The Winding Road Interim Report

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Background

The SUN Network, Rethink Carer Support and Healthwatch Cambridgeshire and Peterborough are all to varying degrees voice organisations, helping people speak up about their experiences of health and social care. People's views are collected and reported in several different ways, and for The SUN Network in particular, this often takes the form of evaluating people's experience of a single service.

The Winding Road project goes beyond these more traditional approaches, to start and finish with the service user, wherever they are in their 'recovery journey.' It is truly person-centered rather than service centered, in that it engages with a group of people with mental health conditions and people who are carers of those with mental health conditions, and simply follows them over time. It recognises that people and their families may or may not be receiving services at any given point and that from their point of view the journey of seeking help is just as big as the journey of using it.

The project has the following key characteristics:

- It is a collaborative project between The SUN Network and Rethink Carer Support – Cambridgeshire and Peterborough
- It has grown out of what people have been telling us about their experience of living with mental health conditions over the past 2 to 3 years, above all that access to mental health services remains problematic
- It checks in with selected groups of people with mental health conditions and carers three times over a year
- It will involve interviewees in various ways of feeding back results and suggesting actions
- It offers interviewees a chance to reflect on their situation over time in a structured way and to generate ideas for a way forward

Aims

The overall aims of the project are:

- To examine people's experience of mental health and mental health services over a one-year period
- To explore whether people's mental health and ability to live life to the full improves during this period
- To cast some light on whether there is any correlation between people's mental health needs at a given point and the level of mental health services they are getting
- To compare perceptions of needs and services between people with mental health conditions and the separate group of carers
- To highlight gaps in services as well as positive factors in people's recovery thus informing local service development
- To offer people a chance to reflect on their progress or lack of it on three occasions and to feel that they are influencing service developments

The project has certain limitations. It does not attempt to be research and so does not claim to have selected samples of people with mental health conditions or carers that are representative of this whole population. It does not attempt to prove any causal relationships between people's levels of mental ill health at any given point and the presence or absence of services.

Rather, it attempts to amplify people's experiences by presenting it in a new way, following people over time and presenting a combination of quantitative and qualitative data. The authors believe that individual experiences, accurately and sensitively reported, can be a vital source of learning for service providers whether or not they are typical of all.

This is an interim report on the interviews, presenting the results of the first round which was conducted between August and December 2019.

Carer Interviews – Jonathan Wells

Method

20 carers of people with mental health conditions were identified using the mailing lists of Rethink and Making Space, together with some recruited via CPFT's CAMEO carer support group. The carers and service users participating in this report are not linked in any way. The carers' interviews are about **their** perspective on the situation of their loved ones.

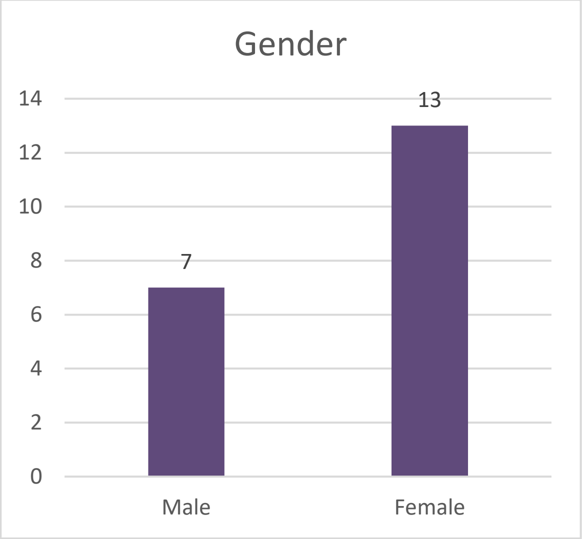
The carers were interviewed by Jonathan Wells in a setting of their choice. 19 interviews were face to face, one was by phone. Sometimes the person with a mental health condition – the subject of the interview – joined us and was free to contribute. At the start people were told about the project as a whole and asked to commit to the three interviews over the full year. It was explained that any information held would be kept anonymously and that any information included in reports would not be traceable to them. It was stated that direct quotes might be used in reports but would be unattributed.

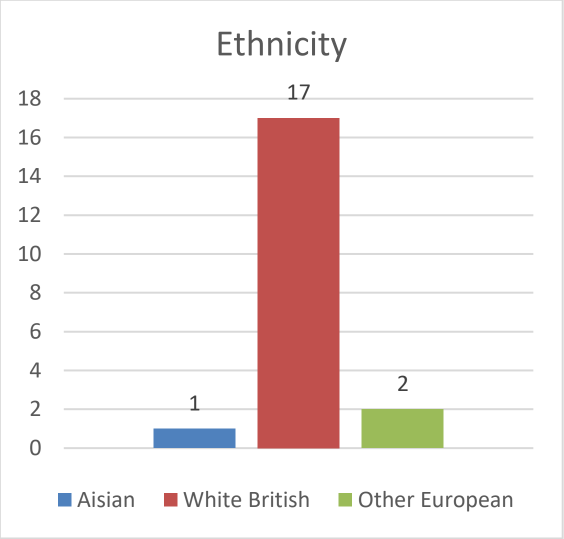
A semi- structured interview was used in each case, using a standard questionnaire which reflects the issues that people have previously expressed as important to them. (An example of this is the equal weight given in the questionnaire to formal mental health services and to other factors in someone's life when looking into what might help). The same questionnaire was used for both people with mental health conditions and carers.

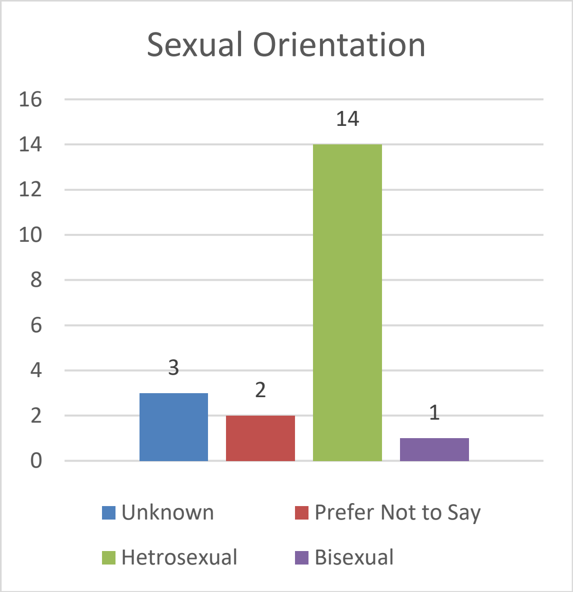
The interviews allowed space for interviewees to comment on any aspects of their loved one's overall situation or care that they felt was relevant.

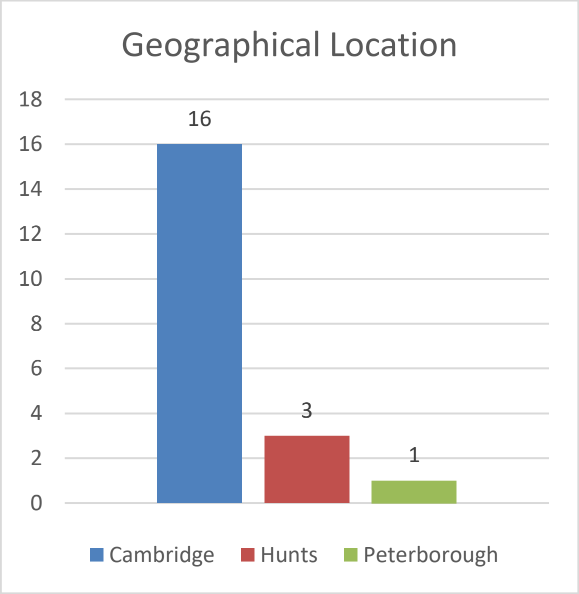
Characteristics of cared for person and Interviewees

The ages of the cared for person ranged between 20 and 68, with the average age being 37. 8 of the 20 were in their 20s.







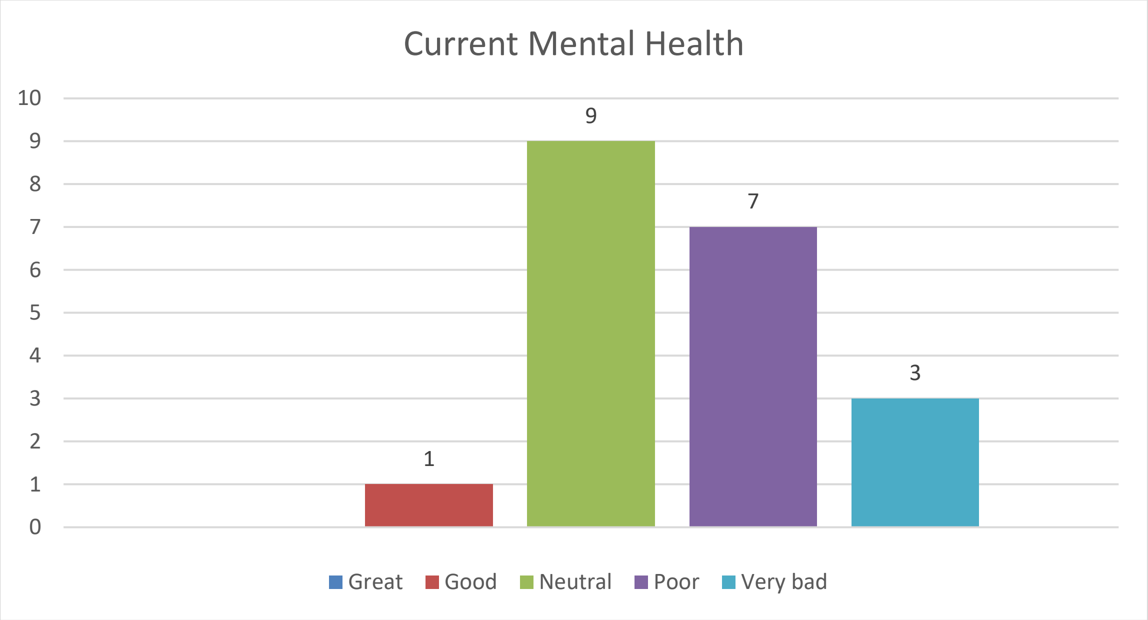


The mental health diagnoses of the subjects were wide ranging. They included schizophrenia, other pyschosis, bi-polar disorder, borderline personality disorder, socially avoidant personality disorder, agoraphobia, depression, anxiety, OCD, eating disorders, attention deficit hyperactivity disorder (ADHD), and autism spectrum disorder (ASD). Sometimes the interviewee was not sure if the diagnosis was tentative or definitive. In many cases the cared for person had more than one diagnosis, either in succession or at the same time.

