
EDINBURGH
COMMUNITY
VOICES
A&E
ALL & EQUAL

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“One of the important things is to be treated on an equal basis. We are individuals. It is so important to be treated like a human being.”

“What I was wanting was not to be treated differently because of a mental health diagnosis, but to be treated accordingly for a mental health diagnosis.”

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Foreword – Why Peer Research?

Becky Leach, Community Collective Advocacy, AdvoCard

People with lived experience of mental health issues bring with them a huge amount of value, precisely because of their experience. They are experts in what their needs are and how they can best be met.

A&E | All & Equal was led and delivered by a team of peer researchers, all of whom have lived experience.

Because of their own lived experience, the peer researchers were easily able to put themselves in the shoes of the people who they would be interviewing, bringing an insight that the project would not otherwise have had. This enabled us to: establish a more equal relationship with the interviewees based on trust and respect; make sure that the interviewees understood the purpose of the research and what we would do with their contributions, and so could give full and informed consent to participating; make the interviews more accessible; and ensure that we created a welcoming, safe and informal atmosphere in the interviews where the interviewees felt that they could speak freely and not be judged.

We had feedback from some of the interviewees afterwards that they felt safe and heard in the interviews, and this is testament to the skills and understanding of the peer researchers and the care they put in to their work. .

We would argue though that not only should people with lived experience be involved in carrying out research regarding issues that affect their lives because of the value they bring to it, but also because they have a right to be involved.

The Mental Health (Care and Treatment) (Scotland) Act 2003[1] gives anyone who has a mental health issue the right to access independent advocacy to make sure that their voices are heard and they are fully involved in the decisions that affect them.

[1] *Mental Health (Care and Treatment) (Scotland) Act* 2003 http://www.legislation.gov.uk/asp/2003/13/contents

The decisions which affect people's lives are not just decisions regarding their individual treatment or support but also wider decisions which are made, for instance regarding service provision or policy.

Further to this, the Scottish Human Rights Commission champions the PANEL Human Rights Approach in the planning and delivery of health and social care services, whereby they are planned and delivered in a way that is Participative, Accountable, Non-discriminatory and equal, Empowering and Legal[2].

Our experience at AdvoCard Community Collective Advocacy is that research is often referred to and drawn upon in decision making processes. If people with lived experience are not involved in delivering research, then their participation in decision making in Scotland is limited. The generation of knowledge and understanding regarding mental health and wellbeing, services and policy affects their lives, so it is essential that they have the opportunity to play a part in this generation, where they play a key role in deciding how research is carried out and identifying the issues to be researched. It is vital that peer research in Scotland is properly supported and funded and seen as both valid and valuable.

[2] http://www.scottishhumanrights.com/careaboutrights/whatisahumanrightsbasedapproach

Introduction

A&E | All & Equal is a peer research project from Edinburgh Community Voices which has been looking into the experiences in Accident and Emergency (A&E) of people with lived experience of mental health issues.

We started to develop the project in early 2015 after hearing from many different people about their experiences in A&E. We decided to record some of these experiences and do something about the issues that were coming up.

Luckily, at this time, funding became available from the See Me Community Innovation Fund, which funds projects that develop or deliver innovative ideas for tackling the stigma and discrimination faced by people with lived experience.

We applied for and secured a Local Grant of £4,000 for a six month project.

The project ran from September 2015 to February 2016.

The See Me Community Innovation Fund fit well with our ideals as it specifies that work should be led by people with lived experience of mental health issues, with them not just being consulted but playing an active role in decision making and delivery, on at least an equal basis with organisations and service providers.

We had a fantastic team of eleven peer researcher volunteers, all of whom have lived experience, who played a lead role in planning and delivering the project:

- Taking the lead in planning, preparing and designing: how we carried out the interviews; the ethics assessment; the information given to interviewees ahead of the interviews; the consent form; and the interview questions. AdvoCard supported this process, but the key decisions were made by the volunteers.
- Carrying out the interviews.
- Helping facilitate and taking notes at the focus group.
- Summarising the interview transcripts, for use when analysing.

- Analysing the interview results, highlighting the issues and themes that arose.
- Planning the group workshops.
- Helping facilitate at the group workshops.
- Planning, helping to write and reviewing this report.

Timeline

September and October – Peer Researcher Training and Planning

November and December – Interviews and Focus Group

January and February – Workshops

Edinburgh Community Voices is a collective advocacy group for people in the community in Edinburgh who have lived experience of mental health issues. Edinburgh Community Voices is facilitated and supported by AdvoCard Community Collective Advocacy.

Methodology

This project was first and foremost about hearing about people's experiences as they themselves interpret and feel about them.

Although we hoped to find out more about the stigma and discrimination that people experience, we did not specify that the experiences people told us about should be ones of stigma or discrimination. This was because people don't always use words like that to define their experiences, because they may not know for certain if their treatment was affected by their diagnosis and because indirect discrimination is not always obvious.

We therefore did not mention stigma or discrimination in the advert for interviewees, instead saying that we were keen to hear about any and all experiences, 'good', 'bad' or 'mixed', and regarding physical health issues, mental health issues or a combination of the two. The only specifications we gave in the advert for the interviews was that we wanted to hear from people with lived experience of mental health issues about their experiences at the Emergency Department at the Edinburgh Royal Infirmary or St John's Hospital Livingston from 2011 – 2015.

We also decided to leave the main interview questions as open as possible, not using the words 'stigma' or 'discrimination' at any point, but including a question that would help us capture whether a case could be considered as such.

