NHS
Bedfordshire, Luton and Milton Keynes
Integrated Care Board

Community Health Services and Mental Health Services

Interviews to gather lived experiences

Author: Anona Hoyle, Communications and Engagement Team

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The communications and engagement team set out to conduct interviews to explore people's experiences with mental health and community services. Our goal was to understand their journeys, identify what works well, and envision improvements for the future.

The interview questions we included cover various aspects of their experiences, from initial interactions with services to their ideal vision for mental and community health support.

The stories start on page 4 of this document and the questions used to aid the interviews can be found in appendix 1.

Key Themes Across Stories:

1. **Multidisciplined teams, Continuity and Consistency of Care:** It is vital to have consistent, joined-up services (physical, mental health, education, and social care) across BLMK that know the full patient and family history to avoid repeated storytelling and ensure meaningful support. Repeated breakdowns in care continuity cause distress, harm, and erosion of trust. Falling out of the system due to moves or life events can sever crucial care ties. Services should consist of team of professionals which 'wrap-around' the patient to provide continuous and effective care, ensuring that the patient sees the same people regularly.

   "Repeating of information constantly is triggering and retraumatising. All information should be available on everyone's records and be read and understood."

   "This disruption has taken a heavy psychological toll. The uncertainty around who will manage my PICC line each week has contributed to stress, anxiety, and physical deterioration, as evidenced by my recent hospitalisation. I feel that internal service politics were prioritised over patient safety—a sentiment no patient should ever have to voice."

   "Wrapping a team of professionals around a patient would help their care and provide a more positive experience."

   "There was a disconnect between the hospital and primary care - everyone pulled away and then no-one left to help care as the hospital thought the GP was doing it and the GP thought the consultant was."

"I have highs and lows in how I feel and this can be exacerbated by lack of access to services and services ability to provide the right care. The care I have received has either been very good or very bad. I found the Bedford Community Mental Health Service very variable depending on the individual care coordinator. The service provided by the crisis team also depends on the individuals that are working at the time you ask for support."

"Communication is key, services need to work smarter, not harder."

2. **Respect and Validation:** Feeling judged, dismissed or misunderstood by professionals worsens mental health and deters engagement. Patients and families want to be treated with empathy, respect, and understanding of their unique challenges.

   "Megan came under the care of the Perinatal team when she fell pregnant, and she says they were wonderful. Took care and time to understand her issues, were empathetic – made her feel listened to – so she readily engaged and opened up to them. She talked to the perinatal team from February so were involved with her throughout most of her pregnancy."

3. **Inclusive Family-Centred Approach:** Care should consider the whole family unit, acknowledging carers' roles and needs, not just the individual patient. Carers play critical roles, navigating systems, bridging communication gaps and often keeping their loved ones safe. There is a call for carer welfare checks, respect, and inclusion in care decisions—especially in crisis or complex care situations.

   "Sarah's psychiatrist was trying to do a medication review. Sarah wasn't responding to the telephone calls, so the psychiatrist contacted me instead. I was able to let Sarah know they wanted to contact her for the review, and once she was aware they were trying to get through to her and knew when and who would be ringing her, she answered the phone."

   "I see my daughter struggling with demons, trying to be a good mum… it makes me sad"

   There has to be an opportunity to tell your story and be listened to, instead of form filling…'

4. **Timely Crisis Support:** Access to immediate, appropriate crisis intervention tailored to neurodiverse and mental health needs remains lacking but is urgently needed. The stories demonstrated that they were met with skepticism, invalidation, or minimisation of mental health or neurodivergent traits.

   "If the perinatal team can do it, why can't the rest of the mental health service?"

   "Crisis support available via a structured mental health unit rather than A&E would be a better and safer environment."

   "Currently there is no instant access to crisis care"

   "The in-patient ward environment is dire and even worse if you are autistic. I understand that given financial constraints it would not be possible to have separate wards for those that are neurodiverse, but what adaptations could be made to improve the environment?"

5. **Flexible, Needs-Based Support:** services are too rigid; time-limited services do not work for complex cases, services need to cross over boundaries, and services need to be adaptable to meet the patients needs. There was an appeal for services that listen, adapt, and don't drop people for missing an appointment.

   "Don't just discharge someone with mental health if they don't engage, there might be a reason, get the carer involved."

   "The IAPT team wanted to talk to Andrew on the phone, he's autistic and non-verbal when he is stressed and will not talk on the telephone. I made a complaint and was told IAPT services are not commissioned for people with autism"

   "Communication is a really big thing; psychiatrists can use too many words. They don't pause when they're talking and there's not enough time for the service user to process. Not everyone is lucky enough to have an advocate."

   "When they thought I was 'well enough' the neuro specialist pulled away, despite the fact that I felt that he still wasn't well… they used to say to me 'you have made a full recovery' – but I hadn't but I couldn't explain what it was.'

   "I was never asked how I would like my care – and no alternatives offered when didn't meet criteria for care."

6. **Training and Awareness:** Professionals must be better trained in autism, trauma, addiction, and mental health intersectionality to provide informed, compassionate care.

   "GPs and their staff should be properly trained and know where to refer people needing support."

   "Concerns that those with addictions aren't taken seriously - She was laughed at which really affected her mental health which further perpetuated her addiction and physical health"

7. **Hope for change –** There is a collective hope for transformation, even amidst exhaustion and cynicism

   "We've told this story for 20 years and nothing changes".

