Crisis Care in Liverpool, Sefton and Kirkby: Service Users' Experiences

March 2016

Contents

Acknowledgements

Liverpool Mental Health Consortium would like to thank everyone who took part in this work and shared their experience with us, whether through a focus group, questionnaire, individual response or on-line survey. All of their insights have shaped this report and recommendations.

Particular thanks to Sarah Butler-Boycott (Liverpool Mental Health Consortium), Carol Bernard (Mersey Care), Leigh Horner (Merseyside Youth Association/Liverpool CAMHS Partnership), Paul Mavers and team (Healthwatch Knowsley).

Claire Stevens, Development Manager, Liverpool Mental Health Consortium

Executive Summary - Main Findings

1) Access to Support before a Crisis

I. Many GPs lack adequate understanding of mental distress and its causes, as well as the full range of approaches to supporting individuals.

II. Waiting times for IAPT (Improving Access to Psychological Therapies) support, as well as waiting times for secondary care-level and specialist psychological therapies are a serious concern and exacerbate the levels of distress that lead to crisis.

III. Information about the support and services available is not always accessible.

2) Urgent and Emergency Access

I. The majority of respondents had not found it easy to access timely or appropriate help in a crisis, even when they knew where to go to access support.

II. Crisis services within A&E were found to be inappropriate and unsupportive.

III. The definition of a 'crisis', and the corresponding threshold for accessing services, is viewed differently by those seeking support and the services which offer it.

IV. The recent developments of the Prenton Suite and the triage car scheme were welcomed, but felt to be too limited in scope and capacity.

V. Young carers highlighted as an issue the lack of respect they experienced from professionals in adult services.

3) Quality of Treatment and Care

I. The negative impact of lack of beds and out-of-area treatments was noted, with a lack of local inpatient care for young people specifically highlighted.

II. Both the location of the Crisis Team within A&E departments and the attitude of professionals within that team were perceived as problematic.

III. The length of time waiting to see the Crisis Team in A&E was found to be unacceptable.

IV. Respondents talked of unhelpful, negative or misinformed attitudes from professionals in relation to physical support needs, dual diagnosis, and personality disorder in addition to not being listened to or respected as an individual and suicidal feelings not being taken seriously.

4) Recovery and Staying Well

I. The majority of respondents felt excluded from the care and support planning process and had not had the opportunity to contribute to recovery planning or advanced statements.
II. The 'Message in a Bottle' scheme for Young Carers was cited as an area of good practice which could be extended to all age groups.
III. Respondents reported a lack of emphasis given to holistic support including family and/or relationships.
IV. Many respondents noted lack of communication between GPs and specialist services.
V. A lack of ongoing support was considered to be detrimental to staying well.

5) Service User/Carer Suggestions

I. Peer support is crucial to keeping people well and reducing the risk of crisis.
II. Greater respect is needed for carers as experts on the needs of the individuals they care for.
III. A 24-hour crisis line with one number across Merseyside is needed.
IV. The development of a well-resourced, voluntary sector or peer-run place of sanctuary would be overwhelmingly welcomed. Key words being: 'safe', 'self-referral', 'drop-in', 'open 24/7'.
V. Night cafés and drop-ins would also be welcomed.
VI. Improved cross-border commissioning and equality of access is key.
VII. Improved information-sharing and communication is also crucial.
VIII. A recovery college-style approach in the community would be welcomed.
IX. Better resourcing of crisis care, including peer support, is required.

Section 1: Introduction

1.1 Liverpool Mental Health Consortium aims to improve mental health services in Liverpool and surrounding areas by offering opportunities for those who have experienced mental distress to develop a collective voice about their experiences, share opinions and insights, and influence the planning, delivery and evaluation of mental health services.

1.2 This report is the culmination of a piece of work we were asked to undertake by Liverpool Clinical Commissioning Group (LCCG), the remit being to consult with individuals who have experienced mental health crisis care within the Mersey Care NHS Trust footprint (Liverpool, Sefton and Kirkby) and to produce a report and recommendations based on their input. This will, we hope, help to inform the development of the local Crisis Care Concordat.

Section 2: Background

2.1 The Mental Health Crisis Care Concordat is an agreement between organisations involved in the care and support of people in crisis. It sets out how organisations will work together to make sure that people get the help they need when they are having a mental health crisis.

2.2 The Crisis Care Concordat is a national initiative but local partnerships bringing together agencies involved in health, policing, social care, housing, local government and the third sector are working to ensure that local needs are met in the best and most appropriate ways. These partnerships are developing local Crisis Care Concordats which take into account the specific needs, infrastructure and demographics of their area.

2.3 The Crisis Care Concordat covers four main themes:

1. **Access to support before crisis point** – making sure that people experiencing mental distress can get help 24 hours a day and that when they ask for help, they are taken seriously.

2. **Urgent and emergency access to crisis care** – making sure that a mental health crisis is treated with the same urgency as a physical health crisis.

3. **Quality of treatment and care when in crisis** – making sure that people are treated with dignity and respect, in a therapeutic environment.

4. **Recovery and staying well** – making sure that future mental health crises are prevented by helping people to access the advice, information, support and advocacy that is appropriate to them, when they need it.

Section 3: Method

3.1 In order to access feedback from people who have experienced a recent mental health crisis in Liverpool, Sefton and Kirkby and, specifically, to ask for their insights into the four themes covered by the Crisis Care Concordat, we first needed to develop a relevant set of questions.

3.2 It was important for us to 'co-produce' these questions with people who had used crisis care services or who were carers/family members of service-users.

3.3 The starting point for this was a Crisis Care Concordat event aimed principally at service users and carers and hosted by Mersey Care at Aintree Racecourse on 17th November 2015.

3.4 This event, attended by 50 people allowed us to hold a workshop covering the four areas of the Concordat and capturing key themes and suggestions from service users, carers and professionals.

3.5 These were then developed into a questionnaire which was posted online, circulated via networks across Liverpool, Sefton and Kirkby and used as the basis for focus groups with key stakeholders – again, focusing on service users and carers.

3.6 We also conducted one-to-one interviews with service users when they were unable to attend focus groups.

3.7 A copy of the questionnaire can be found at Appendix 1.

3.8 We also sourced information from the Patient Opinion website (www.patientopinion.org.uk) where it related to patient's experiences of mental health crisis care within the Mersey Care footprint.