We had five main interview questions which we asked.

1. Why did you go to the Emergency Department?
2. What was your experience?
3. Do you feel your treatment was affected by your mental health diagnosis?
4. Were there any consequences for you of what happened, or did it have any kind of impact on you and your life? This can be positive as well as negative.
5. What could be learned from this? / What would have made the experience better?

After making contact with potential interviewees for the first time, we gave them detailed information about what was involved so that they could make an informed decision about whether or not to take part.

In order to reach as many people as possible, we went out to three other organisations, two in Edinburgh and one in West Lothian, to hold interviews, as well holding interviews at AdvoCard on Leith Walk. This meant that we could engage with people where they felt comfortable, safe and supported, in one instance where they had access to childcare, and in two instances where the duration and/or cost of travel would have been a barrier.

We also held a focus group at one of the organisations, using the interview questions. This was facilitated by Patricia Rodger from AdvoCard Community Collective Advocacy, together with one of the Peer Researchers.

Our Findings

We carried out thirteen interviews, twelve with people with lived experience and one with a carer.

Ten of the interviewees discussed one or more experiences which took place at the Emergency Department at the Edinburgh Royal Infirmary and two discussed experiences which took place at the Emergency Department at St John's Hospital.

One of the interviews concerned an experience at the Pregnancy Support Unit at the Royal Infirmary. We included this because it was an emergency admission and because the person really wanted to tell us about it.

The interview with the carer came about by chance.They found out about the project when we were at one of the organisations and they asked if they could do an interview. The peer researchers decided to include it as an extra perspective.

There were six participants in the Focus Group, which was held in Edinburgh. Four of the participants had experiences which they talked about, while the other two joined in the discussion about the issues raised.

This is what we heard.

(All names have been changed.)

Diagnostic Overshadowing

Diagnostic overshadowing is what happens when a physical health problem isn't treated properly because the symptoms are attributed to the person's mental health diagnosis.

Two clear examples of diagnostic overshadowing came out in the interviews.

Ben

Ben had recently had an operation to remove haemorrhoids. He had a great deal of blood loss following this, and physical exertion, even trying to walk to the GP surgery, left him faint and unable to stand.

When he was in the ambulance, the paramedics asked him about any medication that he was taking. As soon as he mentioned his mental health medication, the paramedics' attitude changed. They told Ben that he was having a panic attack and didn't need to go to the Emergency Department, even though Ben had explained the situation in full. Ben had to argue and absolutely insist that he was physically ill before the paramedics would take him to the Emergency Department at the Edinburgh Royal Infirmary.

There the condition was correctly diagnosed - he had a dangerously low haemoglobin count and needed five days of hospital treatment. If he hadn't been as confident in speaking up and arguing his case, the paramedics would have taken him home and the delay in treatment, or lack of treatment altogether, could have been life threatening.

Ben made a complaint to the ambulance service, the department who had initially carried out the operation and his GP. Ben feels that all three complaints were treated with contempt.

Ben's mental health deteriorated as a result of both the experience itself and the way in which his complaints were treated.

> *"You can imagine what it feels like when you're physically ill, and not only are you physically ill but you're actually unable to do something as simple as standing up, and people just keep insisting that you're effectively faking it because you're mentally ill."*

> *"They're not looking at people, they're either looking at mental health or they're looking at physical, they're not looking at both. And if you have a mental health issue, what you say about your physical health is not being believed."*

Rebecca

Rebecca had a serious injury to the nerves in her shoulders (neuropraxia of the brachial plexii). This affected the movement and feeling in her arms, with limited movement and feeling in her right arm and none in her left.

Rebecca had fallen in her bathroom where she most likely sustained the injury, but had no memory of what happened before the fall. She was taken by ambulance to the Emergency Department at the Edinburgh Royal Infirmary.

After an X-ray did not show the cause of the problem, and her medical notes showed that she was 'known to psychiatric services' (as Rebecca heard one doctor say to another), it was assumed that the problem was psychological.

After this point, no further physical tests were carried out at the Emergency Department and Rebecca was only seen by psychiatrists.

When she was in the Emergency Department, she was given a sandwich. She asked for help to eat it, but was given none. With a great deal of difficulty, by putting her head down to the hospital tray, she managed to eat a small bit of the sandwich.

> *"I didn't know at this point that this would count profoundly against me. Nobody had been there at that point to see how I had eaten it. And this all seemed to add to the theory … that this was some sort of strange psychosomatic episode and that as soon as their backs were turned I would be moving my arms and waving and, you know, gobbling sandwiches."*

Rebecca was moved to the general ward. She was there for nearly a week. The nursing staff there were actively hostile and treated her as if she was malingering and 'faking it'. She asked for help to eat and shower but was given none because it said in the notes from the Emergency Department that she didn't need any. She continued to insist that this was a physical problem, but was still only seen by psychiatrists.

Things only progressed when Rebecca was able to persuade a junior psychiatrist that further physical tests were required. She was referred to Neurology at the Western General Hospital, where the correct diagnosis was very quickly made.

The arm most affected, the left arm, had been put in a sling when Rebecca was initially picked up by the ambulance. But when the X-ray at the Emergency Department did not show the physical cause of the problem, the sling was taken off and Rebecca was left without a sling for about a week, until the correct diagnosis was made.

The delay in treatment and this inappropriate treatment (the sling being removed) made the injury much worse. Rebecca was in hospital for a further five weeks and needed physiotherapy three times a week for over a year. The injury happened four years ago, but Rebecca's left arm has still not fully recovered.