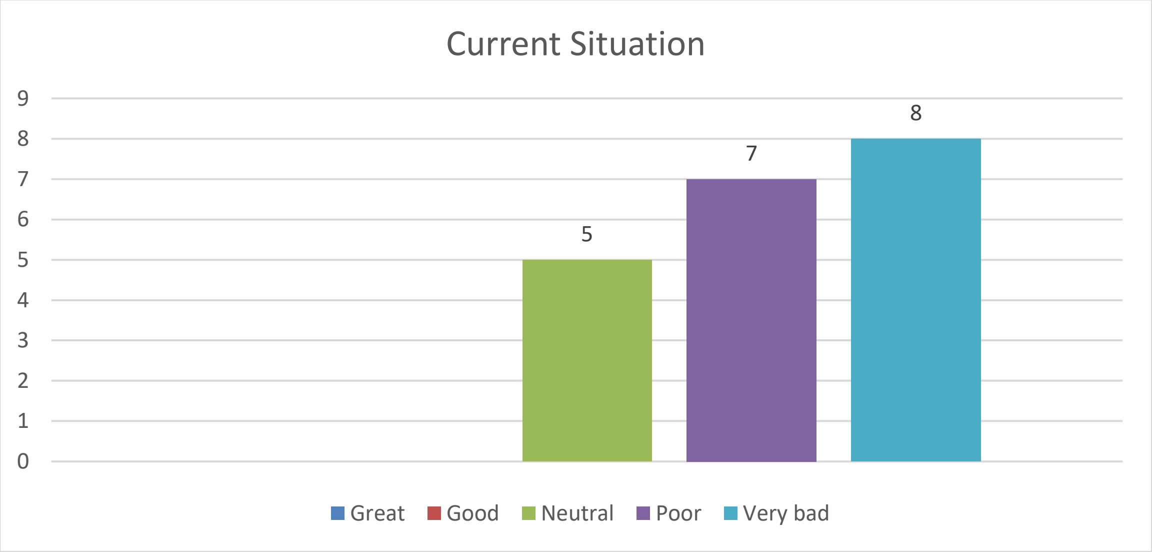
Amongst the carers, the primary interviewee was the Mother 13 times, Father 3 times, Husband twice, Wife once and Sister once.

Numerical Data

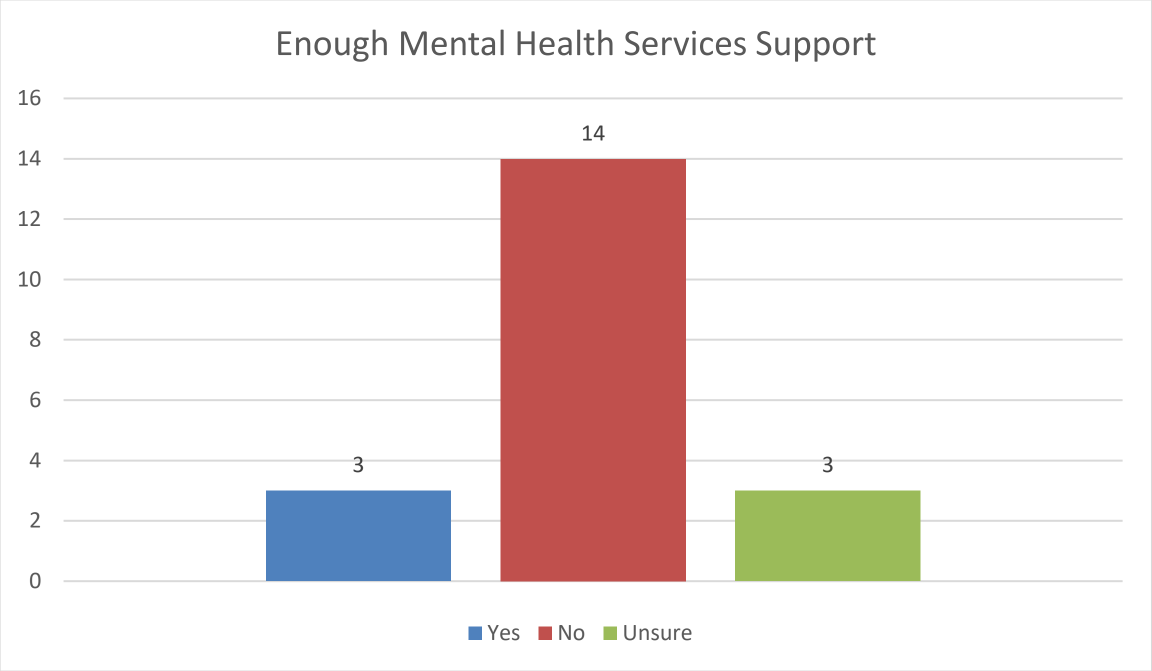
Carers were asked first to rate the current mental health of their loved one, focusing on symptoms, on the following scale:
5 - Great, 4 - Good, 3 - Neutral, 2 - Poor, 1 - Very bad



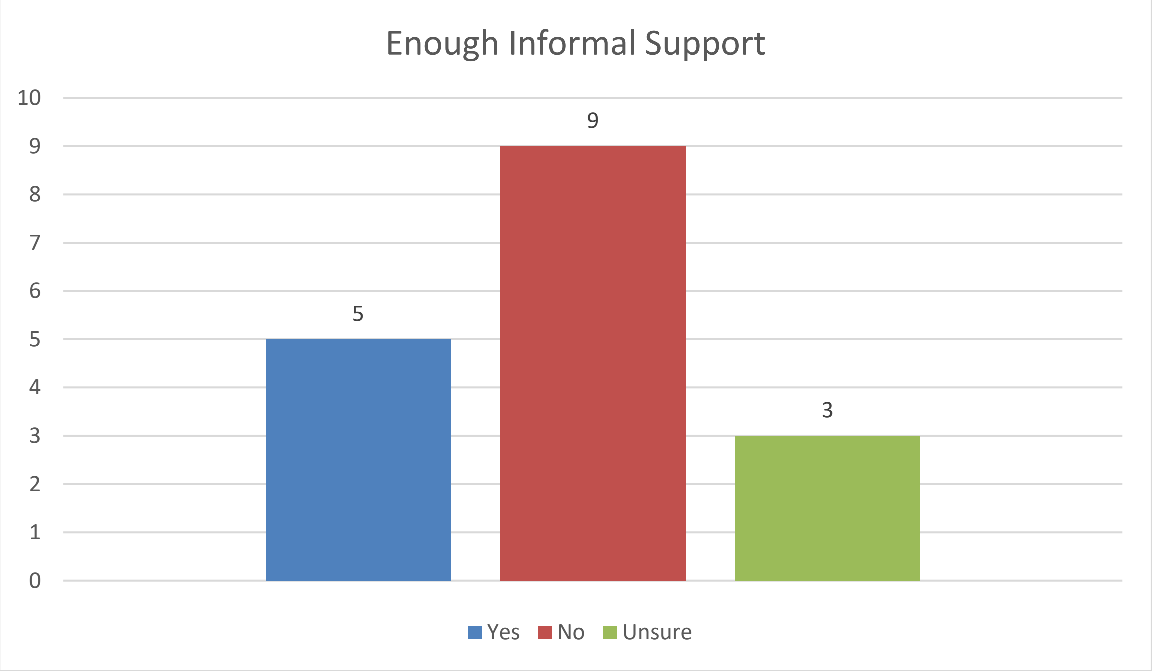
Carers were then asked to rate their loved one's situation and to what extent they were living the life they wanted for themselves on the following scale:
5 - Great, 4 - Good, 3 - Neutral, 2 - Poor, 1 - Very bad