   "This experience has left a deeply bitter taste. I engaged with this review in the spirit of collaboration and improvement, but I cannot overlook the frustration and harm caused by these avoidable service decisions.
   I urge you to use this testimony to underscore a simple truth: if something is working—don't fix it.
   I sincerely hope no other patient will have to endure similar distress due to inflexible or politicised service decisions.
   Thank you again for giving service users a voice. I hope mine contributes to meaningful change."

   "NHS has served me well – 96% of good stuff – but it's the bad stuff you remember. My Physios, Drs and OTs – all were brilliant"

Lived Experience Stories

1. Lindsey's Story

Interview Section	Lindsey's feedback
1. Introduction	I'm a lived experience carer for my daughter Sarah who has a mental health condition. My grandson (aged 10) has just been diagnosed with autism and FDA (ticks) 2nd, so now I'm a second-generation carer. Sarah is now 32, when she was 12, she started to self-harm. Lindsey was told she was an overprotective mother, and Sarah would 'grow out of it', she kept going back and was dismissed. Sarah didn't get any help for 10 years until she fell pregnant. She'd put herself in various vulnerable positions, not taking care of herself and always self-harming through this process. It wasn't until Sarah became pregnant that things escalated out of control. Lindsey supposes for a long time she and husband kept things to themselves, they were overly protected of Sarah at times, due to the support and experiences she received when she was younger. Lindsey went to her GP and broke down, she was worried about her priorities, she had always protected Sarah but now there was a baby on the way who needed to be protected as well. Sarah was referred quickly to the psychiatrist where diagnosis was made, she got into talking therapy. Sarah and her son lived with Lindsey until the son was 5 or 6, Sarah then moved out to live with her partner. 2 years ago, the grandchild became a child in need and went back to live with Lindsey. He's now back with his mum (Sarah). Lindsey is not ashamed of her – *"we just got a brick wall and then withdrew from the system/mental health support".* In Birmingham, Lindsey had an amazing buddy who she saw once a month, it was an hour when they didn't talk about the situation, it was all about Lindsey. This buddy system was organised through the mental health team). It worked brilliantly as Lindsey is not keen on meeting up for group support.

Interview Section	Lindsey's feedback
2. Discovery *"What's Working?"*	Sarah's psychiatrist was trying to do a medication review. Sarah wasn't responding to the telephone calls, so the psychiatrist contacted me instead. I was able to let Sarah know they wanted to contact her for the review, and once she was aware they were trying to get through to her and knew when and who would be ringing her, she answered the phone. The psychiatrist recognised that Sarah was in crisis, they took action straight away, listened to her needs and provided her with support (which was more than the just the medication review). *"Communication is a really big thing; psychiatrist's can use too many words. They don't pause when they're talking and there's not enough time for the service user to process. Not everyone is lucky enough to have an advocate."* Sarah's son (my grandson's) diagnosis has come through. The diagnosis letter is so full of jargon that I know it will give Sarah sensory overload, and I will need to break it down for her. There's no consideration throughout the whole diagnosis process for any extra support that Sarah might require. *"I see my daughter struggling with demons, trying to be a good mum… it makes me sad"*
3. Dream *"What Could Be?"*	Lindsey had an amazing buddy support that she saw once a month – an hour where they didn't talk about the situation – it was about Lindsey. (This was through the mental health team in Birmingham) To treat the patients and carers with respect and have knowledge of their needs. The son's diagnosis needed Sarah to be in the room but there was no consideration for *her* needs. It's about treating the family as a unit. Sarah was told 'its **only** autism, sometimes I have to tell parents their child will never walk.' It was very dismissive, and a complaint has been made. Validate the patient and their needs, acknowledge the mental health condition. Know the history and treat people accordingly. *"I want her to feel validated and listened to"* Sarah would display behaviours that would make it very obvious that she needed additional support, these need to be picked up.

Interview Section	Lindsey's feedback
	"They can't treat the child without treating the mother, her involvement is so important." "Don't just discharge someone with mental health if they don't engage, there might be a reason, get the carer involved."
4. Design *"What Should Be?"*	Appointments can be a long time apart, we need something like the old-fashioned welfare check, it just needs to be someone familiar to check in. The person would need to be someone with mental health knowledge/experience. They could send a text message to confirm the telephone call the day before, so they know it's coming... text to saying x person is calling and to grab a cup of tea. Not having to re-tell the story …. with a complete patient journey across services (not just about the initial diagnosis – about the current situation as well). Should be able to build on the story. Crisis support available via a structured mental health unit rather than A&E would be a better and safer environment. Having the same GP (or clinician) each visit would make Sarah more comfortable. Wrapping a team of professionals around a patient would help their care and provide a more positive experience. "Because of her mental health need she was sent to hospital, but her condition could have been dealt with at the GP surgery".
5. Destiny/Delivery *"What Will Be?"*	Acknowledgment of carers Maybe the carer needs a welfare check? I would love to stay involved in the project as we move forward.