As well as the physical effects, Rebecca's mental health suffered greatly as a result of the distress she experienced, not being believed and the dehumanising way in which she was treated.

"There was a toxic loop going on … with my mental health, getting more and more distressed, despairing of all of it, because I couldn't do anything. So it had an incredibly detrimental effect on my mental health, which was in a very poor state before all of this started and was sure as hell in a worse state after."

"The senior staff, the doctors, the consultants, disbelieved me as soon as they saw a psychiatric record. They didn't accept the reality of what was happening to me, or the fear and distress it was causing me."

‘Attention Seeking’ Stigma

In the two cases of diagnostic overshadowing, Ben and Rebecca both talked about professionals making the assumption that because someone has a mental health issue, they must be ‘faking it’ if they present with a physical health problem. This ties into the wider stigma around people with lived experience of mental health issues which considers them to be ‘attention seeking’.

Lucy’s experience provides a very clear example of this stigma and how it can particularly affect people who self harm when they present at A&E.

Lucy

Lucy had self harmed by burning. She tried to take care of the wound, by herself and with the help of her local practice nurse, but the wound became infected. Lucy rang NHS 24 and was advised to go to the Emergency Department at St John’s Hospital, Livingston.

Lucy was seen mainly by psychiatrists and burns doctors. She felt that she was talked down to, ignored and dismissed by the psychiatrists, that they tried to make the experience as unpleasant as possible and that they asked the same questions again and again as if they wanted to catch her out:

> *“They were very, very clear just what they think, you know – ‘wasting time’, ‘attention seeking’. They don't hide it. … It’s almost like, ‘don't give her any attention, she'll get bored. Ignore her and she'll get bored'.”*

Lucy feels that there is a basic misunderstanding around self harm and why she herself self harms:

> *“I'm not saying that there aren't some people that are seeking attention, but they put everybody in that box. And it wasn't for me. Self harm is for anxiety - if I sit with anxiety and I can't cope with it. I haven't meant to do that much*

damage, so if it's ended up that way, I think they've thought… They just assume that you've done it, run to them for help, and it's like.. I was embarrassed having to ask them for help. I think they just didn't understand."

On this occasion, Lucy had actually delayed going to the Emergency Department in the first place, because she had had a similar experience the last time she was there. Because of this delay, the wound was in a worse state and she needed more treatment in the Burns Unit than if she had gone there when she first needed help.

We heard about a very different experience from one of the Focus Group participants. This person had had an accident at work and scalded their hand and wrist. They received treatment from a nurse practitioner who was very practical, until she saw the scars from self harm on the person's arms, at which point her attitude changed. She seemed genuinely sympathetic, more than she had been before rather than less, indicating that the attitude that people who self harm are 'attention seeking' is not held by all staff.

Staff Understanding and Awareness

"There's a lot of training needed because they don't actually understand it, because mental health is a hidden illness. It's not like if you broke your leg, that you can actually see."

Six people stated that staff do not have enough awareness and understanding of mental health issues. This was not just about staff not understanding a person's diagnosis, but also about not understanding and giving due consideration to the particularly heightened or acute anxiety and distress that people who have mental health issues can feel.

One person felt that representations of mental health in the media, stigma and lack of training contribute to lack of understanding of mental health issues.

Rebecca felt that a lack of understanding was a contributing factor in the diagnostic overshadowing which happened when she went to the Emergency Department following her injury[3].

Two people weren't given their mental health medication when they needed it, and both think this was because of a lack of understanding of mental health issues and the attitude that mental health issues are not as real or as serious as physical health issues.

The first went to the Emergency Department at St John's because of chest pains. They said that the nurses were nice, and were brilliant at dealing with the physical health issues, but didn't understand mental health issues. The person wasn't given their mental health medication and attributes this to the lack of understanding.

The second person was Sophie.

Sophie

Sophie had a miscarriage and was admitted to the Pregnancy Support Unit at the Edinburgh Royal Infirmary.

At the time, she was taking anti-depressant medication every morning at exactly the same time.

When she was told that she would have to stay in the Pregnancy Support Unit overnight, she told the nurses that it was really important that they gave her her medication in the morning. The nurses said yes, she would get her medication. She asked several times because she was worried about the impact of missing a dose on her mental health, potentially experiencing suicidal thoughts, especially after such a traumatic event. Each time, the nurses said 'yes, you'll get your medication'. But the next morning, at the time when she needed to take her medication, she was told that the pharmacy was closed and she couldn't have it.

[3] See page 9.

Sophie ended up leaving the hospital to go home to take her medication, in a state of distress and experiencing suicidal thoughts. She said that the only thing that stopped her from taking her own life was the thought of what it would to do her mum.

Sophie believes that the reason that the nurses did not ensure that she received her medication is because it's a tablet for her mind and not her body, and they couldn't see the importance of it and the impact of not taking it. One of the nurses told her that she couldn't understand why she needed the medication, that her sister-in-law would be able to understand this better because she is a mental health nurse.

> *"She was doing her best to be kind, she just did not have the knowledge, to have a clue what I was talking about when I said I needed my mental health medicine."*

Sophie feels that she wasn't believed when she said how much distress she was in.

> *"If your leg's really painful, do you need to know how much pain someone's in when their leg's sore? Why do you need to understand the mental pain? Why can't you just believe them?"*

She also feels that she would have been able to keep more dignity if she had not had to deal with the anxiety about missing her medication.