3.9 In total we collected feedback from 112 individuals:

50 - Aintree event (Nov 2015)

48 - Focus groups (Dec 2015 - Feb 2016)

9 - Online submissions

5 - Other (including one-to-one interviews and Patient Opinion website posts)

3.10 These individuals' experiences, suggestions and insights are set out below under the four thematic headings of the Crisis Care Concordat.

3.11 We have also included 3 Case Studies which exemplify many of the issues raised.

3.12 People who responded to our request for information were generally happy to have been asked and to contribute. However, some expressed surprise that the Crisis Care Concordat initiative had been launched in 2014 and that it had taken a year or more before their opinions had been sought.

Section 4: Case Studies

Case Study 1

Individual Service User Experience

Shared at Aintree Racecourse Event, Nov 2015

This service user was depressed and suicidal with no-one to talk to. Out of desperation, she went to the A&E department. The waiting room was vast and there was nowhere to have a private conversation, so she had to tell the receptionist why she was there in front of everyone. She was seen by a triage nurse and, by this time, was very anxious and panicked. The triage nurse assessed her as needing to be seen very urgently and she was sent back into the chaotic waiting room. In this depressed, anxious state, she waited for 4 hours, but felt she had to stay. She eventually saw someone from the crisis team who listened for a very short space of time before telling her to go home and have a warm bath.

Her experience of the Crisis Home Treatment Team/Stepped Up Care was a more positive experience on the whole, but it sometimes felt as if they were just checking she was alive rather than having any meaningful interaction.

The solutions she suggested were more community professionals in a preventative role and more support workers to help prevent crises.

Case Study 2

Individual Carer Experience

Shared at Transforming Mental Health Services event, The Women's Organisation, Jan 2016

A Carer looking after a relative with a diagnosis of Psychosis had reached crisis point last November. The Carer contacted the Early Intervention Team but got no response. As the relative's condition deteriorated the Carer contacted the Psychiatrist and the Crisis Team – who refused to come out. In the end the Carer took the relative to A&E, where they had a 7 hour wait to be seen.

The relative was referred to Clock View where there was a 9 hour wait and the relative's situation got worse – they waited over 2 more hours to see the Psychiatrist, who then sectioned the relative – the Carer felt that this could have been avoided had support been in place in the first instance.

Case Study 3

Individual Carer/Service User Experience

Shared at Aintree Racecourse Event, Nov 2015

This individual was the carer for his son and felt that at most of the times when his son needed crisis care, it needn't have got to that point. But doctors, on the whole, wouldn't listen to the carer experience. There were occasions when his son would disappear and need to be found. His mother called the police and he was taken to a s136 suite. He saw his son cuffed to 2 police officers and heard people speculating on what he might have done. He went 3 hours in the s136 suite without being offered any food or drink.

There were occasions when his son could be convinced to attend A&E. As the carer, he would ask them to be as quick as possible because his son would become agitated, but this never happened and his son ended up in situations where he was aggressive towards other people waiting because of his paranoia.

He became ill himself at one point and remembers sitting in a room with no windows. The rooms available were not good.

At the weekend, he said, there is only 1 approved mental health practitioner (AMP) on duty for the whole of Liverpool due, he supposes, to costs.

Section 5: Findings

1. Access to support before crisis point

5.1 The two main aspects of this theme in relation to the Crisis Care Concordat are that a) people experiencing mental distress should be able to get help 24 hours a day – before they reach the point of crisis and b) that when they ask for help, they are taken seriously. On both these points it is clear that responses are variable, with a key finding being that access to support during office hours can be difficult but access to out-of-hours pre-crisis support is largely impossible.

5.2 The main sources from which people seek support when they first become aware that they may be moving towards a crisis point are GPs, voluntary organisations, IAPT services, helplines, friends and family.

5.3 By far the most frequently accessed source of pre-crisis support was GPs although the response received from GPs was highly variable with many GPs felt to lack adequate understanding of mental distress and its causes. Many GPs were also felt to lack awareness of the full range of both clinical and non-clinical approaches to supporting people experiencing mental distress and to fail to treat mental health with parity of esteem to physical health.

5.4 GP services are, of course, not generally available 24 hours a day (apart from the dedicated Out of Hours service), and can be hard to access even during opening hours, meaning that this 'first port of call' option is severely limited for most adults.

5.5 However, there were additional considerations for young people wishing to access GP services without the involvement of their parents. In cases where the young person’s relationship with their parents is related to the cause of their distress this can be particularly problematic. The GP Champs scheme at YPAS (Young Persons Advisory Service) in Liverpool was cited as an example of good practice in that it allowed access to a GP within a youth project. However, it was not felt to be widely known about.

5.6 Where people had either self-referred or been referred by a GP, other professional, family member or friend to voluntary sector, peer support or IAPT services the general feeling was that these had been helpful in preventing or reducing potential crises.

5.7 However, waiting times for IAPT support and other types of counselling or talking therapy were a serious concern and tended to exacerbate distress levels.

"The experience of waiting 3 years for bereavement counselling led to me having a crisis and a criminal record."

"I was being treated for anxiety and depression. It took me 3 months to get access to 5 sessions of CBT. That timeframe is unacceptable and can lead to a crisis."

5.8 Again, there is nothing approaching 24-hour access to talking therapy or similar services, within the Mersey Care footprint.

5.9 Although people were aware of The Samaritans, they found it largely unhelpful as they typically needed more than simply someone to listen to them. They were hoping to find a degree of direction, advice, signposting or practical suggestions but this was not forthcoming.

5.10 The lack of information about available services was frequently cited as a problem; with the overwhelming message being that better, and better-coordinated, information would assist not only individuals and families but also professionals who needed guidance on where best to refer people for appropriate support – both clinical and non-clinical.

5.11 Young people who took part in a focus group told us that they largely find schools unhelpful in their response to mental health support needs. Older people and the family members who care for them appear also to feel unsupported and lacking in information.

5.12 In relation to people being taken seriously when they ask for help, the picture is, again, mixed. GPs were criticised for failing to grasp the importance of mental health in relation to physical health.

"My GP was called away to see another patient during my appointment and actually said "Sorry, I've got to go and treat the sick!" Where is the parity of esteem?"