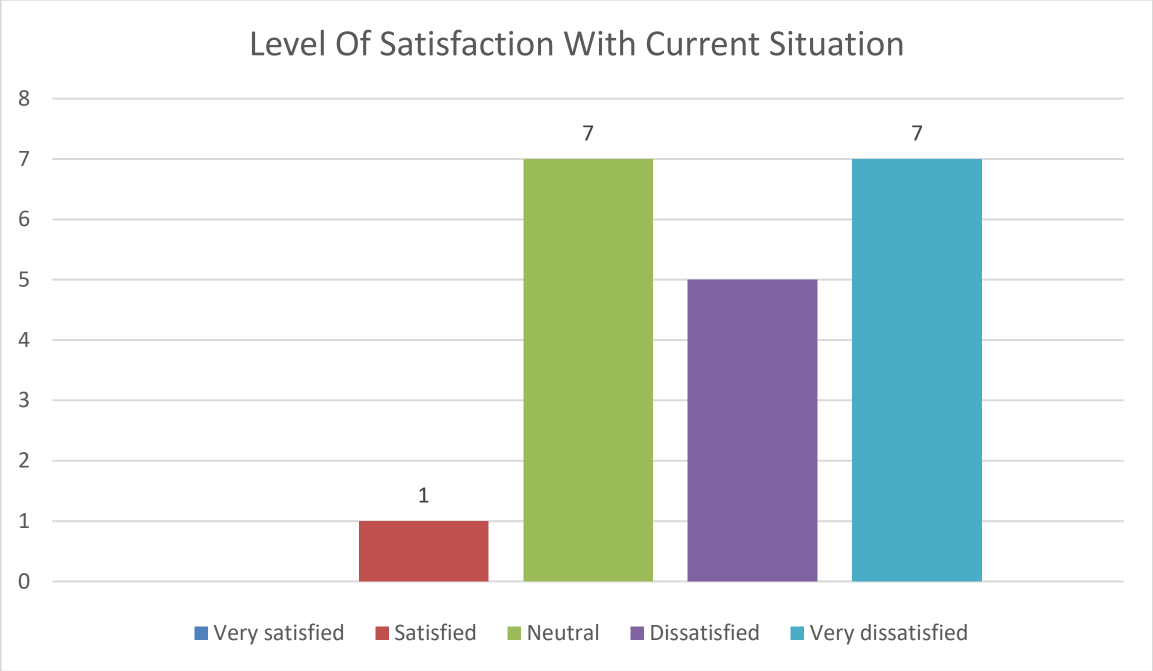
Carers were asked whether the amount of publicly funded support their loved one was currently getting was enough. They were asked to rate this either Yes, No or Unsure



After this question, carers were asked whether they felt their loved one had enough support from other sources to enable them to progress.



Finally, as a way of summing up, carers where asked to rate their level of satisfaction with the current situation for their loved one and themselves on the following scale:
5 – Very satisfied 4 – Satisfied 3 – Neutral 2 – Dissatisfied 1 – Very dissatisfied



Qualitative Data.

These results are reported through a selection of quotes from interview notes, so that the information is personalized and illustrates the range of individual experiences**.**

Current Mental Health

‘I was given the impression that T currently is not troubled by psychotic features such as hallucinations or delusions, but that he is still strongly affected by other features of schizophrenia, such as a lack of motivation and concentration, and his thoughts and speech not flowing smoothly.

I was told his mood is rather flat. His behaviour is settled and he has not been acutely unwell for a long time.’

‘Son tends to have acute psychotic symptoms all the time - for example he has a range of paranoid delusions and thinks neighbours are in touch with him telepathically.’

‘His wife seems relatively well at present in that her acute psychotic symptoms have largely gone.’

‘At present she is relatively stable, but the situation remains tense because of the many relapses she has had in the past.’

‘I was told that he is currently very stressed about a number of things. He has had a recent interview for PIP which was terminated when he fell over. He is now awaiting a PIP interview….’

‘Mother and daughter have not spoken this week ‘which is a good sign’. The past few weeks have been fairly settled for C which is why a score of 4 is given here.’

‘His mental health is variable. Ms I feel he is currently ‘reasonably stable.’ He is not psychotic at present but can be unpredictable in his behaviour and ‘can be verbally aggressive.’ She describes him as agoraphobic and says he doesn’t go out on his own.’

‘When acutely psychotic he becomes very distressed, potentially suicidal and potentially a risk to others. This is not the situation at present, but six months ago it was.’

‘M has never had a mental health diagnosis. However, since childhood he has showed signs of mental instability with consistent patterns of verbal aggression to others, failure to complete studies or hold down a job, self-neglect and dependence on others.’

‘Y has been diagnosed also with anxiety, depression and socially avoidant personality disorder. He has poor sleep. I was told that he has not been out of the house for six years apart from when he took an overdose and the police found him.’

‘L has been v psychotic about a year ago. He now seeks reassurance about things as if he is a little bit paranoid but is generally not acutely unwell. He won’t go out alone….’

‘Mrs N felt her daughter was ‘stable’ at present. The last crisis was about six weeks ago when M was depressed and expressed thoughts of self-harm.’

‘He has just gone back to Uni. At present he seems disorganized, blank in manner and flat in mood. He seems passive and with little energy but is no longer acutely psychotic.’

‘On top of the diagnosis of Aspergers made when he was 17, he now has the diagnosis of bi-polar disorder. At present he tends to sleep till 7 pm and be up until around dawn. He often seems quite depressed at present, over-sedated and sluggish.’

‘She gets anxious and depressed at times She lives at home with her parents and works from home …. which seems to suit her. So, she is not doing too badly at the moment although the past has been very tough.’

‘His mental health is changeable at present. He sometimes is in bed all day and is not at all energetic. He does not go out much and has previously had the label of ‘social anxiety.’’

‘D is ‘relatively stable’ at present. He continues to hear voices which are ‘nasty.’ He is on clozapine (anti-psychotic medication) and an anti-depressant.’

‘B has a diagnosis of Emotionally Unstable Personality Disorder.
She is just about coping at Uni so far this term but is very vulnerable there, giving other students money to look after her, being very impulsive creating crises and not always being honest with her mum about what has happened.’

Current Situation

‘When we began to talk about living life to the full T and his parents agreed that this is just not happening.

T said ‘Old friends don’t come round anymore.’ and ‘I don’t do much.’

‘Son often says he feels lonely and also that
 he has not achieved what he should have done in his adult life. His social life tends to revolve around other people with mental health conditions…’

‘She has no close friends. She sees more health professionals than family and friends. She is not employed and has no current hobbies.’

‘R spends most of her time alone at home. When she goes out it is with him [carer].’

‘V’s life is very limited. She has had tragedies in her past which mean that it is hard for her to make friends and be accepted in her local community. There-fore she doesn’t go out alone.’

‘C has no paid job at present. She is described as having driven a lot of people away.’

‘Z does not go out much at all. He meditates, reads and writes a diary. He ‘almost on purpose fails.’ He tries to make the world fit with him.’

‘His chronic schizophrenia has led to him being isolated over the years and inclined to neglect himself.’

‘Ms I acts as a sort of secretary, making appointments for him and checking his diary with him most days. He has no family involved apart from Ms I and no friends apart from the carer.’

‘He is very reliant on his mother. He does not have enjoyable rewarding things he does at present and has very little social life.’

‘His social life revolves around people at the hostel and in the homeless community. As far as mother knows he has no good trustworthy friends. He has no paid job nor meaningful occupation. He enjoys listening to music (Bob Dylan). He watches TV a lot.’

‘It is easy to see that Y’s situation is very bad and has been for several years. He simply does not go out. When his dog died, he stopped eating and looking after himself and Mum was concerned about self-harm. A lot of the time she feels ‘on the alert’.’

‘L has been getting out a bit helping with a building project. In the summer they had a happy family holiday, he gets on well with his aunt who joined them on holiday. He sometimes goes for long walks with his mum and/or dad. He is said to have a couple of friends but to be anxious about socializing.’

‘M lives alone. Her mother lives not far away with her partner. M sees her mum 2 or 3 times per week. M does not have paid work and her mother doesn’t know if she has things to do that she enjoys.’

‘Whilst he has some friends, they are more often than not into drugs which is not good for him. He is nowhere near living the sort of life that he is capable of.’

‘He seems lonely and has no new friends. He was severely exploited by local criminals in 2018 which has made him wary of new acquaintances.’

‘He has no job and no close friends. He had a girlfriend this year, but they split up.’

‘Mrs S feels D is a very long way from living life to the full. ‘His biggest friend is me.’’

‘Because there is such a long history of disturbed behaviour by B family relationships are naturally very strained at times. Mum still does a huge amount to support her daughter and to try to get her all the help she needs.

B is doing a photography degree. She enjoys this but is inclined to say she is useless. She has major financial problems at present having lost her PIP.’

Formal Support

‘As a family they just wish they had someone with qualifications as a mental health professional to be in contact with as necessary.’

‘Mrs B is grateful that CPFT ‘keep a fairly close track’ of how he is getting on.’

‘On paper this looks like a lot of services, but B’s needs are so complex and her ability to use help constructively is so limited that it still seems inadequate.’

‘He is very grateful for all the good care he and she have had in the past couple of years, from CAMEO and Mulberry 2 especially. As a carer he has felt closely involved in the care planning which is great. ‘CAMEO was fantastic.’ However, he is aware that the Locality Team will be less accessible than CAMEO and offer less support to them both.’

‘I was told that V has had some help from mental health services in the past but is getting none now. She became seen as someone who was hard to engage, and Mr G now feels ‘they won’t touch her now’ (meaning CPFT). He feels her diagnosis of BPD leads to her being excluded from services.

He says with reference to mental health services that ‘there’s an end to everything’ and that when you’ve had some help it then seems as if ‘you go to the bottom of the pile.’ He says: ‘If you don’t fit in with the start and finish thing [meaning time limited services] then you get nothing.’

‘P has no mental health support at present. He did until quite recently have a CPN from the older people’s mental health team of CPFT. He didn’t get on with her very well and felt she did not understand that he was on the autism disorder spectrum. They asked for a change of CPN and now have none. They wonder now if they were penalized for ‘being awkward’.’

‘C has been offered mental health services but has tended to turn down such offers saying she is OK. Mrs G doesn’t honestly know whether her daughter has had treatment from the CPFT Personality Disorder Community Services or not. C is certainly getting no mental health support or treatment from CPFT at present.’

‘Mrs H is glad that Z is under the care of CAMEO. Z has weekly visits from his care co-ordinator and they know who to contact in a crisis. They have phone contact with a family worker from the CAMEO team attached to them as carers.’