> *"I went from quiet and holding it together, though utterly devastated to a crying, blubbering mess, walking out the hospital on my own, my stuff in a bag. … If they'd given me my medicine, I could have kept it together. And I could have gone home and fallen apart, but I fell apart in public instead, and I didn't want to."*

Sophie told us:

> *"What I was wanting was not to be treated differently because of a mental health diagnosis, but to be treated accordingly for a mental health diagnosis."*

Communication and Language

One thing that became clear as we carried out the interviews was the importance and significance of communication and language. When many of the interviewees described their experiences, the conversations they had with staff and what was said to them were very much at the fore. What doctors, nurses and other staff say appears to really stick in people's heads and shape their experience, both at the time and when they look back later.

This isn't just about what is said, but how it is said. For instance, one person told us that a doctor talked very loudly and slowly to them, as if they were an idiot.

Another person made the point that a doctor or nurse can say something and mean it one way, but the patient can hear it in another way and it can have an impact that wasn't intended.

Four people felt that they weren't listened to. For the participants in the focus group, communication was a key issue, and if workers showed kindness, compassion and understanding, that could change the entire experience.

One of the interviewees made the point that it can be difficult to communicate when you're unwell, tired, in pain or distressed, and you can find yourself tripping up on your words, even if you don't have a mental health condition. This can lead to misunderstandings.

There are sometimes other factors that can complicate somebody's ability to communicate and understand, as can be seen in Andrea's case.

Andrea

We interviewed a carer, Mary, whose adult daughter, Andrea, had been taken by ambulance to the Emergency Department at the Edinburgh Royal Infirmary after falling in the street. Mary wasn't with Andrea at the time, and wasn't notified about what happened until several hours after Andrea arrived at the Emergency Department. Andrea has a learning disability as well as a mental health condition.

The learning disability affects her ability to communicate and understand what is going on or what is being said:

> *"She could say something and [the staff] would take that as a given. But it involves a bit of delving to actually really understand what she means. Or she might answer something incorrectly, because she doesn't really understand what they're saying."*

For Andrea, if she becomes stressed, it can trigger her mental health condition and she can start to hear voices and get agitated, so good communication is particularly important. Mary does not think that there was good communication with Andrea, and feels that the whole experience would have been better if there was somebody in the Emergency Department who is experienced at working with people who have learning disabilities and who could have supported Andrea and helped her communicate.

When people had good experiences, good communication played a big part, as can be seen in the case of Peter and Freya:

Peter

Peter was taken to the Emergency Department at the Royal Infirmary by ambulance after falling while running for a bus and hitting his head, while under the influence of alcohol.

He worried that he would be judged because of his alcohol problem, but that didn't happen. The doctor and nurse who attended to him asked him questions, rather than making assumptions, were attentive and really listened:

"I couldnae have asked for much better to be honest, because not only did they listen but they listened, if you know what I mean. It wasn't a case of, 'well, we'll sit and talk to you because that's our job, this is it'. They did reassure me. They did say, 'what happened to you could have happened to anybody'."

Peter was kept in overnight. The next day, before he was discharged, a member of staff spent time talking with him, asking him about what support he had in place for his alcohol problem.

This experience had a positive impact for him, as it helped him realise that alcohol was not the answer:

"If someone helps me, I do remember it. And I did say to them, hopefully it will be a long time before you ever hear about me, let alone see me again, because I'll make sure that my alcohol is cut totally off the record now."

The experience was markedly different from another experience Peter had, where he felt confused about what was happening and felt that he was not taken seriously. That experience has put him off going back to the Emergency Department if he ever needed to.

Freya

Freya had cellulitis. She asked the GP to come for a home visit but the GP refused. The cellulitis got worse and she had to convince her husband to drive her to the Emergency Department at the Edinburgh Royal Infirmary, as she had other extensive mobility issues.

Her husband left her in the car park, but a porter came out and helped her into the Emergency Department. There was a long wait, but she was kept updated about what was happening, everyone was kind and she was well looked after. The X-rays which were taken were fully discussed with her and she felt involved in her treatment. (It should be noted that she has medical training and already knew some of the staff.)

The doctor advised that she stay in overnight. But she was very keen to keep a commitment she'd made to a community council meeting and was worried about her cat, the reaction of a volatile husband and missing her psychiatric medication. The doctor listened to her when she explained this, understood and respected it and agreed to discharge her, on the grounds that she would take the medication they had prescribed.

A taxi was arranged to take her home and it was paid for on her behalf. This meant that she didn't have to ask her husband for the money, to which he would have most likely reacted badly.

Freya feels that she was given special attention because of her mental health condition. Staff were aware that she could become worried and treated her with respect and care.

There were two really positive impacts of what happened. The first was that staff at the Emergency Department told her GP practice that they had to help her with the dressings, and that improved her relationship with the practice. The second impact was even bigger. At the time of the experience, she was starting to build her confidence. It meant a huge amount to her that she was able to keep her community council commitment, as she was starting to feel of value in the community after years of feeling valueless. This increase in confidence eventually led to her leaving her husband, who was volatile and controlling.

> *"If we all knew we wouldn't be stigmatised, it would be so much better. That's one of the things I learned there. It's the reassurance you will not be judged, that you will not be misrepresented, it will not be assumed this, that and the next thing and the fact – yes, because you are an equal you know what you're talking about. But if you need explanation, they will explain."*

> *"One of the important things is to be treated on an equal basis. We are individuals. It is so important to be treated like a human being. And that happened to me, I was treated as a human being, and what a difference that made."*

Environment

Three of the interviewees told us about the environment in A&E, about the effect this had on them and how stressful they found it. This was also discussed in the focus group.

