a basis for a secure recovery process."

"The participants stressed their need for a long-term outpatient treatment contact as an opportunity to be cured and to change their lives gradually. It was important not to try to hasten recovery and not to terminate treatment contact too early, in order to secure the stability of the process."

6.6 Effective care delivered by trusted professionals

6.6.2 Integrated approach to care

Barriers

"Many of the participants complained about previous experiences, from the time before they had taken part in the special dual disorder treatment programme. It was consistently reported that psychiatric staff paid no attention to the participants' substance misuse, and that addiction staff did not recognise their mental illness."

"On the other hand, others stressed that it was important that staff took their psychotic illness seriously and did not only focus on their misuse."

Facilitators

"The participants greatly appreciated that staff were concerned with all aspects of their life situation. They wanted comprehensive outpatient care with a multifaceted programme to meet their medical, social and psychological needs."

6.7 Emotional support, empathy and respect

6.7.1 Relationships with healthcare professionals

Barriers

"Another participant said that he did not appreciate staff that interfered with his private life by expressing their opinions about his use of alcohol, opinions that he had not asked for."

Facilitators

"Mutual honesty in the relationships with the psychiatrist and key workers was also felt to be important. Key workers were looked upon as friends offering companionship in all types of activities, as well as opportunities to talk about things that were not influenced by psychotic thoughts."

"One participant likened his relationship with the key worker to that between a mother and son, and found it as crucial for his survival. She cared for him both with warmth and some degree of strictness, and listened to him when he was sad. She made him aware of his improvements in most life areas and looked for him when he withdrew."

"Staff members who listened and really tried to understand the participants' problems were experienced as confirming their human dignity. Staff devoting time to the participants and giving attention to their situation, boosted feelings of self-worth. Even when the participant was misusing a substance, such expressions of acceptance and respect were important to experience human dignity."

Edland-Gryt & Skatvedt (2013) [+]

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

“For clients, information about the help offered at the centre may be difficult to understand. The room they enter from the street did not have any posters displaying information.”

“Most clients express that they do not trust “the system” or the staff who can help them due to experiences of neglect from the same system in the past, for many of them from early childhood.”

“One example is clients who have lost faith in the welfare system and who withhold information from the staff so that it becomes difficult to give relevant help. When a client feels that he or she is neglected by the staff, the threshold for reporting what they need seems to grow higher.”

“Many clients said that they had a low level of trust for many public services, and that they have a poor opinion of the social services and the substitution treatment system. A lack of respect for the services is the greatest barrier to trust.”

“If you do not trust the people working at the centre, you do not dare to ask for help.”

“Some of the staff are just here for the money. They do not really care about us, and are more interested in talking to each other.” - (54 year old woman)

“Drug problems and mental disorders may make it difficult to come to the centre and turn up for appointments, even in a lowthreshold service like the one in this study.”

“Some expressed the fear that information about them was delivered to evil forces.”

Facilitators

“Another client described how he had contacted the centre by telephone one day after he had been there several times. Due to anxiety, he did not want to visit the centre for his appointment with staff. He did not dare to go into the city centre where the centre is located. Instead a psychiatric nurse had offered to come to his place.”

“(. . .) so he came home to me – in a cab!! And we just sat there, talking for more

than two hours! They are flexible, and that really helps me. (Smiling)" - (21 year old man)

"Respect for the clients also has a bearing on trust. Many clients said that they were met with respect by the staff, and that this differed from some of the other services they had experienced. According to clients, respect is not what they usually encounter in treatment services and in society at large."

Edward & Robins (2012) [+]

6.6 Effective care delivered by trusted professionals

6.6.2 Integrated approach to care

Barriers

"At times there was an indication of receiving mixed messages from different clinicians involved in the person's care, eliciting anger from the client."

*"They really have no idea what the **** they're talking about. My current psychiatrist says I can smoke pot but can't drink. However, the senior doctor at the behavioural health unit where I was hospitalized said I could drink but can't smoke pot."*

Facilitators

"My life didn't really seem to click and come together until I started treating both of my diagnosis (sic)."

