

What is crisis care in Leeds really like for us?

*Service-user perspectives gathered by
'Together We Can'*

October 2014



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“Feeling so much inner tension and desperation and so much fear that it feels like I can snap - like I am hurtling towards something so scary unless I 'come down' and get help.”

Survey Responder September 2014.

Foreword by 'Together We Can'

'Together We Can' formed in 2014 as an independent mental health network of people with lived experience, coordinated by an expert advisory group of representatives and supported by Leeds Involving People. By working in partnership with commissioners and strategic decision-makers, our aim has always been to help improve the mental health services in the Leeds areas for those people in need. We are all people who have been through the mental health 'system' in Leeds and so we offer a unique insight into just what it is like to be a 'service-user' in Leeds.

We aim to include the views of as many people with mental health needs in the Leeds area as possible; we connect with these people face to face and through social media. At the time of writing, we are 88 members strong and growing.

A significant number of our members have recent experience of a mental health crisis. While our ultimate aim is to avoid crises altogether, we hope that by presenting this snapshot of people's experiences and expectations, we can have a role in the development and improvement of crisis support available.

It has been a great privilege to have our views and opinions listened to as part of the both the Leeds Mental Health Framework and the forthcoming Crisis Care Concordat in Leeds. We hope that by continuing to work in partnership with the Mental Health Partnership Board, our members' and supporters' views we can help to improve mental health crisis support in Leeds.

October 2014

Key Messages

Every conversation we had with our friends and peers told an individual story, but there are five recurring themes:

1. Many causes of crisis are non-medical, including issues around housing, benefits and a range of social issues coming together at a bad time. Those crises can only be resolved and prevented by addressing non-medical causes in a joined-up way.
2. People in crisis are often desperate and extremely vulnerable and need treating with patience, respect and dignity.
3. A large number of people with mental health conditions have coexisting issues around drugs and alcohol. Leeds has a wealth of support for people in recovery, but there are few avenues of mental health support for people approaching crisis point.
4. Currently people are being seen in inappropriate places or by inadequately skilled staff; there is a real need either for a crisis assessment unit independent of A&E.
5. There are some great initiatives in the community to keep people well, but their opening hours restrict access.

Methodology

As a member of the Leeds Mental Health Partnership Board, Together We Can carried out a short piece of research into experiences of crisis care in Leeds. We hope that these insights contribute to the evolution of crisis support in Leeds as well as the emerging Crisis Care Concordat.

The Together We Can Expert Advisory Group talked with our friends and peers and developed a survey to be sent out to people with experience of crisis care whom we couldn't meet in person. The survey ran initially from August 2014 to October 2014, but we aim for this to be an ongoing piece of work with new people continually being invited to share their experiences and hopes.