5.13 There is some evidence that people who are already in touch with services or aware of local service provision felt that they were not always trusted to know what help they required, when they requested it, and were sometimes denied access to the services they had requested.

5.14 Concern was expressed that people seeking to refer themselves for psychological support (from IAPT services) when experiencing a decline in mental wellbeing were being referred to A&E rather than given an appointment for talking therapy or counselling services. This left people feeling "palmed off" and let down.

"I recognised that I was starting to go down the route of feeling that I wanted to end it all but I knew Talk Liverpool could help get me back on track. As soon as they heard the word 'suicidal' they referred me straight to A&E. But that was exactly what I was trying to avoid. Why didn't they trust me to know myself?"

5.15 People who were unaware of what services might be available to them were often left with the sole option of going to their GP to ask for help and, again, GPs were generally thought not to have enough knowledge to be helpful. This lack of awareness extended beyond clinical support and talking therapy options but also included awareness of practical sources of support such as Advice on Prescription, social prescribing options, peer support groups and community-based support. Typical comments included:

"My GP is not aware of mental health services."

"My GP hasn't got a clue."

"My GP increased my medication when it was already having negative side-effects."

"My GP wasn't keen to refer me to a psychiatrist and I wondered whether it was because of the cost."

"You have to be quite 'focused' to get a GP appointment so if I'm feeling bad I'd rather grin and bear it…"

"Doctors used to give you a mental health questionnaire but I haven't had it recently."

"If you don't say you're suicidal they just prescribe anti-depressants."

"You're lucky if a GP knows about mental health. They know about giving tablets. They're not interested in people's mental health."

5.16 Friends, family and peer groups were frequently cited as sources both of 24-hour support and of being taken seriously. However, there was a recognition that, like professionals, these groups needed greater awareness both about 'Mental Health First Aid' and about sources of advice, information, support and advocacy.

2. Urgent and emergency access to crisis care

5.17 This element of the Crisis Care Concordat is concerned with 'parity of esteem' and ensuring that a mental health crisis is treated in the same way as a physical health crisis.

5.18 The people we engaged with when compiling evidence for this report had accessed crisis care in a number of ways, including via GPs, A&E, the police, the ambulance service and existing contacts with Community Mental Health Teams (CMHTs), Community Psychiatric Nurses (CPNs) and community organisations.

5.19 Approximately two-thirds said that they had not found it easy to access timely or appropriate help in a crisis, even when they knew where to go and what to ask for.

"I know where to access help, I know I can go to my GP, to A&E or 'phone 999. However, once these services are accessed I have been left waiting for long periods of time - in A&E, on both occasions, I waited for approximately 8 hours. On one occasion I waited for 8 hours and then was told the crisis team was too busy, so I was looking at waiting another 4 hours or I could go home with some diazepam. I was not

assessed and sent home with a 6 diazepam and promise of a follow-up with a psychiatrist."

"Once 'in the system' with a CPN it was relatively easy to get their help, but up to that point I was very isolated and it was extremely difficult to get support from any NHS mental health specialist. I am a psychotherapist and so in a personal capacity was able to support my partner up to that time, but it was extremely distressing for him and myself. A&E Crisis Team Assessment room and procedure are horrible and whenever I have supported someone accessing this service at the Royal and Aintree I have witnessed the person being judged and dismissed by the CPN and Psychiatrist, not in a supportive and understanding way but in a brash and cold manner. It is also almost impossible to get Crisis Team on the phone."

"I have found that crisis team will only assist when literally my Uncle has attempted suicide. CPN and social workers are non-existent."

"There is very little support available in a crisis. GPs are often not equipped to deal with mental health. Even if you've used secondary care services frequently in the past, you still have to start all over again. The only place they can tell you to go is A&E which is far from ideal. Although the ambulance and police have been involved in my crisis care, this is not exactly a choice!"

5.20 In many cases the only place people could think of to go, or the place which they were advised to access, was an A&E Department. There was, however, an overwhelming feeling that this was generally not the most appropriate place to go and could, in fact, exacerbate/escalate people's mental health crises unnecessarily.

5.21 Concerns were also raised about the level of communication and the level of awareness about available services both within and between organisations which should be working in close partnership – and which are signed up to the

Crisis Care Concordat. Even when an individual or family is in contact with a particular service, access and communication do not always run smoothly.

"I've tried to phone his key worker but with no success and I've also just been referred from pillar to post within Mersey Care and every time the reception person at Broadoak tries to transfer me to the Access Team the phone just goes dead!"

"Moss House and GP do not communicate."

5.22 These problems can be compounded when communication and information-sharing between different services breaks down. A recent post on the Patient Opinion website underlines a lack of communication between Aintree Hospital and Mersey Care.

"My mother started having visual and audio hallucinations (and) has been ringing relatives as she does not know if it is day or night. She went to A&E and then returned home after a medical assessment of general health. She was walking around the block of flats asking neighbours can they see or hear these people. We have received numerous phone calls regarding people worrying about her, but we didn't know what to do or where to turn to. Her GP got involved and we are waiting for memory test but things have escalated so bad. How is that that a sick elderly pensioner is trying to cope, but we don't know where to turn to?"

5.23 The response from Aintree (quoted below) noted that the hospital Trust is not a mental health provider and made a referral to Mersey Care but did not note that Mersey Care has a team located at Aintree who could, potentially, have provided some 'on site' support and signposting.

"We're very sorry to hear of your frustration around the care your Mum has received recently. Unfortunately, we as a Trust do not provide mental health services and we are therefore unable to provide the care she may need. We understand from your comment that your Mum's GP is now involved in her care, but if you would like more information on

mental health services available locally, you can visit the Mersey Care NHS Trust website: www.merseycare.nhs.uk"

5.24 An example of a situation where professionals dealing with both physical and mental health problems did not adopt an holistic approach early enough is illustrated by this carer's experience.

"My husband, as well as having physical health problems, had a psychotic episode. Because I didn't know what else to do, I had to 'phone for an ambulance. He was passed between doctors and we weren't given any answers. He ended up, in a psychotic state, on a respiratory ward. After a week, a neurosurgeon eventually agreed that it was an interdisciplinary problem. My husband ended up in a care home, which I didn't feel needed to happen. If you're not prepared or not able to stand up for yourself, you don't get your questions answered. It's really frustrating for carers."