The following issues were raised:

- The surroundings feeling cold and clinical.
- Feeling exposed or not having enough privacy.
- Feeling unsafe or vulnerable.
- There being a lot of drunk people around, coming into your personal space.

> *"If you're out in the street… if a drunk person was coming towards you, you'd do your darndest to avoid them. But being in a hospital and having to sit there, you can't really do that."*

One person, who went to the Emergency Department at the Royal Infirmary because they had been experiencing chest pains, described sitting on a hard chair in a cubicle with nothing else in it and the curtains open for two hours, feeling exposed.

Another person, who was also there because of chest pains, felt exposed while waiting in a trolley in a corridor.

For these people, the stress created by environmental issues like these was exacerbated by waiting for a long time and not knowing what was happening.

Some of the interviewees told us that they don't mind the waiting itself, they understand why it can take a while to be seen. What's stressful is not knowing what's happening or feeling like you've been forgotten.

One of the Focus Group participants wanted the curtains in their cubicle to be left open rather than closed, as they could easily feel paranoid and wanted to be able to see that the doctors and nurses were not talking about them behind their back. When they asked the staff to leave the curtains open, the staff were happy to do so.

So while having the curtains in the cubicle open might create or increase anxiety for some people, for others it can be helpful. Flexibility seems to be key.

Ailsa

Ailsa was seven months pregnant. She had problems with depression and anxiety and had recently experienced suicidal thoughts due to changes in her medication. One day, her neighbour tried to attack her and threatened to kill her and her baby. She couldn't sleep that night, and a combination of the lack of sleep and the severe anxiety she was experiencing caused her to collapse the next day.

Her mum went with her in the ambulance to the Emergency Department at the Edinburgh Royal Infirmary. When they arrived, her mum was told that she would have to go in by a different entrance. Ailsa was wheeled into a cubicle, on her own with the curtains left open. She was distressed and anxious and started to have a panic attack.

> *"I don't know whether they leave curtains open on purpose or whatever but the whole experience felt unsafe, there wasn't a sense of safety about it. … Not only when you have mental health problems, but when you're pregnant on top of that, you feel especially vulnerable."*

A drunk man then came into her cubicle and started talking to her. A man in a uniform came in and made the drunk man leave but then told Ailsa to stop crying. A nurse also told her to stop crying and quieten down.

> *"I think I felt like a nuisance. Like I was a bit hysterical and I just needed to quieten down about the whole thing."*

Ailsa asked the nurse to get her mum, and the nurse said yes but then forgot to do so and it took a long time for her mum to be brought through.

The baby was checked, and then Ailsa was sent home while still in tears.

Ailsa doesn't think that the staff knew about her mental health issues, as they didn't ask her or her mum anything about her medical history or any medications she was taking.

She described the whole experience as cold, distressing and frightening. She would have liked to have felt more safe and secure, to have received more care and compassion and to have been listened to and not dismissed. She feels that her mum should have been allowed to stay with her for the whole time, and that staff should maybe ask about mental health issues so they can provide more support.

Police Involvement

Four people told us about very different experiences where there was police involvement.

One person was taken to the Emergency Department at the Edinburgh Royal Infirmary after they had a 'meltdown' in the street while under the influence of alcohol. The police looked after them for the whole time while they were waiting to be seen, even though there was a change of shift, and took them home once they had been seen by a psychiatrist and discharged. The person described the police as 'brilliant' and felt that they received better treatment at the Emergency Department because they were accompanied by the police.

Another person went to the Emergency Department at the Royal Infirmary after developing a bad migraine, including sickness and confusion, following an operation. It was presumed that they were drunk and that the sickness was self-inflicted. The staff called the police and the police took them away without their coat and cigarettes.

One of the focus group participants told us about a time when they sat on the wall of a bridge with the intention to kill themself. They were talked down by the police and

taken to the Emergency Department at the Royal Infirmary by paramedics, before being taken into custody for 48 hours and charged with Breach of the Peace. They did not receive their mental health medication in this time and nobody referred them for further psychiatric care.

Michael

Michael had become mentally unwell when he was at home. He was 'on a high' and hearing voices. His support worker called the police and the police took him to the Emergency Department at St John's Hospital, Livingston.

He expected to be admitted to the psychiatric ward from the Emergency Department, but that didn't happen. He was seen by the duty consultant who told him that they couldn't assess him because he was high. The duty consultant then told the police to bring him back in the morning.

Michael was taken to St Leonard's Police Station in Edinburgh and kept in the cells overnight. When he was taken back to the Emergency Department in the morning, he was referred to the Acute Care and Support Team.

He told us that it would have been better if he had been admitted when he was first taken to the Emergency Department because the nursing staff know him, and could have talked to him or 'talked him down'.

He was charged with Breach of the Peace and given a fixed penalty, and feels that if he had been looked after in the Emergency Department or in the psychiatric ward when he arrived, and not taken to the cells, this would not have happened.

He also feels that being kept in the cells overnight had a negative impact on his mental health.

He said that it would be better if there was a place of safety that the police could take you to in these kind of circumstances, so that they didn't have to take you to the cells.

After Discharge

People's experiences in A&E don't always finish at the point when they are discharged.