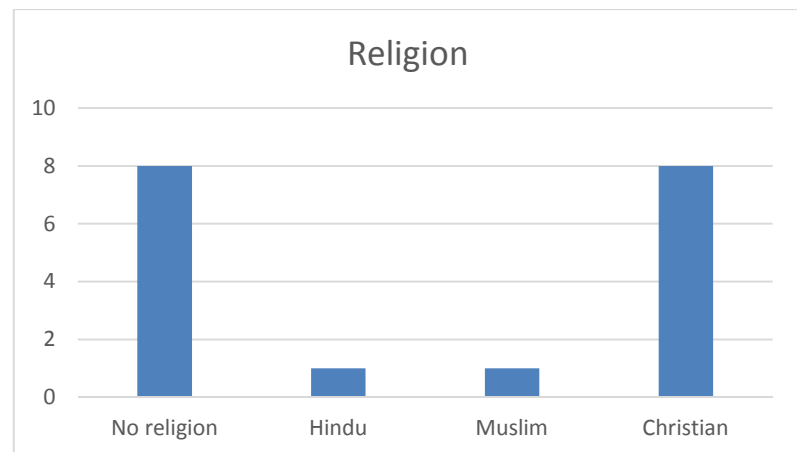
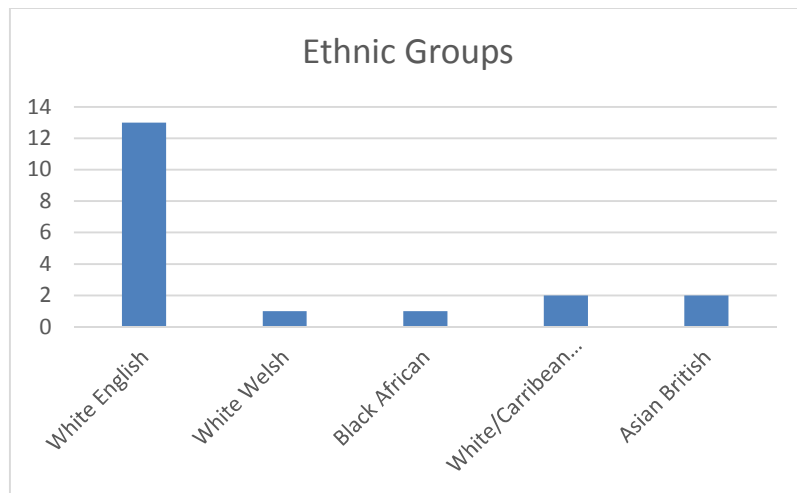
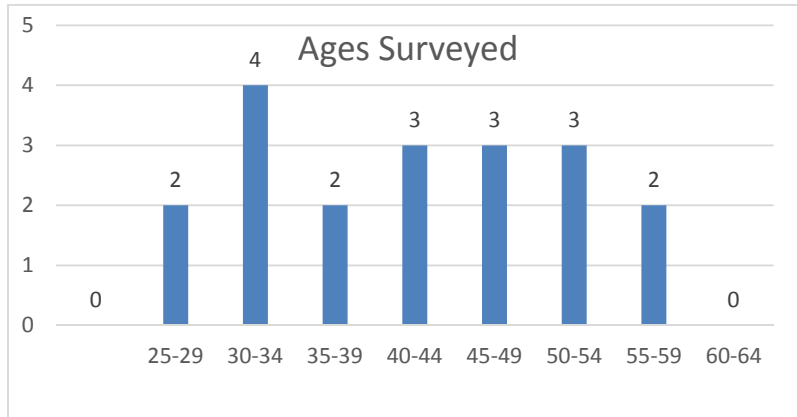
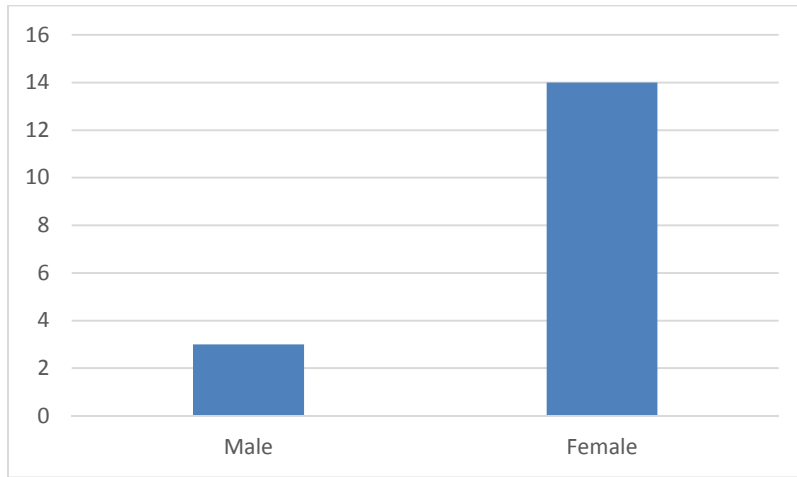
We contacted people through our membership database, the University of Leeds, Twitter and Facebook, contacts at Leeds Irish Health and homes, Touchstone, Mind, Volition, Healthwatch, Young Minds and People in Research.

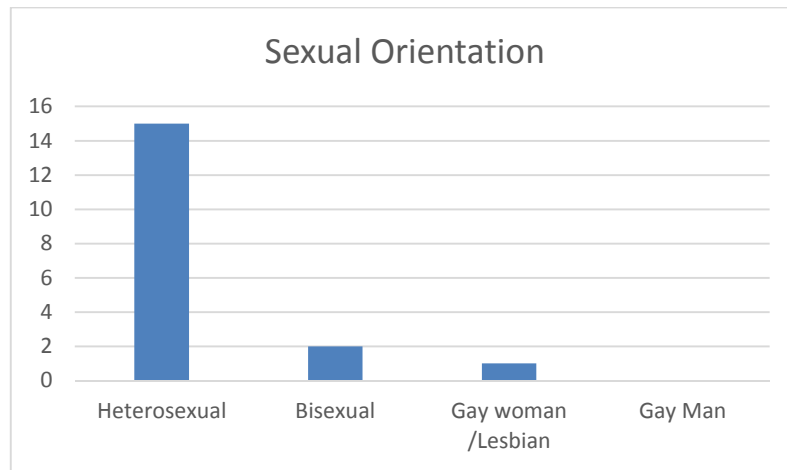
We asked these open questions:

- What is your personal experience of crisis?
- Describe what happened the last time you accessed crisis care in Leeds.
- Which services in Leeds have helped you to recover and stay well after crisis?
- Describe your vision of an ideal crisis care service.
- Is there any additional support that would help you to avoid crisis?

The perspectives summarised herein are from approximately 45 people, including 25 people who responded to the paper-based and online versions of the questionnaire. A significant contribution was made by Touchstone's Alcohol Group during a focus group session.

Those who completed the survey were asked people for equal opportunities data to ensure we had a range of people across Leeds:





Limitations of equality data

Only the survey respondents completed equality monitoring forms. Informal conversations with people in our network reached a broader range of ethnic backgrounds and ages, specifically young British-Asian women. Similarly, the number of men at the Alcohol Group goes some way towards redressing the gender imbalance in survey responses.

A Note on Terminology

There is considerable debate about the most helpful and understanding way of talking about mental health issues. That means that care must be taken to ensure that the terms used do not carry implications that are not intended. A further problem is that many commonly used words carry derogatory connotations. Throughout this report we have attempted to use terms which are as neutral as possible; we refer to the experiences in question as ‘experiences’ rather than as symptoms of an illness. Finally, we refer to people who have these experiences as ‘people’, rather than as ‘patients’.

Where possible, real quotes from people have been used to tell the story as we want this report to be a platform for these voices.

Introduction

In 2011, Mind published *Listening to Experience: An Independent Inquiry into Acute and Crisis Mental Healthcare*. In light of their findings, they published a set of recommendations focusing on four main areas:

- Humanity
- Commissioning for people's needs
- Choice and Control
- Reducing the medical emphasis within acute care and facilitating a more collaborative, person-centred approach in bringing about healing and recovery.

In all there are five full pages of recommendations from Mind, which Together We Can endorses. Indeed, our research revealed similar themes in Leeds in 2014. Our intention is, equally, to form a positive vision for evolved crisis support in Leeds, but we are unflinching in quoting people's negative experiences as necessary.

As a result of the Crisis Care Concordat, all areas of the UK should be reflecting on their crisis care provisions, what is working well and what needs improving. Through this report we aim to add to the evidence base of what it is like currently for people in Leeds, what works well for us and what needs to change in order to better support us when we are at our most vulnerable.

Crisis Needs

What is a crisis?

"When I have exhausted all my coping things and I am in danger of hurting myself"

"I knew I needed help and I reached out for it. I knew I needed to be somewhere other than my own home to start to get better;"

Crisis is different for different people, there is no one typical presentation of a crisis. The one common factor is that all people in a mental health crisis need urgent help. The mental health charity Mind states that a mental health crisis may take the following forms:

- suicidal behaviour
- panic attacks/extreme anxiety
- psychotic episodes
- other out of control behaviour (Mind, 2010)

The people of Leeds who responded to our survey echo Mind's findings. They describe a crisis as a feeling of desperation due to extreme anxiety or confusion, feeling scared and out of hope.

People who responded highlighted various triggers for their crisis, including:

- Stress and anxiety
- Housing Concerns
- Delays in getting ESA and the phone calls associated with this
- Long waiting lists for counselling.

What do people need in crisis?

One of our questions was to ask people what they felt they needed in a crisis. There were common, interconnected themes across many responses.

A Place of Safety

Overwhelmingly people report a sense of feeling in danger and in desperate need of a place or feeling of safety.

"... I didn't need to be cast aside because I wasn't deemed 'acute enough..."

When people are feeling at their most vulnerable, home does not always feel like a safe place, but people report an increasing tendency to leave people in their own homes. Sometimes people needed to get away from their home situation and did not have the support of friends or family nearby. 'Calm' was often what people were looking for.