5.25 A further difficulty in relation to accessing crisis services is that the definition of a crisis, and the threshold for accessing services, may vary or may be viewed differently by support services and the individual experiencing the crisis.

"You need agreement between the professional and individual who needs care so that it is not just defined by professionals. For one person, it could be that they're depressed, for someone else that they're suicidal or have stopped taking their medication. We know ourselves better than anyone else does."

"I tried to refer someone to Talk Liverpool, but they assessed him as being 'in crisis' so he couldn't access talking therapies. Later they assessed him as not being in crisis, but time and trust had been lost."

5.26 A further concern was that people fall through the gaps between services because when they first seek help they are assessed as being below the threshold for crisis support.

"You almost have to have attempted suicide before you're deemed to be in enough crisis to need help."

"His Dad was turned away twice from A&E for not being 'critical' enough. He was seen the 3rd time, but the young carer's views were not taken into account."

5.27 Experience of the emergency services had been largely positive and the police were generally thought to be helpful in a crisis.

"Although the police turning up can be very embarrassing and there is reluctance to contact them because of the thought of a criminal record, in my experience the police can be the most understanding out of all the professionals."

"A police officer just let me talk for 20 minutes, it was like a counselling service."

5.28 However, there was also criticism of the attitudes of some police officers who were felt to have insufficient understanding of the behaviors associated with people experiencing a mental health crisis and the ways in which these could be either exacerbated or managed safely depending on attitude and interaction.

5.29 The recent development of the Prenton Suite at Clock View was felt to provide a more appropriate crisis care setting than A&E departments but the limitations of its resources/capacity were recognised. The same was also true of the Triage Car scheme operated by Merseyside Police in partnership with Mersey Care. Whilst this was seen as a welcome innovation (as was the additional mental health and 'vulnerability' training provided to police officers working in the Triage Car team) it was felt to be too limited in its scope and capacity.

"When I had a crisis in work, my manager phoned 999. Instead of the ambulance taking me to A&E which is a horrible environment when you are experiencing a mental health crisis (due to it being very chaotic). I was assessed by a CPN in my work (I believe they are called street triage) which meant I didn't need to go to hospital. This was incredibly helpful, made me less scared and a lot calmer. Another helpful aspect, I first accessed A&E in the summer of 2014 and was referred to stepped-

up care where I was followed up by a CPN. I then didn't have further contact with mental health services until the summer of 2015 where I again went into crisis and was referred to stepped-up care. I was followed up by the same CPN. They had checked the system, saw that this CPN dealt with my case last time and so allocated me to her again. This consistency was incredibly important and reassuring, it meant that she already had a rapport with me and knew a bit about me and my background."

5.30 There was some criticism of ambulance response times at weekends. Likewise, A&E departments - and access to mental health crisis support via A&E - were also noted for being particularly overwhelmed at weekends.

5.31 As previously noted, a particular concern for young people was that they could not necessarily access a GP in confidence. In some cases, the reason for their distress could be related to their parents and they, naturally, did not want their parents with them when they sought help, but in other cases they simply wanted to speak to a dispassionate professional.

"I psyched myself up to make an appointment with the doctor. When I got there, they wouldn't see me because I'm under 16. I wasn't allowed to see the doctor by myself and so it ended up with everyone having to know about my crisis. It's like 'you have the right to confidentiality, BUT…' I now know that you can use YPAS drop-in GP Champs if you're over 12 to speak to a doctor on your own. I didn't want to tell my mum because she'd be too sympathetic. People being nice can make you feel worse."

"I tried to battle it myself for 12 months. I'd built up to going to see a doctor over about 3 weeks and was then told I couldn't see a doctor by myself. I had a panic attack afterwards and went home and self-harmed."

5.32 A particular issue for young carers was the lack of respect they experienced from adult professionals. At times, even feeling blamed for their parent's crisis.

"There may be many professionals involved with the parent of a young carer, and what comes up all the time is that young carers don't feel they're taken seriously as an expert by professionals. There's a lack of respect just because they're young. Also, young people are often blamed – 'Your Mum wouldn't be so bad if it wasn't for you'."

5.33 In summary, whilst A&E services are open around the clock and thus, technically, 'accessible' despite long waiting-times, they are not thought by anyone to be an appropriate venue from which to provide mental health crisis care or assessment. Other, potentially more helpful, services are less immediately accessible and accessing them can be something of a lottery.

3. Quality of treatment and care when in crisis

5.34 We asked people about the quality of the crisis care which they or their loved-ones had received and whether they felt that they had been treated with dignity and respect.

5.35 A key focus, as in the section on 'Access' (above), was on the inappropriateness of A&E departments as locations for people experiencing a mental health crisis and the ways in which this can escalate an already critical situation.

"People - young people in particular - who are very distressed can't wait in the waiting room that long."

"Going to A&E, nurses who don't understand, being in distress in front of other people in A&E who have physical problems and stare at you. You end up feeling more vulnerable and scared. You're not kept an eye on, so you can go the toilets and self-harm or leave and no one would be the wiser. A&E is not equipped with the resources or the staff to deal with people experiencing a mental health crisis. You're made to feel like you shouldn't be there because your problem isn't physical. You feel like a burden."

"A&E Team - The wait to see them is horrendous and in an environment guaranteed to make you feel more distressed. The very first thing out of their mouth the last time I used them was 'we haven't got any beds'; not what I wanted anyway. They were completely dismissive of my feelings and went on to suggest that I wasn't really in crisis or feeling depressed - it was apparently 'just' my BPD (Borderline Personality Disorder) and therefore behavioral. Apparently if I hadn't actually attempted suicide this was not a serious desire. It's a wonder they didn't tell me to come back when I had. They had no suggestions other than hospital or the home treatment team."

5.36 However, it was not only A&E crisis care which was felt to be inappropriate. Other, specialist, mental health care services were also sometimes seen to fall short.

"Home Treatment Team - I don't know how this experience is supposed to help anyone in any way. They send different people to see you each day so you never have the time to trust them. They do not seem to know anything about you and very often seem to have little idea about how to talk to someone who's distressed. Each one who appears on your doorstep asks you the same set of questions, particularly how you're feeling on a scale of 1 - 10 - not a very useful gauge, but they don't seem to know what to say/do if you say 0/1. I could go on at length about the shortcomings of this team, but it will wind me up too much! The most unhelpful thing is that there is nowhere to go apart from A&E & no-one seems to know what to do with you when you're suicidal."

