Patient Journey of Service Users with Complex Mental Health Needs: A Qualitative Study

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Acknowledgements

This report is the work of members of staff from the School of Psychology at Liverpool John Moores University, with the collaboration of Cheshire and Wirral Partnership NHS Foundation Trust. The aim was to explore service user and carer perspectives on out-of-area placements and their overall experiences of care for complex mental health needs.

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Executive Summary

Introduction

Cheshire and Wirral Partnership NHS Foundation Trust (CWP) provide a wide range of community and inpatient, physical, all-age disability and mental health care services. The Trust also provide care to a specific cohort of patients who have been defined as having complex mental health needs. This is a broad term used to describe patients who currently receive a package of care commissioned by NHS Cheshire CCG either in an inpatient or community setting, as well as new referrals into the NHS continuing healthcare service who are eligible for NHS funding. This includes patients who are detained under Section 17 of the Mental Health Act or Section 117 aftercare, or who are out of scope, have learning disabilities, are children, those living with dementia who do not have complex or specialist needs, those with acquired brain injuries and those with physical disabilities.

Mental health services for adults, as they are currently configured, have been designed to provide predominantly community-based interventions. It has long been recognised that patients with complex mental health needs cannot be adequately supported within standard service delivery models, resulting in a pressing need to consider the best models for this group of people. Unfortunately, there is a paucity of information on the experiences of the service users themselves, particularly in respect of those with complex presentations. With this in mind, the present study aimed to evaluate the perspectives of service users and carers with lived experience of specialist placements, as well as their overall experiences of care.

Evaluation

Qualitative data was generated through in-depth interviews with eleven service users with complex mental health needs and ten carers of those with complex mental health needs. The interviews explored their perspectives and views of their experience of contact with relevant services and of the way treatment decisions were made in respect of their care.

Main Themes

Theme 1: Relationships with staff

- Benefits of positive interactions with staff.
- The importance of strong therapeutic relationships.
- Disparity in staff attitudes.

Theme 2: Treatment options, pathways and availability

- Early intervention in childhood.
- The impact of receiving a mental health diagnosis.
- Benefits of appropriate intervention.
- The importance of timing in respect of therapy.
- The need for structure.

Theme 3: The role of autonomy in recovery

- Involvement in treatment decisions (or lack thereof).
- Lack of person-centred care.
- Over-reliance upon medication by staff.

Theme 4: Improving staff training and risk assessment skills

- Training to reduce suicide attempts following discharge.
- Suicide prevention staff training.
- The need for specialised training.
- Reducing stigma.

Theme 5: The impact of out-of-area placements

- The social impact of out-of-area placements.
- Benefits of local placement for family visitation.
- Complexity as a barrier to support.

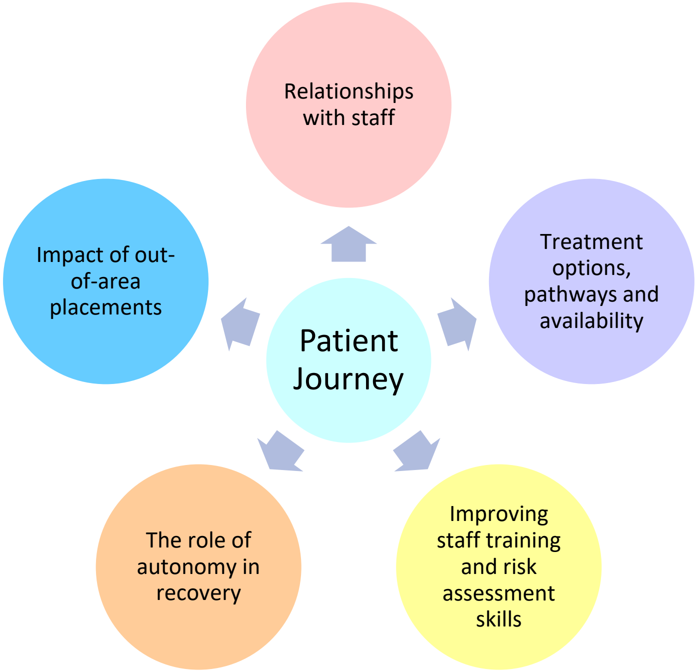

Figure 1. Patient journey themes diagram.

Impact of Study

The voices of service users with complex mental health needs and their carers have largely been excluded from discussions around service evaluations, with only a few studies focusing on the perspectives and experiences of these individuals. This study gave eleven service users and ten carers the opportunity to have their voices heard. As a result, recommendations for improving future practice were made by those with first-hand experience of the services. These recommendations focused upon improvements that can be made in respect of staff training, out-of-area placements, co-production between service users and staff, and increased support for service users and their families upon discharge into the community. It was demonstrated that strong therapeutic relationships have a considerable impact on both service users and their carers, and that tailoring treatment plans to suit the individual and their complex needs can have a positive impact upon their recovery journey, as evidenced by the following service user quotes:

> "Some of the staff members that have helped me over the years, if it wasn't for them, I wouldn't be here. […] You just don't ever forget those staff members because you knew that, if that staff member hadn't been there, then you wouldn't – I wouldn't – be here now."

> "I think person-centred is a very big thing and I think people don't value it enough. It helps that service user feel valued and they think, 'they are listening to me. They are taking in my experiences and who I am, not just treating me based on my diagnosis.'"

Recommendations and Future Directions

The following recommendations (see Figure 2 below) were put forward by the service users and carers and should be implemented in future practice where possible:

Recommendations	Staff to support in the building of strong therapeutic relationships by demonstrating mutual respect, encouragement, honesty and transparency.
	The importance of early intervention to be recognised and for psychological support to be offered more routinely in childhood and adolescence.
	The importance of structure, boundaries and routine to be recognised and promoted by staff e.g., regular visits and pre-arranged activities.
	Service users to be given more autonomy in respect of their care, particularly in respect of concerns about medication and side effects.
	Increased support for service users and their families upon discharge into the community and additional training for staff to support with this transition.
	Person-centred care to be prioritised e.g., individualised care plans and therapeutic approaches.
	Staff training on stigma and managing self-harm and suicidal behaviours e.g., de-escalation techniques.
	To consider the option of having a link to home communities for those in OAPs e.g., ongoing contact with a CPN or psychiatrist.
	Patients to be given a choice about how their problems are formulated (e.g. diagnostically, dimensionally or in terms of a psychosocial formulation).

Figure 2. List of recommendations for implementation, based on service users and carer interviews.

1. Background

1.1 Who are CWP?

Cheshire and Wirral Partnership NHS Foundation Trust (CWP) provide a range of services, in both inpatient and community settings. These include mental health, physical health and learning disability services within Cheshire, Wirral and neighbouring areas. The Trust also provide specialist services within Liverpool, Bolton, Warrington, Halton and Trafford.

1.2 Patients with complex mental health needs and out-of-area placements

Currently, adult mental health services include inpatient units, rehabilitation services and community-based interventions. Community services may include additional provisions that can be accessed depending on risk or diagnosis assessments. People with complex mental health needs often have such significant clinical and/or risk needs that they cannot always be adequately met by such generic services. Some service users experience a mix of mental health problems, and they may require extra care or support to manage those problems. Recent recommendations for effective support from mental health services suggest that individuals presenting with complex behavioural and mental health needs are less likely to receive the provision of care they require due to their need for longer-term, highly specialised support (Department of Health, 2007). The majority of these people have a diagnosis of psychosis, severe negative symptoms, and cognitive impairments. Many also have co-existing mental health problems and physical health concerns resulting from poor lifestyle conditions and side effects of psychotropic medication (Killaspy, 2014).

There are many different types of support and treatment that can be provided for these individuals, but it is not always clear which is the best to offer. When a patient is ‘placed’ in an out-of-area placement (OAP), it is usually because it is not considered that there are suitable psychiatric services in their home area. Often, such placements can result in the patient being moved a significant distance away from their home, away from local services, family and friends. Gaining an in-depth understanding about service users who have such complex needs and the experiences of the care they have received will help us to think about how services should be best delivered in the future.

Individuals presenting with complex needs are often accommodated in OAPs that are a long distance from their loved ones and communities (Chinn et al., 2011), due to the inability, or arguably the unwillingness (Allen, 2008), of local services to meet their needs. There are growing concerns about the impact of OAPs on service users, both clinically and financially (Rambarran, 2013). In addition to being costly to the NHS and local social care authorities, individuals placed out-of-area can become socially dislocated, achieve poorer outcomes (Beadle-Brown et al., 2005), experience disruptions to their lives (Galante, Humphries & Molodynski, 2019) and, in some cases, be over-supported (Rambarran, 2013). The issue of distance can also cause complications for the ‘home’ services who made the referral, as it can be difficult to maintain contact regarding the suitability of the placement and the person’s care, which can hinder their rehabilitation and eventual reintegration into their home community (Care Quality Commission, 2019; Chinn et al., 2011).