England Kennedy & Horton (2011) [+]

6.10 Involvement of, and support for, family and carers

6.10.1 Failure to provide information to family/carers

Barriers

"When directly asked, most family members (68%) said they were not included in treatment or treatment planning."

"One [family member] said the family "should" be more involved".

"Most [Families] had not received (...) information on "family support groups" (83% had not), or assistance with family difficulties."

“When asked if they had participated in support groups, family members stated that were “bitch fests” or too “cliquey””

Facilitators

None reported

Fraser et al. (2003) [-]

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

“[A] tendency for services to focus on one problem, rather than looking at the whole range of issues affecting the individual (some reported that they had been prevented from accessing mental health services until they had addressed their substance use problems, or that they had been rejected by mental health services after it had been discovered that they were encountering substance use problems).”

Facilitators

“Many participants had mixed and generally poor experiences of statutory health and social care services, but were more likely to report positive experiences of voluntary service provision. Positive aspects of service provision mentioned by respondents included:

- practical help with housing & employment, and support in accessing a wide range of services;*
- quick or immediate access to services;*
- positive and consistent relationships with workers; and*
- peer support (for example in the context of group work).”*

6.8 Fast access to reliable health advice

6.8.1 Service structure

Barriers

“Difficulties in accessing services due to long waiting times or inflexible appointment systems (particularly in accessing support before mental health or substance use problems became established or reached crisis point).”

Facilitators

None reported

Green et al. (2015) [+]

6.7 Emotional support, empathy and respect

6.7.1 Relationships with healthcare professionals

Barriers

"Other participants encountered programme-related problems that arose as a result of the effects of mental health medications and their ability to attend treatment sessions."

"The amount of frustration I was going through [substance related] recovery, going through group therapy and treatment that way, at the same time attempting to (...) figure out what's going on with your mental issue (...). I went on Effexor, and I was missing appointments because I couldn't drive, those drugs were just kicking my ass, then I got a phone call, told I couldn't miss anymore or I would be kicked out because my recovery comes first. What good is my recovery if I'm going to die in a car crash on the way there?"

Facilitators

None reported

Hodges et al. (2006) [-]

6.3 Attention to physical and environmental needs

6.3.1 Housing issues

Barriers

None reported

Facilitators

"[Most] helpful experiences were reported in relation to supported accommodation and the relationships built with individual providers. These included support workers, community psychiatric nurses and occasionally social workers."

"[This service user] no longer begged as the project had provided him with accommodation and helped him obtain a methadone script."

"This project was viewed by one service user as being particularly good at resolving practical issues and addressing wider needs than simply the diagnosed problems. Staff helped with accommodation issues, clothing and practicalities such as form-filling."

"They helped me get my flat. They helped me get out the gutter. Being there for me, just talking to me, getting me clothes. I'm dyslexic and any forms I get I come straight here."

6.5 Continuity of care and smooth transitions

6.5.1 Fragmented care

Barriers

"A service user commented on the lack of consistency and continuity in staff provision which was difficult to cope with. (...) Another service user described being passed on to five psychiatrists, allocated two social workers and three community psychiatric nurses. This man indicated that he would have benefited from more consistent care."

"I got five CPNs in a row. I find it hard enough to trust one person over a long period of time then to be asked to be moved to another person in two weeks, on to another person and then another it's just impossible."

Facilitators

None reported

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

"The lack of dedicated dually trained staff was considered by service users to be hugely problematic."

Facilitators

"A second service user also praised this service, which provided him with counselling and a counsellor. The doctor was easy to access, the key worker was supportive and put him at his ease."

"Staff acted in a straightforward and open manner, allaying the service user's anxieties sufficiently to allow him to feel safe. Ex-user involvement and the knowledge that staff had first-hand experience and knowledge of mental health and substance misuse complications helped this process."

