Changing Futures Service User Scoping

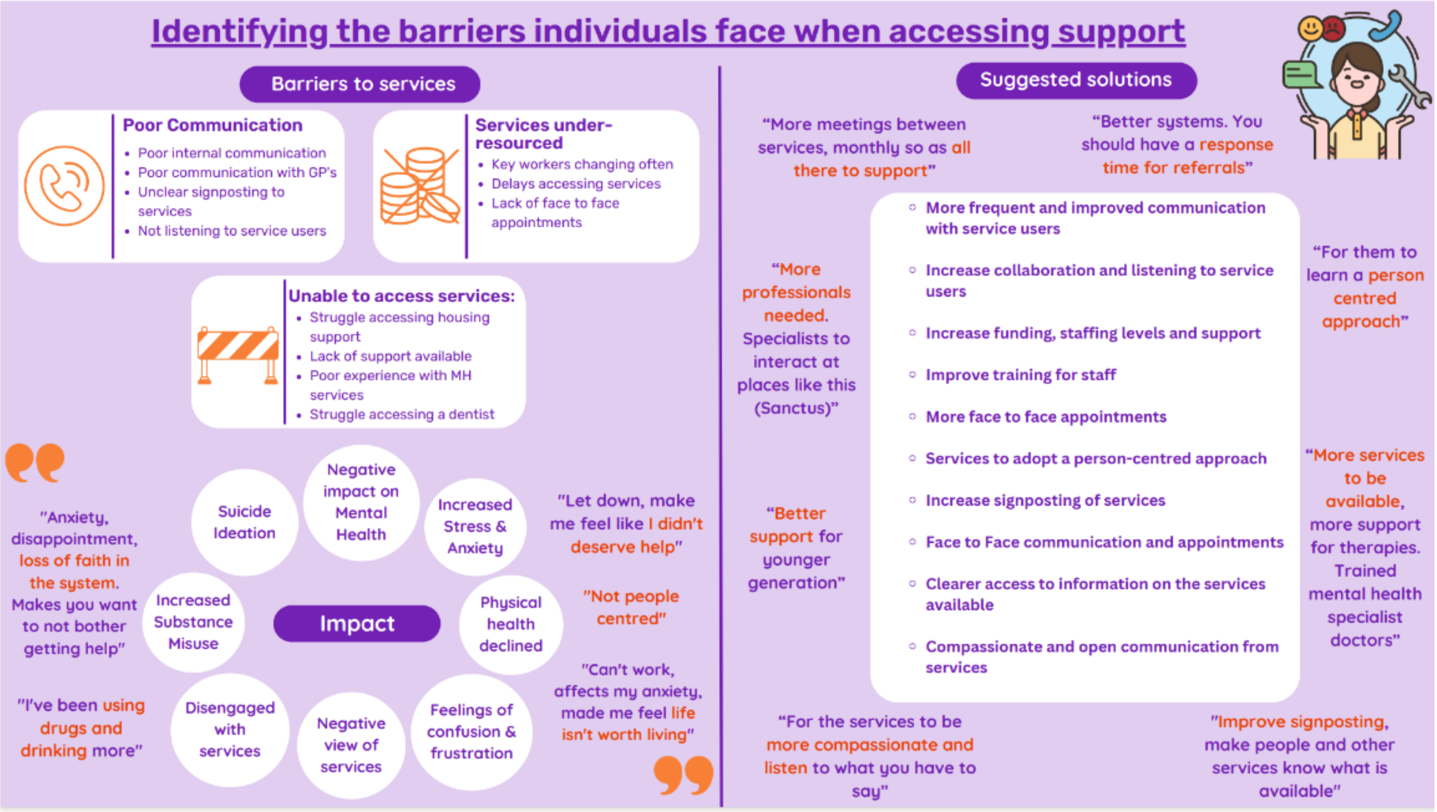
As part of Changing Futures, Essex County Council and Phoenix Futures explored the views and experiences of the current 'system' from individuals who access services in Essex. These individuals were able to speak about any part of the system which they had accessed and their experiences.

We spoke with 100 individuals across the county who are or have accessed services within Essex. Those who took part had ages ranging from 18 – 74 and were of all backgrounds.

Our aim is to be able to develop an honest and transparent approach, without a culture of blame or accusations, which will enable true system change and make services more accessible for those with multiple disadvantages.

To enable us all to facilitate change, we first need to understand gaps in services as well as barriers to accessing and retaining service users.

The following visuals summarise the findings of this scoping exercise. You can find a more thorough exploration of the data collected and the process used to develop the themes in the 'Narrative' section below.