2. Mr and Mrs Davies' story

Interview Section	Mr and Mrs Davies feedback
1. Introduction	Mr and Mrs Davies are carers for their son Andrew. Andrew was diagnosed with Asperger's Syndrome at the age of 7. The family subsequently waited an additional three years for a formal statement. Was recommended CAMHS – Andrew saw a great professional, who was a psychologist not therapist. At age 17/18 he was diagnosed with anxiety disorder. *"He would go into a full melt-down and self-harm, banging himself against a wall or pinching himself so hard to draw blood."* He is 27 now, over 6 foot tall and lives at home with them. Andrew is academically bright; he likes routine and does not respond well to anything unplanned. The family always has to plan everything to the finest level of detail.
2. Discovery *"What's Working?"*	Currently there is no instant access to crisis care Andrew was referred to the Cambourne Centre for anxiety disorder and IAPT services The IAPT team wanted to talk to Andrew on the phone – but he's non-verbal when he is stressed and will not talk on the telephone. Mr Davies made a complaint and was told by CNWL that there were not any autism services commissioned from MKCCG. They were referred to MindBLMK. Andrew had 6 sessions with MindBLMK. His support worker provided appropriate assistance during these sessions, but the support concluded after session number six. He now has a private support worker 'Magic Hannah'; the Davies' pay for Andrew to have an appointment with Hannah every week.

Interview Section	Mr and Mrs Davies feedback
	It can take a long time for Andrew to be able to verbalise what he is thinking. For example, he does not like the heat – it took him over 3 years to be able to open up and explain why. This stems from when he was sitting his school exams in the hot summer and was not allowed to take off his jumper or have a drink during exams.
3. Dream *"What Could Be?"*	The CAMHS support system worked well (10 years ago) when they had a named psychologist. The Davies' could contact her every time they needed support or advice which they received either by email or via a session. *"It's good being able to dip in and out of the system when you need it, knowing there is continuity of support"* To be able to receive support for the length of time you need it – for example the 6 sessions Andrew had with MindBLMK worked really well, but that was the maximum number allowed. The Davies' offered to pay Mind privately to continue to provide the services, but this was not allowed. Everyone needs a magic Hannah, Hannah is still treating Andrew. Magic Hannah has lived experience –- she has empathy, understanding and skills to work with Andrew, The dream would be a joint partnership, between us (family carers, Andrew and clinical psychology They pay Hannah privately for support, £80 per hour … it's invaluable support, always available, with no time limit. *"Doctors that know where to send you, they respond to requests for support quickly, we should be able to talk to someone with appropriate qualifications. We shouldn't have to wait for referrals to be made, and services should be provided with no time limit."* *"When I ring it's because Andrew needs help – he can't wait days of even weeks for support"*
4. Design *"What Should Be?"*	No waiting time GPs and their staff should be properly trained and know where to refer people needing support. They should have the necessary skills to provide timely assistance without long waits, and there should be no time limit on the amount of support provided. *"Must work together, the left hand doesn't know what the right hand is doing."*

Interview Section	Mr and Mrs Davies feedback
	Patient Centred Care, Andrew needs to see the same people. *“Six weeks…. It takes this long to get trust. Six weeks… it fixes nothing.* *If you don’t join the system up – nothing will change.”* Schools are too big, this leads to more mental health issues To have carers support services available – *“due to recent cuts, our support group has lost the support worker who would always point us in the right direction”* *“It would be good to have more friendship groups – there are groups for people who don’t have capacity, but a lack of groups for people who are bright and autistic.”*
5. Destiny/Delivery *“What Will Be?”*	Multidisciplinary team that involves parents/carers and are patient centred (10 weeks of trying to get DOLS assessment for lack of capacity.) Clinicians need to understand autism characteristics and treat the patient. Crisis support needs to be 24 hours and there needs to be different ways to access it. *“The last thing I can do (as a carer) is talk about my son when he’s in the next room”* For health care professionals to promote the Autism Alert card – the card is intended to be shown if the cardholder finds themselves in a situation where they need help and support or cannot easily explain their behaviour to people around them or to the emergency services. Andy and Wendy are happy to be involved in further co-design
6. Closing and Reflection	No community groups are available. Andrew is bright – very little available for him Mental health act is biased against autistic people.

Interview Section	Mr and Mrs Davies feedback
	DWP need to do Oliver McGowan training. Following the interview, we received an email from Mr Davies: *We have discussed it a lot and have so much more to say. Anything to help.* *It is extraordinary how we seem to be doing this constantly and nothing really changes.* *I hope this time will be different - it is imperative given the state of services and what may come.* *Thank you for listening.*

3. Jenny's Story

<table>
<tr><th>Interview Section</th><th>Jenny's feedback</th></tr>
<tr><td>1. Introduction</td><td>Jenny volunteers for Drug and Alcohol Family Support. The volunteers have lived experience.

Jenny had a daughter (now passed) – 20+ years on heroin from childhood trauma.

Megan, her granddaughter (her daughter's daughter) came to live with her at the age of 11, as she was removed from her mother. She has complex PTSD; she's now 22 with a young child called Daisy (Jenny's great granddaughter).

Megan had to be diagnosed privately at the age of 14 because of the long wait for services</td></tr>
<tr><td>2. Discovery

"What's Working?"</td><td>Overall – concerns that those with addictions aren't taken seriously. Her daughter felt, and Megan feels like they have been laughed at – which further exacerbates symptoms.

"She was laughed at which really affected her mental health which further perpetuated her addiction and physical health"

GPs – lack of empathy regrading mental health

"Addicts are self medicating… they self-medicate to get rid of the pain"

Took 3 years for Megan to get a diagnosis of PTSD (2018) – because clinicians didn't believe her pain.