‘Ms I believes that her brother’s main mental and physical health needs are being met by the NHS.’

‘Mrs J feels that even though J is under the care of the Locality Team they have very little impact on his life. Because of negative experiences in the past they both struggle to have any trust or faith in what the service provides. This has led to J not wanting to engage with the service and then being indirectly threatened with discharge.’

‘M has never had care or treatment from NHS mental health services and is not under the care of CPFT.

He has no relationship with his GP. He has never had social care despite being in a homeless hostel.’

‘Y is currently getting no support or treatment from CPFT or any other mental health service such as CPSL Mind.

Y has been mentally unwell for around 10 years and there is a very long history of attempts to get help from MH services, mostly negative.’

‘Mrs M can see that L is getting some good support and treatment from CAMEO. His care co-ordinator is ‘good and flexible.’ She is pleased he will have this service if he needs it for three years.’

‘M is under the CPFT Personality Disorder Community Service. The Consultant Psychiatrist ‘was good.’ ‘The psychiatrist listened.’’

‘Generally, he is happy with the provision: ‘They really have tried to meet his needs.’’

‘E has support from the Locality Team. He is on medication although there have been errors with this at the pharmacy. He recognizes that he has bi-polar disorder. A psychiatrist who has known him for some time is still involved which provides some good continuity. He has had the same care co-ordinator for a year and she does some of the tasks that Mr P previously did. Although these aspects of services are positive, Mr P feels their impact has been limited.’

‘H has not had any treatment from CPFT. She is on anti-depressants prescribed by the GP. She seems to benefit because she has not spoken of suicide recently.’

‘H has been under the care of the Locality Team for over 2 years. He is on anti-depressants which he takes ‘on the whole.’ He is having CBT which has not yet had much effect.’

‘D has been under the care of CPFT for many years. The current psychiatrist sees D about once every three months but is also very much contactable by phone or email in between times. This is very much appreciated by Mrs W and their relationship with this doctor is clearly very positive.’

‘It is difficult for B to use mental health services at present because she is moving between home and Uni. She is not actually getting any mental health care or treatment at present.’

Informal Support

‘T has a very loyal family around him but not much apart from that.’

‘K has some good friends, but they are a mixed blessing. His mum is very loyal to him but the family is very divided in various ways.’

‘She doesn’t really engage with her community which means chances to gain independence and develop skills and self-confidence rarely arise.’

‘P has great support from his wife, but as a couple they are very isolated. They get some practical help from other family members but not a great deal of emotional support or understanding of what they are going through.

Mrs F said ‘I’m not always enough…’ [meaning that she cannot always meet his needs and wants more care shared with the NHS].’

‘Z is very well supported by his family including his stepfather.’

‘M’s patterns of behaviour are very entrenched and it is hard to see them changing dramatically. He remains very vulnerable and is a long way from living a fulfilled life. He is in a homeless hostel. He is supported by his mother who is in her 80s and no one knows what will happen next.’

‘She is glad the family are there for him [L], ‘we’re the only ones who know how he is.’

‘Family support is good, as long as mum can ‘hang on in there.’’

‘Lots of informal support – family and friends – is available to M but he is still struggling to use it.’

‘Father and son are very close but basically E’s life is still very limited and he is not in a position to easily make friends and progress in his recovery journey.’

‘Mrs Q feels H has some things going for her now. She is going out more with friends – shopping, eating drinking ice skating. The family are still intact after some very difficult times.’

‘He has a great deal of support from his mum, but it is not at present enabling him to progress away from a very withdrawn and limited way of life.’

‘D is well supported by his mother and brother, but this is not enough to enable him to lead a fuller life. D’s future is still a great worry for the family.’

Final Comments

‘Mrs B also stated that she remains very concerned about the poor working relationships between mental health services (CPFT) and substance misuse services (CGL) locally. Someone in her family has already suffered tragically because of this…’

‘Mr C and his wife have grave concerns about how B will cope when they are no longer there for her.’

‘Mrs F made the point that if mental health do not understand the autism spectrum, they can waste an awful lot of time trying to work with people in ways that simply won’t be successful.’

‘The strains of dealing with C over the years have worn Mrs G down and she desperately needs more informal support for herself and psychological therapy which she has so far not been able to access.’

‘Ms I is anxious about the future for her brother and herself’.

‘Parents are ‘frightened for him [L], when we’re gone.’’

‘Mrs N has learnt to live on tenterhooks. She has had an incredibly tough and conflicted relationship with her daughter and cannot be sure that things will improve for her although the current situation is relatively stable.’

‘Good efforts to help, but little effectiveness.’

‘Mrs R is very anxious sad and frustrated about her son’s ongoing mental health problems and his very limited life.’

‘Other things that would help are:

- More resources like Lifecraft where people can get peer support and be accepted for who they are
- More expert help with PIP appeals and other DWP issues
- Free legal advice
- More chances for self-help and mutual support’

Discussion.

These 20 interviews with carers have provided rich intelligence about the situation of 20 local people with mental health conditions, as perceived by their family.

The Winding Road project consists of three set interviews over the period of a year, and this interim report relates to the first set of interviews. Thus, it is a collection of snapshots, providing a baseline for the project as a whole.

The demographic data highlights the high proportion of females, usually mothers in this sample, which is typical of well documented patterns of informal caring where the brunt is known to be borne by women. Other demographic data reflects biases in the sample – such as the lack of respondents from Peterborough and Fenland. This is regrettable but not unexpected.

The numerical data shows that most people scored their loved one’s mental health as currently ‘neutral’ or ‘poor’, with the current social situation being rated a little more negatively. This tended to reflect the carer awareness of the limitations on their loved one’s life and the battles they had fought and expected to have to fight again. A clear majority felt they were not getting enough formal help, with more mixed results on the question about whether their loved one was getting enough social support to help them progress. This tended to reflect a view that whilst the family was doing what they could, they were struggling to help their loved one build social and working relationships.

Overall satisfaction scores were fairly negative but with some elements of cautious optimism shown by the 7 scores of 3 (neutral).

The quotations from interview notes, (which themselves include some direct quotes from interviewees), are considered the heart of the report. They include insights into the care received and what is most important to those ‘on the receiving end’, which should prompt reflection by the report’s readers.

Whilst caution is required in extracting messages from a limited set of interviews, some themes have emerged strongly, and they are noted in the section below.

Carer Interviews Conclusion

The main themes from these interviews are as follows:

- Diagnoses seemed of limited value in leading to effective treatments; they were quite often multiple, changing over time and not well understood by families
- The current situation of people was often pretty grim; most often because of the negative impact of their mental ill health, but also because of stigma discrimination and harassment, many people were isolated and had few roles in their communities on which to build
- This isolation was also strongly felt by carers, with stigma and ignorance often being major factors in causing this
- 60% (12 out of 20) of the cared for people discussed were currently getting help from CPFT; good communication, listening skills and effective treatment were especially valued by interviewees, and CAMEO stood out as an ‘exemplar’ service
- The past and the future weighed very heavily on the carers and the person with a mental health condition; even if their current mental health was quite stable, traumatic

earlier experiences in their lives or in dealings with mental health services created tension and mistrust between the person and both their families and mental health professionals; at the same time parental anxieties about the future for their loved one were also frequently reported

- The huge burden of care for the carers interviewed and the negative impact of this came across strongly; a significant number had been or were being treated for depression, whilst several had sacrificed jobs and financial rewards for their carer role; there was a sense of an uneasy relationship with professionals, with a lot of unexpressed tensions about what a carer could reasonably be expected to do
- There were several instances of people with chronic mental illness not having much of a life at all; because their symptoms were not acute, they seemed to be of low priority both for skilled clinical rehabilitation, and for assets-based determined and energetic help into meaningful employment and skills development
- It was striking how many parents had bought a pet, usually a dog, for their loved one and how positively they spoke about their impact

Service User Interviews – Lois Sidney

Method

The aim was to recruit 20 service users to the project, however, to date we have recruited 15 people currently living with mental health challenges. These people were recruited through social media, our own SUN Network emailing list, chance conversations with service users whereby they were invited to join the project, or referrals from other services such as CPFT or Illuminate. These interviews are about their perspective on the situation of their own mental wellbeing.

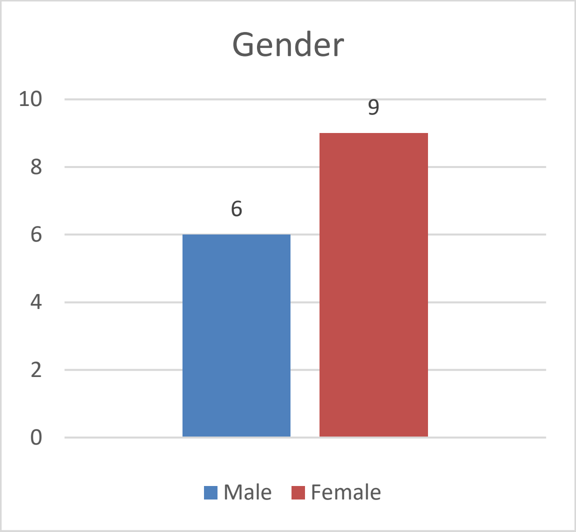
The service users were interviewed by a member of The SUN Network team in a setting of their choice. All 15 interviews were face to face. At the start people were told about the project as a whole and asked to commit to the three interviews over the full year. It was explained that any information held would be kept confidentially and that any information included in reports would not be traceable to them. It was stated that direct quotes might be used in reports but would be unattributed.