Identifying the barriers individuals face when accessing support

Barriers to services

Poor Communication
- Poor internal communication
- Poor communication with GP's
- Unclear signposting to services
- Not listening to service users

Services under-resourced
- Key workers changing often
- Delays accessing services
- Lack of face to face appointments

Unable to access services:
- Struggle accessing housing support
- Lack of support available
- Poor experience with MH services
- Struggle accessing a dentist

Impact
- Suicide Ideation
- Negative impact on Mental Health
- Increased Stress & Anxiety
- Physical health declined
- Feelings of confusion & frustration
- Negative view of services
- Disengaged with services
- Increased Substance Misuse

"Anxiety, disappointment, loss of faith in the system. Makes you want to not bother getting help"

"I've been using drugs and drinking more"

"Let down, make me feel like I didn't deserve help"

"Not people centred"

"Can't work, affects my anxiety, made me feel life isn't worth living"

Suggested solutions

"More meetings between services, monthly so as all there to support"

"Better systems. You should have a response time for referrals"

- More frequent and improved communication with service users
- Increase collaboration and listening to service users
- Increase funding, staffing levels and support
- Improve training for staff
- More face to face appointments
- Services to adopt a person-centred approach
- Increase signposting of services
- Face to Face communication and appointments
- Clearer access to information on the services available
- Compassionate and open communication from services

"More professionals needed. Specialists to interact at places like this (Sanctus)"

"Better support for younger generation"

"For them to learn a person centred approach"

"More services to be available, more support for therapies. Trained mental health specialist doctors"

"For the services to be more compassionate and listen to what you have to say"

"Improve signposting, make people and other services know what is available"

Understanding the impact on individuals navigating the current system

Barriers to services

Poor Communication
- Lack of Communication between services
- Repetition of information
- Lack of communication with service user

Mismanaged referrals & transfers
- Poor transition from YP to Adult services & GP to MH
- Referrals not picked up
- Medication not being transferred

Empathy & understanding
- Service users not feeling listened to
- Lacking empathy and attentiveness
- Poor understanding from both services and service user

Loss or lack of support
- Service users felt unsupported
- Losing access to services when moving areas
- Long waiting times for support

"Makes me feel unimportant, just a statistic"

"Put anxiety through the roof"

Impact

Suicide Ideation

Negative impact on Mental Health

Increased Stress & Anxiety

Physical health declined

Feelings of frustration

Negative view of services

Lost access to services

Increased Substance Misuse

"I felt lost with no support"

"Not able to have support as no one knows who to refer to"

Suggested solutions

"A phone call so I knew I hadn't been forgotten and to see how I was coping"

"Support worker to help transition"

"There is trust, honesty and confidentiality and no-one is judged"

"People to be more understanding and work at the pace and ability for me"

- More frequent and improved communication with service users
- Increase collaboration between services and listening to service users
- More support to be made available
- Increase levels of staffing
- More face to face appointments
- Improve awareness and understanding of service user needs
- Increase signposting of services
- Reduce complexity in accessing services - single point of access
- Improve transitions between services

"Improve the way services communicate with each other"

"One point of contact to access all services"

"More funding. Better continuity of Care"

"Explain more about what's happening and what will happen next"

Understanding how the current system makes individuals feel

Impacts

Impacts on Mental Health
- Worsens already poor mental health
- Repetition of their stories retraumatizes
- Felt alone & not worth helping

Feeling unsupported
- Negative judgements impact level and quality of support
- Not always taken seriously, not a person-centred approach

Hard to access services
- Lack of accessibility & support
- Lack of service knowledge
- Long waiting times for services
- Confusion with services set up

Impacts - In their words

"System is not working, causing people mental and physical problems, causes people more anxiety"

"Not treated equally, looked down on"

"Makes it worse, calls from different people. Having to retell your story to everyone a million times"

"Drug abuse, prison, self-harm, suicide"

"It's not easy to navigate the system unless you have someone to help you with it and know what to do and where to go"

"Too long a wait for services to interact"

"Makes people feel lonely and no one cares about your feelings, isolation"

"Very confusing, disheartening and it takes a long time to get any support and it does not always feel like the right support"

"Too much paperwork - Support lacking for learning difficulties, find it particularly difficult and confusing"

Suggested solutions

- More frequent and improved communication with service users
- Increase collaboration between services
- More support and increase staffing
- Adopt a community and person-centred approach
- More access to appointments
- More empathy and less judgement
- More listening to service users

If you could change your experience...

"More staff/regular contact"

"Support workers available to more people"

"Getting into services quicker"

"To have been listened to"

"More communication both ways and being helped when needed"

"Waiting times reduced"

"Better inter-service support"

"Help sooner as my mental health badly deteriorated to time waiting"

"Be given 1:1 support"

"More access and understanding of needs"

"Be honest about my situation sooner than later"

"Smoother/easier pathway into services. No wrong door policy"

"More face to face appointments"

"Clear pathways on the treatment plan"

Accompanying Narrative

Introduction

Changing Futures Essex conducted a scoping exercise to gauge how individuals experiencing multiple and complex needs [1] accessing services across the twelve district councils feel about the support they have received from those agencies and the wider local system [2]. Individuals may not have all personally experienced multiple and complex needs but were all accessing services such as mental health services and drugs services which are very commonly accessed by people experiencing multiple and complex needs.