5.37 Comments were also made about the negative, unhelpful or misinformed attitudes of professionals in various contexts. These included in relation to the needs of

a) people with physical health support needs:

"The services from the Trust did not offer any support which recognised I am a wheelchair user and I have chronic life threatening condition. It

offered interventions that were contraindicated and would have caused injury."

b) people with dual diagnosis

"Dual diagnosis can be problematic - you can't seem to get help for both the addiction and the mental health problem at the same time. The same can be true if you've got both a physical and mental health problem."

c) people with specific faith support needs:

5.38 One respondent was upset that their religious views were not taken into account when treatment/support was offered. They had made a request for a psychiatrist who shared their faith but this was not provided and had exacerbated their crisis. Another said,

"The Church Minister at Liverpool Cathedral who said I was mad and ignored totally what I was asking for. I found no help at the Church, which could have been a good bridging location if it was more organised and linked to more services in the Community, which in the end I had to find and seek out myself out of pure desperation."

d) young people at school.

"When my friend was diagnosed with depression, she told staff in her school who said she wasn't depressed, it was hormones. She was suspended for 2 weeks for speaking out."

5.39 None of the participants in the young people's focus group felt that their schools/teachers were equipped to deal with young people in crisis. Indeed, most would choose not to confide in a teacher and several felt that teachers were not sufficiently knowledgeable about mental health and could actually promote potentially harmful misinformation.

"In an assembly last year, the teacher said if your friends were anxious, to tell someone straight away because mental health is contagious and that anxiety will spread across the school."

"My friend told me she was suicidal. She wouldn't speak to anyone and she started cutting again. I didn't know what to do because I was scared to break confidentiality. In the end, I told the safeguarding officer."

"One of my friends 'phoned me in tears and they were suicidal. I didn't know who to tell because teachers aren't supportive. I didn't want to tell her Mum. I finally told my Mum and she spoke to my friend."

5.40 Only one participant shared a positive experience with an individual teacher.

"There's one teacher in school who I can trust and she's been there for years. I don't have to keep repeating my story. During some lessons I can go and sit with her and do activities and she'll help you through it and distract you. I'd be lost without her."

5.41 The lack of in-patient beds was also noted, as was the pressure to be placed 'out of area' for treatment due to local bed shortages. Several people commented on the negative impact this can have on both the service user and family members.

"There are a lot of delays around bed availability. The number of Knowsley residents placed outside of the borough is concerning."

5.42 This was also specifically highlighted in relation to the lack of local inpatient care for young people.

"Young people currently have to go to Chester."

"Adult services are not appropriate for young people."

5.43 The situation for young people at the point of transition from Child and Adolescent Mental Health Services (CAMHS) services to adult services can further complicate the quality of service received and the number of agencies/services involved.

"My son was under the care of Alder Hey CAMHS, but once he was 16 they could no longer offer support. At 17, he was actively suicidal, had OCD, and his suicide attempts were exacerbated by his tics. He could attempt to kill himself 10 times a day. He had a knife. Alder Hey told me to ring Aintree; Aintree told me to ring Alder Hey. I had to ring for an ambulance, which took 4 hours to arrive. There was then a discussion with the ambulance staff as to whether he should be taken to Alder Hey or Aintree. There was a 3-hour wait in the waiting room. When we eventually saw the practitioner, they didn't listen, just talked. They said they didn't want to admit him and asked him what he wanted to do, saying there were no beds. They agreed to keep him overnight in the Medical Assessment Unit and it was agreed that he could go to look at the facilities at Chester's young peoples' unit in 4 days' time. He looked, but didn't want to be admitted. There was no follow-up at all. He now refuses all support because of an instance when the details of an appointment at Seymour were written up in full and copied to me as the parent. He's lost faith in services and doesn't trust me. He's now eligible for adult services, but I don't think he'll want to engage with those either."

5.44 The quality of Out of Hours support was also raised.

"Plans can work well during the day-time when you know the individuals involved, but often fall apart out-of-hours."

"Out-of-hours support is almost like a call centre."

5.45 A further issue was the feeling of not being listened to or respected as an individual when trying to make contact with services or to explain one's feelings.

"When a crisis arrives, please ring back - don't ignore calls, don't promise to call back and then don't call... When prescribing emergency meds, actually get in touch with the GP and coordinate a plan... As a carer, I have no support and no confidence that when I ring the so-called crisis team they will be able to assist."

5.46 One young person described the frustration of being misunderstood and, therefore, misdiagnosed.

"My crisis was when I realised that something was different with me. Anxiety meant that I described my feelings as little voices, which set them on the wrong track. I was kind of listened to, but not completely, and things didn't move forwards."

5.47 However, when people felt they had been properly listened to, in a suitable environment, it made a huge difference.

"The university support was private and respectful."

"After some time and being pushed from pillar to post, I eventually got support but was very difficult to find. My new GP assigned me to Talking Therapy but took a long time of talking with other GPs."

"When, as his carer, I demanded help because he was a danger to himself and others, he was given a social worker. This helped."

"It is most helpful if people actively listen to what you're experiencing and attempt to support you in finding a way through the crisis, regardless of your diagnosis or the pressures on services. This happens very rarely in my experience."

4. Recovery and staying well

5.48 The participants in this research were all asked for information on how involved they'd been in recovery planning and developing ongoing care and support plans, including what advice, information, support and advocacy services they'd been made aware of or linked into.

5.49 The response was mixed but the majority reported feeling excluded from the process. However, the overwhelming feeling was that if you don't engage with and involve service users and carers in their ongoing treatment and/or support, it won't work for them.

5.50 When asked whether they'd been offered the opportunity to contribute to recovery planning or advance statements, the majority of respondents said they hadn't.

"No, I wanted to access ongoing CPN support, however, I was told that because I was diagnosed with a personality disorder and not a mood disorder I couldn't access this support. Also this level of support is for people who can't maintain a job or a home whereas I was able to maintain both. I said that I may be able to maintain a home/job at this moment in time but in six months with my mental health continuing to decline this might not be the case, he replied that they don't have the funding available. There is no emphasis on prevention or intervention, they are only interested when you are actually in crisis."