Much more understanding in schools of mental health. Her granddaughter's Head of Year had no understanding of mental health. Megan had a welfare officer (one person in school of 2,000). Waited 10 months for CAMHS and got her into The Bridge.

The Bridge was wonderful – priority was education but also their emotional wellbeing.</td></tr>
<tr><td>3. Dream</td><td>Impossible to get mental health support for her family members. Those in DAFS are still having the same issues as 20 users ago, it leaves patients self-medicating to get rid of the mental pain.</td></tr>
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Interview Section	**Jenny's feedback**
"What Could Be?"	If they had help with their mental health, it could solve the addiction issues. For CAMHS to offer services that work for PTSD *"CBT services don't work – they should provide services like hypnotherapy which access the sub-consciousness"* "GPs and Hospital staff don't ever link mental and physical health … childhood trauma has anatomical changes to the body"
4. Design *"What Should Be?"*	Certainly not prescribing methadone … it needs more of a controlled approach in terms of dispensing and over a period of time. The system doesn't work currently for addicts; it needs a radical approach. Wouldn't be possible and politicians wouldn't want it, they are trialing dispensing rooms in Glasgow (and have a different system in Portugal), this approach this takes the danger away from the user. No joined-up approach between community/mental health and physical services, they could do so much more. For services to be joined up across boundaries, Megan was accessing perinatal services in Central Bedfordshire, she then moved to Milton Keynes and would have had change provider. She didn't want the disruption so the provider suggested she didn't tell that she'd moved so she could continue accessing the team she trusted and knew her. Megan has high social anxiety (she's physically sick before going to work), GPs should take mental health issues seriously and understand the impact it has on other aspects of the individual's life. Professionals need more empathy, compassion and to be non-judgmental Jenny felt very protective of her family members – but has also felt judged by health workers.

Interview Section	Jenny's feedback
	Megan came under the care of the Perinatal team when she fell pregnant, and she says they were wonderful. Took care and time to understand her issues, were empathetic – made her feel listened to – so she readily engaged and opened up to them. She talked to the perinatal team from February so were involved with her throughout most of her pregnancy. *"If the perinatal team can do it, why can't the rest of the mental health service?"* It is worth noting, however, that she has not had a health visitor since Daisy was born 3 years ago and has therefore fallen out of the system. This is not a problem in this situation, but other children may not be so lucky (safeguarding issues).
5. Destiny/Delivery *"What Will Be?"*	Having joined-up services and not having to go over your story over and over again. *"Repeating of information constantly is triggering and retraumatising. All information should be available on everyone's records and be read and understood."* Don't turn people away from mental health services because of addiction – there is an obvious link Make sure ALL medical professionals are aware of the patient's history and behave appropriately. (She told a story where Megan felt like she had been manhandled by a doctor as a teenager (for her scoliosis – unrelated to any mental health treatment) – but had the doctor known about her history, he may have treated her differently. Jenny is very happy to stay involved from a lived experience through any future procurement.
6. Closing and Reflection	CBT doesn't work for people with PTSD Every time her daughter went to an appointment, she would have to explain herself all over again. Mental health would be worse than before – continuity of care is so important. Need therapies that will treat the subconscious brain … only treatment available on NHS is for the conscious brain, would like hypnotherapy therapies.

4. Bill's Story

Interview Section	Bill's feedback
1. Introduction	Bill worked as a GP for 29 years before retiring in Nov 2019. He acknowledges that his decision to retire was based on the fact that he just wasn't enjoying the job anymore, and around that time also lost his father so felt he needed a break. However, once retired he found that he struggled to adapt – now feels like he was probably a little bit institutionalised and had some PTSD. Bill recognizes now that he was probably already developing depression. Even so, he approached 2020 with good intentions - 2020 was going to be a new year – then the pandemic hit and bill was diagnosed with prostate cancer. After that his mental health deteriorated and in June 2020 Bill tried to take own life by jumping in front of train. Amongst other injuries, Bill lost his left leg and had a bad brain injury. Bill believes that he only lived because of the swiftness of the air ambulance and Bedford Hospital and Addenbrookes, all of which saved his life and pulled him through. Quote: *NHS has served me well – 96% of good stuff – but it's the bad stuff you remember. My Physios, Drs and OTs – all were brilliant.* Bill was treated in hospital for 7 month and came home in January 2021 – which he describes as a huge hurdle to get over. CCS were brilliant – within about 3 hours had physio and OT at his door to check up on him. They organised carers to come in for a month to help settle him in and teach him what he needed to know. Another staff member who really helped him was a brain injury psychologist called Scott. When they thought I was 'well enough' the neuro specialist pulled away, despite the fact that Bill felt that he still wasn't well. *Quote: they used to say to me 'you have made a full recovery' – but I hadn't but I couldn't explain what it was.* Scott was able to explain that because of his brain injury Bill was likely to feel mentally tired more quickly, won't be able to work things out in his head as quicky and that his working memory won't be as good. Just being able to give him that explanation made Bill feel in more control. Bill felt that the CCS staff were interested and attentive – they held zoom meetings between the 3 of the support staff to involve him in his care plan. *Quote: I was very bereaved about the life I was going to lead in retirement.*