It is important to note that the intention is not to be accusatory or to assign blame, but rather to provide an opportunity for people to be honest and open about their experiences of services - both positive and negative; and moreover, that this can provide the beginning of an open dialogue to help drive service improvement and wider system change for people experiencing multiple and complex needs.

As part of the scoping exercise, Phoenix Futures attended a broad range of services based across the county and interviewed 100 individuals who were able to speak about any part of the system which they had accessed and their experiences, in particular:

- barriers to accessing services,
- the impact on individuals when unable to/ prevented from accessing support;
- areas for improvement within services and the wider system;
- potential solutions to address these barriers.

As noted above, the exercise also provided an opportunity for people to talk about their positive experiences of services, and some of which is captured in the feedback below:

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[1] *Multiple and complex needs include but is not limited to: homelessness, mental health issues, substance misuse, interactions with the criminal justice system, neurodiversity, and domestic violence. People with multiple and complex needs will have experienced trauma and require a coordinated approach from services to meet their needs.*

[2] *The system: i.e. the services and support that might be accessed by a person experiencing multiple and complex needs in an area, including how different organisations and people within the system interact with each other and with people experiencing multiple and complex needs.*

"Housing - pretty good. Drug services - Excellent."

"Find it easy to use online services."

"All good. My experiences have been positive".

"Accessing services hasn't been too bad and have been able to see GP in person and able to get through to them on the phone when I need to".

"My experience of accessing mental health services was very good and I was referred by my GP very quickly".

"I went seamlessly from GP to *the drugs service* to *community rehab* to peer mentoring course to volunteering".

"GP has been helpful".

"Good experience with MIND".

Figure 1 - Quotes from participants regarding their positive experiences with services.

Methodology

The Service User Scoping was developed from the Fulfilling Lives evaluation which was carried out by the team in Lambeth, Southwark, and Lewisham (although the difference being that it would be undertaken near the start of the programme to inform the direction the Changing Futures Essex programme would take).

The objectives and questions as set out below were developed with the support of Dr Sarah Senker and the Essex Recovery Foundation who provided input into the final wording and terminology used to provide a more solution focused approach. The full questionnaire used can be found in Appendix A.

Changing Futures practitioners attended different services including NHS mental health services, drugs services, libraries, wellbeing services and others to meet with a range of people whose demographics can be seen below (Figure 2). Other than this basic demographic information, the data was kept anonymous. The Changing Futures Essex team developed a questionnaire which was intended to answer three key objectives. This questionnaire was asked of each of the 100 participants (participants).

Following the advice of Social Finance, who supported the national Changing Futures programme, it was decided to undertake a Thematic Analysis of the participants' feedback, thereby thematically coding the responses and emerging themes.

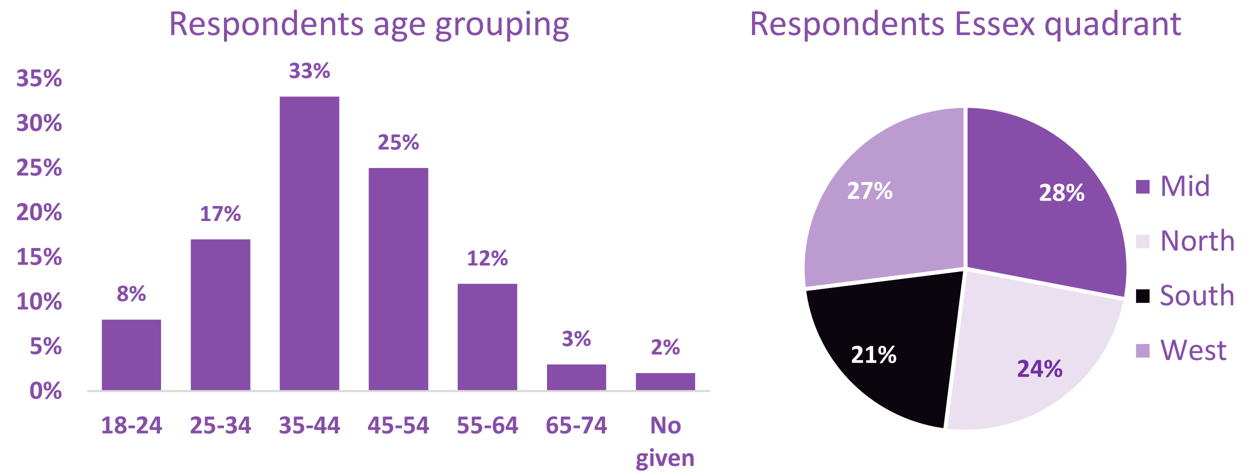

Figure 2 - Bar chart showing the age ranges of participants and a pie chart showing the split in locality of participants.