"I was left to get on with my crisis on my own, with a family member whose idea of helping me recover was to drag me out furniture shopping. I ended up wandering around the Park, drinking to block out the pain and contemplating sleeping under a hedge because I couldn't face going home."

Someone to talk to

In the surveys people detail their experience with the Crisis *Single Point of Access* phone number. There is an awareness of the phone-line and people are using it during a crisis but the response is largely negative.

"... I phoned up the crisis team once and after going through the switch board I was put through to someone to talk to about my distress but the person was just trying to make me laugh and was making fun of me which I didn't need or want. This has put me off asking for help again..."

The consensus appears to be that the single point of access phone number is an excellent idea and it seems to be easy to get hold of someone from it, however, the response people are getting is not ideal.

Attitudes

"Crisis assessment was patronising, negative with no empathy. Some of the crisis assessment team are superb but only around 15 percent of them, the rest are dire. I was told they'd phone me back when I'm not distressed!"

Many comments received on the survey forms were related to the attitudes of the staff encountered during a crisis. People felt they needed to be:

- Taken seriously
- Shown respect
- Receive a warm and caring response
- Understood

Does the reality match up?

A&E

"A&E treats people who self-harm appallingly, there is a major training need. Basic compassion is needed e.g. "I'm really sorry you're feeling like that"; instead I was made to feel like I was taking up a bed. "Why are you wasting our time", "Don't come back again". I was discharged when I had self-harmed and had no phone or wallet on me). It felt like shaming."

There is an overwhelming response that A&E is not the place to be treated during a crisis, unless life-saving treatment is needed. There is a need for an alternative resource for people to be seen in a safe, friendly and compassionate centre especially for people in a crisis.

The Touchstone Alcohol group also highlighted the need for any service to cater for those with dual-diagnosis. They report being turned away from A&E in a crisis because they smelled of alcohol or were 'frequent fliers'. They also stated that nurses in A&E treat them unfavourably because of their alcohol problems and as a result do not receive the mental health treatment they need. Any such crisis assessment centre would have to consider the needs of people who misuses substances alongside a mental health problem.

"....It would be really helpful to have someone sat with patients in A&E whilst they're withdrawing, or the offer of Librium. Or even a private room where patients can be with someone who is able to help take their mind off their withdrawal. This level of understanding and support in hospital would make them more likely to stay in hospital for their appointments...."

Community CPN Service

"I called my CPN as I was struggling to cope, this was at 10.30am, I was promised a call back after they had checked my notes. I got a call at 4.55pm 5 minutes before they closed and the advice I was given "try not to think negative thoughts". The call ended and later that night I self-harmed again due to lack of support."

"Read my care plan. What is the point of having one if no-one bothers to read it?"

Again sadly the comments received about the CPN service in a crisis are overwhelmingly negative. People report CPNs taking too long to respond to a phone-call, the CPN not turning

up when they should, not reading the care plan and in the end just telling the person to call the crisis number.

Day Centres

There are currently three centres for daytime community support at Lovell Park (City Centre), Vale Circles (Hunslet) and Stocks Hill (Armley). These all offer a range of social and therapeutic activities on a healthcare professional-referral basis. The positive benefits of these were highlighted in the surveys, with particular reference to the work they do in both recovery and staying well to avoid reaching crisis point again.

“Going to Lovell Park has really helped, everyone who uses this service are nice and friendly. The relaxation class has really helped my anxiety.”

The main issues raised about the day centres were the 9-5pm, Monday-Friday aspect of the service; people were concerned about the lack of support during the evening and weekends. People overwhelmingly express views in favour of expanding these services, offering more classes at the centres and possible appointments with psychiatrists here as they feel like it is a safe environment.

Other services in Leeds include Touchstone, Dial House, and ICS.

The experiences of Dial House are mixed positive and negative. People say that when it is open and accessible it is a fabulous service but that there is limited and that admission times favour people who happen to hit crisis at 6pm.

“Dial house may be good but if I'm under CMHT they will just think everything is fine with me because I haven't rang. I haven't called because been told to go elsewhere when you're at your lowest, it knocks the stuffing out of you and it's even harder to dare ask for help again”

Recovery and Staying Well

Part of the Crisis Care Concordat highlights the importance of prevention of a mental health crisis. Within Leeds the survey recognised many facilities to aid recovery and to help people stay well. One service that received significant praise was the use of NHS Mental Health Peer Support Workers.