Interview Section	Bill's feedback
	Bill did have dealings with the Crisis team – and although he didn't have a bad experience with them - the trouble was he knew how to speak to them. Learnt as a GP to only give the crisis teams the negative and so knew as a patient how to get them off his back. Consequently – didn't come to see him – day before suicide went missing in the car (and was actually scouting for suicide places) Crisis team called again – and actually downgraded him to low risk. Bill also received care under Addenbrookes liaison psychiatrist – and trauma psychologist – under neuro psychology. Back under Bedford – CPNs (Community Psychiatrist Nurse) and key workers – not brilliant. Bill did say there was a disconnect between the hospital and primary care, Everyone pulled away and then no-one left to help care for him as the hospital thought the GP was doing it and the GP thought the consultant was. Bill has never had confirmation as to whether or not he has been discharged from the hospital.
2. Discovery *"What's Working?"*	The MDT approach is so important. Fragmentation of team working – its not that they are bad individuals – but something not gelling. View as a retired GP – is the practice the right place to go? Depends on the GP. If GP is just administrator and gatekeeper, then they are doing themselves down. District nurses attached to surgery – then they became more geographical. Lost the professional relationship – maybe PCNs will help that to grow those relationships back now.
3. Dream *"What Could Be?"*	General practice under so much pressure – if you send someone back to the GP care – need to understand what we can expect from that? What capacity is there for follow up. Continuity of care and making sure that the services work for the patient.
4. Design *"What Should Be?"*	The MDT meeting between the support staff and patient worked really well and made the patient feel comfortable and listened too.

Interview Section	**Bill's feedback**
5. Destiny/Delivery *"What Will Be?"*	Services currently done for economic and financial reasons – but not necessarily providing good care. Whole thing needs to be connected up and well communicated. (and well handed over if not same clinician)
6. Closing and Reflection	It should be about the patient.

5. Kirsty's Story

Interview Section	Kirsty's feedback
1. Introduction	Kirsty has lived experience as a service user, she has a CPA (Care Programme Approach), she has long-standing Serious Mental Illness and has been sectioned during her journey. Kirsty made her first attempt to take her own life at the age of 21. Initially Kirsty was diagnosed with bipolar affective disorder and was treated for this. There was a lack of review and professional curiosity, so Kirsty remained mis-diagnosed for a large part of her life. During Covid Kirsty stopped taking her medication for bipolar and at this point she questioned her bipolar diagnosis and Kirsty has more recently been diagnosed with Autism and ADHD. The medication given to Kirsty for bipolar disorder has resulted in other long term conditions, which affect her overall physical health.
2. Discovery *"What's Working?"*	Kirsty experiences highs and lows in how she feels and this can be exacerbated by lack of access to services and services ability to provide the right care. In her experience the care she has received has either been very good or very bad. She has found the Bedford Community Mental Health Service very variable depending on the individual care coordinator. The service provided by the crisis team also depends on the individuals that are working at the time you ask for support. Kirsty reflected that the in-patient ward environment is dire and even worse if you are autistic. Kirsty understands that given financial constraints it would not be possible to have separate wards for those that are neurodiverse, but what adaptations could be made to improve the environment? She reflected that staff attitude is key, staff morale is affected when staff are over worked and don't have the staffing levels to provide the care they would like to. Kirsty commented It is clear when there are staff that are just there for the money and clear when there are staff that really want to care for patients and provide a great level of care. In the inpatient wards, recovery is slowed if patients don't have the right levels of supportive care, for example not having enough staff to be able to access the garden space or take their allowed visits away from the hospital ward. For some

Interview Section	Kirsty's feedback
	inpatients they are able to come and go as they need from the ward but this still relies on a level of staffing to 'let them out'. Having access to these facilities can really speed up recovery for some. Kirsty now works with a mental health care coordinator who has a specialism in autism, she has a strong relationship with her support worker, they have got to know each other and Kirsty feels well supported and knows that she can access this support when she needs it. They communicate mostly via Whats app and her support worker is extremely responsive and understands Kirsty's needs. Kirsty's relationship with a previous support worker had broken down – there needs to be a way for this to be recognized and residents need to have the ability to change support workers if this is the case.
3. Dream *"What Could Be?"*	Through Section 117 aftercare funding Kirsty is given direct payments and is able to spend the money independently on things that are the right support for her. For Kirsty that is a personal assistant (although Kirsty had to recruit this person herself which has been difficult) to help her stay organised and a personal trainer. Working with a personal trainer has had a very positive impact on her mental health and her ability to keep herself well. *"He's better than any medication, I feel on top of the world when I come out of a session"*
4. Design *"What Should Be?"*	GP's hand out medication too readily, there needs to be a change in the perception of what needs to be done to support people with their mental health. There is a real discrepancy in what services people can access in Bedford town centre to those available to people who live in more rural areas. Those with lower level mental health needs are kept under review by their GP for long periods, it is only when their condition escalates significantly they are seen by Community Mental Health Services. But the GPs do not have the time to talk in detail with patients and give them the right support.