The 'Objectives'

The participants were asked the following questions to answer each of the three objectives.

1. **In your experience, what are the common barriers to accessing services?**
    1. What are your experiences of accessing services in Essex, good, bad, or average?
    2. What barriers, if any, have you encountered and what impact have these had on you?
    3. What solutions do you suggest?

2. **How does the current system negatively impact people facing multiple and complex needs when moving between services?**
    1. Have you had experiences of moving/transferring between services?
    2. How did this move go? What worked well and were there any gaps/barriers? How did these gaps/barriers affect you?
    3. What solutions do you suggest?

3. **What are the common ways that the current system makes people feel, particularly those facing multiple and complex needs?**
    1. How do you think the current system as a whole affects people with multiple disadvantage?
    2. What solutions are there to empower individuals and create more effective interactions?
    3. If you could change one thing about your experience, what would it be?

Participant case study

There were several participants that showed a clear and full picture of their journey through parts of the system. One of these has been selected below to illustrate how people living in Essex experiencing multiple and complex needs navigate the system. There are other examples provided in Appendix B.

Participant 49 (Female aged 45-54 from North Essex)

Participant 49 reported long waiting lists and needing to be alcohol free before being able to access Mental Health services. For GP's, waiting for referrals to come through and then waiting on an appointment created feelings of frustration for Participant 49, and she felt that the appointments are short. She stated that she would *"not feeling like you should take up too much time"*. The impacts these barriers have on the person is noted as *"Makes you suffer in silence/magnifies problems"*. A suggested solution was to give more information on the referrals and be open and honest about waiting times.

Sharing their experience of transferring between services Participant 49 stated *"Starting from the beginning by repeating life history. She said it "Takes time to build trust". This* gave her a negative experience and she felt she was *"not informed of the maximum transfer time so you have light at the end of the tunnel"*. This left Participant 49 feeling *"Like taking steps back on any progress made. No specific point of contact"*. This then formed part of her suggested solution of having *"one individual to manage your case between all agencies for continuity of care"*.

Feeding back on the current system and how it affects people with multiple and complex needs the Participant 49 felt there *was "Too much box ticking and not treated on an individual basis. Need more face to face meeting"*, recommending *"More face to face work. Individuals set tasks to be included in their process to give value and meaning"*. Participant 49 also shared that the one thing they would change about their experience they *"Should have asked for help sooner"* reflecting on her own accountability for her care.

Thematic Analysis of the Responses

Objective 1 – Identifying the barriers individuals face when accessing support.

Common barriers that many participants found when attempting to access support can be grouped into 3 main themes, these are; 'Poor communication', 'inability to access services' and 'under-resourced services'. These are expanded upon below to show that these issues exist across the whole system and the negative impacts that these barriers have on people.

Experiences of accessing services in Essex.

Poor communication:

Unclear signposting and information about the services available has resulted in those experiencing multiple and complex needs struggling to know where to turn for the correct support for their needs. Poor communication between services results in people being 'passed from pillar to post' around the services without being given a reason. Some participants reported frustration building while awaiting a response for a referral and not being told a general response time, all of which increased anxiety.

"Mental health - totally unclear process of who you go to, nobody seems clear on who to go to either"

"Feel like I am not listened to"

"Did not know what I should have been having. It took to crisis before anyone listened"

"Been waiting to hear from the alcohol service for over 2 months, I referred myself"

"Not enough info, not responding to emails, not listening to needs"

"I try to get to see doctor but was fobbed off with meds. Tried to get concerns raised but no one listened"

"Mental health and home care support, found these to be frustrating. Lack of communication and care plan took ages to put in place".

"As a younger adult who needs support to communicate needs effectively. Mental health don't like me to have an advocate and want me to speak for myself. Vitaminds also did not send me all information for my CBT course".

Figure 3 - Quotes demonstrating the 'Poor Communication' theme.

Inability to access services:

Participants refer to a number of issues they feel are barriers to them being able to access and receive support through some services, these include substance use, relationship status, financial and housing situations.

“Being homeless has been a barrier, not having money to get around where I need to be”

“Mental health do not want to know due to drinking”

“Moved from out of area, struggled accessing mental health and housing”

“Went to care for my mum so gave up my council place. Told made myself intentionally homeless”

“I have PTSD and suicidal tendencies. I have gone full circle with mental health, gone through 4 services and now referred back to my own GP again. Deemed too complex. MH crisis team don’t help. Been told no help unless I go through A&E”

“Housing is nearly impossible… If you are single, you are not classed as important on the housing list, just because you don’t have a family”

“People haven't wanted to help me. I felt I needed support around housing, but they wanted me to stop addiction first”

Figure 4 - Quotes demonstrating the theme 'Inability to access services'.

Services are under-resourced:

Participants comment on a lack of resources equating to longer waiting times, not being able to see services in person and services not accepting new patients.