6.6.2 Integrated approach to care

Barriers

"Service users were particularly critical of mental health services (in particular inpatient facilities) inability to address drugs and alcohol problems alongside presented mental health issues. They related how mental health services did not routinely address drug use. Staff were not interested in it and were therefore not helping service users address the duality of presenting problems."

Facilitators

"Communication between his key worker, counsellor and doctor was good (...). [His care plan] included rapid referral and access to a psychologist. When released from prison, he was quickly picked up by the service and rapidly started on treatment."

6.7 Emotional support, empathy and respect

6.7.1 Relationships with healthcare professionals

Barriers

"One service user felt that his relapse after six years of abstinence had been caused by the single-minded approach to his previous addiction, which excluded other issues. He felt the care pathway offered following his relapse was a punishment rather than a support and experienced a sense of betrayal, which added to his vulnerability."

"I've been off heroin for 6 years and they were still on at me every time they seen me. Are you back using heroin? And it got to the point where I didnae like going any more and I did try to kill myself. I tried to take an overdose it didnae work and I was honest with them; I told them that I took heroin for the first time in 6 years and it was like I was being punished for telling the truth."

Facilitators

"The service team worked collaboratively with him to organise his care plan. (...) He felt he was being listened to and could provide active input into his care plan."

"He particularly appreciated their persistence and perseverance in trying to engage with him, their proactive stance and the way in which the providers installed a sense of self-worth. Consistently good levels of communication helped different service providers to work well together."

"The service also welcomed the woman back after relapses, a flexibility greatly appreciated."

"She [GP] had faith in me and she trusted me and it was the first time a doctor had ever given me trust and we worked together."

6.8 Fast access to reliable health advice

6.8.1 Service structure

Barriers

"Service users also felt excluded from services because of behaviour linked to drinking or drug taking where they actually needed help and support for these behaviours rather than rejection."

"There was a general lack of awareness concerning available services and routes of access."

"Long waiting times were a general problem. At one drug problem service facility, a waiting time of up to three years had been reported. Another service user spoke of waiting a year and a half to see a psychiatrist. She received no reminder notification of her appointment and overlooked the date. She subsequently gave up trying to access a psychiatrist."

"This service was not available at weekends and was missed."

"I find the weekends difficult because there's no structure during the weekends."

Facilitators

"[The alcohol and addictions team] (...) also referred him to other groups and services for more help with unmet needs."

6.9 Involvement in decision making and respect for preferences

6.9.1 Service-user focused approach

Barriers

None reported

Facilitators

"Other positive comments received concerned the way service users were consulted and engaged in their care planning."

Holt & Treloar (2008) [-]

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

“Some service user participants were concerned that use of the term comorbidity would increase the stigma of those in drug treatment and discourage people from accessing services.”

“Yes, I think it [the terminology] scares a lot of people from asking or accessing or even just being involved or having anything to do with it [treatment] because it automatically tells them that it is, “you have got a problem and it’s a serious fucking problem, it’s a serious word.” Mental, comorbid... to me it just sounds [like] “shit, I don’t need another label.”

Facilitators

None reported

Johnson et al. (2013) [++]

6.3 Attention to physical and environmental needs

6.3.1 Housing issues

Barriers

“Housing is the number one problem getting out, but a lot of women don’t make requests for housing help because it’s embarrassing.”

“The time of transition back into the community was described as a period during which numerous supports and resources would be beneficial to women.”

“Just getting’ outta’ jail and transitioning, ya’ know, like into the real world. Like they don’t know how hard it is to try to get a job when you have a record and all that – just everything’- living situations, like apartments or whatever.”

“Participants described lack of stable housing, difficulty securing employment (...) as relapse triggers.”

“When the 28 women who reported post-release substance use were asked what they would have needed to avoid drinking or using the first time, several patterns emerged from their short-answer responses. Practical support was the most commonly mentioned. Women would have liked “more help transitioning to the real world.” This included help finding housing that was safe and not near women’s old using neighborhoods, help getting needed medications, more pre-release planning, help setting up post-release mental health counseling, and help obtaining a steady job and transportation. Several mentioned that they needed someone to ask for help when they ran into obstacles so they did not get overwhelmed by these practical transition tasks. They suggested that optimally, this transitional help should involve direct mentoring rather than simply provision of “how to” information.”