Eilidh

Eilidh was taken by ambulance to the Emergency Department at the Edinburgh Royal Infirmary, after falling from a ladder and injuring her leg. In the ambulance, the paramedics assured her that somebody would make sure she made it home okay, as this was something she was worried about.

She was generally happy with the medical treatment that she received. But after being discharged, she was given no help to get home, even though it was one o'clock in the morning, she was on crutches and barely able to walk, did not have enough money for a taxi and did not have a friend or family member who could pick her up. This was so stressful that she says it's put her off going back to the Emergency Department if she ever needed to, because she would be so worried about how she would get home again.

> *"Because of the mental health, I haven't got as many friends as I used to have, and the ones I know, they don't have transport, they just don't. There's too much of this attitude that everybody's got somebody to phone and they can just ask them to do this and ask them to do that, and I just don't have that."*

Complaints and Feedback

Two of the interviewees made a complaint about their treatment, and neither was happy with the response. One felt that the department tried to brush the issue under the carpet. The other felt that their complaint had been treated with contempt, and also found the NHS complaints system difficult to negotiate.

One person really wanted to complain, but by the time they had recovered enough, both physically and mentally, too much time had passed and it was outwith the window of time in which they could have made a complaint to NHS Lothian.

> *"When you get out you're just so bloody relieved to be out, you kind of don't want to go there again, you don't want to revisit it. I was in a kind of extended shock, I was battling with daily living. I didn't have the energy or the wherewithal to make the complaints that I wanted to make."*

Another person's family encouraged them to make a complaint, but they also didn't feel able to complain because of the state of their mental health.

Two people told us that they would not have known how to go about making a complaint.

There generally seemed to be a reluctance to complain, either because the idea of it is too stressful or because you don't want to be seen as 'one of those people'.

When we were discussing this issue in the first of our group workshops, which was just for people with lived experience[4], it was suggested that perhaps the word 'feedback' should be used instead of complaints, because a 'complaint' feels like a big thing and people don't always want to criticise. It was also said that people are put off sending a complaint or feedback because complaints procedures can come across as very bureaucratic.

We had an example of how things can be done differently. One of the interviewees compared her experience in A&E with her experience when she was giving birth a couple of months later. It had been a difficult birth, but she had had the opportunity to go back for a debrief to discuss what had happened and speak to the staff involved. This enabled her to give feedback directly and also process the event mentally and emotionally, something she found incredibly helpful.

[4] See page 31.

Impact – Mental Health

A strong theme that came up in the interviews was the impact on mental health, with people's mental health being made worse as a result of what happened in the Emergency Department.

We were given the following reasons for this:

- The experience was distressing or stressful.
- The way they were treated made people feel bad about themselves.
- For one person, the complaint they made afterwards was treated with contempt and they felt ignored.

Impact – Returning to A&E or Hospital

Eight of the interviewees and one of the focus group participants told us that their experience has made them reluctant or scared to go back, to A&E, and in some cases, to hospital altogether.

For one person, it was the stress caused by the environment in the Emergency Department that made them reluctant to go back.

Another person is reluctant to go back because they felt judged:

> *"There's no way that I'd go back to A&E. Just to be sitting there, and feeling as though I've got to explain myself, instead of explaining what's wrong."*

Another person said that they cut themself off from the NHS completely after their experience, as they had lost confidence in it.

Three people had had good experiences in A&E on other occasions, but one bad experience was enough to put them off going back.

There is potentially a big problem here, if people who have mental health issues are delaying treatment or not getting treatment as a result of the experiences they've had. This could have a major impact, not just for them and their health but potentially also for the NHS if more complicated or expensive treatment is required as a result of the delay.

The reluctance to go back to A&E or to hospital can extend beyond going back for treatment themselves. The person whose experience was at the Pregnancy Support Unit told us that they didn't visit their father in hospital when he was ill, even though they badly wanted to, because the idea of going anywhere near the Royal Infirmary filled them with dread.

What Could be Learned? / What Would Make Things Better?

We asked everyone the question, 'What could be learned?' or 'What would have made the experience better?' This is what they told us.

Staff should:

- See people as individuals and as human beings.
- Not make assumptions.
- Listen to people and believe them.
- Treat the physical symptoms, even if they don't know the cause.
- Stop the approach of ignoring people so that they get bored and stop self harming, it doesn't work.
- Show more care, compassion and kindness.
- Make sure people get home okay.
- Help people access the resources that are there for them.

Other things that would help:

- Better communication between staff when shifts change.
- More understanding and awareness of mental health.
- Follow through of care after treatment.
- A place of safety that's not a police cell.
- More privacy so that patients can speak to staff confidentially and not be bothered by disruptive patients.
- If you have brought someone with you for support, that person should be able to stay with you the whole time.
- Someone in the Emergency Department, like a buddy or befriender who could support people with mental health issues if they don't have support with them. This person could also help them communicate what they need and what their wishes are.
- Complaints should be taken seriously and lessons learned from them.

Stigma and Discrimination

There were three very clear examples of stigma and discrimination which came through in the interviews. In the two cases of diagnostic overshadowing[5], assumptions were made by medical staff because they knew that Ben and Rebecca both had a mental health diagnosis.

Rebecca:

"They were making assumptions based on no knowledge. I have no history of presenting with psychosomatic disorders like that, that's not what my psychiatric history shows."

The assumptions made led directly to appropriate treatment for Ben and Rebecca's physical health conditions being delayed which in turn had a significant impact on their physical recovery. The way in which they were treated by staff, because of assumptions made, also had a significant impact on their mental health.