“Been in 2 temp accommodation, still without a home. Only got housing as I had a heart attack”.

“Not enough support if come from out of area”.

“Lack of staff, lack of resources”.

“Dentist not taking NHS clients - big waiting list”.

“Too many people wanting help, not enough recourses”.

“Waiting times, unable to speak to someone. Being told your situation isn't bad enough”.

“Can't get a face to face appointment with my GP and no dentists in Harlow are taking new patients”.

Figure 5 - Quotes demonstrating the theme 'Services are Under-resourced'.

The impacts of these barriers:

Participants highlighted how these barriers impact their wellbeing and which path this leads them down without the support they need. The following were identified by multiple participants and have been themed below, accompanied by some supporting quotes:

- Increased stress and anxiety.
- Physical health declined.
- Negative impact on Mental health.
- Suicide ideation.
- Increased substance misuse.
- Negative view of services.
- Disengaged with services.
- Feeling of confusion and frustration.

"I felt I was in the wrong. No one listened"

"Can't work, affects my anxiety, made me feel life isn't worth living".

"Living on the streets, trying to access accommodation".

"Confused and lost"

"Affected my mental health badly, at wits end, could of resulted in suicide"

"Lots of stress, depressed, health made worse".

"I've been closed because I've not engaged because I've not made appointments" (Couldn't afford travel costs)

"Staying in, feeling isolated".

"I've been using drugs and drinking more".

Figure 6 - Quotes demonstrating the impact of these barriers on participants.

Solutions to these barriers:

Participants provided some helpful suggestions that they feel would have improved their experiences, by reducing the barriers they found when trying to access support from the system.

- A common theme for discussion was more contact and open communication from services throughout the process of receiving support, including while on the waiting list. One participant suggested *"Having an ex-service user allocated to you whilst waiting, to explain the process and have contact while waiting".*

- Some shared that they thought services should listen to clients' needs and there should be more collaboration on their plans for care and support *"People to care and actually listen and work in different ways with everyone"*.
- Suggestions around improved accessibility of treatment included booking methods, face to face appointments and increased availability of services, with some key suggestions highlighted as *"online booking systems that are useable and available", "Having places closer to me* (Mid Essex)*", "Give them more money for more staff", "Should not have to wait or have telephone treatment"* and *"More places like Streets2Homes where people can go and someone in the Council who could signpost to places".*
- Numerous participants also suggested the need for further education and training for staff, to ensure they have knowledge of the full spectrum of support services. This would allow for clearer signposting to people, making them aware of all the options available and this would enable a person-centred approach. Participants specified some services they feel this would benefit them most *"Put back in training and for them to learn a person-centred approach"* and *"Doctors need education on other services and what supports available".*

Objective 2 – Understanding the impact on individuals facing multiple and complex needs when transferring between services in the current system.

Participants highlighted their experiences from transferring between services and any gaps or barriers they found during this time, with some similar themes appearing in the responses for this section and the previous one. The themes were analysed as being 'poor communication', 'mismanaged referrals and transfers', 'lack of empathy/understanding' and 'loss or lack of support'.

Experiences transferring between services:

Poor Communication:

Similar experiences were shared around poor communication for transferring between services as was identified in the section above, such as a lack of communication between services and with service users. A key issue raised was the feeling of repetition involved when changing services. The lack of sharing of the persons information between the multiple services caused frustration and delays in receiving vital support.

"Having to say your story over and over again would be easier if services shared more information".

"My mental health contact kept changing and I had to keep repeating information".

"I do not feel I am listened to by the adult diabetic team and that there are not enough appointments given".

"My continued care was impacted. Details of medications not transferred some medications stopped".

"Moved from GP into MIND, MIND onto Crisis Team, Crisis team back to GP. No communication between services, nobody taking responsibility of my care, lack of knowledge".

Figure 7 - Quotes demonstrating the 'Poor Communication' theme.

Mismanaged referrals & transfers:

Numerous participants shared that they felt their referrals and transfers were mismanaged in some way when moving between different support services. This included referrals just not being picked up, poor transitions between young people to adult services, or from GP to mental health services, resulting in a lack of quality support or even being without medication for a period of time.

"Moved from Cheltenham to Essex. Lost all access to all services especially access to my CPN."

"Released with nothing, happened a few times when released from prison".

"referred to one service who can't help then discharged to GP to be referred to someone else".

"Struggled to get my prescriptions initially, my medications were not correct".

"I moved areas and housing service was not helpful. I needed my gateway account sorted out when I arrived but no help. I ended up homeless but with no support".

Figure 8 - Quotes demonstrating the 'Mismanaged referrals &transfers' theme.

Reduced support:

The result some participants shared when transferring between services, was that they felt unsupported and not listened to. They felt they were not being given the attention and support they required in that moment, often waiting long periods of time for the support to be implemented in a way they were comfortable with.