In 2016, the Department of Health pledged to eliminate all unnecessary mental health OAPs by 2021 as part of the Five Year Forward View; however, the latest figures demonstrate that, if anything, the numbers are rising (Mahase, 2019). In 2018, £112 million was spent on OAPs, with 6% of placements deemed inappropriate (Mind, 2019). One of the main reasons for the reliance upon OAPs appears to be a lack of local services offering specialised support (Chinn et al., 2011); however, this is likely to be due to a lack of incentives for providers to develop local services, as well as a tendency towards risk avoidance and financial incentives to place individuals elsewhere (Beadle-Brown et al., 2006). Modelling research suggests that, with adequate funding of community-level treatment, we can reduce the length of stay and referral rates to OAPs in the future (Paton & Tiffin, 2018). As little regulation exists surrounding such placements, and because OAPs are often viewed as a way to contain those that NHS services find troubling (Care Quality Commission, 2014), the patient experience needs to be examined.

There is a paucity of information on the impact of OAPs on those with complex needs, with only a few studies exploring the experiences of the service users themselves. Unfortunately, individuals with challenging behaviour and intellectual disabilities are often excluded from participating in service evaluation, despite their ability to offer useful insight into possible adjustments and service improvements (Chinn et al., 2011). With this in mind, the present study aimed to evaluate the perspectives of service users and carers with lived experience of specialist placements, as well as their overall experiences of care. This study is part of a larger, mixed-methods evaluation using descriptive and inferential analyses of patient records and written medical notes, as well as conducting in-depth interviews with clinicians; however, this report will focus solely upon the qualitative interviews with service users and carers.

2. Methodology

2.1 Design

This study employed a qualitative approach, using semi-structured interviews to explore the experiences and perspectives of service users with complex mental health needs and carers of those with complex mental health needs.

2.2 Participants

Eleven service users and ten carers were interviewed about their experience of contact with relevant services and of the way treatment decisions were made. In terms of inclusion criteria, it was a requirement of the study that participants were recognised by the Trust's clinicians as having complex and long-term recovery needs and long-standing mental health problems, or caring for someone with these issues, who may have been placed out-of-area in the last five years. Participants were excluded if they were under the age of 18 or were unable or unwilling to provide written informed consent to participate in the study (see Figure 1).

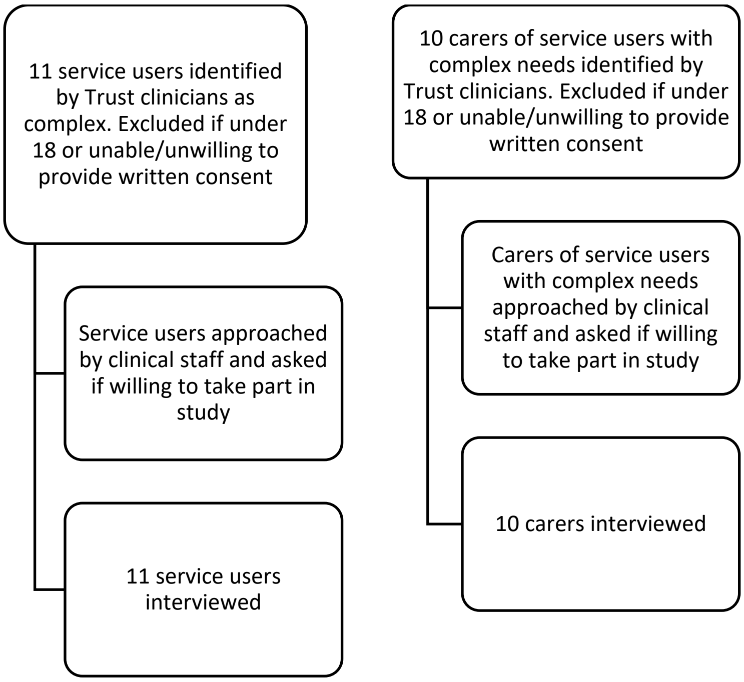

Figure 1. Recruitment process for qualitative study.

2.3 Procedure

Participants were given a participant information sheet and consent form to sign prior to taking part in the study. Once written consent had been provided, the interviews were undertaken remotely, due to ongoing COVID-19 restrictions. The interviews lasted between 15 and 79 minutes and were carried out between August 2021 and April 2022.

Semi-structured interview schedules were designed with questions to facilitate discussion about experiences of care and decision-making. During the interviews, participants were asked in general terms to discuss their experiences of contact with mental health services, as well as the care they received. Prompts were included to guide the discussion if necessary, covering areas such as involvement in decision-making, autonomy, placements, psychological therapies, relationships with staff and experience of discharge. Interviews were recorded using a digital audio recorder and transcribed verbatim. Recordings were stored in a password protected file. Participants were given pseudonyms to anonymise interview data.

2.4 Data Analysis

With appropriate ethical approval and the participant’s permission, the discussions were recorded, transcribed verbatim, and subjected to thematic analysis. Transcripts were checked against the audio files for accuracy by AB and HR, who conducted the interviews. The analysis of all transcripts was conducted and discussed by seven members of the research team, each with different disciplinary backgrounds (PS, TN, LS, AB, HR, JT and PAM). The data were analysed following the principles of qualitative thematic analysis using NVivo software (Braun & Clarke, 2006), adopting a critical realist perspective and using the framework approach.

The iterative coding process enabled the continual revision of themes until the final classifications of major themes were agreed by the team. During repeated rounds, frequent comparisons were made across codes and the interview data to develop, review, and refine themes (Braun & Clarke, 2006) on the basis of the complementarity, convergence, and dissonance of ideas across data sources (Farmer et al., 2006). To establish procedural reliability and conceptual credibility (Leung, 2015), additional members of the research team with experience in qualitative methods examined a sample of transcripts to compare their perceptions of the interview data and analysis with the main analyst's interpretation. All findings were critically tested within the research group and any disagreements were resolved by discussion.

2.5 Ethical Considerations

Ethical approval was obtained from the NHS Health Research Authority and Research Ethics Committee: Integrated Research Application System (IRAS) prior to study commencement [REC Ref: 21/WM/0020]. Ethical approval was received in March 2021 from HRA and Health and Care Research Wales (HCRW). The study was undertaken in compliance with the research protocol at all times. Personal data were documented on a password protected and encrypted computer and all personal data were handled in line with the General Data Privacy Regulation (GDPR) legislation.

The appropriate steps were taken to ensure the safety of the participants and researchers throughout. All participants were informed they did not need to answer any questions they did not wish to and that they were free to withdraw from the study at any time without detriment to themselves. The study design and materials were reviewed by individuals with lived experience of complex mental health difficulties. The researchers also ensured they had support and escalation procedures in place if they were concerned about their own feelings around participants' comments, and robust reflective and supervisory practice was followed at all times.

3. Findings

The service users who took part in the research were predominantly men (N = 7) and from white British backgrounds (N = 10). One of the service users had a diagnosis of Asperger's Syndrome. The carers were predominantly women (N = 7) and their ethnicity data was not collected. At the time of the interviews being conducted, seven of the service users were inpatients and four were living in the community.

Following the thematic analysis process, five key themes were conceptualised regarding the patient journey of care for complex mental health needs. These themes were as follows: (a) relationships with staff, (b) treatment options, pathways and availability, (c) the role of autonomy in recovery, (d) improving staff training and risk assessment skills, and (e) the impact of OAPs. These themes were present in each transcript to a varying extent. Whilst the majority of participants were happy to share personal details of their care experiences, others appeared more comfortable focusing the discussion on practical aspects of care. In the latter case, data analysis involved more interpretative work on behalf of the researchers to examine underlying ideas. For ease of understanding, all participant quotes will be accompanied by a pseudonym and identified as either a service user (SU) or carer (C).

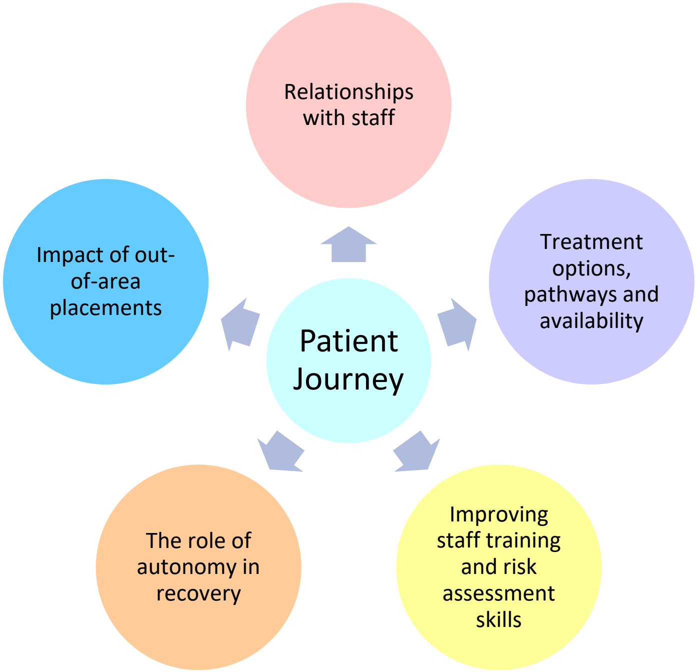

Figure 2. Patient journey themes diagram.