"First, I'm homeless. I had no place to go. I had no job. So I was just drinking."

Facilitators

"Short-answer responses provided by all 39 women about their ideal post-release treatment program overwhelming related to provision of comprehensive treatment. This comprehensive treatment would include help with (...) [finding] a safe home or placement in the community like a sober house that's not a lock-in like residential treatment. (...) Recognizing that it is difficult to find such comprehensive care in one place, several women said that ideally, they would have a support person such as a recovery or transition coach to help with appointments, practical issues, counseling, and recovery."

6.3.2 Employment issues

Barriers

"Just maybe programs where they can transition you, I mean transition you fully back into the world. To society. You know, maybe placing women into employment if they're able to work, or in sober housing (...)."

Facilitators

None reported

6.5 Continuity of care and smooth transitions

6.5.1 Fragmented care

Barriers

“Other common things women said they would have needed to avoid their first post-prison substance use included (...) better or more continuity in mental health treatment.”

"[Service users] just get bounced around and sign a lot of paperwork."

Facilitators

None reported.

Kozloff et al. (2013) [+]

6.3 Attention to physical and environmental needs

6.3.2 Employment issues

Barriers

"Furthermore, services that offered recreational activities and vocational services were successful in engaging youths and helped them abstain from substance use."

Facilitators

None reported

6.5 Continuity of care and smooth transitions

6.5.1 Fragmented care

Barriers

“Even when youths with drug charges were released on bail on condition that they enter addictions counseling, they felt that the system failed to connect them with services. Participants reported significant gaps between services they had received, notably between acute withdrawal management ("detox") and residential treatment.”

Facilitators

None reported

6.6 Effective care delivered by trusted professionals

6.6.2 Integrated approach to care

Barriers

None reported

Facilitators

"Participants also reported being more likely to attend agencies that successfully integrated services—a "one-stop shop" for services for co-occurring disorders as well as for basic needs and health care."

"Youths generally endorsed services that catered to their individual needs. Service use was facilitated by program flexibility, including the ability of staff to see youths who lacked valid identification."

"Some participants advocated for separate facilities for those seeking a harm reduction model and those aiming to be abstinent, "geared [to] where you are in your life at that particular moment."

6.7 Emotional support, empathy and respect

6.7.1 Relationships with healthcare professionals

Barriers

None reported

Facilitators

"Youths cited the relationship with service providers as a key influence."

"The therapeutic relationship has been identified as an important factor influencing help seeking."

"[My caseworker] (...) went above and beyond (...) calling me when I wouldn't return her call (...). It took a long time for me to come around. And she was really persistent with me (...) helped me get through a lot of stuff."

6.8 Fast access to reliable healthcare

6.8.1 Service structure

Barriers

“Timely access to resources was a major influence. Youths felt frustrated if they did not meet narrow intake criteria or had to wait months for an appointment.”

“When I wanted to go to rehab, I basically had to go to detox, then wait until there was an opening at the rehab centre (...) I relapsed in the time I had to wait (...) I had a friend that basically relapsed, got so depressed he [hanged] himself. If only there was a place in the rehab.”

Facilitators

None reported

Kuo et al. (2013) [+]

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

“I wish for more therapy and to see the doctor more. You can only see the doctor 15 - 30 minutes sometimes, and just once a month.”

“Women expressed a desire for treatment to be tailored to their own unique needs, whatever these might be.”

“The logistics, such as transportation, of accessing treatment were also described as a significant limitation for this population. (...) Other logistical considerations included the provision of child care.”

“I think postpartum would be easier to relapse because (...) [of] all the triggers of and the stress of being a new mom and everything.”

Facilitators

None reported

6.6.2 Integrated approach to care

Barriers

None reported

Facilitators

“Women noted preferences for addressing dual diagnoses (...). Women did note the interdependence of depression and substance use, and the importance of looking at them same time in some cases.”