“Moving from child diabetic team to the adult diabetic team at hospital. I feel the service was nowhere near as attentive”.

“Home treatment team wasn't really long enough”.

“Disrupts my life, makes it difficult to access services again”.

“Was in Linden Centre, moved to Maldon for a month. Because out of area, struggled to get back into Chess accommodation”

“Moved on from YOT to Probation - Big difference, YOT much more relaxed, probation more strict”.

“Not well, felt unsupported and relapsed”.

Figure 9 – Quotes demonstrating the ‘Reduced Support’ theme.

How did these issues affect you:

Participants highlighted how the issues identified in transferring between support services impacted their wellbeing. The following were picked up by multiple participants and have been themed below, accompanied but some supporting quotes.

- Increased stress and anxiety.
- Physical health declined.
- Negative impact on Mental health.
- Suicidal ideation.
- Increased substance misuse.
- Negative view of services.

“Panicked, impacted my mental health. I need my medication”.

“Quite considerably. Lost access to my mental health support and struggled to get it back since”.

“High anxiety”.

“It affects my health as diabetes ends up taking over completely”.

“Mental health got worse, suicide attempts”.

“Not knowing where you are staying”.

- Lost access to services.

- Feelings of frustration.

Suggested solutions:

Many participants shared their thoughts on ways the issues they faced could have been overcome, enabling them to receive the support they needed in a timely, less stressful manner.

On the topic of improving communication and reducing the repetition of their stories, multiple people raised the question of services access to their information. Whilst Changing Futures Essex acknowledges the difficulties around sharing and data protection, participants shared that they thought the services *"should have access to the same computer systems"*, and specifically mentioned that there could be *"One system that all medical services can access"*. This would help to improve the collaboration between the services, which was a common request throughout the responses.

In helping to support people's transitions between services, the suggestion was made to have a *"Support worker to help transition"*. Multiple responses alluded to the benefit in having someone to guide them through the process, as having long waiting times in between transitions can leave people without support. This in turn can lead to increased stress and anxiety over whether they have 'fallen through the cracks' and been forgotten about, making them feel unworthy of support. Extra support would help to *"Explain more about what's happening and what will happen next"* and therefore alleviate the uncertainty while waiting on support to start. There was recognition that *"More funding"* would be needed to achieve *"Better continuity of care"* overall. In particular, the need for a *"Better transition between hospital and home"* and *"Housing people - rehab on release from prison"* to create smoother transitions.

Some participants felt there needed to be improvement within the support services around awareness and understanding of the person's needs *"by asking how the issues affect people and how people can be supported"*. They suggested an approach which placed the individual at the centre of their care, including them in decisions about their care and giving them the opportunity to feel part of the team, taking steps to supporting themselves. Specific services this was raised for were highlighted in the following responses, *"Government. A lot more awareness around mental health"* and *"Just feeling like the doctors do not listen to the issue, problem at the time".*

A suggestion that really stood out and which encompasses a lot of the issues people raised, was that when services are engaging with people they should *"Just explain to people. There is trust,* *honesty and confidentiality and no-one is judged"*. This again highlights the importance of communication, understanding, rapport and respect.

Objective 3 – Understanding how the current system impacts those facing Multiple and Complex Needs.

Participants shared how navigating the current system makes them feel as people facing multiple and complex needs. When theming the responses, it was found that many participants felt it can negatively impact on their mental health, it made them feel unsupported and it made it harder for them to access services.

"Completing the same assessment with each service you are with – repeating".

"Negatively. Often get told to sort your drug problem out before my mental health will see me and visa versa. It's like the chicken and the egg, what comes first? They both affect me!"

"Set us up to fail, tax everything. People with mental health don't have the ability to work".

"Too much paperwork - reading difficulties makes applications harder. Support lacking for learning difficulties".

"Not knowing what services are available for particular areas, MH, disabilities, housing."

"Not enough support for homeless in South, like Sanctuary in Chelmsford".

"Not being able to deal with 1 person for all issues, confusing as they are dealing with different people in different departments".

"Sometimes there are too many appointments to get to, can't remember everything, services close quickly".

"People who are isolated unable to get to appointments".

Figure 11 – Quotes demonstrating how navigating the current system made respondents feel.

Suggested solutions:

Participants shared their opinions on what they felt would help to empower individuals and create more effective interactions with services.

Numerous participants felt that support could be offered to help support all their needs in one service, *“Having a service that would pick up patients that have disabilities, [mental health] and learning disabilities”*. They also felt that services could collaborate more through *“Better communication, more support services for dual diagnosis, where mental health and alcohol services work better together”*. Again, a key theme raised around this type of person-centred approach was to have someone coordinating their support, *“To have 1 keyworker allocated to deal with all aspects”.*

There was acknowledgement from participants that they needed to push to be more involved in their care but that when they do that the services need to be willing to include them, *“People have to be willing to engage and services need to be willing to listen and open to provide support, without dictating and having an open mind”.* If people are not satisfied with the support, they are receiving they need to voice these concerns, *“Individuals need to speak up more about services. Let your voice be heard”*.