"For my partner, only after CMHT became involved. For myself as Art Psychotherapist with clients, was involved through a multi-agency or therapy Care Planning approach."

"None - none at all, and when I asked my GP for certain medicine as I was worried, I was refused and told I had to be in crisis to get the medicine, but usually it is too late in that situation. I was trying to prevent a crisis and the GP was not interested in what I was saying."

"No. I've asked for a CPN - none provided. I've also asked for a copy of care plan - yet to receive this."

"No. During my last crisis I presented at A&E, was seen by the home treatment team and then unfortunately admitted to an acute ward. I'd been on the waiting list for a long time for a specific type of therapy. There was no plan other than that I continue waiting, with no help or support offered as to how I might make it through that wait. Indeed, I was discharged from hospital abruptly after a suicide attempt on the ward and told I would be sent an outpatient appointment. This never happened."

"You're often offered things you don't want, so then if you don't turn up they say you're not compliant. 3 DNAs and you're out."

"Alder Hey CAMHS does not appear to develop detailed emergency plans with individuals."

5.51 However, some people were able to provide examples of more positive experience.

"I was referred to counselling at college. Pills only get you out of the numbness, but you need to resolve the issues. They asked if I agreed with their interpretation that it was depression and included me in planning about what would happen next."

5.52 The 'Message in a Bottle' scheme was felt to work well for Young Carers, provided their wishes were taken into account, and this is something which could be used far more widely for people of all ages.

5.53 There was a general feeling that despite the good intentions of approaches such as the Triangle of Care there was still not enough emphasis given to holistic support which includes family/relationships at its heart and that signposting to ongoing sources of support was still not reliable enough.

"Often, if you have a physical health emergency, you'll be provided with information on who you can contact if you need help or if any follow-up is needed. This is not the case with mental health crisis care."

"You need support to understand your own journey and 'triggers', and planning for future crises with the whole family."

5.54 Communication between specialist services and GPs did not seem robust enough and GPs were sometimes not thought to provide sufficient, ongoing, post-crisis checks.

"There was no follow-up from my GP to find out whether I was still feeling the same."

"Professionals need to be more assertive in checking on people they've not heard from and offering follow-up support."

5.55 However, where consistency of care was available, the benefits were invaluable.

"My Dad has had the same CPN for years, so if there is a problem I know who I can ring."

"If you're plugged in, staff can check up on your wellbeing and that of your carers. The Early Intervention Team at Mossley Hill have been helpful but the service has been cut and reduced."

Section 6: Suggestions from Service Users and Carers

6.1 Having asked people about their own experiences we then asked them to share their thoughts and suggestions as to what, if anything, they'd change about the crisis care system and what they'd like to improve. Many of their suggestions were broadly in line with current strategic priorities.

6.2 Peer support was seen as being key to keeping people well and reducing the risk of future crises.

"More peer led befriending programmes to enable people with mental health problems to socially engage and not become isolated, potentially one of the key indicators of increased need of support resulting in a crisis scenario."

"More funding for befriending, peer led and free alternative specialist long-term on-going intervention."

6.3 Improved awareness by the public and health professionals, including GPs, of services such as Healthwatch and related online/telephone directories such as Wellbeing Liverpool/Live Well Liverpool was also suggested as being desirable.

6.4 Carers, including young carers, consistently underlined the need for better information-sharing, more respect as experts on the health of their loved-ones and improved access to support for their own mental wellbeing in order to prevent crises of their own. One carer illustrated the problems she'd experienced in negotiating the system.

"It would be good to know what each of these teams do and how they should respond – Early Intervention, Crisis Team and Stepped Up Care. As a Carer I would like to know what I should be doing in the first instance and where I should be going for support and how to put this in place. There is some difficulty arranging a Mental Health Assessment, there are long waiting times to access the Prenton Suite and there is a problem with the whole system. There is no discharge planning and the three mental health teams are not working together."

6.5 There was overwhelming support for a 24 Hour Crisis Line provided there was one easily memorable and accessible number across Merseyside (preferably covering all local NHS mental health trusts i.e. Mersey Care, Five Boroughs Partnership and Cheshire and Wirral Partnership), trained professionals to respond to calls, a willingness to take service users' and carers' knowledge and suggestions seriously and practical responses beyond referring people straight to A&E.

"Why hasn't Sefton Council got a Crisis Line? If there's no one to contact, it makes the experience worse for service user and carer."

"Knowsley needs a single 'phone number for crisis care, there are 2 at present. Also, if we want 1 crisis number, does this mean for Mersey Care patch or across the geographical community?"

"Provide a crisis line! There used to be one in Aintree – where is it now?"

6.6 There was also a lot of interest in the development of a Sanctuary House model or models across Merseyside. Some people were aware of the model used in Manchester and felt it would be useful to provide something similar for Merseyside.

"We need a Sanctuary House like in Manchester. Counsellors on standby, coffee, cake, study groups, a meditation and relaxation room – but it depends on the distance you have to travel."

"There should be somewhere else that is open 24/7 which could be part of the hospital or in another setting that is available for people having a

mental health crisis. A&E is not a private setting, you are sitting there having the worst time of your life feeling completely suicidal amongst other people who are drunk, who are kicking off, families with children, and people with physical injuries. It is no way a place for people needing mental health support."

"Increased provision of self-referral based 24-hour support 'centres'/hubs where staff are there to support crisis and not simply turn people away after a few hours. The 24 hours that a person experiences crisis is most important and in Liverpool we need some kind of a system where people can literally turn up to a safe, welcoming and comfortable 'home' like environment to go through their distress with appropriate support, including RMNs/CPNs and support from people with lived experience of MH crisis."

"When someone is having a mental health crisis and phones 999, they should be assessed at their home or a place where they feel comfortable - they should not need to go to hospital to be assessed. The support people receive when accessing A&E for mental health support is atrocious and ends up making you feel more scared and vulnerable - something definitely needs to be done about it. There needs to be a safe place that people can go to no matter what the time of day or night to access crisis support."