Theme 1: Relationships with staff

Benefits of positive interactions with staff

Irrespective of their overall opinions of the care they had received, all service users were able to provide examples of positive interactions they had had with staff members, including psychiatrists, nurses, occupational therapists and psychologists. This was also discussed by some of the carers, but to a lesser extent. A common theme appeared to be the willingness of staff to make time for service users, even in the simplest of ways, such as asking them about their day, displaying genuine interest in their lives and comforting them when they were upset:

> "When staff members made the extra effort to show an interest in you or to help you through something that you were struggling with, that was definitely really helpful. Just being validated in how you felt." – *Chloe (SU).*
>
> "I can't fault the staff here, they're really good. What makes them good is they'll come and have a chat to you if they can see you're a bit down or something. […] They're always trying out activities for you, they always like to get you out and about, you know, they don't want to see you just lounging around. They're always up and doing things for you, which is good." – *Trevor (SU).*

> "I think it's just the fact that they can listen to you, and they are non-judgemental. It doesn't matter what you say, they won't freak out. They are just there to support you and listen to you, and not judge you and not panic if you've a symptom." *– Chelsea (SU).*

Some service users valued staff members taking a more active approach towards their care; for example, not only listening to their problems, but also providing advice and "helping with issues on the ward too" (Sam, SU). Jacob (SU) discussed how he particularly appreciated it when a member of staff recognised that, due to his difficult family background and diagnosis of emotionally unstable personality disorder, he would benefit from supportive boundaries being implemented and short-term goals being set in order to support him in feeling safe as an inpatient. Although most participants were able to identify instances of unhelpful staff attitudes, it appeared to be positive interactions with staff that they remembered most:

> "Some of the staff members that have helped me over the years, if it wasn't for them, I wouldn't be here. […] You just don't ever forget those staff members because you knew that, if that staff member hadn't been there, then you wouldn't – I wouldn't – be here now." *– Chloe (SU).*
>
> "Well, since I've been in the hospital system, I've had lots of psychology OTs dealing with me, and they have helped me. Some of them have really helped me." *– Micah (SU).*
>
> "I can't thank the staff enough. They've been wonderful. I have a really good psychiatrist who listens very intently, and he is brilliant. I get on really well with the psychologist and the occupational therapists, and my CPN. They are all absolutely brilliant." *– Chelsea (SU).*
>
> "Probably the most useful thing that happened to us as carers, in those early days – this was in the private hospital – I think it was a registrar sat us down and said, 'well, this is what it looks like now, and I know you think you've lost your daughter forever, but at some point in time, believe you me, things will improve, and do things that hopefully she'll be able to achieve in the future.' But I can't tell you how beneficial that was, I have to say." *– Percy (C).*

Some of the carers were mindful of environmental stressors on staff members, possibly as they were able to be more reflective on their experience as a whole in comparison to the service users, and appreciated staff for not letting this impact their job performance:

> "The staff at [hospital name] are, on the whole, incredibly lovely and want the best, and work incredibly hard under huge pressure." *– Andrea (C).*

The importance of strong therapeutic relationships

Building upon the previous sub-theme, some participants were able to provide examples of what they believed to be factors indicative of a strong therapeutic relationship. Common desirable qualities discussed were a level of mutual respect, honesty and transparency. Service users appreciated it when they felt included in the decisions that were made about their care and were kept informed about any changes. Carers also valued this, provided that their loved one wanted them to be involved in these matters. Jacob (SU) discussed previous unhelpful experiences with staff and recalled how he would feel let down if they were unable to attend appointments or follow through with agreed plans. He explained how it made a positive difference when a member of staff was honest with him and treated him with respect by explaining to him why plans had changed and what would happen instead. Chloe (SU) spoke in detail about a strong therapeutic alliance she had built with one particular team:

> "I was fully informed about what I was taking and why I should be taking it. It felt like they had my best interests in mind, because they explained to me how it would work. […] They did things very gradually and one step at a time and made sure that you were really ready and able to cope in the community before they would let you go, which I think was really, really good for me." – *Chloe (SU).*

As Chloe (SU) explained, the strong therapeutic relationship that she had built with her team resulted in a positive outcome in terms of her care, as she felt supported and ready to return to living in the community due to their personalised treatment plan. She also stressed the importance of therapeutic relationships later on in her interview:

> "I think that, if staff members were more encouraging, and more understanding and had more time for the patient, I think that therapeutic relationships would more likely be formed. Obviously, those therapeutic relationships are what ultimately get you to a place where you start getting better because you trust the people around you. You feel like you're working with them to help you recover, rather than working against each other and having that patient and staff divide." – *Chloe (SU).*

Other service users chose to speak more specifically about particular clinicians they had built a strong therapeutic relationship with and the positive impact it had had on their care, as well as discussing the qualities that had contributed to the building of such relationships, such as that of co-production of treatment plans between service user and clinician. This was echoed by some of the carers, who noticed their loved ones' symptoms improve as a result of working with certain clinicians and teams:

> "I probably speak about [clinician name] a lot because I've got a lot of respect for him. I think he's a very, very good psychiatrist. He does a lot of positive risk-taking. He takes into account everything you want and he's very patient. He was very much on board with me doing as much as I possibly can." – *Jacob (SU).*

> "The therapy staff she's had, so the psychologist… her psychologist, her social worker, her named nurse, have all been really, really good and she's developed really good relationships with them to be able to, obviously, disclose what's going on and speak to them." – *Ruth (C).*

> "That hospital, to us, was fantastic. We'd got [doctor name]. None of the tactics that were used at [hospital name], like interrogation by doctors, interrogation by psychologists, were used at [hospital name]. They stepped back, they let [service user name] have a little bit of rage, watched how he reacted. And [service user name] flourished in [city name]." – *Betty (C).*

The carers highlighted the need for consistency in the building of strong therapeutic relationships. This often proved difficult during times of high staff turnover, for example, during the COVID-19 pandemic. They felt the pain of their loved ones when trusted members of staff left and often watched their symptoms deteriorate as a result of this, with some service users refusing to engage with new teams:

> "When people are suffering from mental health issues, they need to have somebody that is there for them, not 27 people who don't have a clue who she is. They need one person, who

> really knows what's going on. […] To get the therapies into place, you need to build up a therapeutic relationship with them. And because of COVID and lack of staff and shortages, you don't build that up. So, it's this vicious circle." – *Amanda (C).*

> "So [doctor name] threw everything away, he put the building blocks in, to rebuild [service user name]. All the stuff that was written about it, the observations – half of them absolute rubbish – he put it to one side, and he started to build [service user name] up again. We got him right back again, on his bicycle, cycling. [Doctor name] was going to look at his discharge and everything, he was going to handle everything. And then what happened, once again? He leaves." – *Betty (C).*

Disparity in staff attitudes

An element of care that all participants focused on was disparity in staff attitudes, although some were more subtle than others in their descriptions of this. An underlying theme of the discussions was the expectation participants held about what a healthcare professional *should* be like and the qualities they *should* possess, with some staff members falling short of their expectations. Matthew (SU) described feeling as though the majority of staff in one of his placements were "just there for the wages" and Jacob (SU) provided examples of staff members presenting as unavailable, uninterested and lacking in engagement, which he found disheartening. As outlined previously, the types of staff qualities appreciated by service users and carers were kindness, compassion, transparency and being willing to listen and provide advice if needed. Participants, on the whole, appeared to hold the belief that, in order to work in the field of mental health, you should be a naturally caring person, and it was interactions with those that did not appear to have an empathic nature that they found distressing:

> "Some of them, I get really good relationships with, and I can talk to them about anything, or they can help me when I'm having an incident and I'll instantly stop. But then I do have bad times with some of the staff that are quite rude and disrespectful towards yourself, and just overall, not nice people. I don't see why they're working in a job where you've got to care for people if they're not caring." – *Sarah (SU).*

> "Just staff that you could tell weren't in the job because they cared, but just because it's a job for them […] You could tell the difference between people who loved doing the job and did the job because of the job, and who were just there to make a bit of money, because some people would just want an easy shift. So, they just drugged people up so that they would sleep, and so that they could have an easy shift and go home, whereas the people that genuinely cared in their jobs, they would go above and beyond to help other patients or make that time to spend with people." – *Chloe (SU).*

> "Well, friendly qualities: nice, pleasant. They're the qualities that they need when they are mental health staff. Friendly, caring attitude, or they shouldn't really be in the job, should they?" – *Micah (SU).*

> "There were some fantastic nurses but, again, yes… she absolutely… yes, you just think, 'why are you in this job?' […] I mean, where she is now, we've just received, this morning, a reply to a letter of complaint about their staffing, staff falling asleep on duty. You think, she's on a one-to-one, you punish her because she's ligatured but her one-to-one is asleep, what's that all about?" – *Ruth (C).*

Jacob (SU) and Peter (C) took the time to consider the environmental factors that may have influenced negative staff behaviours, by contemplating the emotional impact of working in healthcare:

> "I think staff who are quite… I don't want to say rude, but I think you may know what I mean. I think that's due to them being so burnt out and they don't have the capability to be as compassionate all the time because it's draining for them." *– Jacob (SU).*
>
> "It's hard for people who work on the wards to take time to explain to you what's happening because they've got loads of other patients, do you know what I mean? And understaffed as well." *– Peter (C).*

Most of the service users reported experiencing care that they perceived to be unfair or unkind at some point in their treatment journey:

> "In [hospital name], they actively encouraged you, and were always there to help you and genuinely seemed to care, whereas in [hospital name], they just added to patients' traumas by using non-legal restraint techniques and saying some pretty awful things to get patients riled up, rather than trying to help them." *– Chloe (SU).*
>
> "The thing is, I know it's not best practice, but the staff were talking to me horrible, being horrible to me, treating me horrible, some of the staff, for about 18 months." *– Sam (SU).*