Along the theme of receiving the type of support they feel best suits them, participants shared they wish people were given “*more time to go to appointments before closing them. Asking then what they want”* and *“If people were given training and offered more opportunities to be seen on a 1:1 basis.”*. Participants felt that in some services, work can be group-oriented support but *“Groups don’t work for everyone”.*

On accessing services many people shared throughout the survey the frustration and confusion with who was able to support which need best, that *“there should be a 'central booking system' somewhere you can go to that can direct you to the exact service you need”.*

Participants shared their thoughts on what could be included as part of their support plan, outside of what could be considered the normal direct support of the issues at hand, *“Spiritual wellbeing, person-centred rather than pills”* and *“More drop-ins, café's for people who can talk about their experiences”*, with another sharing experiences of where this has worked well for them, *“Activities for people to feel empowered, recently completed a sailing trip which was amazing and made me feel included. Those trips encourage people. Services offering activities I feel helps.”*.

Conclusions & Solutions

The participants of the scoping questionnaire showed insight and understanding into the gaps and barriers of the system and gave realistic and solution focused ideas on what could be done to improve support and outcomes for those facing multiple and complex needs in Essex. The overall themes that were found to support most of the suggested solutions have been summarised as:

- More frequent and improved communication with service users
- Increase collaboration between services and continuity of care
- Increase staffing /resources
- Adopt a community and person-centred approach
- Increased access to appointments
- More empathy and less judgement
- More listening to service users

One of the key messages from this piece of work is that people facing multiple and complex needs are struggling to navigate the system without additional support. Across Essex there is a 'No Wrong Door' policy, which means individuals should be able to get support for their care needs no matter which service they approach first and be referred to the correct one. Although there are examples of great work happening, many of the responses to this questionnaire do not reflect that being practiced consistently.

Increasing the frequency and quality of communication of service users would help them to understand their care and what stage they are at in referral processes. Using a flexible approach to communication styles, language that feels less judgemental in the views of service users and increasing collaboration between services would help with continuity of care and further aid this understanding and service user buy in in their own care. Increasing the number of peer mentors with lived experience of the service would support service users in feeling supported to navigate the system, as well as build recovery capital and skills for the peer mentors involved in the programme.

Centering people at the heart of their care and decisions made about them is another suggested solution from this scoping work. Models such as the 'My Team Around Me' approach being piloted by various Changing Futures areas involve holding professionals' meetings which are chaired by the service user. This means they have oversight into what is being said by all services about them and their care, building trust and holding all parties, including the service user, accountable for the actions agreed in each meeting.

Stigma that service users faced when approaching services is another issue that needs to be addressed to improve outcomes. By centring them at the heart of their care, we can help to reframe them as part of the solution rather than the cause of the issue. Training of professionals at all levels was suggested by the participants to help them learn to challenge stigma and understand how to be flexible to the needs of those facing multiple and complex needs.

Appendix A - Questionnaire

Scoping questions for Service Users and Partners in Essex

As part of Changing Futures, ECC and Phoenix Futures are exploring with partners and service users their views and experiences on the following three questions. We would value your input to help us review local systems within Essex and the barriers for service users and partnerships accessing current services and the transitions between them.

1. In your experience, what are the common barriers to accessing services?
   a. What are your experiences of accessing services in Essex, good, bad, or average? (MH, GP, Treatment services, Housing, etc)
   b. What barriers, if any, have you encountered?
   c. What impact have these barriers had on you (or your service users)
   d. What solutions do you suggest?

2. How does the current system negatively impact people facing multiple and complex disadvantages when moving between services?

   a. Have you had experiences of moving/transferring between services? (MH teams, young persons to adult services, referred onto different treatment services, etc)
   b. How did this move go? What worked well and were there any gaps/barriers?
   c. How did these gaps/barriers affect you?
   d. What solutions do you suggest?

3. What are the common ways that the current system makes people feel confused and/or isolated, particularly those facing multiple disadvantage?

   a. How do you think the current system as a whole affects people with multiple disadvantage?
   b. What solutions are there to empower individuals and create more effective interactions?
   c. If you could change one thing about your experience, what would it be?
   d.

1. In your experience, what are the common barriers to accessing services? Mental Health service, GP's, Treatment services, housing etc.	
a. What are your experiences of accessing services in Essex, good, bad, or average and why? (MH, GP, Treatment services, Housing etc)	
b. What barriers, if any, have you encountered?	
c. What impact have these barriers had on you (or service users)	
d. What solutions do you suggest?	
2. How does the current system negatively impact people facing multiple disadvantages when moving between services?	
a. Have you had experiences of moving/transferring between services? (MH teams, young persons to adult services, referred onto different treatment services, etc)	
b. How did this move go? What worked well and where were there gaps/barriers?	
c. How did these gaps/barriers affect you?	
d. What solutions do you suggest?	
3. What are the common ways that the current system makes people feel confused and/or isolated, particularly those with facing multiple disadvantage?	
a. How do you think the current system as a whole affects people with multiple disadvantage?	
b. What solutions are there to empower individuals and create more effective interactions?	
c. If you could change one thing about your experience, what would it be?	