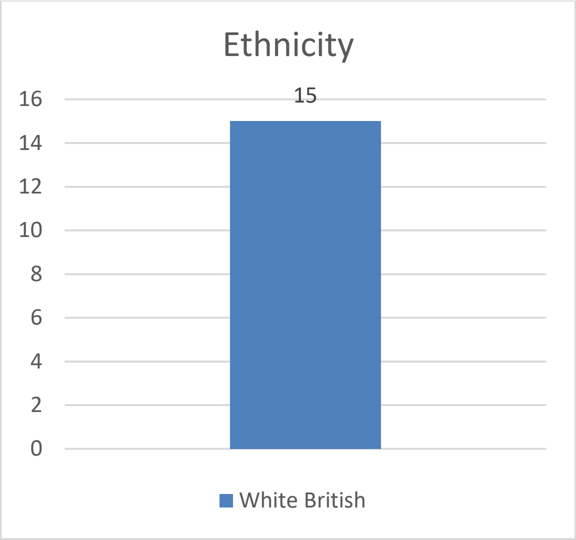
A semi- structured interview was used in each case, using a standard questionnaire which reflects the issues that people have previously expressed as important to them. (An example of this is the equal weight given in the questionnaire to formal mental health services and to other factors in someone’s life when looking into what might help). The same questionnaire was used for interviews with people with mental health conditions and with carers.

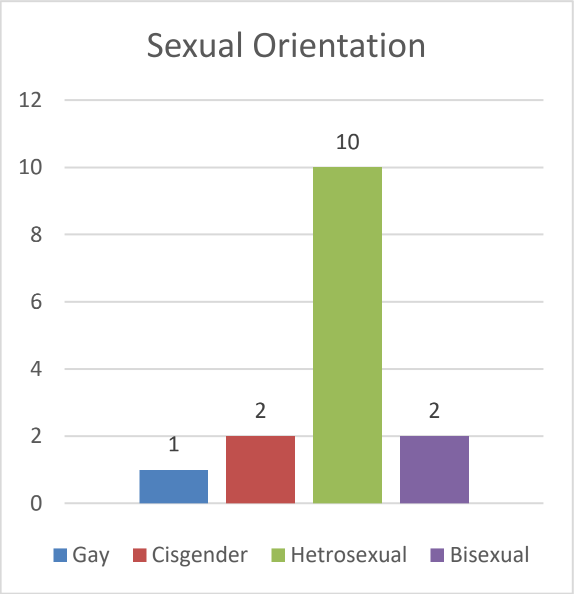
The interviews allowed space for interviewees to comment on any aspects of their overall situation or care that they felt was relevant.

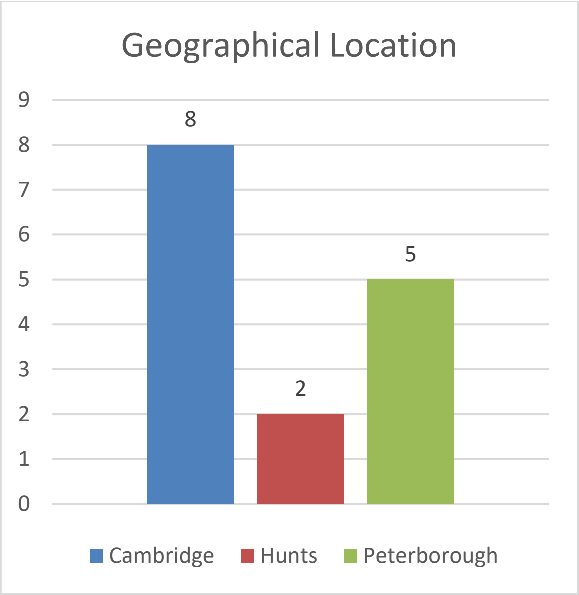
Characteristics of Interviewees

The ages of the participants ranged between 32 and 68. 7 of the 15 participants were in between 50-55.









Numerical Results.

Service users were asked first to rate their current mental health, focusing on symptoms, on the following scale:
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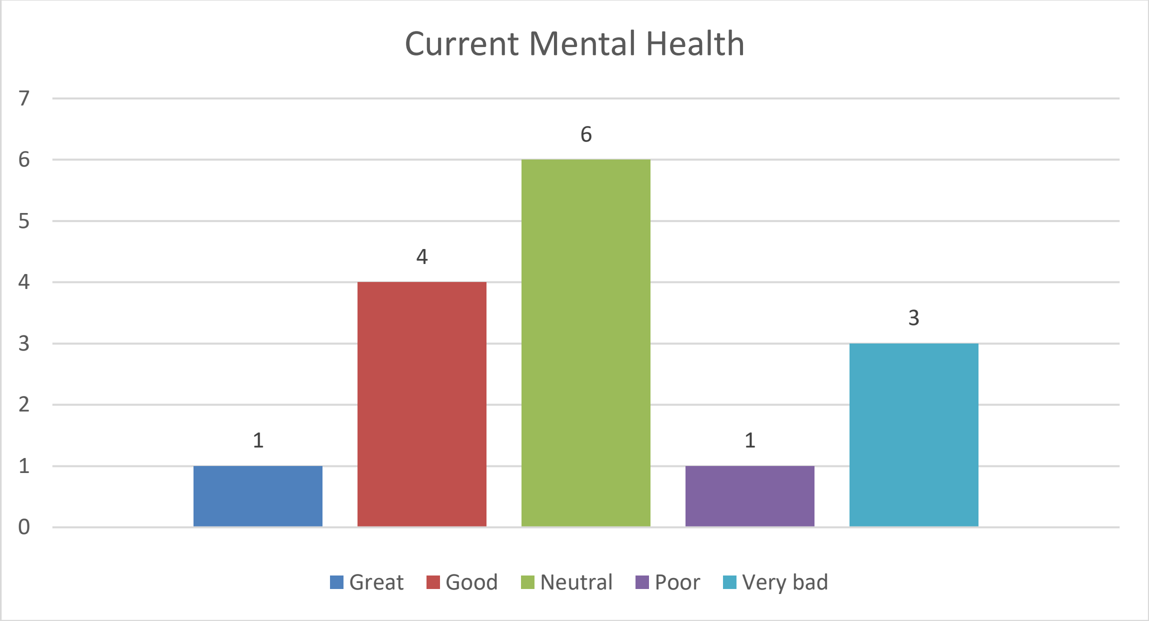
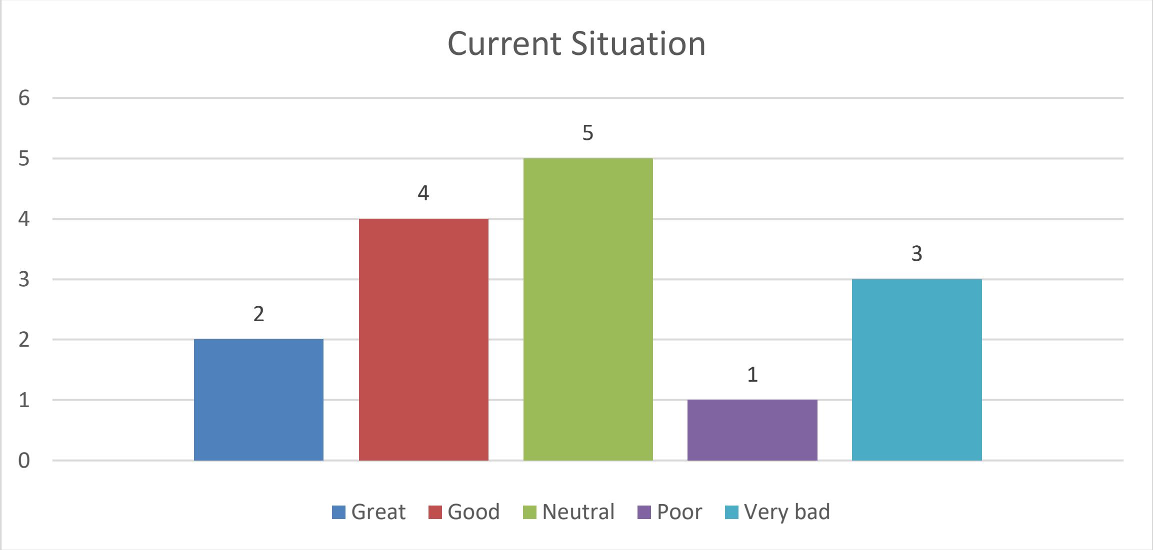
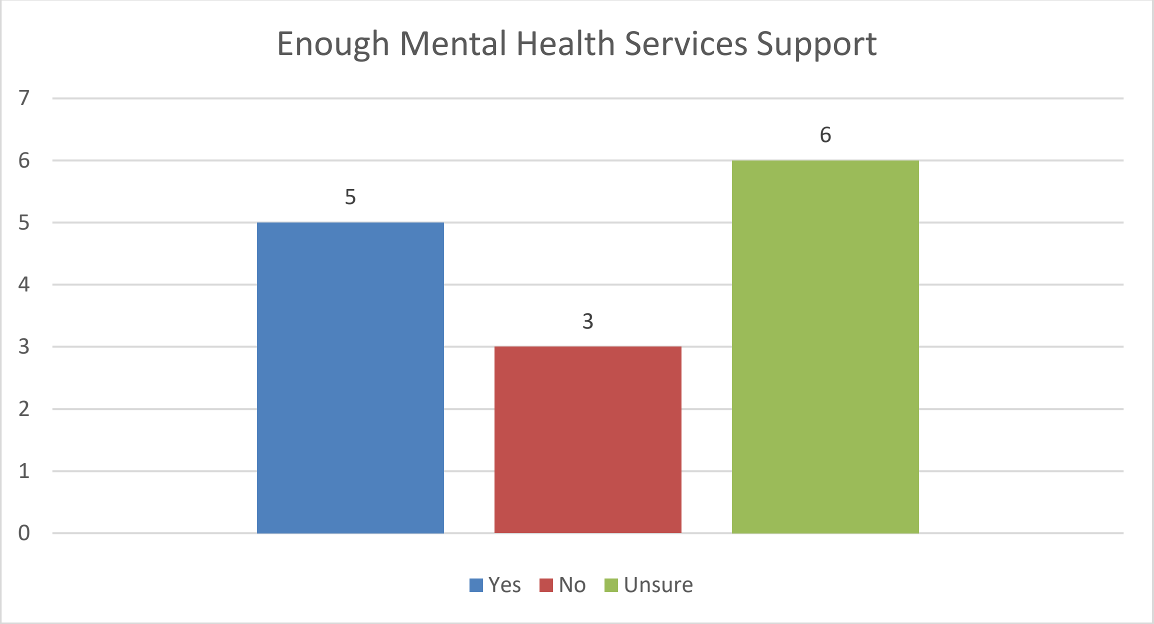