Luciano & Carpenter-Song (2014) [+]

6.6 Effective care delivered by trusted professionals

6.6.2 Integrated approach to care

Barriers

None reported

Facilitators

“The young adult men attributed shifts in health, functioning, and psychological well-being to integrated treatment for psychosis and substance use.”

Penn, Brooks & Worsham (2002) [+]

6.3 Attention to physical and environmental needs

6.3.1 Housing issues

Barriers

“The women also mentioned the importance of living in environments that are not drug infested. Suggestions included adult foster care, subsidised housing and other safe locations.”

“The women identified the need for a dedicated client advocate to assist the clients in a variety of areas. They were especially vocal about need help with Child Protective Services (CPS). (...) Also mentioned was [a need for] assistance with legal issues, mental health resources and navigating complex social care systems.”

Facilitators

None reported

6.3.2 Employment issues

Barriers

"The need for (...) vocational rehabilitation was also mentioned."

Facilitators

None reported

Rethink (2015) [-]

6.4 Clear, comprehensible information and support for self-care

6.4.1 The provision of information/training

Barriers

"For many people, there is a lack of information about what support is available locally. Some people felt that GPs were not always aware of services they could signpost people to or refer in to, especially voluntary sector community group and services. Where people do know of services being available there are often long waiting lists, or services are not local to them. A number of people talked about the difficulty of accessing services outside of working hours, which is also a barrier."

Facilitators

None reported

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

"For me, it is entirely about stigma. I have not specifically asked for treatment support with drugs/alcohol because I don't know if I can bear the double whammy of being labelled (within the NHS system) as having problems both with my mental health and with addiction."

"Many people felt that more training and awareness raising among health professionals might help create an environment where there was less stigma. People

also felt there was sometimes a presumption of how someone with dual diagnosis would present to services."

Facilitators

None reported.

6.6.2 Integrated approach to care

Barriers

"Identification of dual diagnosis, both in mental health or drug and alcohol teams and in other health settings was also raised. Often the focus seemed to be on one problem only, with little acknowledgement of any other underlying needs. This had led to delays in accessing appropriate services and long, circuitous routes to the right support."

"Often I have been told that the mental health service can't do any work with me until I address my alcohol use, but the drug and alcohol service say they can't work with me until I address my mental health - but the two issues have been linked to one another so this makes it difficult and also becomes a game of "ping pong" where I bounce between the two services."

Facilitators

"People wanted support that was tailored to their needs and where services worked more closely together. One respondent talked about their local area, where funding cuts had led to the community mental health team and drug and alcohol service operating out of the same building. This had led to a much more integrated approach, with both teams realising they could improve outcomes by working together. This was echoed by other respondents, who felt that a more holistic approach was required. Where this more joined-up approach was available, people had seen clear benefits."

My mental health service has a good understanding of what is (and what is not) available locally to help support my needs around alcohol as they attend regular meetings with the local drug and alcohol service. This means that when addressing my mental health issues, or wanting to look at maintaining my wellbeing as a whole, I have been able to discuss the whole picture with my mental health workers.

6.7 Emotional support, empathy and respect

6.7.1 Relationships with healthcare professionals

Barriers

"Where dual diagnosis had been identified, people expressed a frustration that there was often a rush to 'blame' drug or alcohol use for mental health problems. This does not reflect the complexity of their experience. Many responses talked about drug or alcohol use as a coping strategy for the symptoms of mental illness, especially in the context of not accessing appropriate services when needed."

Facilitators

"Where people had had experiences of health professionals listening to them and not rushing to conclusions, the results had been positive. Many people indicated that they would like a more open, non-judgmental dialogue with health professionals, with their concerns being taken seriously."

"I have become so well that I am no longer under mental health supervision and I am no longer abusing alcohol. It has taken a long time to get there but I will always be massively grateful to the two people who looked beyond the alcohol and saw the struggling person."