Interview Section	Kirsty's feedback
	It is good that there are Community Connectors and social prescribers who can offer more support, but there are not enough people in these roles and there is a lack of awareness of what they offer. CBT is not an effective treatment for people who are neurodiverse. 24/7 access to crisis support is vital to help people manage their condition and prevent further escalation and attendance at A&E.
5. Destiny/Delivery *"What Will Be?"*	GPs should have full awareness of all services to support people with mental health needs so they can effectively sign post them to the right support, this may be VCSE / community organisations. The communication from the GP needs to be right so that residents don't think they are being 'fobbed off' to volunteer organisations, when they may well have the specialist skills to give them the best support.
6. Closing and Reflection	Kirsty's message to those that are having a similar journey is 'To ask everyone you can for help, and take the help. Don't give up and fight for what you know is right. Be persistent, know what you want to ask for and ask for it, if you are able to, do research beforehand'

6. Mary’s story

Interview Section	Mary’s Feedback
1. Introduction	Mary is a carer for her mother and father, and she also has a long-standing serious mental health condition that impacts her life. Her elderly parents lived independently in the south of the country. However, with both parents' health deteriorating, including dementia and other health conditions, they all agreed it would be better to move to a village in Bedford to live closer to Mary. Mary purchased a home in Ravensden and arranged for her mother to receive respite care in a care home within Bedford Borough while the move was completed and arrangements were finalised for domiciliary care. There were numerous challenges in arranging support for her mother and father, which led Mary into a mental health crisis.
2. Discovery *“What’s Working?”*	Mary’s mother was receiving respite care in a care home in Bedford Borough. Residents at the care home receive support from a GP Practice in Central Bedfordshire. Due to her condition, she needs an air mattress to prevent pressure sores. The O/T team supporting her mother was from Bedford Borough, while the district nurse team came from Central Bedfordshire. This caused issues as there were disagreements between the two teams regarding who should fund the needed air mattress. The air mattress is supplied by the company Mediquip. They advised that since Mary’s mother was staying at the care home temporarily, a deposit for the mattress would be required due to care homes often losing or not returning equipment and this would be Mary’s responsibility to pay for. It took over 5 weeks for the mattress to be sourced, during which time Mary’s mother developed a pressure sore. Mary mentioned that she had contacts in the O/T team and could escalate the issue to them, and had no idea how anyone who was not familiar with the system would be able to navigate.

	While her mother was in the care home, Mary also worked with the O/T team to ensure that the new home in Ravensden was suitably equipped for when she left respite and moved there. Mary had assessed the suitability of the home before purchasing it, ensuring there was sufficient room for bed hoists, ramps, doors, and corridors wide enough for her wheelchair. However, the O/T team advised that the home did not meet the required specifications.
3. Dream *“What Could Be?”*	The responsibility for arranging or paying a deposit for equipment used in a respite care home should not fall on the family or carer. There should be efficient coordination between occupational therapists and district nurses to ensure that necessary equipment is provided. Delays due to discussions or arrangements regarding which local authority should provide funding should be avoided. Families need information about planning for when their parents become old and unwell, including which service area is responsible for what and the sequence of required actions. Clear guidance should be available. Information should also be made available about room sizes and the angles of rooms from doorways. For example, although Mary assessed the home herself, it did not meet the requirements of the O/T team. Agreed standards that everyone adheres to would be useful.
4. Design *“What Should Be?”*	For the services to be joined up and the care providers to work with one another. The carers should not have to be involved in some of the behind the scenes bureaucracy.
5. Destiny/Delivery *“What Will Be?”*	

6. Closing and Reflection	Mary's mum is now a permanent resident in the care home (she developed pressure sores whilst waiting for the air mattress), her risk of skin breakage is very high so it is safer for her stay there. Mary's dad has also moved into the care home so is getting the care and support he needs. They are happy that are able to continue to be together. Mary on the other hand, has a house in Ravensden that she now needs to sell.

7. Peters Story

Interview Section	Peters Feedback
1. Introduction	Since his late 20s Peter has been suffering with osteoarthritis in his spine – he has been in a lot of pain over the years. He is now managing the pain with painkillers; he is not able to walk far and uses crutches and a wheelchair depending on the circumstance. Peter used to work as an engineer but has now re-trained and works from home delivering mental health training. Peter has also been diagnosed with mild emphysema and COPD and he is diabetic.
2. Discovery *"What's Working?"*	Peter has had a positive experience in the most part with NHS services. He has a supportive GP practice who help him manage his pain medication and have been quick to refer him onto other services for his osteoarthritis, COPD and diabetes. He sometimes has issues getting through to the practice reception to make an appointment but once the appointment is made he feels he has received a really good service from the practice team. Because of the medication he is on, he has to have a regular review of his prescription which can delay getting his medication as he need an appointment before it can be re-issued and he is sometimes worried he will run out. He also has a different GP each time which means he has to spend a proportion of any GP appointment running over his history before being able to talk about the reason for the appointment. Whilst the process to refer him to other services has been quick and the initial care he has received he has felt has been excellent, he has found the aftercare lacking. One example is his referral to the pain management clinic. Peter had a great experience with the surgical team he was referred to, however there is no surgical procedure that can help him so he was referred to the pain clinic. This referral took 18 months - there was no communication during this time. When Peter was under the pain clinic they provided physiotherapy and acupuncture neither of these worked which Peter knew would be the case. He was referred on to the HydroHealth scheme, although there was a 3-month waiting list. This service has been brilliant and Peter has found being able to move in the water without walking aids has been great for his physical and mental health. He was allocated a 12-week programme for