One participant could not decide between a 3 and a 4

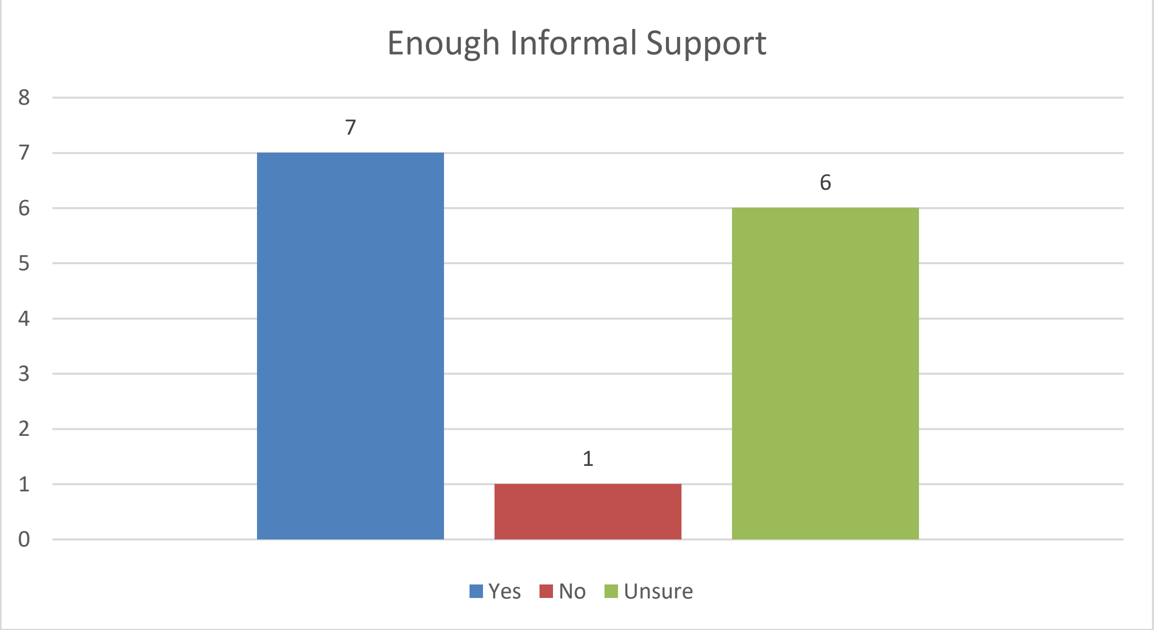
Participants were then asked to rate their situation and to what extent they were living the life they wanted for themselves on the following scale:
5 - Great, 4 - Good, 3 - Neutral, 2 - Poor, 1 - Very bad



Participants were asked whether the amount of publicly funded support they were currently getting was enough. They were asked to rate this either ‘Yes’, ‘Not sure’ or ‘No’.

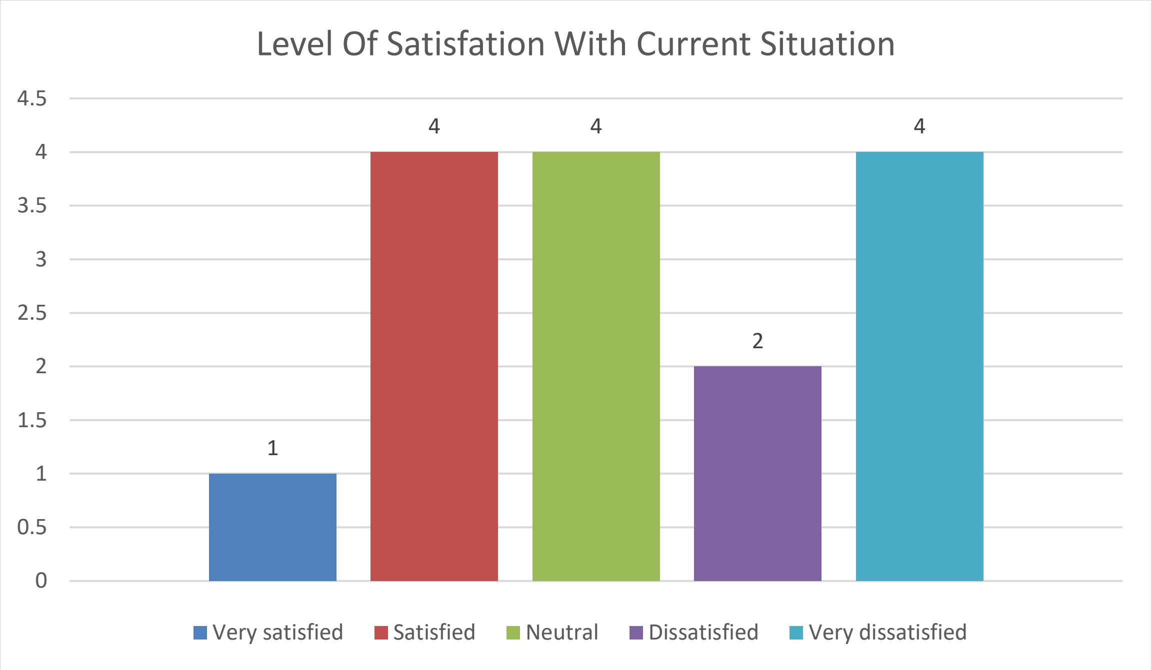


One participant had had such a negative experience of services that they had no desire to attempt to re-engage. After this question, participants were asked whether they felt they had enough support from other sources to enable them to progress.



One participant felt that they had lots of support from family but did not consider it their family’s job to support them.

Finally, as a way of summing up, participants where asked to rate their level of satisfaction with their current situation on the following scale:
5 – Very satisfied
4 – Satisfied
3 – Neutral
2 - Quite dissatisfied
1 – Very dissatisfied



One participant selected both option 1 and 2 as it depended on how they were feeling. Crisis point was a 1, other days were a 2.
One participant said she would pick 0 if it was an option.

Qualitative Data

These results are reported through a selection of quotes from interview notes, so that the information is personalized and illustrates the range of individual experiences**.**

Current Mental Health

‘At the moment I feel I am in a good place. I feel like life is moving forward positively, like I am getting my life back together. I have involvement projects coming up to look forward to, and hopefully, more things will come from them’

‘I feel quite happy, although I still have symptoms. I get very little psychosis at present which I am very happy with. This is controlled by medication and self-care.’

‘Stable today, but this can vary day to day. Great fluctuations in mood. Still looking for help and support as I feel nothing is available to me. I would like targeted treatment’

‘I feel very isolated, but I don’t feel ready to engage with other support’

‘I feel very stable at the moment and I have done for a while. Feelings and moods are stable, and it is a relief to not have to put a mask on for the benefit of others. I feel I can be myself’

‘I use my own recovery tools. I have a book with who and what can help me with my mental health. Go out for walks. I feel I am now in a position where I can be supportive of others and offer something back’

‘I cannot maintain stability of mood, thoughts or feelings. I’ve only ever known poor mental health, and I waited 30 years for a diagnosis of Bipolar and BPD. Lack of understanding from friends, family and myself, and lack of support from services contributes.

‘’I feel like I am bobbing along, conscious that I am only just holding my stuff together. My anxiety is just about manageable. I feel like I am walking on a tightrope and it could go either way. Constantly feel on the cusp of tears. Feelings of anticipation of what will happen next. There is always something to sort or manage for other people. This feeling is my norm and I would like it to stop. I don’t feel I ever have had the time to give myself the time out to acknowledge what I feel and need’

‘Been on a two-year journey of trying to seek help and support. I feel very disappointed that there hasn’t been the help and support for me. It’s been a struggle to find a service that can help. Feel I have been trying to be strong, but recently that all collapsed. Moved from a different area to Cambs and was told all support had to start from the beginning. Not able to take meds due to not being able to get prescription renewed so feel in crisis’

‘Feel suicidal all the time’

‘I have chronic schizophrenia. At present I am getting on quite well. I occasionally hear voices, but they are not nasty ones. Sometimes, I’m not sure what is going on around me. I might still have some delusions….’