Theme 2: Treatment options, pathways and availability

Early intervention in childhood

The need for early intervention in childhood, or at least prior to the worsening of mental health symptoms, was stressed by seven of the participants. Sarah (SU) and Sam (SU) both expressed their frustration at how, as children, they felt their behaviour should have been acknowledged as an indicator of a need for additional support; however, they felt invalidated by the excuses people made for why they were acting the way they were:

> "I'd say it was hard to get help when you were younger because they just put it down to emotions and, oh, it's – what's it called – puberty and stuff like that." *– Sarah (SU).*
>
> "I was mentally disturbed from a young age at primary school, at secondary school, and it never really got picked up on. […] No one ever asked a question or questioned why I was behaving the way I was behaving; I was just treated as a young offender." *– Sam (SU).*

This, in turn, led to the service users engaging in even more extreme behaviours in order to manage their emotional distress. This resulted in a vicious cycle of offending and/or causing harm to themselves. The majority of service users believed that they could have recovered more quickly, or experienced less severe symptoms, if they had been offered an intervention earlier in their lives:

> "I definitely think that, if I had received the right help earlier on, that I would have avoided as many admissions and as long as I was in hospital." *– Chloe (SU).*

> "I think, because I was with the Early Intervention Team, they should've really been asking all the right questions and all that but that never happened, so we never got to the bottom of my problem, so I carried on offending." *– Sam (SU).*
>
> "I think an early intervention would have prevented being arrested in a psychotic episode. I think, in the community, I was ill for about three, four years before I had the psychotic episode. Early intervention would definitely have helped if they had taken it seriously in [city name]." *– Chelsea (SU).*

This was something the carers agreed with, arguing that, unless service users presented with very severe symptoms, they were not taken seriously:

> "Don't let the young person get to the point where they are at crisis before people step in and do something. […] I was begging people to help me. I didn't know who could help us. And it was only when she got to the point where she tried to kill herself, that people took her seriously. When a young person asks for help, they need to be treated there and then, not told, 'we've got a really high demand, and we'll see you in six months.' By six months, that family is in crisis, or that young person has killed themselves." *– Amanda (C).*

The service users did not go into detail about the interventions they would have liked to have received at the time; however, Sam (SU) did suggest that, instead of being asked surface level questions about how his week had been, it would have been more helpful if people had drawn attention to his behaviour and asked why he was acting in this way and how they could help him to break the cycle of offending. Christine (C) suggested that early intervention in schools could be beneficial for those with complex mental health needs, for example, providing education about mental health difficulties and available support to children and young teenagers. Amanda (C) agreed that early intervention prior to engaging with Children and Adolescent Mental Health Services (CAMHS) would be beneficial, in order to avoid service users being exposed to dangerous self-injurious behaviours on mental health wards.

Diagnosis

Another topic that was discussed at length with regard to treatment availability, early intervention and medication was the impact of receiving a mental health diagnosis. It was a topic that divided the participants, with some stressing the importance of having a diagnosis in terms of their sense of identity, and others discussing the hardship of being given a diagnosis they did not agree with, and how they had been treated differently depending on the 'label' they had at the time:

> "I guess what has been helpful is, first of all, a diagnosis. Once I received a diagnosis, I could then get the right treatment. For a long time in the community, they were like, 'personality disorder,' but they did the proper personality disorder questionnaire, and I don't have one, so that meant I was diagnosed with bipolar disorder. Then, after that diagnosis, I got the right treatment, so the diagnosis was important. […] They had previously diagnosed me with Munchausen's, basically […] saying I didn't have anything wrong with me mentally, but I couldn't get out of bed, I couldn't do things, so I knew there was something wrong, but they were like, 'there is nothing wrong with you,' so it was the diagnosis that really stuck." *– Chelsea (SU).*

> “I don’t like the treatment they give me because I don’t agree my diagnosis. They’re not accommodating my needs because they think I’ve got a SAD diagnosis, but I don’t think it is, my family don’t think it is, people don’t think it is. But they don’t listen.” *– Sarah (SU).*

> “Even in inpatient, they look at your diagnosis and they’re like, ‘he doesn’t need medication.’ I was having very bad mood swings and fluctuations, but they assumed it was just emotionally unstable personality disorder.” *– Jacob (SU).*

It became apparent from the discussions that different diagnoses were met with different feelings, such as relief, anger, or confusion, and that this was often linked to the stigma associated with certain conditions. The participants spoke about difficulties they had encountered in respect of diagnostic fluidity and how they found it difficult to manage when diagnoses changed, or they did not agree with the diagnosis that had been given:

> “When I wasn’t diagnosed properly, I was very keen on getting a diagnosis because I knew my diagnosis wasn’t right. You look at the criteria and I’m like, that’s not me.” *– Jacob (SU).*

> “[Service user name] has had problems since we adopted him when he was six. He was from a very abusive background in every way. Diagnosed with ADHD as a young child. Later on, diagnosed with Asperger’s. Then in his early twenties, diagnosed with schizophrenia. It’s been hard understanding all the changes and understanding what these diagnoses mean. […] All these diagnoses, and names given to it, it helps in the long-run with professional people, do you know what I mean?” *– Peter (C).*

> “They have now said, the psychologist has said, that she doesn’t have an emotionally unstable personality disorder. They’re seriously thinking she’s not autistic. What she’s got, and a lot of the traits are the same, is complex PTSD.” *– Ruth (C).*

In terms of cycling through different diagnoses, several of the participants were generally dismissive of psychiatry and felt that a diagnosis of personality disorder was a ‘catch-all’ diagnosis for which services struggled to provide appropriate support. Some viewed personality disorder as the chosen diagnosis for when they were not responding to treatment for another condition or were perceived as difficult to manage. Unfortunately, there appeared to be indirect consequences of this diagnosis, and it did not always equal optimum care. Some of the participants were quite reflective in their discussions and contemplated whether or not a diagnosis was helpful in terms of their sense of self:

> “Looking back, I can understand why I might have wanted to because it would have fulfilled that self-identity, which I wasn’t too sure about, and I wanted some confirmation. Whereas now, I don’t really think about my diagnoses. I look at it in a different way now. I can understand why someone might want a diagnosis. It’s comforting to know you haven’t made everything up. It gives you a sense of identity, I guess.” *– Jacob (SU).*

> “I don’t know, do you label people or don’t you? I don’t know if there is anything they can do apart from maybe just have more information out there, but then if you get labelled too soon, then you try to become that label.” *– Christine (C).*

> “It seems there’s a rush to diagnosis, particularly with young women coming in with complex mental health issues, which doesn’t necessarily fit. And getting the right diagnosis is also critical in terms of them getting the right treatment.” *– Andrea (C).*

Although diagnostic fluidity may be beneficial in practical terms, the participants evidenced their views that people can perceive others differently based on their diagnosis and that some individuals build their identity around their diagnosis in order to negotiate a better understanding of themselves. With this in mind, it may be helpful for clinicians to be mindful of the potential impact on the individual and their family when issuing or changing a diagnosis.

Benefits of appropriate intervention

A positive finding of the study was that some of the participants reported considerable benefits of engaging with therapy and the psychology team. Although it often took time to find an intervention that suited their complex needs, service users spoke of how their lives had changed for the better as a result of gaining insight into their thoughts and behaviours through appropriate intervention:

> "It was at a specialist personality disorder ward that I did DBT therapy, and it was the DBT therapy that got me better." *– Chloe (SU).*

> "It was the psychology, it helped me to understand myself and my inner workings and all that. […] When I did 'Life Minus Violence,' the big course, that was the one that really helped me because they helped me to… during the course, they helped me to understand that I was a victim. For years, I was in denial that I was a victim." *– Sam (SU).*

> "I felt the schema therapy was really suited towards my bipolar condition, because it went over things that happened when I was psychotic, which I felt ashamed about. It kind of rewired my brain into thinking less shame and guilt." *– Chelsea (SU).*

For some service users, such as Sam, Chloe and Chelsea, engaging with the right type of psychological therapy led to a dramatic breakthrough and the beginnings of recovery. Andrea (C) also told the story of her daughter's recovery as a result of trying a new form of brain-stimulation therapy called Repetitive Transcranial Magnetic Stimulation (rTMS), describing her as a "new person" after engaging with the treatment:

> "We took her to have rTMS in [city name] and she has basically been fine since Christmas, and she's now just been discharged. […] I can't tell you the difference it's made. […] So, we're now trying to work with the team at [hospital name], really, to get rTMS brought into [hospital name], to be available on the NHS so that more people can benefit." *– Andrea (C).*

For others, it simply resulted in feeling more able to communicate their needs to members of staff in helpful and productive ways, as well as having a better understanding of how to manage and de-escalate their symptoms. Service users spoke of learning how to problem solve effectively and recognise when they were feeling anxious, whilst others discussed how writing down their feelings led to better communication with staff. Despite this, some service users such as Catherine wished that psychological therapies were more readily available, expressing that she wanted "more time to talk it through at counselling sessions."