“For the first time I felt like someone with the ability to help me really understood what I was going through.”

“The peer support recovery group at St Mary’s hospital was what helped me gain the tools to stay well”.

Another service that is highly commended by respondents is the work that Leeds Mind does in supporting people, running groups and offering peer support.

Throughout the surveys people are aware of the immense benefits of ‘talking therapies’ to help them stay well and avoid further crises. However in many cases the problem of long waiting lists and people often getting worse during the waiting times.

One issue highlighted is that often people are not aware of all the services in the community that are available. Like the single point of access phone number, they would like a single number to call for signposting to appropriate community services.

The issue of welfare is highlighted as a contributory factor to staying well. In many cases the need to get adequate, reliable and non-judgemental support on claiming welfare support was stated. One person stated that it took her 3 weeks for any money to come through from ESA and she had no idea where she could get help on this. Having to make long phone calls to the DWP to sort this out whilst her depression and anxiety levels were high did not help. If there was a consistent and reliable source of support to help claimants many crisis episodes could be prevented.

CONCLUSION

Putting together this report has been eye-opening. We learned a great amount from the people who responded with stories. Although there are some positives in the survey responses, people do seem to have concentrated on the times when things have gone wrong. However, there is no single response where the story is wholly positive, there are areas to improve across the board.

When people experience a mental health crisis they are at their most vulnerable and unwell. They need treating with humanity and compassion and sadly not everyone in Leeds is receiving this basic care during this time. How people are treated in these circumstances makes a huge impact on their recovery and willingness to seek help again should they need it.

This report has given us lots of evidence but we believe this is only the start of the project, we aim to continue to speak to people about their experiences and continue to pass these on to the Mental Health Partnership Board. There are people we know of who wanted to contribute to this but just couldn't due to the time constraints; expect more from us in the future!

Recommendations

People want to be treated in a warm, caring and respectful way when they come into contact with services during their lowest point. For many people, a crisis is the point of entry into the mental health system and so it is vital that this is as positive as possible for them.

There are a number of recommendations that people have given that are local to Leeds. These can be broadly split into five themes:

- Expansion of existing services
- Communication between staff and agencies
- Alternatives to A&E
- Needs of Dual Diagnosis
- Adequate benefits support

Expansion of existing services

Some services were commended during the survey. In particular, credit was given to the Adult Social Care day centres, peer support workers and counselling services. However the fact that these are all 'day-time' services was highlighted. Mental health problems can often be worse at night-time and weekends when everything is closed and there are no support services available.

Communication between staff and agencies

Communication between staff and different agencies was highlighted as a problem in more than a few cases. People reported being reluctant to contact a service through fear that they'd be then not allowed to access another.

Use of the care-plans and advance statements was also brought up, with the feeling that staff were not reading them adequately or in some cases not using them at all.

Alternatives to A&E/police custody

Whilst conducting the surveys we heard of people still ending up in local police care during a mental health crisis. It is widely accepted that police custody is not the appropriate place for caring for someone in a crisis. We would like the numbers ending up in custody suites to fall to zero.

We also heard stories of people experiencing inadequate care in A&E. Again, we do not believe A&E is wholly appropriate for people in a mental health crisis. People responded by

stating they would prefer to be seen in a community based setting with a non-clinical feel. When asked of their ideal vision of crisis care, people responded with ideas of a house like setting that was bright and welcoming, catering for diverse needs.

Needs of Dual Diagnosis

When designing any mental health service it is imperative to consider the needs of people who also have problems with substance abuse. There was an in-depth discussion with Touchstone's Alcohol Group on how they would like to be cared for during a crisis. They mentioned that it would be really helpful to have someone sat with patients in A&E whilst they're withdrawing, or the offer of Librium, or even a private room where patients can be with someone who is able to help take their mind off their withdrawal.

Adequate benefits support

In many survey responses the issue of benefits cuts and inadequate support in claiming benefits was highlighted as a massive trigger for crisis episodes. People reported having delays in the system and therefore delays in receiving any money, causing distress and financial worries. People seem to have no idea on where to turn to for advice and support with claims and for when cuts happen. Our recommendation is that services to offer help are promoted and advertised so that people can be signposted to areas of support.

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Authors and Acknowledgements

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