Quadrant:	Age Range:	Male/Female:

Appendix B– Further case studies

Participant 52 (Male aged 18-24 from North Essex)

Feeding back on their experiences in the system and any barriers they may have faced, Participant 52 reported they had a bad experience attempting to get an ADHD assessment and struggled to see a GP. A barrier for them was access to housing, they felt there was not suitable housing for their age group. They also reported it was a *“Struggle to get mental health support due to drug use”*. These barriers caused them problems with anxiety and depression. The suggested that generally there needs to be *“better support for the younger generation”*.

Feeding back on the current system and how it affects people with multiple and complex needs, the participant *felt “It is not really helpful. Struggle because of my age (Don't feel supported)”*, reiterating their solution that there is a need for more support for younger people. They shared that the one thing they would change about their experience is *“That I could of got support earlier”*.

Participant 59 (Male aged 18-24 from South Essex)

Feeding back on their experiences in the system and any barriers they may have faced, Participant 59 shared the following, *“When I have been really unwell with my mental health, I have found the service to be awful and they don't help. They don't return calls, they don't give appointments and the reports they write are incorrect. When I was homeless, housing were unhelpful, they don't take into consideration you are unwell and trying to do things becomes so hard it makes you more unwell. Trying to get a GP appointment is impossible, the only time this was good was during Covid was after I tried to kill myself and the safeguarding doctor at my surgery kept in contact and would have face to face appointments with me. Social care are a waste of time”*. Further barriers to accessing services were *“Mental health closing you when they say they have tried to contact you by phone and sent letters, when I've never had missed calls or received letters. Services using words you don't understand and you feel like an inconvenience”*. The impact these experiences had on the participant meant that they became overwhelmed and then disengaged from services.

Recommending possible solutions and improvements to services, Participant 59 said *“People to care and actually listen and work in different ways with everyone. More help around housing, I know it's hard but people on the street, unwell impacts everyone. I know I committed crime because my mental health got worse and my drug use increased. Mental health services - easier* *access and understand because at times I didn't know who I was under and what their role was”*.

Participant 59 reported that they had experiences of transferring from young people (YP) to adult services for mental health, social care and probation. Sharing that *“The YP services were good and worked with you differently, but the adult services just expect you to do things. Just because you go from 17 to 18 doesn't mean you all of a sudden understand things, are now able to do things that you couldn't do the day before. Social care and mental health service just don't want to know”*. They feel that these experiences of transferring from YP to adult services meant they *“withdrew more into myself and find it difficult to engage and become more disillusioned that I will ever get better and think why bother engaging as no-one wants to help”*. They suggested that people needed to be more understanding and needed to work at a pace and ability that suited them more.

Feeding back on the current system and how it affects people with multiple and complex needs, the participant felt that *“People don't want to engage because they are mucked about or think why bother because the service don’t want to know”*. When asked if they had any recommended solutions the participant thought some services needed *“to care about what they do and stop treating people like inconveniences. Mental health services to stop closing people so early just because you appear to be getting better, you need help maintaining that so it doesn't keep becoming a crisis”*.

Participant 90 (Female aged 18-24 from Mid Essex)

Feeding back on their experiences in the system and any barriers they may have faced, Participant 90 said that it is difficult to get through to the doctors, they wanted therapy rather than just be given medication, but it can take months to even get a call back. And even then, if you have too many problems you are deemed unsuitable for those therapies, making their issues worse and extending the time it took to get better. Their view on solutions were *“More services to be available, more support for therapies. Trained mental health specialist doctors”*.

Discussing their experiences of transferring between services Participant 90 stated *“I used CAHMS services as a teenager and had a social worker but was not moved on. I had to ask for help from my doctor myself when my mental health plummeted”*, they included that they were offered more therapy through Mental Health services until they turned 16/17 and they were then left without support or medication. This resulted in them not attending school after secondary school and their mental health continued to get worse. They recommended *“More services for teens leaving secondary school, especially if they do not want to medicate younger kids they must improve the alternatives”*.

When considering how the current system affects people with multiple and complex needs, they said *“It definitely worsens the already prevalent mental health problems as you're just left in the lurch waiting for a phone call or an email months later. Which means you can't get on with normal life. You feel abandoned”*. They again emphasised that there is a need for more mental health doctors, nurses and specialists to open up more appointments sooner and to be able to have more in depth support. They shared that the one thing they would change about their experience would be to *“Seek help sooner and be way more social so that they pay attention more to you, not let me be pushed around by services”*.