The importance of timing in respect of therapy

Whilst some service users such as Jacob were not offered any psychological therapies at all, which he described as an "unmet need," others were offered psychological support, but either felt that it was the wrong type of therapy for them, or that it was the wrong time for them to engage with the treatment. In respect of trauma therapy, several of the service users reflected on how this form of therapy could have helped them, had it been offered at the 'right time'; however, they disengaged when offered the treatment due to feeling unprepared to tackle their trauma:

> "The trauma work is really difficult to do because you have to relive your trauma and talk about it and stuff. I think it would have helped me, but I just wasn't in the right frame of mind at the time." *– Chloe (SU).*

> "I couldn't do anything properly before that at the medium secure. I was too unstable; they couldn't get me stable enough to even engage properly with the psychologist. […] I think the clozapine gave me the stability to then start to do my psychology, you know what I mean? I was too unwell to engage properly with the psychologist before that." *– Sam (SU).*

Some of the carers voiced their sadness and frustration at the situation, particularly when their loved one was in the position to be offered psychological support, but they were unwilling to engage due to the fact that the timing was not right:

> "She is supposed to be having DBT, CBT, MAD, talking therapies, but she just denies being ill and she doesn't access any of the help. Until the person admits that there is a problem, you can't put these therapies into place." *– Amanda (C).*

> "The sad truth is that when somebody's not very well, it's at the point where they're sort of least in the place to accept help and be open to it." *– Andrea (C).*

> "I think, sometimes, it's about the person. If they cannot really, straightaway, relive their trauma, and their trauma is there and they can't get it out, I don't know if there's that much that can stop them, at that point, of feeling that bad." *– Christine (C).*

This raises the question: does everything have to fall into place at the same time (such as medication, psychological intervention, positive relationships with staff) in order for an individual to feel they are recovering? The service users also mentioned other issues that contributed to the failure of psychological interventions, including high staff turnover and lack of specialised training:

> "I have done schema therapy. I didn't find that helped because it just made me worse, and they didn't know how to calm me down. […] They just let me talk about my past, and they didn't know what to say to help me because I'd get so upset." *– Sarah (SU).*

> "Whenever you get a psychologist, they always end up leaving after so long and you're never able to finish any piece of work, which is really debilitating." *– Jacob (SU).*

The need for structure

Adding to the discussions about the importance of appropriate intervention, service users also mentioned the benefits of structure in terms of their recovery. This was particularly important in inpatient settings where the service users described the days as long and uneventful. They spoke about how something as simple as having a visit from a family member or engaging with pre-arranged activities such as crafting or playing games could provide them with something to base their day around and look forward to, also serving as a distraction from their thoughts on bad days:

> "The visits were the only kind of structure that you would get in your day, so knowing that you had a visit later on in that day did help you have something to look forward to, rather than not having anything to think about other than what's going on in your head." – *Chloe (SU).*

> "There was no structure. That was where I deteriorated rather than got better, because for me, personally, I need to have a schedule for the day. […] They don't understand that being in an environment that is constantly unsettled does not help me. It's detrimental on my mental health." – *Sarah (SU).*

Another service user spoke about this in terms of boundaries and the need for person-centred care on the wards, as some patients may benefit from stricter boundaries than others:

> "If you're not used to healthy boundaries, if your parents weren't very nice and they'd taken advantage of things a lot, I think those people need very stern boundaries. Not restrictive, but healthy and caring boundaries which can give them some independence. On the ward, there wasn't anything like that." – *Jacob (SU).*

Theme 3: The role of autonomy in recovery

Involvement in treatment decisions

An important topic discussed by all of the service users was that of autonomy in respect of the decisions made about their care. It appeared that the level of involvement service users had differed greatly depending on where they were placed and who was caring for them. Some service users were able to recall times, often presently, where they had a high level of involvement in their own care. They were able to discuss how they felt their voice had been heard when it came to matters such as medication changes, care plan reviews and ward leave, which appeared to result in a sense of validation. Some of the carers also had positive experiences of involvement in treatment decisions and felt they were given a voice in terms of the care of their loved one. The involvement of service users in their own care and treatment appeared to aid their recovery and result in more positive feedback on their experience, highlighting the importance of joint working:

> "I feel like I had quite a good say in my treatment. Before I started medication, they always discussed it with me, and we explored options. I always had the final say in my medication. Again, with the therapy, I had a lot of say in what kind of therapy I wanted." – *Chelsea (SU).*

> "I've been involved in the processes with like, you know, your CPA meetings, your ward rounds, your care pathways. So, you know, I've been involved with my pathway, like, it took a fair few years, but we got there in the end." – *Trevor (SU).*

> "I found it all very interesting, looking at how to arrange certain plans and I even wrote some of my own risk reviews." – *Jacob (SU).*

> "I'd go into the meetings with a… I forget the terminology now, but a weekly meeting or a fortnightly meeting and discuss medication changes or whatever. Obviously, I know nothing about what psychiatric medicines are going to work best. […] So yes, they involved me in things like that." *– Christine (C).*

Despite this, the majority of discussions around autonomy highlighted the lack of input service users had into the decisions made about their care. This was particularly apparent in terms of medication, where service users reported a complete lack of involvement in most cases. They discussed instances where they had been concerned about side effects they were experiencing and had voiced these concerns, only to be dismissed by staff. This often had a negative impact on therapeutic relationships:

> "They just didn't give me a choice. They just basically said, 'you've got to take this. If you don't take it, then we'll put you on a depot. Even if you refuse a depot, you're still going to have it,' so it was just forced, which made me feel more against the staff or paranoid about the staff." *– Chloe (SU).*

> "The community consultant wasn't listening about the uneasy feeling on the depot. He was just dismissing it. They even dismissed it in here, but I'm on a different depot now, and it's hugely agreeing with me." *– Eric (SU).*

> "I just felt that, when it came to the medication, sometimes I didn't really have much of a say. […] It took a while for me to get them to see my point of view on the medication and for them to give me a chance." *– Sam (SU).*

In some instances, service users reported a complete lack of autonomy, extending to all decisions made about their care:

> "In the NHS wards, I never felt listened to, or that I had any kind of control, or that anything I said had any gravity in it that someone would listen to me and try and take it into account." *– Chloe (SU).*

> "They discuss it as a team and don't involve us, so we don't know what's being said, we don't know what people are doing and we're just finding out after they've had their meeting of what they're doing." *– Sarah (SU).*

> "My care was completely in the hands of the psychiatrist and the psychologist and the MDT. I had no say in what type of care I received." *– Alex (SU).*

This lack of involvement appeared to have a detrimental impact on service users' mental health and resulted in withdrawal from services. Chloe (SU) discussed how she felt staff "disregarded" anything she said and, when questioned about why they were not listening to her, they would "just say that I'm ill or something." Chelsea (SU) described this as the "paternalism of the psychiatric system" and commented that it left her feeling like "just part of the system" in certain placements. It was also evident that carers felt excluded from discussions around treatment decisions in most cases; expressing their frustration at being ignored when they felt they knew the service user best and could have provided valuable input into what would have benefitted them at the time:

> “There’s a sort of disjunct between staff who might come in and know everything, or have access to notes and making decisions about somebody who they’ve only known for a few weeks, maybe, and then if the parents aren’t consulted – I mean, there were so many times when I said that, ‘I’ve been with her since she was born, I can give you…’ you know, ‘I’m here to talk to you, and she’s happy for me to talk to you about whatever,’ but that was never really taken up.” *– Andrea (C).*

> “It took a long time for me to get my name down as being her nearest relative […] and I wrote to services several times about this. I think they were really, really lacking in involving me. […] I don’t think I’ve felt recognised, really.” *– Ruby (C).*

> “Nobody would listen to us because they… specifically at that last one when we were, you know, the consultant just kept saying, ‘as we’ve discussed, this is not the right place for [service user name], so actually we feel now she is ready to be discharged.’ We were like, ‘but, but…’ You know, we were a bit like, ‘you’re not listening to us, you’re not… how do you think we’re going to manage her? She’s so low and her…’ You know, her thing was, ‘I don’t want to be here.’ It was a case of, ‘how am I going to kill myself?’ Not when, how.” *– Ruth (C).*

Interestingly, one of the service users highlighted the lack of input he felt ward staff had in respect of decisions that were made about the patients they worked with on a day-to-day basis, arguing that their opinion should be valued as much as that of more senior members of staff:

> “The nursing assistants, the support workers, the OTs, the nurses themselves, I believe that they should be given a lot more power in decision making over patients in the future, because they’re the ones that see the patients on a day-to-day basis for three or four days a week, for twelve hours. The doctor, the psychiatrist, in terms of the medium secure, they might see you once or twice in a three-week period for 15 to 20 minutes each.” *– Alex (SU).*

Lack of person-centred care

In addition to the reported lack of autonomy in respect of treatment decisions, participants discussed an overall lack of person-centred and holistic care. This was particularly apparent in discussions around inpatient care. Whilst the service users appeared to understand that they could not always have an active role in every decision made about their care, they expressed a desire for treatment decisions to be considered on a person-to-person basis, as opposed to a ‘one size fits all’ approach:

> “There weren’t really, like, specific care plans or specific individual things that they would… it wasn’t tailored around the people. It was just blanket rules, and they were just putting everybody on the same kind of medications that were just drugging people up so that people were too tired to do anything else, other than sleep.” *– Chloe (SU).*