Assumptions made in the Emergency Department about the cause of Rebecca's condition were re-iterated in the notes that were sent to the General Ward. Rebecca was treated in a horrific way when she was in the General Ward as a result of these assumptions and the belief which the nursing staff on the ward appeared to hold that people who have mental health issues are 'attention seeking' and that they will fake physical symptoms in order to manipulate and get attention.

This 'attention seeking' stigma can also be seen in Lucy's case[6], previous experiences of which led to her actively delaying attending at the Emergency Department because she expected to be treated badly. This delay meant that there was a longer recovery time and Lucy needed much more intensive treatment.

These are the only clear and explicit examples of stigma and direct discrimination that we were told about. Showing the prevalence of stigma and direct discrimination

[5] See pages 8 – 10.
[6] See page 11.

is difficult as people with lived experience don't always know it their mental health diagnosis is known when they attend at the Emergency Department.

Indirect discrimination can perhaps be seen to a much greater extent in our findings.

Indirect discrimination is where a group of people are not treated in a different way from other people but are put at a disadvantage because how things are or the way in which things are done does not meet their specific needs or impacts on them negatively.

The environment in the Emergency Department and the lack of help for getting home can be stressful for anyone who attends, not just people who have mental health issues. However, for many people with mental health issues, the stress and anxiety experienced as a result of these things can be heightened by a considerable degree. At the time, as well as being horrible in itself, this stress and anxiety can affect people's ability to communicate effectively and understand what they are being told and questions they are being asked, which can in itself lead to poorer health outcomes if the communication difficulties lead to misunderstandings which affect the treatment they receive.

In Eilidh's case an assumption had been made that she would have someone who could support her and help her get home, but as a result of her mental health issues, that was not the case. Assumptions like these can disproportionately affect people who have mental health issues, who often do not have the support networks that other people have, sometimes because of wider stigma towards people have mental health issues.[7]

As referred to earlier, eight of the interviewees and one of the focus group respondents told us that the experiences they had have made them reluctant to go back to the Emergency Department or hospital, or to access other NHS services, if they ever needed to. Where there is direct or indirect discrimination, the impact of the discrimination could extend beyond the incident itself if, on later occasions, the people affected delay going for help when they need it, or don't go at all, and the

[7] Leach, Jonathan (2015), *Improving Mental Health through Social Support: Building positive and empowering relationships* (London: Jessica Kingsley Publishers), pp.15 – 16.

delay in or lack of treatment affects their recovery or health or leads to them losing their life.

The impact of direct or indirect discrimination could also extend beyond the incident itself when a person's mental health has been affected. There is a question that should be asked here of the extent to which consequences for mental health are taken as seriously as consequences for physical health.

Sophie's case[8] is a clear example of mental health not being taken as seriously as physical health. The emphasis of the Scottish Mental Health Partnership, in February 2016, on promoting 'parity of esteem between mental and physical health provision'[9] indicates that Sophie's case is reflective of a wider inequality in Scotland between how mental health and physical health are considered and resourced.

[8] See pages 13 – 14.
[9] The Scottish Mental Health Partnership (2016) *Why Mental Health Matters to Scotland's Future*, 2016, p.2. http://www.scottishrecovery.net/resource/scottish-mental-health-partnership-why-mental-health-matters-to-scotlands-future/

The Change We Want to See

We held two workshops in January and February 2016, the first just for people with lived experience and the second for people lived experience, professionals and other stakeholders. Based on the interview findings and the discussions at the workshops, this is the change we want to see.

Mental health and physical health would be seen and treated as **equally important**.

People with lived experience of mental health issues would **not receive poorer treatment for physical health issues**.

The **stigma that people who have mental health issues are 'attention seeking' would no longer be prevalent** and would not affect how people with lived experience of mental health issues are seen and treated.

People with lived experience would be seen by all as individuals and treated with **care, kindness, compassion, empathy and understanding**. They would be listened to, taken seriously, believed and not judged.

Staff would have a **greater awareness and understanding** of mental health. They would **not make assumptions**. They would treat the symptoms presented, even if they didn't know the cause. They would **take people's mental health into account in order to support them**.

People with lived experience would be **involved in the decisions** about their treatment. They would be kept informed of what treatment they were getting and why they were getting it. They would be spoken to in a way that they understand, without being treated like an idiot.

People with lived experience would **feel safe** in the Emergency Department.

Personal space and privacy would be protected.

There would be **follow through of care** after treatment.

Services would be **accountable**. Complaints would be taken seriously and lessons learned from them.

Staff would be supported for their own wellbeing.

How can we bring about this change?

It is essential that human rights are at the centre of any work that is done to bring about change. It is also important that we recognise and build upon good practice.

Here are some specific ideas for bringing about change that we explored during the workshops:

Redesign Complaints and Feedback

The complaints system is clearly not fit for purpose. There is space for innovation in this area, we could have a totally new way of doing things which could make a big change by identifying where there are problems and responding to them and acting upon them on both an individual basis and a department or organisation wide basis. The system could also enable people with lived experience, or any patients, to give positive feedback and show appreciation when they have been treated well. Good practice could be highlighted and learned form.

An open and non-adversarial culture would be essential. Patients would be encouraged to come forward. Procedures would be easy to navigate rather than bureaucratic. The NHS would respond quickly, address any issues, admit any mistakes and be willing to learn from them.