"There needs to be an alternative to the offering from secondary care (i.e. without any input from clinicians) that gives people somewhere to go (an actual physical place, not a virtual one) at any time they are distressed, remembering that everyone's crisis is different, and that talking and listening are the most important things. Ideally this would either be run by a voluntary sector organisation or by people who've used services themselves. This doesn't mean it could be run on a shoestring - it would need proper investment; perhaps by taking some away from ineffective crisis care in secondary services. It would need to

be accessible, informal and community-based and offer sanctuary in the true meaning of the word."

6.7 However, others were unclear about the role of such a facility and requested further information.

6.8 The geography of the area and the fact that the commissioning of service provision does not necessary follow natural geographic boundaries was referred to frequently and this was a particular consideration in relation to Sanctuary-style provision. One respondent in Kirkby noted:

"A&E is often the worst place to be taken to. There is a need for a safe space. There is nothing accessible this end of Merseyside. There is probably a need for more than 1 safe space in order for it to be accessible. It needs to be open at all times and developed as a venue that is de-stigmatising. Consideration should also be given for the opportunities for service users and carers to come together. The Maggie Centres re. palliative care might be a good model to follow. Feeling safe and feeling that you are part of your own recovery are the most important factors."

6.9 Related to this was the need for improved cross-border commissioning and equality of access to crisis care and support, preferably with a single number to call followed by referral to appropriate local services.

6.10 Night cafés were seen as being potentially helpful for those who did not want to be alone 'out of hours' but did not wish to access A&E or, indeed, feel it was appropriate for them. These could potentially act as an open access first step towards referral to a Sanctuary House. The preference was generally to have such facilities run and staffed by voluntary sector providers with clear referral pathways and protocols in respect of access to clinical support.

"Night time and evening cafés or drop in activities, as this can be the hardest time of the day for people with MH distress and difficulties and yet is least catered for."

6.11 Street cars and access to the Prenton Suite at Clock View were generally welcomed but these resources were thought to be underfunded and only able to provide a 'sticking plaster' to a much more serious situation across the area.

6.12 There was support for the expansion of Recovery College-style approaches in the community with an emphasis on prevention and/or recovery for anyone who self-defines as needing support.

"Peer support and access to support groups that include education, social skills and coping mechanisms."

"Access to courses."

Section 7: Conclusion

7.1 During the course of compiling this report, we spoke to, or had contact with, a varied group of individuals, from adolescents to senior citizens, all of whom had experience of mental health crisis care either as service users or as carers for people in crisis. We have endeavored to emphasise their voices and experiences within the report and to draw our recommendations from the themes which emerged from their input. We hope that these voices will not only be heard but that they, and the recommendations they have influenced, will form an important element in the co-production of the Crisis Care Concordat for Liverpool, Sefton and Kirkby.

Section 8: Recommendations

1. Service user/carer engagement/involvement should have happened from the beginning of the Crisis Care Concordat development process (over a year ago), including representation at Steering Group level. This should now be written into the Terms of Reference and take place as a matter of course throughout the remainder of the process, including any evaluation process.

2. Given the high proportion of local GP appointments relating to mental health (NHS Liverpool CCG itself estimates that 1 in 3 local GP appointments are mental health related) there needs to be greater investment in GP training in mental health awareness, crisis prevention, informed onward referral to appropriate support services (including peer support) in all sectors and awareness of non-clinical and practical approaches to the management of mental distress (including Advice on Prescription, advocacy services and access to Wellbeing Liverpool, community education-based models and peer support) as well as the full range of clinical options. The GP Champs scheme for young people should serve as a model for GP access by young people across the area.

3. It is imperative that more resources are directed towards reducing waiting times for psychological/talking therapies, increasing the number of practitioners able to offer these services, including Out of Hours, whether through NHS-delivered IAPT services or improved resourcing of voluntary sector/independent services.

4. A 24 Hour Crisis Line with one number across Merseyside must be a priority provided that staff are fully trained to make appropriate responses and referrals – and that appropriate services are available within inpatient facilities and in the community to deal with crises when they arise, including Out of Hours.

5. A Sanctuary House (or houses) or similar models of non-clinical support would be a welcome alternative to A&E or other forms of clinical intervention. Any such provision would need to be as accessible as A&E whether through self-referral or referral by a range of cross-disciplinary partners.

6. All signatories to the Crisis Care Concordat should work towards moving crisis care away from A&E departments and towards a community-based model,

including sustainable funding for facilities/services such as the Prenton Suite, triage cars, night cafés, drop-in facilities and Sanctuary Houses.

7. Communication between crisis services, GPs, service users and carers must be improved as a priority. A ‘no wrong door’ approach to crisis care would be welcome but requires improved communication and understanding between (and within) services and with service users.

8. More attention and respect should be paid to service user/carer suggestions/requests regarding the approaches which would be most helpful in averting/reducing their levels of crisis (e.g. psychological support/peer support as alternative to hospitalisation) – whether or not there is a care plan in place. This includes young carers. The expertise and support needs of carers, including young carers, must be respected and this respect, as noted in Point 7, must include two-way communication with carers of all ages.

9. User/carer co-production of care plans must be standardised and must take place once the immediate crisis has been resolved. Advanced statements and/or Message in a Bottle schemes should be a measurable requirement in respect of all individuals accessing mental health crisis services and could, perhaps be tied to a CQUIN by commissioners.

10. More attention must be given to the physical health and social care needs of individuals experiencing a mental health crisis and of their carers and families.

11. The Crisis Care Concordat should recognise the positive impact of peer support in relation to prevention of, and recovery from, mental health crises, whilst also recognising that peer support requires adequate resourcing and should not be viewed as a cheap alternative to clinical interventions.

12. There remains a need to maximise public access to information about sources of support in respect of recovery and staying well. As part of the, post-crisis, care-planning process all service users/carers should be informed about resources such as Wellbeing Liverpool (www.wellbeingliverpool.org.uk or 0300 77 77 007) and similar information sources in Sefton and Kirkby. This is in addition to the need to increase GP awareness of these resources (see Recommendation 2).

Appendix 1

Experience of Crisis Care Questionnaire

Background Information

We have been asked by Liverpool Clinical Commissioning Group (LCCG) to find out the views of individuals who have experienced support for a mental health crisis in Liverpool, Sefton & Kirkby, & to produce a report & recommendations. This will help to inform the local Crisis Care Concordat, which acts as an agreement between services (NHS services, the emergency services & others) about the care & treatment of people experiencing a mental health crisis.