> “I think person-centred is a very big thing and I think people don’t value it enough. It helps that service user feel valued and they think, ‘they are listening to me. They are taking in my experiences and who I am, not just treating me based on my diagnosis.’” *– Jacob (SU).*

It was interesting that Jacob (SU) spoke about the need for person-centred care in respect of his diagnosis of emotionally unstable personality disorder, as he reported experiencing a sense of stigma. He felt that clinicians would see the label he had been given and disregard him or assume he was treatment-resistant because of it; therefore, he really valued the staff members who would see him as more than just his diagnosis and treat him accordingly. Two other service users also spoke of their frustration at the lack of person-centred care, vocalising that their individual needs should have been taken into account throughout their treatment, rather than simply classifying them as offenders:

> "I've been in the system now, since my last offence, for 18 years. I mean, that's just too long. It is wrong. Just somebody with mental health problems shouldn't be locked up for 18 blimming years when they're showing no blimming signs of aggression." – *Micah (SU).*
>
> "They're keeping people under sections when they're showing no symptoms of psychosis, like, they're exhibiting no risk to self or others, and they haven't for over a year, two years. They've had no issues in terms of mental health or risk to self or others. […] I feel like the doctors just have far too much power. People are being kept in these places, talking about medium secures, people are being kept in there unjustifiably and I think it's wrong, to be honest." – *Alex (SU).*

Andrea (C) highlighted the fact that holistic care does not have to be expensive or particularly time consuming, with small acts of kindness going a long way for certain service users. The input of carers is particularly valuable in this respect, as services may lose sight of the benefits of self-care activities when focusing upon measurable treatment outcomes:

> "In terms of holistic care, some of these things do not need to be expensive, but even things like, I don't know, getting somebody to come in and do somebody's nails or their hair, or a facial or reflexology. These little things can make such a difference to how somebody feels about themselves and how comfortable they are." – *Andrea (C).*

Overreliance upon medication by staff

As well as reporting a lack of autonomy regarding medication decisions, service users also discussed an overreliance upon medication by staff and a feeling of being over-medicated:

> "I started on an antidepressant – fluoxetine, it was – and it made me so suicidal, like really badly. They wouldn't take me off it, they just kept me on it. As I've gone to each hospital, I've just been put on more and more meds." – *Sarah (SU).*
>
> "Forcing medication on me was not helpful. Forcing medication on me that made my mental health suffer even more, didn't allow me to sleep, didn't allow me to relax. That was not helpful." – *Alex (SU).*
>
> "The main thing that I struggled with was being forced to have medication that I didn't want to have. Some of it did help me, even though I didn't want it at the time, but then the worst bit was when they decided to put me on a depot. I had really horrific side effects, but no matter how hard I tried to ask to change or to come off it, I was stuck on that depot for quite a long time. It made me very, very unhappy." – *Chloe (SU).*

Chloe reported feeling as though medication was often used as a tool to keep service users subdued and quiet, in order for staff to have an easier shift. She also spoke about an incident whereby she felt that medication was used as a solution to a serious incident that she felt should have been handled more sensitively:

> "When a staff member came in afterwards and I told them that I'd been raped, they disappeared, came back with a pot of, like, PRN medication, told me to take that and then they just left me again." *– Chloe (SU).*

Theme 4: Improving staff training and risk assessment skills

Suicide attempts following discharge

As discussed previously, individuals with complex mental health needs are more likely to have significant risk needs due to the nature of their problems. Four of the service users expressed having experienced suicidal thoughts and engaging in self-injurious behaviours at some point in their lives, although it is likely that many chose not to discuss these painful memories within their interviews. This was a topic discussed to a slightly greater extent within the carer interviews, with five carers choosing to share instances of their loved one attempting to harm themselves. Something that some of the service users failed to understand was why they had been discharged back into the community when they felt they were still actively suicidal, as this usually led to further suicide attempts and readmissions:

> "I was actively suicidal, but they still discharged me. As soon as I got off the ward, I ran into the middle of the road, into oncoming traffic." *– Chloe (SU).*
>
> "I was still actively suicidal, actively hating myself, actively doing stuff, like things that were quite a danger to myself. And they still discharged me, because they said it would be more beneficial to be in the community. I do agree with them, it does, but at that time, I was not ready to be discharged." *– Sarah (SU).*

Percy (C) also expressed his concerns about the rushed nature of his daughter's discharge back into the community after being very unwell, insinuating that services were more focused upon short-term goals rather than long-term plans:

> "Something as a carer that was not good at the time, was made very clear to us really, the main interests of the hospital at that stage was to get her well enough to send her out. And what treatment happened thereafter really didn't seem to be a great concern. […] Some of the things that happened both in checking in, in terms of her safety, and in terms of her treatment, in terms of how she was going to be integrated back into the community in some way, was a bit concerning." – Percy (C).

It is important to consider findings from the recent National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH, 2022) annual report in relation to these statements. Over the 10-year period between 2009 and 2019, there were 5,218 (29%) patients who died by suicide in acute care settings, including inpatients (6%), post-discharge care (15%) and crisis resolution/home treatment (14%). Nearly half (46%) had been in contact with mental health services in the week before their death. The majority (84%) of patients were viewed by clinicians as presenting with low or no short-term risk. The service users in our study reported feeling that any form of sudden discharge put unnecessary levels of stress onto both themselves and those who were caring for them in the community, as everyone involved felt unprepared for the situation that they had found themselves in. The carers were of the same mindset:

> "My mum was just in bits, like saying, 'how can you discharge her when she's like this?' but the staff agreed that they would take me home, and they literally took me to our front door, pushed me inside the front door, and then they left." – *Chloe (SU).*

> "She had a bad experience at [hospital name]. They sent her home suicidal, and, within five minutes, I had to sit on her and get the police. They actually just shoved her through my front door and told me that I had to get her off that ward, that she was fine to come home. Yes, horrible, that was a horrible experience. Yes, with them all looking out the window at me, trying to get her in the car when she was trying to run to the motorway." – *Christine (C).*

> "We had the meeting, they said, 'right, yes, no, she needs to be discharged.' It was like they weren't listening to us. […] When they brought her down to us, to bring home, we sat there and looked at her and thought, 'something is not right.' […] So, we got home and she kind of just sat on the couch and didn't want to do anything, wouldn't have a cuppa, didn't want to go to her bedroom, nothing, she was just… it was horrible. Then she said, 'I think I'm going to have a bath.' […] I don't know what made me, but I just opened the door and said, 'well I'm coming in anyway.' She was sat, fully clothed, in the bath with blood coming out. She'd cut down her arm, blood coming out of that and a really, really tight ligature on her neck. […] Anyway, they came out and, good enough, you know, I was like, 'please don't leave her here with us because we can't… we don't know… we're out of our depth basically.'" – *Ruth (C).*

The general consensus appeared to be that staff would benefit from additional training into how to support someone who was struggling with their mental health to reintegrate back into the community and promote relapse prevention. Chloe (SU) discussed how a contingency plan would have been beneficial prior to discharge, with other service users reporting that a gradual approach would have been much more helpful than feeling as though they were being discharged before they were ready, with a lack of ongoing support. This recommendation was supported by Chelsea (SU), who had experienced such an approach in her own treatment and felt the benefits of it:

> "Gradually reintroducing me back into the community was really helpful. Rather than saying, 'you have all this leave,' I was started off on a small amount of leave and then it gradually increased. At the time, I didn't like it but actually, I think it was a good strategy to introduce me back into the community." – *Chelsea (SU).*

Jacob (SU) spoke of the need for ongoing community support following discharge in respect of both service users and their carers, with Chelsea (SU) and Peter (C) supporting this recommendation with examples of their own positive experiences:

> "I think just things like that, you can offer independent places and places which are within CWP to help that person and their family be able to support them, so they don't feel as alone. I think sometimes it's just having a safety blanket to know you can fall back onto something without necessarily needing it." – *Jacob (SU).*

> "I felt very prepared. They have something called the 'MhIST' Team, Mental Health Independence Support Treatment Team. They prepare you for leaving hospital and they support you as soon as you are discharged. There is a lot of support there." – *Chelsea (SU).*

> "They did come to home visits, and they were consistent with the support. And [service user name] enjoyed the visits." *– Peter (C).*

Suicide prevention staff training

Building upon the previous sub-theme, some of the participants expressed concerns about a perceived lack of staff knowledge around managing self-harm effectively, both on inpatient wards and when preparing service users to be discharged back into the community. Depending on the situation, this could involve a lack of action:

> "On one of the wards, I used to joke they wanted a respite from me, so they'd send me down to the PICU whenever they couldn't be bothered dealing with my risks anymore" *– Jacob (SU).*
>
> "About two hours after I took that pill, I was told that I was being discharged that day, even though a couple of days before, I had attempted to take my life." *– Chloe (SU).*

Or what was perceived to be an escalation of the situation:

> "That broke down rather quickly because they didn't understand self-harm, and every time I did self-harm, they would call the police. Then I'd get more distressed because the police had been called. It would make me 10 times worse. Then I'd end up being arrested or something. It could have been prevented if they would have sat with me, helped redress it and then told me to go to A&E, but instead they phoned the police every single time" *– Sarah (SU).*
>
> "There were some fantastic staff. There were some amazing staff who she worked with. They were really supportive, and some absolutely useless ones. When she ligatured one night, the kneejerk reaction was, 'right, we're going to move her.'" *– Ruth (C).*

Both of these situations proved harmful for the service users in different ways. This shortcoming did not extend to all staff members; however, certain negative experiences had left a lasting impression on the service users' minds. It is interesting to consider Sarah's (SU) recommendations, as she believed that following a calming protocol of caring for her and her injuries and then signposting her to A&E would have de-escalated the situation and resulted in a better outcome. This would not involve costly, in-depth staff training and could be brought about using patient and public involvement volunteers with lived experience of suicide and self-harm talking to staff about what would have benefitted them when they were seeking support for self-harm. These findings should be cross-referenced with the relevant parts of the staff survey.