6.10 Effective care delivered by trusted professionals

6.10.1 Failure to provide information to family/carers

Barriers

"A number of responses, both from carers and others, highlighted the lack of support available to carers. Many felt that they were left to step in when the people they supported fell through gaps in services. This put a lot of pressure on carers and they were unclear where they could get support for themselves."

Facilitators

"[Services should:] Encourage patients to involve family with their care plans. Liaise with family members. Inform family members when patient's health is obviously deteriorating. Take a common sense approach to confidentiality and contacting relatives to maintain the patient's safety. Advise relatives as to how best they can help."

Sorsa & Åstedt-Kurki (2013) [+]

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

“The participant felt annoyed at people who wanted to help her, or whom she regarded as feeling pity for her life situation (...). [This] creates a barrier to the use of services. She preferred to manage her problems herself”

“The experience of disbelief in receiving any help was rooted in a deep-seated mistrust of the workers in the social and health care services. She claimed that she was incapable of letting anybody come too close to her as a person.”

“One reason for avoiding the services (...) was the fear of the children being taken into care. This fear became a reality at a psychiatric hospital when a social worker enforced the taking into care of one of her children.”

Facilitators

None reported

6.9 Involvement in decisions and respect for preferences

6.9.1 Service user-focused approach

Barriers

“When her story became known to local social workers, she lost her freedom of choice and the services assumed a stronger role in counselling. The system enforced the use of specific services, and she was not allowed to choose them. She felt discouraged by the service system, but found out that adjusting to the rules was necessary so that she could regain custody of one of her children.”

Facilitators

None reported

Tsai et al. (2010) [+]

6.3 Attention to physical and environmental needs

6.3.1 Housing issues

Barriers

“Three [service users] reported having no choice because of a court order or miscommunication between staff. Although few clients felt forced into housing, many (40%) described having few to no housing options.”

“Housing options were provided by treatment staff or through their own searching, and sometimes these were superficial options (e.g., choosing dirty halfway house or own clean apartment).”

“Clients moved from place to place based on what was available and where treatment providers suggested they go.”

“Clients often said they did not think or ask about other options, because either they did not care at the time due to their desperation or they did not realize there were other options. For example, when one client in supervised housing was asked why he did not get his own apartment, he responded, “I didn’t know about anything like that. I was offered just the one avenue. I didn’t know about any other thing, and at the time, it didn’t really matter, to get off the streets was good. You don’t think about things like that, especially if you don’t know those options are available. But you’re not picky at that point in time”

“Negative experiences and perceptions of housing also played an influence on where clients chose to live. Five out of 14 (35.7%) clients in apartment housing expressed negative perceptions or experiences with group living, and did not want to live in that type of housing.”

“Barriers to housing were mostly reported in the context of seeking independent housing. Financial factors emerged as a major barrier, mentioned by 24 (60.0%) clients. As one client succinctly put it, “living circumstances is demographics ziplocked in economics”

“Financial factors included low income, waiting for government benefits, bad credit, and whether apartments accepted housing vouchers (e.g., Section 8 which is a federal rental subsidy).”

“Other barriers to independent housing included criminal history (...). Six clients reported that their criminal history created difficulties with finding and being approved for independent housing.”

“If you have a landlord that knows that you might have an illness, I got a feeling that they look at people differently so that pushes them to go wherever they can be accepted. There’s a hotel down here don’t accept people from Thresholds. I mean, I guess, somebody went in there and did a couple things wrong... That’s got to quit because people should be able to have the opportunity to live where they want to live. If they can afford the rent, live where they want to live without having a label on their door, you know, or a cross or something, written in blood to watch out for this individual.”

“The only barrier described by clients seeking supervised housing was the waiting list for some of the units.”

“Reasons for preferring supervised housing were structure, a substance-free environment, and staff and peer support.”

“Because I need policing. You know, I need policing, I need somebody to help me stay on the right track. And without their policing, I don’t know, I’d probably still be out there trying to sleep in the cold, or somebody else’s house where they didn’t really care about me. They just wanted me for the money once a month and the rest of the month, they talk to me like I was stupid or like I’m crazy.”