Definition of Crisis & Crisis Care

Defining crisis involves many different perspectives, including your own definition of crisis, the definition of services, & definitions focused on risk. Generally, if a person's mental or emotional state gets worse quickly, this is called a mental health crisis or emergency. A crisis might include thoughts of suicide or self-harm, self-neglect, being extremely distressed, going missing, or something else.

Crisis Care covers all of those services that might respond to someone who is having a mental health crisis. This includes NHS services, community organisations, the ambulance service, the police & others.

How to Get Involved

In order to find out people's views, we will be holding a series of focus groups & one-to-one interviews with service users in Liverpool, Sefton & Knowsley. We have also developed a questionnaire for those who prefer to write their answers. Any responses that you choose to share with us will remain anonymous.

You may have had just one experience of using crisis care or several different experiences. Please answer the questions as best you can, based on your experience & what you would like to tell us about.

Our findings will be presented as a report & recommendations which will be submitted to Liverpool, Sefton & Knowsley CCGs & their partner organisations, & will inform local Crisis Care Concordats.

If you would like more information or have any questions, please contact Claire or Sarah on 0151 237 2688 or **hello@liverpoolmentalhealth.org**

1. Are you filling in this questionnaire as?

Individual who has experienced a crisis ☐

Carer ☐

Young carer ☐

Family member ☐

Friend ☐

2. Which services have you used when experiencing a crisis?

A&E Crisis Team ☐

Ambulance ☐

Community/Support organisation ☐

CPN (Community Psychiatric Nurse) ☐

Crisis Home Treatment Team ☐

Crisis Phone Line ☐

GP ☐

Police ☐

Social Worker ☐

Support Worker ☐

Teacher/Tutor ☐

Other (please tell us which service) ☐ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

3. When you were in crisis, did you find it easy to find help?

Yes ☐ No ☐ Partly ☐

Please explain, if you would like to: _

_ _

_ _

_ _

_ _

4. **If no, was this because you….?**

    Tried to seek support but were told your crisis was not severe enough ☐

    Were put on a waiting list ☐

    Were scared to ask for help ☐

    Couldn’t find a service out-of-hours ☐

    Were bounced between services with no one taking responsibility ☐

5. **What help did you find?** (e.g. A&E department, Ambulance service, Counselling/Talking Therapy, GP, Police, Other)

    _

    _

6. **Did you feel listened to?**

    Yes ☐ No ☐ Partly ☐

7. **Were you able to contribute to decisions about the care you received?**

    Yes ☐ No ☐ Partly ☐

8. **Did you find the professionals who provided your crisis care to be helpful, respectful, & ready to listen to you?**

Yes ☐ No ☐ Partly ☐

9. **Which of these words describes the environment in which you were cared for** (please tick all that apply)?

Calm ☐ Tense ☐ Private ☐ Crowded ☐

Clean ☐ Dirty ☐ Dark/Dingy ☐ Light ☐

Tidy ☐ Shabby ☐

10. **Was the support you received right for you at the time?**

Yes ☐ No ☐ Partly ☐

11. **Looking back, what was the most helpful aspect of the support you received?** ____

____

____

____

12. **What was the least helpful?**

____

____

____

13. **What would you change, if anything?**

____

____

____

14. Once the immediate crisis was resolved, were you given…?

Follow-up/ongoing support ☐

Information on who to contact if you found yourself in a similar situation again ☐

Referral to a service ☐

Signposting to peer support ☐

Other (please tell us what this was): ☐ _______________________

15. **Did you have the opportunity to plan in case of a future crisis** (e.g. recovery planning, emergency plan, advance statement)? **Please explain:**

____

____

____

16. Would you know what to do if you had a crisis in future?

Yes ☐ No ☐

17. If you had the opportunity to improve crisis care, what would you suggest?

____

____

18. **Now that you've had time to reflect on your experience, what do you think might have prevented you getting to the point of crisis in the first place?** (e.g. shorter waiting times, information, knowledge of who to contact, better support from professionals, being able to talk to someone)

____

____

Equality/Diversity Monitoring

Answering the following section is optional, but responding to it will help us to get a clearer picture of experiences of crisis care across a variety of communities.

1. **Are you:**

In a Civil Partnership ☐ Cohabiting ☐ Divorced/Separated ☐ Married ☐
Single ☐ Widowed ☐ Other ☐ Prefer not to Say ☐

2. **Gender:**

Male ☐ Female ☐
Is this the gender you were assigned at birth? Yes ☐ No ☐

3. **Sexual Orientation:**

Asexual ☐ Bisexual ☐ Gay Man ☐ Heterosexual ☐ Lesbian ☐
Other ☐ Prefer not to Say ☐

4. **Religion:**

Buddhist ☐ Christian ☐ Hindu ☐ Jewish ☐ Muslim ☐ None ☐
Sikh ☐ Other ☐ Prefer not to Say ☐

5. **Ethnicity:**

Arabic: ☐
Asian/Asian British: Bangladeshi ☐ Indian ☐ Pakistani ☐ Other ☐
Black/Black British: African ☐ Caribbean ☐ Other ☐
Chinese: ☐
Mixed Ethnicity: Asian & White ☐ Black African & White ☐
Black Caribbean & White ☐ Other ☐
White: White British ☐ White Irish ☐
Traveller of Irish Heritage ☐ Gypsy/Roma ☐
Any Other White Background ☐
Other Ethnic Group: ☐ Prefer not to Say: ☐

6. **Do you consider yourself to have a long-term illness, disability or health problem?**

   Yes ☐ No☐ Don't Know ☐ Prefer not to say ☐

7. **What is your age**? _ _ _ _ _ _ _ _ _ _

8. **Which area of Liverpool, Sefton or Knowsley do you live in?** _ _ _ _ _ _ _

   _

Thank you very much for participating!

Contact Details:

Please return this form to: **hello@liverpoolmentalhealth.org** or **Liverpool Mental Health Consortium, 151 Dale Street, Liverpool L2 2AH.** If you would like to be sent a copy of the report when it is finished, please also let us know your contact details.

If you have any questions or concerns about the questionnaire, please feel free to contact Claire or Sarah at the email above or 'phone **0151 237 2688**