The need for specialised training

As discussed previously, the need for specialised training into the management of suicide and self-harm was mentioned by several participants. Discussions centred around a need for improved awareness into how to react to instances of self-harm in an appropriate manner without unnecessarily escalating the situation and resulting in further distress. Sarah (SU) reported feeling as though some staff members had been "thrown in at the deep end" and told to "deal with it," which she did not deem adequate when dealing with matters of life or death. Jacob (SU) also spoke about the benefits of providing certain members of staff with additional training to support them in having specialist areas of knowledge that they could impart to their colleagues during working hours, therefore reducing overall training costs. He discussed this in relation to suicide and self-harm, personality disorders and OAPs:

> "I think, with some mental health conditions, there's just no awareness around it. No one has any clue what it is, what it means and things. I think that's the issue. Even in services, the staff are so burnt out and they don't have the time or the energy to show compassion or constructive feedback. […] I think it's about thinking a bit more creatively and getting staff who are specialist or training them up in those areas to give them quite a good amount of training, so they don't necessarily have to go miles and miles away themselves to these different units and they can stay within the area." *– Jacob (SU).*

Reducing stigma

A key area that seemed to resonate with the participants was the level of stigma associated with some mental health conditions. This was particularly apparent in the case of personality disorder, which was a diagnosis shared by a number of the service users. Unfortunately, they explained that it was common for members of staff to treat them differently once they became aware of their diagnosis. In some cases, this extended to them being viewed as treatment-resistant or difficult to work with. Jacob (SU) described experiencing a culture of stigma throughout his interactions with different staff members at various services, which had an impact on his overall experience of care:

> "I think my experience in general with mental health services hasn't been great. Because of some of my diagnoses, there's a lot of stigma towards them and I think it's a stigma that's held from all levels of professionals. It's held from support workers, nurses, occupational therapists, psychiatrists, psychologists. It's shared through them all." *– Jacob (SU).*

The participants were in agreement that staff would benefit from specialised training into personality disorders and how to treat them, as they believed the stigma they experienced was a consequence of lack of knowledge and understanding:

> "I think there should be more therapies available for people with personality disorders because they seem to have a lack of insight on people with personality disorders. I think they just need training on it." *– Sarah (SU).*
>
> "When she was in [ward name], she came out of there with a diagnosis of emotionally unstable personality disorder. […] We've since found out the professionals don't really know how to treat it and how to treat the person. We felt, all along, it's a bit of a, 'if we can't figure out what's the matter with them, we'll give them that.'" *– Ruth (C).*

Jacob (SU) also discussed how, in his experience of being diagnosed with personality disorder, it can be beneficial to combine various types of psychological interventions to support service users to manage their condition; however, this may prove difficult without specific training.

Theme 5: Impact of out-of-area placements

The social impact of OAPs

The majority of service users (7/11) had been placed out-of-area at some point in their treatment journey, due to their complex needs. They explained that, for the most part, they had understood the need for this decision, as local placements offering specialised support had not been available; however, there were inevitable consequences to being placed miles away from their local community. The most notable impact was on the service users' social lives, as their loved ones were required to travel considerable distances in order to visit them:

> "Obviously, my mum couldn't visit me as often and stuff, so I got homesick a lot. […] My family, and particularly my mum, is a protective factor for me that helps me stay on the right track because I wanted to get better for my mum. So, obviously, being further away from her and not being able to have as much contact with her, that did initially make me worse." *– Chloe (SU).*
>
> "It was hard because my mum had to travel up. I could only see my family… not that often, so it would be once a week, maybe once every two weeks. […] It was taking so long to get there, and petrol money and stuff like that. […] It was detrimental on my mental health because I couldn't see my family, and it was detrimental on my family's mental health because they couldn't see me." *– Sarah (SU).*
>
> "It used to get me down sometimes because erm I'd only see my family like once a week, do you know what I mean? And I used to see them all the time, so it was like… not good really. I remember coming from hospitals to hospitals saying, 'what's the point of moving me from here to here when you're putting me out of area from my family, and they were like, 'well, it's the only hospital that's available.'" *– Trevor (SU).*

The discussions with carers focused more so on the logistics of travelling to OAPs such as time constraints, work responsibilities and a lack of funds:

> "It was a struggle because, you know, trying to keep up a full-time job and […] trying to pay your bills and then worrying about getting up to see your daughter because you know that you've got to get up there and see her." *– Diana (C).*
>
> "If it's an hour or an hour and a half away, or longer each way, then I have to take a full day out, and then often arrange childcare, or take time off work or childcare at the weekends, because my partner works very often at the weekends. Yes, it's not something I can just… you go and pop over and do it. I have to make arrangements to be able to go and see her, which I am really happy to do. It can't be as frequent as I'd like, or probably she'd like." *– Ruby (C).*
>
> "So, her out-of-area, we had no choice on where she was going. It was obviously decided by the team of professionals, based on her clinical needs. But for me to go up there, as I said to you, it's a 10-hour round trip, a big drive up. I mean, luckily I can drive, but I put the petrol in my car, I take up the stuff for her, and there is no help with regard to that, no… I mean, if I was unemployed, I don't know how I would be able to afford to put petrol in the car, to go and visit." *– Amanda (C).*

Christine (C) also highlighted the lack of warning she would receive from staff in respect of her visits being cancelled. She described instances whereby she would be an hour into her journey and would receive a call informing her that her daughter had had "an incident" and would not be able to see her, which she reported would have been less of an issue had her daughter been placed locally. As the service users explained, the distance between themselves and their families proved difficult for everyone involved; however, Chloe (SU) did reflect that, “it was a bit easier knowing that I was getting the help that I needed, even if it was away from home.” On the whole, it seemed that the social impact of OAPs mainly affected those with a high level of family involvement in their care. It was less of an issue for those who had infrequent contact with their families, as the lack of familiar surroundings provided them with an opportunity to focus on their treatment without distractions:

> “Being placed out-of-area doesn’t really… it didn’t really affect me because it didn’t matter, really, where I was because my family, my mum and my stepdad, they’d only come and see me every few months anyway. It didn’t really bother me. […] Maybe someone, if they’ve got someone who wants to come and see them every single week or twice a week then I imagine that would be a problem.” *– Sam (SU).*

> “I think, at times, it would probably be better at a focus level to concentrate if you were in an unknown area. […] I can understand why people wouldn’t like that because they might get scared. Say they do have a very good relationship with their family, they may not want to go out-of-area because they’d miss their family, which I would understand if my parents were nice people.” *– Jacob (SU).*

The participants had some recommendations for how to make the transition from a local placement to an OAP as seamless as possible. Chloe (SU) had been abruptly moved to an out-of-area adolescent intensive care unit as a teenager and had found it very distressing, as she had only been given “five minutes’ notice” about the transfer, which left her with a limited amount of time to emotionally prepare and say goodbye to her loved ones. This was also something that Ruth (C) experienced, despite her daughter having been reassured by staff that she would not be moved only two days prior. Chloe (SU) reflected on how this situation would have been considerably less distressing had she been given prior warning of the move and had time to process the change with her family. Jacob (SU) had a further recommendation about creating a sense of familiarity within an OAP, which was strengthened by Ruby’s (C) experience of watching her loved one deteriorate without familiar faces caring for her:

> “I think something that comes to mind immediately is being able to have someone you know from the original area. If you get moved and you’re very close with your CPN or your psychiatrist, even if they were able to have catch ups with you whilst you were at that unit. […] I think it’s being able to have that familiarity within that area, which might feel quite desolate to you.” *– Jacob (SU).*

> “I think she became more institutionalised there and she deteriorated, and quite possibly it was the move to a new area where she didn’t know anybody and felt isolated. I don’t think that was helpful at all and her mental health has not been very good there at all.” *– Ruby (C).*

Benefits of local placements for family visitation

Service users with experience of both local and OAPs reflected on the benefits of being placed near their home communities. Unsurprisingly, the most notable benefits of a local placement were reported as being easy access to friends and family, a sense of belonging, and familiarity of surroundings:

> "It meant that I could see my friends and family, but more because, obviously, they didn't have to travel as far to come and say, 'hello' to me. My mum was trying her hardest to come every day." – *Chloe (SU).*

> "I'd say it's a lot better because, obviously, you'd see your family more, you get to go home more – because you're not that far away." – *Sarah (SU).*

> "I think it's best staying local, myself. I think you have a better experience when you're in your own area where perhaps more people know you." – *Micah (SU).*

Two service users discussed how their familial relationships had improved as a result of being placed locally because when they were placed out-of-area, they would rarely receive visits due to the associated time and cost required for the journey:

> "Now I'm here, and now I can go out on my own every day, I'm seeing my parents and my family and my sisters and that a lot more because now they're just coming and they're just saying, 'we're going into [city name] tomorrow, do you want to come with us?'" – *Sam (SU).*

> "My mum comes to visit regular now, and I've just been given permission to go to mum's in [town name] every weekend. I've done so now for the last four weekends, Saturday and Sunday." – *Matthew (SU).*

Complexity as a barrier to support

As discussed previously, most of the service users who had been placed out-of-area expressed their understanding of why this was the case, for example, because specialist placements had not been available in their local area:

> "There were no personality disorder units locally, that's why I had to go to [town name]. It was personality disorder, you see, so that's why they told me it was out-of-area." – *Sam (SU).*

> "When the possibility of doing the DBT came around, I didn't want to move even further away from home, but in my head, it was, kind of like the last resort or the last hope of being able to recover." – *Chloe (SU).*

The manner in which the service users discussed these placements was interesting, often referring to them as a "final chance" or a "last resort." It appeared that both the service users and carers viewed this perceived complexity as a barrier to support, often citing difficulties they had encountered when trying to access psychological support or a community placement. The service users expressed their frustration at being deemed 'too risky' or 'too complex' to access the support they required, with the carers echoing these concerns:

> "They've done all the help they can possible, and they're just keeping me here because nowhere will accept me." – *Sarah (SU).*

> "When I was on one of the acute wards, no placements would accept me because of my risks. I was never harmful to anyone else, but some of my incidents I had, they had to report to quite a lot of the NHS Trusts because no one had ever seen them before. I think, when you a tell a placement that, they get quite concerned." – *Jacob (SU).*

> "It's like even getting placements for her, there's nothing. Because she's complex, most of them were saying, 'oh, well we can't take her because she's complex.'" *– Diana (C).*
>
> "Unfortunately, so much has been written about him, that when they send these to accept him, nobody will accept him, because they think – and he's absolutely great, everybody likes him. I think they think they're accepting a mad axe-murderer, but he's not. It's under control, his illness has been under control now for quite a long time, many years." *– Betty (C).*

Jacob (SU), who had previously discussed his experience of staff stigma towards his diagnosis, reported that, in addition to having his requests for placements denied, he had struggled to find a psychologist who was willing to work with him due to his diagnosis of complex post-traumatic stress disorder and emotionally unstable personality disorder. He felt that this was an avoidable barrier to accessing the right type of specialised support for his needs.

4. Conclusions

This report highlights the views and perspectives of individuals with lived experience of complex mental health needs and puts forward recommendations for service improvement, including focus on therapeutic relationships, early intervention, autonomy, staff training and OAPs. In recent years, several documents and initiatives such as NHS Choices and Patient Advice and Liaison Services (PALS) have highlighted the importance of considering service user experience and the need to focus on improving this experience where possible (NICE, 2011). However, service users with challenging behaviour and intellectual disabilities have often been excluded from participating in service evaluation, despite their ability to offer useful insight into possible adjustments and service improvements (Chinn et al., 2011).

The findings from this report demonstrate that many service users and carers had, at times, experienced fantastic levels of care for complex mental health needs. They highlighted positive interactions they had shared with members of staff who were empathic and non-judgemental towards them, discussed the benefits of co-production, spoke of the importance of being involved in decisions made about their care and shared how access to therapeutic support had aided their recovery. Those whose experience of care had been less positive were honest about the areas in which they felt they had been failed, with discussions mainly centred around difficult encounters with staff they felt were in the job for the 'wrong reasons,' a lack of autonomy, stigma associated with their mental health condition and being placed away from their home communities with a lack of support.

Recommendations made by the participants were in line with the NICE (2011) guidelines on service user experiences in mental health. They also highlighted the need for staff to work in partnership with service users and their carers, take time to build strong therapeutic relationships as an essential part of care, aim to foster the autonomy of service users, avoid stigma and promote social inclusion, and agree discharge plans with the service user and include contingency plans in the event of problems arising after discharge. Despite the existence of these initiatives, there is evidence to suggest that further work is needed to deliver the best possible experience for users of NHS services.

A strength of this project is that it is one of the first studies to obtain such in-depth data from individuals currently being treated or supported by services. Furthermore, the study did not sample on the basis of diagnosis. Instead the focus was on high complexity, irrespective of diagnosis. Accordingly, the findings are more relevant to ‘real world’ service provision and to the users of these services. The findings in this report should be interpreted in the context of some methodological limitations, as the results may not be representative of the rest of the UK (as data was only collected from the North West area, where the service is situated), although many of the issues we identified are likely to apply across other areas. One limitation to consider is the lack of diversity in terms of ethnic minority groups, as the majority of service users were White British (10/11), with limited participation from those from BAME communities. It is important to note, however, that our numbers are largely representative of the ethnic background of the local community, with only 3.19% of Cheshire West and Chester residents classified as BAME (Cheshire and Merseyside Health and Care Partnership, 2021). Nonetheless, it is important to ensure all views are captured moving forward and specific targeting of certain ethnic groups may aid future research and work.

5. Recommendations and Future Directions

The following recommendations (see Figure 3 below) were put forward by the service users and carers and should be implemented in future practice where possible:

Recommendations	Staff to support in the building of strong therapeutic relationships by demonstrating mutual respect, encouragement, honesty and transparency.
	The importance of early intervention to be recognised and for psychological support to be offered more routinely in childhood and adolescence.
	The importance of structure, boundaries and routine to be recognised and promoted by staff e.g., regular visits and pre-arranged activities.
	Service users to be given more autonomy in respect of their care, particularly in respect of concerns about medication and side effects.
	Increased support for service users and their families upon discharge into the community and additional training for staff to support with this transition.
	Person-centred care to be prioritised e.g., individualised care plans and therapeutic approaches.
	Staff training on stigma and managing self-harm and suicidal behaviours e.g., de-escalation techniques.
	To consider the option of having a link to home communities for those in OAPs e.g., ongoing contact with a CPN or psychiatrist.
	Patients to be given a choice about how their problems are formulated (e.g. diagnostically, dimensionally or in terms of a psychosocial formulation).

Figure 3. List of recommendations for implementation, based on service users and carer interviews.

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7. Appendices

Appendix 1. Service User Interview Schedule:

Interview Schedule: Service user

1) Can you tell me about your experience of contact with mental health services?

2) What are your thoughts about the care you received for your mental health condition?

3) If you have been an inpatient, how did you find the decisions that were made in respect of your care?

    a. What was your involvement in the decision-making process?
    b. Did you experience a sense of autonomy in respect of your care? Why/why not?
    c. Could you tell me more about the psychological therapies you received?
    d. Were you prescribed psychotropic medication? Could you tell me more about your experience of this?
    e. Did you feel prepared to be discharged? Why/why not?
    f. How would you describe your relationships with staff? Did any of these relationships continue afterwards e.g. with social workers? Were these relationships consistent? Why/why not?

4) If you have been placed in any out of area placements, how did this affect you?

    a. Have you been in any local placements? If so, how did this affect you?
    b. If you were placed out of area, what was your understanding of why this was the case? Did you feel you were involved in the decision-making process? Did you feel it was the right decision for you? Why/why not?
    c. What helped and what was not as helpful in respect of the move?

5) Overall, in terms of your experience of contact with mental health services and the care you received, what helped and what was not as helpful?

    a. In terms of positive experiences, why do you think these aspects were successful?
    b. In terms of negative experiences, why do you think these aspects were unsuccessful? Were there placements that did not work? If so, why?
    c. Do you have any suggestions about possible improvements that could be made?

6) Is there anything else you would like to discuss?

Appendix 2. Carer Interview Schedule:

Interview Schedule: Carers

1) Can you tell me about your experience of caring for someone with complex mental health needs?

    a. Once admitted, was the service provided as you expected?

    b. If the person you care for was admitted to an out-of-area placement, were you introduced the service?
    c. Was it explained to you what the placement looked like?

2) When the person you care for was detained under the mental health act, how did you feel?

    a. Were you involved in the decision for the person you care for to be detained under the mental health act?
    b. Was the person you care for happy for you to be involved in the decision?

3) Were you asked your views about what led to the admission?

    a. Were you asked for any family history?
    b. Were you asked about any events leading to the admission?
    c. Were you asked about any triggers that led to the person you care for being admitted?

4) What are your thoughts about the care they have received for their mental health condition?

    a. Were you involved in any of the decisions about their care?
    b. Was the person you care for happy for your involvement in their care?
    c. Is there anything you think could be improved?

5) When the person you care for was admitted to hospital, how did this affect you?

    - Were there any issues when visiting them? What were they?

6) If the person you care for was placed in out-of-area placements, how did this affect you?

    a. Were there any issues when visiting them? What were they?
    - Expensive
    - Distance/Travel issues
    - Ill health/disability to self
    - Person you care for refused visits
    b. Was there a specific contact person in the ward?

    - If yes, were they available 24/7?
    c. Was there any impact on the relationship between you and the person you care for?
    d. What were your experiences of visiting the person you care for, in an out-of-area placement for the first time?

7) Is there anything that you think would’ve helped the person in not needing to be admitted to hospital?
    a. Was the person you care for involved with community services?
    b. What do you think may have helped their mental health difficulties?

8) Is there anything else you would like to discuss?