Facilitators

“Almost all clients reported they had a choice about moving into their current housing, i.e., they did not feel obligated or coerced.”

Villena & Chesla (2010) [++]

6.3 Attention to physical and environmental needs

6.3.1 Housing issues

Barriers

“Informants who lived in SRO hotels perceived their unstable, unkempt, and crime-ridden housing and neighbourhoods as barriers to improving and/or maintaining their health. (...) The eight SRO hotels that served as recruitment sites for this study are located primarily in undesirable sections of the city and those with the highest crime rates.”

“Patrick lived in an SRO hotel where the property posed health risks like rodent and bed bug infestations. He described how his current living situation, specifically the uncontrolled bed bugs, led to severe mental distress and to “the verge of a

breakdown at one time.” (...) Thus, his bed bug infested housing created a domino effect on his health in that it impacted both his mental and physical health.”

“The bed bugs got in all my belongings. I ended up being moved into 5 different rooms. It was like torture.”

“[A]ll of the SRO hotels in this study were wet housing [where drug/alcohol use were tolerated]. However, informants commented that this type of social milieu made it more difficult for them to avoid the temptations of drugs/alcohol. (...) For those individuals who were in recovery, it became easier to relapse.”

Facilitators

None reported

6.5 Continuity of care and smooth transitions

6.5.1 Fragmented care

Barriers

“(...) the ever-changing assignments of health care providers and their inconsistent presence created fragmented relationships and made it difficult for individuals with COD to trust them.”

“I got some therapy through interns at this programme (...) [a]nd after getting a good feeling with this person, as far as him understanding where I'm at ... all of a sudden, his internship was over. (...) I felt like I'm being abandoned.”

Facilitators

None reported

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

“Although he trusted his case manager and psychiatrist, he was skeptical of his medical doctors.”

“I distrust doctors (...). My biggest obstacle is finding trust in somebody who's supposed to be there to help you, not just collect a big check.”

“[Leila] perceived that her appearance, her mental history, and alcohol addiction contributed to difficulties in obtaining adequate diagnosis and care for her health. (...) Repeatedly, Leila's clinical presentation led her to be treated as if she were psychotic when, in fact, she was in severe withdrawal with and delirium tremens.”

“I feel that a lot of them misdiagnose you (...). As much as you tell them, they don't listen because the way you look. I mean, I got so bad with drinking that I would have urine on me. They don't give you the adequate treatment that I believe is deserved.”

Facilitators

None reported

6.6.2 Integrated approach to care

Barriers

“Informants underscored the importance of incorporating past histories (i.e. trauma), their financial status, their housing status, and/or their health insurance coverage when providers structure their treatment plan.”

“Experiences with health care providers described by informants suggest that providers do not comprehend their vulnerabilities and competing needs.”

Facilitators

None reported.

6.8 Fast access to reliable health advice

6.8.1 Service structure

Barriers

“Accessing and navigating the health care system is a challenge for anyone, especially for those afflicted with mental illness and substance abuse. Although most participants were fortunate to have health insurance, understanding the health system was a barrier in coping with their health.”

“Many individuals with COD (...) are at risk of having their services denied. Informants in this study indicated that the clinic and hospital bureaucracies were impasses in managing their [physical] health. (...) A missed appointment resulted in a reprimand and denial of further services. (...) Whatever the reason, it is clear that

the VH's [Veterans Hospital] rules were poorly constructed for a person with COD, who may not always be able to keep medical appointments.”

“They said that I missed an appointment, and I couldn't have my pills. I have to take pills for cholesterol and heart (...). I went without them for a whole month. (...) She schedule me a month later. And that irked me. It really pissed me off 'cause I coulda died within that month.”

Facilitators

None reported

VoiceAbility (2014) [-]

6.5 Continuity of care and smooth transitions

6.5.1 Fragmented care

Barriers

“In the last few months I had a breakdown. I went to [a crisis house] for 4 months with their crisis team. We sorted out my flat. Since then, they said they'd get me a [community psychiatric nurse], but I haven't heard anything. I was promised everything (...) it never occurred. (...) It's like I've been left, it's like they think 'now you've recovered' (...) I'm scared i'll reverse back into it.”