‘I’m anxious, but I feel empowered. My concentration is coming back after two years. I feel like I’ve come out of 2 ½ years of hell’

‘My mental health is really bad. A couple of weeks ago I was stood on the train tracks wanting to kill myself and ended up driving to A&E at PCH so I could try and see a psychiatrist. Because no-one will review me, I’ve not been on medication for several months and my mental health is significantly deteriorating’

‘I tend to struggle around my birthday and recently was feeling suicidal. I get really anxious’

‘Some good bits and some not very good. A good event was when I caught the train to Whittlesford and back – this gave me confidence. Not so good was when I was in McDonalds and began to wonder whether a group of teenagers were talking about me. I got a bit paranoid’

Current Situation

‘I don’t know what else I need to do to get help’

‘I keep myself busy. I like to do karaoke and do this at a couple of places locally which I really enjoy. I now not working and I’m on benefits’

‘I set up a bipolar café two years ago and I attend that. I can be myself there, there is no judgement. I have my allotment which I love’

‘I have lived at my current address owned by a mental health housing provider for 12 years. I haven’t been acutely unwell for at least 15 years. I cook and clean for myself and manage my own finances. I get out of the house every day. I get bored sometimes and feel like I don’t have enough friends. People I know tend to be other long-term mental health service users. I sometimes wish I had a paid job’

‘I feel overwhelmed by the condition of my house, but don’t feel like I have the capacity to start sorting it out. I used to have hobbies and interests, but due to physical and mental health, I no longer do anything. I feel I am trying to manage to much other stuff to focus on myself’

‘Help is now in place but because it has taken so long, I had really hoped I would be further along in my recovery journey. I feel like my recovery has gone backwards. I want to just get my life back on track and start living, but this has all been delayed due to lack of support and care’

‘I cancel events and personal meetings etc as I am unable to face it. I feel like I am only managing to keep together the basics…..work and the needs of my husband and children. I feel like I have to pretend to be ok whilst everyone around me falls apart, or I put on a front to family and friends. I really struggle with groups, not managing to make time for me. Huge anxiety about social situations. My work hours have changed, I used to work shifts which gave me alone time. Now I work 9-5 which means my free time is always looking after the needs of my family. My husband is a hoarder and the house has got on top of me’

‘Because of self-education, I am developing an awareness of my behaviours, but because I am learning alone, I sometimes hit crisis and access crisis services. I feel forced to educate myself as no-one else will educate me on my condition (BPD)’

‘I am now living my life to the full. I am able to drive again which has given me independence. My relationship with my daughter has improved. I am trusted more. I feel like my family is coming back together in a way that works for all of us. Moving from a drug den to a beautiful home has offered stability and comfort. I volunteer for the maintenance of a local nature area. I yarn bomb, leaving supportive recovery focused quotes. Crafting offers me a mindful practice. I eventually become able to recognize what strengths I already had. I am now a qualified peer support worker’

I can finally begin to explore my world and find out what I am capable of doing. I trust how I feel about my emotions so am able to cautiously push the boundaries whilst understanding that I can’t go too far too soon’

‘Living each day to the full is very difficult as my mental health fluctuates so severely each day. I am in the best place I have ever been. I have felt debilitated by my illness and feel lonely and isolated. Having a dog helps’

‘My recovery is turbulent. My partner has lost his job, nothing has changed for me since my diagnosis and I feel really demoralized as I can’t get the help I feel I need. My ability to function is variable day to day. I don’t go out, feel hopeless, angry, and I hide away. My husband takes care of the children and he suffers with his own mental health due to the situation’

‘I feel ambitious and driven. I look after myself now and take care of things. I no longer have anxiety attacks. I am dealing with life and the little challenges I have to face’

‘I do enjoy life, but after work, chores and self-care I feel there is not a lot of time left in the week. It feels like everything I am doing is just going through the motions. I don’t feel free. I am scared of making changes and stepping out of my safe zone, and to be honest I don’t even know what it is I really want. I don’t feel a sense of possibility about the future and everything has to be really planned. Life is good but it feels limited’

‘Routine is important to me and I have quite a good weekly schedule at present.
On Wednesdays I go trampolining which I’m good at.
On Thursdays I do kung fu which helps him feel safer when I go out on my own.
On Fridays I do badminton which I enjoy.
I have some good friends but would like a partner.
The diagnosis of Aspergers means that I have certain strengths. I am good at Maths and got a 2.2. degree at Anglia Ruskin in Maths and Chemistry. Unfortunately, I have not found a job that suits me”

Formal Support

‘I currently have enough support. I am accessing the GP. I was seeing a psychiatrist and had a CPN for a few years. I was offered psychology but turned it down. It would have been nice if someone had suggested it was a good idea for me to take this up as I didn’t really realise at the time. I was drinking heavily and when I left the psychiatrist, I had to look for my own ways to stay well. GP looks at co-morbidity issues like smoking and weight and this actually helps. I see the GP once a year for 10 minutes and they say ‘How are you?’ and I don’t even know where to begin to answer knowing that I only have 10 minutes so I don’t answer’

‘I am currently with the recovery coach service from being discharged from services. This has been a perfect way to ease me back into having no support. It has ensured that I have not gone for specialist mental health support to nothing. Having the recovery coach service has given me the opportunity to get involved with other things (The SUN Network, CPFT, Mind)’

‘The continuity of care from the Locality team has been variable. I am aware of staffing issues but I saw 7 locum psychiatrists in a year. Getting into services wasn’t easy and I had to not take no for an answer. GP eventually made the referral. My hospital admittance came from my care coordinator. Navigating mental health services was challenging and I needed the help of a friend. Discharge information was given verbally when I wasn’t in a position to retain the information. Didn’t know where to go after that to get help. I witnessed restraint in the hospital which was distressing. I felt it was a quick and easy option to control a situation’

‘I have found my mental health deteriorated after the birth of my first child. I was under the care of the perinatal team and mental health services where I received a lot of support. I had a period of time in hospital and it was there that I received my Emotionally Unstable Personality Disorder (EUPD) diagnosis. Since then I have not been able to access any help. All mental health support has been denied. Referrals to Psychological Wellbeing Service (PWS) and Personality Disorder Community Service (PDCS) have been refused. I have had the opportunity to attend CPSL Mind’s PD group. There is nothing out there that feels positive about PD. It doesn’t look at the strengths of people with the diagnosis. I finally got a diagnosis after struggling half my life with my mental health only to find there was no help anyway. People have horrible views of people with PD’

‘I feel I am getting the support I need through my CPN and support worker and I am very happy with the care I get. I have been in receipt of care for over 10 years now but feel I wouldn’t be where I am now if I hadn’t had that help for so long. I am worried about my care being reduced as I am not sure how I would cope’

‘I am currently not involved with any services. I do need to engage with therapy at some point, but I don’t feel ready at the moment. I want to explore my world a bit more and build up my resilience before I do that. I feel reengaging could bring emotional instability and I feel scared and concerned that I may not be able to access mental health support at the time I need it’

‘I am not accessing any services at present. I don’t feel the need to, and nor would I want to if I was offered. My experience of CPFT has not been good or helpful. I have been stigmatized and restrained in hospital which has created trauma. I felt my discharge process from hospital was rushed and I was not included in the process and was left with no after care or support. A new consultant came into Springbank and it felt like they wanted to clear out all the old patients. It took me two years to get back on my feet with several suicide attempts. If I needed help again, I would use the support network I have created for myself, not services’

‘I cannot access any services and the thought of becoming unwell is frightening to me, as I have no sense of identity and no idea of who I am if I don’t have BPD. My mental health needs are not being met as I fall into the too complex/not complex enough gap’

‘I don’t access any mental health support. I am on anti-depressants. I have had a Primary Care Mental Health (PCMH) referral and I am on the Choices counselling waiting list but they are long waiting lists. I have had various talking therapy sessions which I have paid for myself, but they have only been short and not specific to my needs, so they feel like they haven’t really helped at all. I feel I have not been able to access the right care at the right time’

‘Right now, yes, it feels like there is some support in place, but it has taken 2 years to get it. Although it is challenging, I understand that it will get better. Over the two years I have been doing my own research into what else can help as nothing came to fruition through the GP’

‘No services are in place any longer. My wife is doing her best, but it is not fair on her having to deal with everything on her own. I feel I have nothing other than NHS 111 option 2’

‘I am on medication that means I need a monthly blood test at Tenison Road for blood tests. I have a chance then to speak to a mental health nurse, but I don’t really bother. I see a psychiatrist once every 6 months but am thinking of asking for a new one as I feel pressured by this one to increase my medication and I don’t want to. I rarely see a GP. I see a Mind support worker for an hour a fortnight and I have to pay for this. I also attend a council funded badminton group which helps me feel I have achieved something’

‘I have used the Sanctuary. They saved my life. I am due to see a psychiatrist, but I have retold my story so many times as there is no consistency in staff’

‘I have disclosed to GP’s several times that I felt suicidal and was never told about NHS111 option 2, I found out about it elsewhere. (asked by SUN Network about various local services) I haven’t heard of The Sanctuary. Not aware of things like Recovery Coaches, Recovery college, CPSL Mind and have only just heard about IAPT (PWS) I don’t rate the services I have received as bad, but I had no idea of what other services were out there. I use the Samaritans a lot which is helpful’

‘I am pretty much aware of everything on offer, it’s just that none of them will see me. I seem to fit in between the gaps of different support. Too ill for one, not ill enough for another, the wrong type of ill for the third. I sometimes feel like the people who need the help most are the least likely to get it’

‘I am not getting help from mental health services but that’s OK, I don’t feel I need any. I am not getting help from social services either but am ok about that.
I get some support via the voluntary sector. I call in at Lifecraft and used to use groups there, but I have noticed they are no longer available. I call in at the Edge café in Mill Road, Cambridge, I appreciate the breakfasts there. I enjoy an art class at the Edge café.
I have been in touch with Russell Street social care resource for people with learning disabilities in Cambridge and hope they might help me find a job. More dynamic and consistent help into employment recognising my strengths in Maths would have been helpful (especially in Cambridge where such companies have proliferated in the past 10 to 15 years). I am on no medication and don’t need to be. I don’t often see my GP’