	the shallow pool. Some people he met had been attending those sessions for a year, this made Peter question why he was only given a 12-week programme and why there was a 3 month waiting list. Peter's 12-week programme finished in February and since then he has continued to attend the HydroHealth sessions as often as work commitments allow, but goes to the 'deep swimming' sessions at Stopsley, there is not a waiting list for these sessions which are held for a group of 10 people.
3. Dream *"What Could Be?"*	Following Peter's initial diagnosis of Diabetes, the initial appointment he received with a specialist was excellent, he was then referred to the Luton Integrated Diabetes Service and was told they would contact him and invite him to support sessions. He has yet to receive any contact from the Diabetes Service. People should not be left to fall between the gaps like this. Peter has had a really positive experience of occupational health services, as soon as the GP practice referred peter, the team were in touch with him. They have provided assessments at his house and installed frames around the toilet, hand grips and hand rails. They assessed that he should have the bathroom converted into a wet room but this was blocked by Peters private landlord. They also secured a grant to convert the garage to a downstairs bedroom and wet room – again this was refused by his landlord. Peter has since moved and the OT team once again assessed the house and made all of the required adjustments. Peter uses a mobility scooter and has a car on the Motability scheme without it he would be confined to his four walls as public transport is not a viable option for him. Peter is anxious about the possible change to PIP by the government as this is the way Peter is able to pay for his Motability vehicle.
4. Design *"What Should Be?"*	When diagnosed with mild emphysema and COPD, Peter was advised to stop smoking. His GP quickly referred him to the Stop Smoking Service, Peter met with a 'brilliant young lady' within 2 weeks of the referral being made and together they developed a plan for him to stop smoking. Peter has now been smoke free for 2 years. This help and initial support was brilliant.

5. Destiny/Delivery *"What Will Be?"*	Communication needs to be improved if you are referred to a service they should contact you initially to let you know they have your details, explain who they are what they will do and when you are likely to get an appointment. If the initial contact from a service is 6 months down the line from when you are referred you may miss the email as you are no longer expecting it. The first communication should be early, email can be the best way of communicating as you then have a record and trail of the messages. Peter used system online through his doctors to keep track of letters from the hospital and other services and also uses it for his repeat prescriptions. He finds it more up to date than the NHS App which does not always have his most up to date prescriptions showing.
6. Closing and Reflection	"Communication is key, services need to work smarter, not harder." Peter had a lot of praise for NHS services and the levels of care he has received, but the referral process and communications has let the overall experience down.

8. Elizabeth's story

Interview Section	Elizabeth's Feedback
1. Introduction	Elizabeth has had a lot of personal and professional experience with mental health services. She has struggled with her mental health for long time – on and off antidepressants – last year tried really hard to come off them as had been on them a long time. She has struggled for some time with insomnia and since Covid has struggled with anxiety. Was able to reduce her medication to half a tablet every other day – but then found she couldn't sleep. GP suggested that she referred herself to Talking Therapies. The referral form was long and difficult to complete – but was eventually referred to 1-2-1 therapy. Had first appt – which Elizabeth describes as a 'car crash' … right from start she felt like the therapist didn't care about her. The therapist was short with her and harshly told her that she didn't score high enough and therefore didn't meet criteria (because she had gone back on medication) and would discharge her and refer to online course. Don't want anything to do with talking therapies … medication now upped and still on it.
2. Discovery *"What's Working?"*	Professionally have just built a relationship with older CAMHS part – using some of our hubs to run A perinatal nurse at the hospital has been really engaged. 'Mind the bump and mind the baby' groups – also going very well. – through the family centres Some doctors who are brilliant and really listen to you – and some that just brush you off.
3. Dream	Referral processes can't just use a checklist - treat patients like individuals. Elizabeth feels that even when she has come across services as a professional – always seems to be a list.

"What Could Be?"	Her son has SEN issues and childhood trauma. An Educational psychologist was brought in for him - but CAMHS turned him down 3 times – didn't get support until he was permanently excluded. No preventative measures – only seem to see people in crisis. *Quote: 'There has to be an opportunity to tell your story and be listened to, instead of form filling…'* As a Family Hub coordinator – working in a project about perinatal mental health – really struggled to get any engagement with services. Funded a Child and adolescent therapist last year – but no leadership or management. Steering group now doesn't have a representative from ELFT- had a meeting booked, no one turned up – really hard to make any progress as just no engagement from them. Need more guidance about coming off medication – and to provide alternatives to medicine in the first place. *Quote: I was never asked how I would like my care – and no alternatives offered when didn't meet criteria for care.*
4. Design *"What Should Be?"*	Speech and language service have recently started early advice sessions. Families can self-refer and get 20 minutes with a clinician. It's a triage really – but helps to figure out next steps – relatively easy thing to put in. An easy win Technology can be great – but can also be a disaster. Let's not rely on a computer to make a decision about whether someone is in crisis or not – that needs a human response.
5. Destiny/Delivery *"What Will Be?"*	Build into teacher training better understanding of SEND needs, which is only increasing in mainstream schools. Secondary school is a big issue – big change. Primary school is much more nurturing. MHST (mental health support teams) great resource – need more and in every school. CAMHS – high level need, and MHST for low level need – gap in between. PHSE – very hard to cover all you need to in any depth. Scope for health teams to come in and train staff in schools.

	Build peer support networks locally. No forms to fill in – no criteria to meet … Need a safe space to be able to go to. Services need to be well advertised – minimum barriers and make sure some good experiences are shared to build trust in the service.
6. Closing and Reflection	*Quote: Start listening – bring humanity back into the service. It’s got lost somewhere – not just in mental health but across the board.* Also need to work more efficiently … I would tell them ‘Don’t go to talking therapies … ‘ ‘Don’t know what I would tell them – because what do you do and where do you go?’ Support for people on the waiting list … it’s such a long wait – what is the support while you wait? Waiting well…. and local signposting whilst you wait. Peer support – need to be led by healthcare professional to help, - probably going through a body like the patient carer forum because they are parents – and not clinical. Need to be regular and consistent.