Pro-active individual, person to person, debriefs are already being used elsewhere. These show promise and could be developed for use in A&E.

Training led by people with lived experience

People with lived experience should be involved and play a lead role in delivering staff training. Training should focus on human rights, equalities and using a less judgemental approach, as well as specifically tackling stigmatising attitudes.

Support Communication

Self harm report cards are already available from the National Self Harm Network[10]. These can help somebody who has self harmed or taken an overdose, but is too distressed, anxious, disassociated, or otherwise unable to effectively communicate verbally what has happened. These should be made more readily available, for instance at services and GP and A&E reception desks. If they were more readily available, it could reduce the stigma around using them by normalising them.

There could also be a more general simple form that could be used by anyone who would struggle to communicate verbally, whatever their reason for attending. This could include not just what had happened, but also any preferences for treatment, anything that makes them feel anxious or anything that helps.

Explore role of volunteers

The role of volunteers could be explored. Some people might find it helpful if there were volunteers who could sit with them and chat when they are feeling anxious and don't have anyone with them for support. These volunteers could also help them communicate their needs and wishes. A volunteer transport service might also help, so that there is someone who can drive people home if they are unable to use public transport and have no other way of safely getting home.

Open up and build spaces for human contact

One to one human contact can be incredibly powerful. Spaces could be opened up and developed where NHS staff and people with lived experience can have an informal chat to build awareness and understanding that people with lived experience are people too, as are doctors, nurses and other staff. This could potentially break down barriers and stereotypes and build empathy.

[10] National Self Harm Network (2008) *Self Harm Report Card* http://www.nshn.co.uk/downloads/Self_harm_report_card.pdf

A Human Rights Perspective

Cathy Asante, Scottish Human Rights Commission

The interview findings raise a number of issues when looked at through a human rights lens. Of course, people with mental health issues have the same human rights as all members of society. This includes the right to life, the right to freedom from inhuman and degrading treatment, and the right to private and family life, all of which can be engaged when a person is denied health care or is provided with inadequate health care. The right to private and family life also includes the right to privacy and to make decisions regarding one's own health care, with the support to do so, if required. These rights are protected by the European Convention on Human Rights and the Human Rights Act 1998.

The state and its public authorities, such as the NHS, also have a duty to take active steps towards achieving the right to the highest attainable standard of physical and mental health for its citizens, under a United Nations treaty which the UK has signed, the International Covenant on Economic, Social and Cultural Rights. This does not mean a right to be healthy but an obligation to provide services which are:

- **Available** in sufficient quantity.
- **Accessible** to everyone without discrimination, especially the most vulnerable or marginalised people. This includes being physically accessible and affordable and includes the accessibility of health information;
- **Acceptable**, respecting issues of confidentiality and being sensitive to cultures, communities and gender;
- Scientifically and medically **appropriate and of good quality**.

All of these rights must be provided to everyone on an equal basis, without discrimination on the basis of a person's particular characteristics, such as whether they have a mental health diagnosis or not. These rights are further protected by another important United Nations treaty – the Convention on the Rights of People with Disabilities. This treaty recognises and protects the rights that disabled people, including those with mental health issues, have on an equal basis with others. It also

sets out obligations to remove the barriers that disabled people face in achieving those rights. The rights mentioned above appear in this context, breaking down in more detail what it means to realise those rights for disabled people. For example, the right to health specifies that people with disabilities must be provided with the same range, quality and standard of health care as other people, as well as those health services that they require specifically because of their disabilities.

These rights all come into focus when considering the interview findings. The right to health should be considered if a person with mental health issues is not receiving adequate treatment for their physical health issues due to assumptions about 'attention seeking'. In those circumstances, are people with mental health issues receiving a quality standard of health care without discrimination? In individual cases, failing to provide health care could lead to serious distress or life-threatening consequences which might engage the right to life or the freedom from inhuman and degrading treatment. Are systems set up in a way which ensures they provide those aspects of health care required specifically because of a person's disability? This might be essential medication for management of their mental health issues, tackling risks of self harm, or providing communication support to a person with a learning disability.

As the interviews show, many of these experiences have an emotional and psychological toll leading, in some cases, to a fear of approaching services. This may, in turn, contribute to deepening health inequalities between people with mental health issues and the rest of the population, if people feel discouraged from seeking treatment for health issues that need to be addressed. In human rights terms, active steps must be taken to remove those barriers so that health services are indeed equally accessible to all.

A&E | All & Equal - Conclusion

We heard about a number of issues in our research. While it is not possible to gauge how widespread the issues are, it is unlikely that these are isolated incidents. Even if the issues only affect a small number of people, for those people who are affected, the distress or avoidable harm experienced, the impact on their lives and the infringement of their human rights is significant enough in itself to justify action.

We believe that the change we have outlined is realistic and achievable. Through our discussions, we identified a number of ideas for making change happen, improving people's experiences and tackling discrimination. We are keen to develop these further and potentially put some of these into action, as well as identifying and developing other ideas, possibilities or opportunities.

It is important that any work that happens has human rights at its centre. It should involve everyone who has a stake, with people with lived experience playing a leading role, and requires commitment and investment from staff, providers and policy makers.

We would like to invite anyone who is interested in developing the ideas identified, developing new ideas or otherwise taking action, to get in touch

You can contact us by email, phone or post: collectiveadvocacy@advocard.org.uk, 0131 554 5307, AdvoCard, 332 Leith Walk, Edinburgh, EH3 5AY.

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