Informal Support

‘My family are supportive. I play golf twice a week with a friend who has mental health issues as well. I work as a volunteer one day a week which helps’

‘My friends are very supportive’

I have a poor support network. My girlfriend isn’t very supportive, she is pushing me to get a diagnosis. I also don’t want to burden people’

‘I do yoga and have my allotment. Also some really lovely friends and I have my sister’

‘There is only my wife and she is already doing too much’

‘I have no support from family as I had to move to Cambridgeshire. I set up a mental health support group in St Neots and chat to others there. I have found support and empowerment with The SUN Network. I have had to find things for myself as nothing has been signposted to me’ ‘only one friend and my husband know my story. I tried to tell my mother, but she denied it ever could have happened. I don’t like to burden people or ask for help’

‘My family are great, but they are not educated in my diagnosis (BPD) and don’t understand it or help me change. They can only support what they see right in front of them. Family and friends support should not be in place of having an actual service run by professionals. My family can’t always be there either. I can’t always be honest with them about how awful I feel (suicidal) as I don’t want to burden them with that’

‘I now have an amazing support network. People at the craft group I attend. My mum has been the person most dedicated to my recovery. My partner turned my life around and was the spark to a more positive recovery for me. My daughter is the center of my world and in the darkest moments has been what stopped me going too far. Although I no longer use diagnosis I was diagnosed with PD’

‘I have good support from my partner and their family. And support from friends and work’

‘I have good support from my family and the few friends I have’

‘I have great support from my family and husband. They have picked up the pieces. Family have given support when services haven’t. Although this is amazing, they are not qualified mental health specialists’

‘I have no family, and my friends are my safety net. They looked out for me when things were very bad. They acted on my behalf as I was completely shut down at my lowest point’

‘I access The Edge café which has helped me get close to others. My family are supportive, I have my mum and my sister who I can talk to. I have another sister that I meet socially. I wish I had more friends. I have good friends, but I would like to make more which I am doing slowly’

‘Happy where I live and appreciate the support of family and friends. I would like a partner’

Final Comments

‘I had 2 or 3 years in my 20’s where I was in a horrible job and drinking loads and didn’t know that help was out there. It’s hard when you are first ill as you have no idea where to go’

‘I am looking forward to the future. I have passion and enthusiasm for life rather than feeling like each day is a chore and only being able to get through one day at a time’

‘There is no help out there at all. Now not seeing psychiatrist I have been discharged from perinatal team. Feel sorry for GPs as they are so limited with what they can do and offer. Mine is trying to help me. The NHS never seems to know what is or isn’t available or they just don’t want to let you know there is nothing so pass you around from service to service’

‘The biggest challenge, especially for men is admitting you need help’

‘The challenge people face is knowing what services are out there. No-one seems to signpost’

‘I want to move forward into employment but feel I am hanging in a void’

‘Crisis immediate response is not immediate’

‘There is only so much a GP can do. My GP never wants to say there is nothing else she can offer, and I don’t want to hear that either’

‘I don’t feel like I am living. Just existing. Lonely and lost trying to survive. It feels like a battle and having to justify my needs’

‘My medication was meant to have changed weeks ago but this hasn’t happened’

‘I have had to push and push and push for support’

‘I don’t know what help is out there and neither does my GP’

‘I really hope that next time we talk, I am still here, and things have got better. It feels like they just do assessment after assessment after assessment. No-one seems to have a way of reading notes and I never speak to the same person twice. Before PRISM came in, I could actually get help, now I just feel I am costing the NHS a ton of money, as I’m always seeing the GP, always in A&E, constantly calling NHS 111 option 2 or PRISM. They have spoken to the psychiatrist about me so many times, surely it would have been cheaper just to let me see them myself. I feel like they treat me like I’m being difficult if I try to explain to them what helps me and they are sometimes so patronizing, you’d think I was a complete idiot. I’m not. I hold down a good job and manage a team and know my stuff, but it’s like they expect me to be quiet, grateful, undemanding and accept whatever they decide to give to me even if I know it’s not right for me’

Discussion

These 15 interviews with service users have provided a valuable insight into the daily lives of those living with poor mental health or diagnosed mental health conditions.

The demographic data reflects the feeling that men are less able to acknowledge their mental ill health and ask for support. All our participants were also white British which gives us less of a varied cultural insight at present. We also have certain areas of the county that are under-represented such as Huntingdonshire and Fenland. We have a cross section of sexual orientation considering the numbers interviewed although none of the participants identified their sexual orientation as affecting their mental wellbeing either way.

The numerical data shows that most people scored mental health as currently neutral or good but credit that to family and friends support rather than being able to access mental health support services. The level of satisfaction with the current situation contradicted the previous answer with the people neutral, poor and the largest segment reporting that their situation is very bad. This again appeared to be due to not being able to access services and having to find alternative wellbeing ideas and support.

Only 4 of the 15 respondents felt that they were receiving enough support from mental health services at this current moment in time.

Participants were unsure whether they were receiving enough other support mainly due to them not wanting to feel a burden to their family and friends and partly as they felt family and friends were not qualified to support them with their mental health. Also factored into this response is the lack of awareness of alternative support available.

Overall satisfaction scores were generally neutral to very poor with participants identifying falling between the gaps as one of the contributing factors along with lack of consistency with service personnel.

The quotations from interview notes, (which themselves include some direct quotes from interviewees), are considered the heart of the report. They include insights into the support received and what is most important to those ‘on the receiving end’, which should prompt reflection by the report’s readers.

Whilst caution is required in extracting messages from a limited set of interviews, some themes have emerged strongly, and they are noted in the section below.

Service User Interviews Conclusion

In conclusion, there are some prominent themes emerging from these interviews that very much align with feedback received by The SUN Network concerning mental health provision, and those themes are:

- Signposting. There are a lot of people who are unaware of what services are available to them and are therefore not able to access support
- Gaps in services. There are people unable to access any service despite trying to access many and they end up falling into a gap between services with only crisis care services to rely on
- Professional knowledge. Many professionals within mental health services are not equipped with the knowledge required to signpost or are simply not signposting
- Discharge from services. Service users feel that they are discharged too soon, or discharged to nothing, likened to ‘falling off a cliff’ and hitting crisis point, or given information that they are simply unable to retain so leave not knowing what’s next
- Carers. There is a heavy reliance on carer support which is unpaid and typically not qualified in the field of mental health. Service users feel they are burdening loved ones but rely on them in the absence of support
- Stigma. There is still stigma surrounding mental health that prevents people feeling able to ask for help, or being equally collaborative in their treatment options
- Consistency of service. Service users are retelling their stories repeatedly due to either attempting to access numerous services and being turned away, not seeing the same person within one service twice, or communication between services or departments not at a level whereby notes can be shared or accessed by all relevant people
- Access. Many people are simply unable to get support for their mental wellbeing at a time when they need it, or are being told that they are not ill enough to access

- PCMH. PCMH is being seen as a barrier to services and an unnecessary hurdle that does not offer effective intervention and delays treatment due to long waiting lists
- Waiting lists. Waiting lists for the majority of services are long and people cannot access at a time that they need to
- Medicalised model. People feel the option of a medicalised model is the preferred treatment by professionals
- Crisis care. Crisis care is unable to respond as immediately as people would like them to
- Diagnosis. Diagnosis can lead to exclusion from services due to now being considered too complex

Overall Conclusion

The overall conclusions drawn from this interim report show the similarities between the services user and carer experiences. These themes are not new but have been problematic for service users and their carers for a significant period of time and encompass the whole county.

Participants were able to appreciate good support when they had it. But there were several negative themes. The sense of hopelessness and frustration. The lack of continuity of service and service staff. The seemingly unattainable level that thresholds are set at. Awareness, signposting and gatekeeping of services, Barriers to access, gaps where the services are not joined up. The heavy reliance of friends and family to pick up the slack in unpaid roles.

It is recommended that personalised pieces of work that use the mental health service as one journey from a service user perspective, along with meaningful collaborative and co-productive joint working are utilised by commissioners and service providers to enable us to anticipate positive shaping of the future of our mental health services.

This report will be widely circulated to all stakeholders and partner agencies, with interviewees being asked if they would like a copy. Comments are invited. In the next phase of the project it is clearly important that the format of the interviews is not significantly changed, but if an improvement can be made that does not interfere with our method, we will make it. We will add a chance in the semi-structured interview for people to contribute ideas for better services that can be as radical as they would like.

Appendix 1

The Winding Road – Questionnaire

1. Details	
Name: (initials)	Service User or Carer (delete one)
Age:	
What gender do you identify as?	
Ethnicity	
Sexuality	
Location	
2a. Current Mental Health **(symptoms)** Please rate your current mental health on this scale: 5 – great 4 – good 3 - neutral 2 - poor 1 - very bad	
Use your own words to say how your mental health is at present:	
2b. Current Mental Health (recovery) Please rate your ability to live life to the full at present on this scale: 5 – great 4 – good 3 - neutral 2 – poor 1 - very bad	

Use your own words to say what your life is like at present:

3a. Support – Mental Health Services

Please rate whether you are getting enough support from mental health services (CPFT(NHS) CPSL Mind etc.) on this scale:

Yes/No/Not Sure

Use our own words to say more about this:

3b. Support - Other

Please rate whether you are getting enough support from other sources (family, friends, other things to do) on this scale:

Yes/No/Not Sure

Use our own words to say more about this:

4. Satisfaction
How satisfied are you with this situation – on this scale?
5 – very satisfied
4 – satisfied
3 – neutral
2 - dissatisfied
1 – very dissatisfied

Any final comments:

interview number	1 2 3	date
initials of interviewer		