9. Omar’s story

We had arranged an interview with Omar, unfortunately he was admitted to hospital so unable to meet with us.

Omar was keen to share as his story and sent us an email from his hospital bed.

Omar’s Story
Background I am currently undergoing chemotherapy (Cyclophosphamide) as part of a treatment plan for myocarditis, and while I do not have cancer, the impact of the treatment—including the side effects—has been substantial. My case is medically complex, with a history including many conditions. Given this background, consistent and expert management of my PICC line has been critical to both the success of my treatment and my quality of life. **Timeline of Care and Escalations** 1. **Initial Success July 2023 to May 2025.** I was initially assigned to Mandy, a community nurse with cancer care experience, under the Cambridgeshire Community Services (CCS) team. From the outset, she provided exceptional care. Her clinical competence, reliability, and proactive support in managing chemotherapy side effects made a real difference. Crucially, while Mandy was managing my PICC line, it remained stable and did not migrate—a major concern in my case. **2. Disruption Begins – 2024 – 2025** Despite this stability, a decision was made to transition me to a rotating nursing model. This was implemented even after multiple pleas—verbally and in writing—not to disrupt a functioning arrangement. This decision, I believe, was rooted more in local operational politics than clinical reasoning. 3. **Negative Outcomes from Staff Rotation – April 2025** Once Mandy was temporarily unavailable, CCS assigned other nurses, including one nurse, whom I had previously raised concerns about. Unfortunately, during her visit:

Omar's Story

- The bio patch was mishandled, requiring urgent correction.
- Mandy had to return, redress the line, and document the issue with photos.

Shortly afterward, another nurse was assigned. Following this, I was informed by clinicians at Hammersmith Hospital that my PICC line had migrated three dots—a substantial movement.

4. **Escalations and Emails Sent – April 2025**

- The Vascular Nurse, at the L&D Hospital was supportive and acknowledged the risks of repeated PICC reinsertion. She confirmed I may have limited future options for line access and attempted to advocate for me, but her efforts were reportedly met with resistance from CCS.
- I also raised concerns directly with managers at CCS (key issues below) and never received a response.

Key Issues

1. Failure in Continuity of Care

The most troubling issue is that my case demonstrated success—both clinically and emotionally—when continuity was respected. Why dismantle a working, safe arrangement? There was no clinical justification provided for the change, and the consequences were immediate and serious.

2. Clinical Risk from Line Migration

Repeated nurse changes have led directly to line migration, increasing my risk of infection, hospitalisation, and potential complications from future access site depletion.

3. Mental Health Toll and Distrust in Service

This disruption has taken a heavy psychological toll. The uncertainty around who will manage my line each week has contributed to stress, anxiety, and physical deterioration, as evidenced by my recent hospitalisation. I feel that internal service politics were prioritised over patient safety—a sentiment no patient should ever have to voice.

Request and Reflection

Omar’s Story
This experience has left a deeply bitter taste. I engaged with this review in the spirit of collaboration and improvement, but I cannot overlook the frustration and harm caused by these avoidable service decisions. I urge you to use this testimony to underscore a simple truth: if something is working—don’t fix it. Mandy’s consistent care was a lifeline. Undermining that, against clinical indicators and patient feedback, was both negligent and insensitive. I sincerely hope no other patient will have to endure similar distress due to inflexible or politicised service decisions. Thank you again for giving service users a voice. I hope mine contributes to meaningful change.

Appendix 1

Interview Section	Suggested Questions
1. Introduction	• Could you tell me a little about yourself and your experience? • What's something in your life right now that you feel proud of or grateful for? • When you think about your journey with mental/community health services, what words come to mind?
2. Discovery *"What's Working?"*	• Can you tell us about your experience with community/mental health services? And specifically think about: • The very beginning of your journey and when you were referred into services. What was your experience of the GP – was it helpful? Are there lessons we can learn from this? • When you accessed the service – did they give you care in the way that worked best for you? • Did you ask for care to be delivered in a specific way and what was their approach? • What did the service do that made a positive difference for you? • Were there specific people, approaches, or moments that stood out as especially helpful? • What strengths or qualities did you notice in yourself during that time?
3. Dream *"What Could Be?"*	• Imagine the best possible mental/community health service. • What would it look and feel like? • What would your ideal experience of care and support include? • How would staff interact with people accessing the service? • How would you know you were being heard, valued, and respected?

4. Design *"What Should Be?"*	• Based on your experiences, what changes would make services better for people like you? • What practices, if adopted more widely, would lead to more positive experiences? • What role could people with lived experience play in shaping or delivering services? • How could the system better support your recovery or wellbeing journey?
5. Destiny/Delivery *"What Will Be?"*	• What do you think could help improve services? • Would you be interested in contributing to change (e.g., co-design, peer support)? • What support or encouragement would you need to stay involved in shaping services? • What gives you optimism about the future of mental and community health?
6. Closing and Reflection	• What's one thing you want service providers or decision-makers to understand about your experience? • What message would you give to someone going through a similar journey? • Is there anything else you'd like to share that we haven't asked?