Facilitators

None reported.

6.6 Effective care delivered by trusted professionals

6.6.2 Integrated approach to care

Barriers

“They just look at my mental health, not any drugs I may use. I've had counselling at the [mental health] day centre and mentioned these things to them, it's just gone over their heads.”

“My old day centre was great ... alcohol units [are] not so good. [You get] 12 weeks, and [then] you're gone. You miss a few sessions, and that's it ... [and] you can't get counselling elsewhere for non-alcoholic related issues, because you drink too much!”

“The alcohol service were great, but they didn't acknowledge my mental health difficulties. I discovered they were massive when I stopped drinking. I was doing a detox, but no-one said 'you could probably see someone about the voices.' That's why I relapsed, I thought, I need to have a drink. If they had worked together my recovery would have been much better.”

“I had to pretty much hide my substance use, so it didn't affect my referrals.”

Facilitators

“I've had great help in dual diagnosis (...) when I moved to Camden they referred me to Response - a street project, they'd support you with drugs if you have mental health problems (...) I have a key worker, a psychiatric doctor I can see whenever I need, and a helpful GP. I have a care coordinator for my prescription. He helps me with my benefits, any appeals or tribunals ...maybe I've been lucky to be referred to this agency (...) I can call during the week. I know where the help is, I can get support.”

Neutral

“I want my doctor and keyworker to liaise. I very rarely see the same doctor but my relationship with my keyworker is very consistent and I always see the same lady, whom I get on with extremely well.”

6.7 Emotional support, empathy and respect

6.7.1 Relationships with healthcare professionals

Barriers

“I was 23, my GP was quite a bit older. She just asked, 'have you been taking drugs?' She was very accusatory (...) I was terrified about getting told off (...) I talked to my GP about my mental health and lied about my drug use – ‘it's just a bit of weed’”

“People in mental health don't want you to drink. You're trying to see someone and be honest but it means you can't get support. Mental health don't accept that you have a drink to help you handle stuff.”

Facilitators

None reported

Warfa et al. (2006) [+]

6.6 Effective care delivered by trusted professionals

6.6.1 Care environment

Barriers

"Some participants mentioned that they used support or alternative services, often culturally specific. AA and IM used Somali support services, while BM visited an Ethiopian community centre. AA and IM also used more general support drop-in services, as did MA."

"Some participants believed that better cultural awareness and sensitivity could improve mental health services. AA thought that there should be more services like that of the Somali support he received. IM asked specifically for a Somali social worker."

"My whole life depends on this because I can't speak to them in Somali. I would have liked to have a Somali social worker, that is what I would have liked to have ... The only thing I would have changed in the system is if I have a Somali social worker, I can't come and see [the support worker] every day. (...) 'I would have liked people [health providers] to know about my culture and I know about their culture.' (IM, Somali).

"The majority of interviewees were encouraged by their healthcare providers to stop using drugs or alcohol, but rarely reported specific advice or specific intervention to deal with substance abuse. BM and DA stated explicitly that no practical advice was given to them."

"Both black Caribbean participants remarked that hospital staff and other health professionals showed a lack of sensitivity with regard to culture."

"Others felt that their health professionals could provide more time and care. AA and MA both stated a need for regular home help. DD (black Caribbean) and MA (white British) both stated that they felt that not enough time was being spent with them in the meetings they had with their clinicians."

"They didn't wanna know what was on my mind and that, just trying to get me out in about 5 minutes ... you did sort of feel like you wasn't part, you were just like a number, basically all you was a name of a client, service user, you weren't a person."

"They're supposed to have leaflets out there saying no weed ... they ain't got it."

"My religious needs. They're not recognising things ... because they come from a different society than what I've been brought up in; they believe in some way that they're controlling me just because they got me here (...)"

Facilitators

None reported