

THE END

Our learning and recommendations

When we started this study, while we were very interested in the lives of people with psychosis, we had expected that we would also learn more about Early Intervention in Psychosis services.

We had planned to conduct a thematic analysis and expected to be able to draw out clear themes about how services helped people, if and when they let people down, and how services could develop and improve.

In the end, we heard 14 very different stories, which initially made it difficult to draw out clear themes that were relevant to most of the stories. However, some themes did come through strongly - but they were not about services.

They were about the conditions in which people were trying to manage, and recover from, their psychosis. In this section, the equivalent of the 'Discussion' in a traditional report, we present some of these themes as the key messages to take away from our work.

One aspect where it was easy to find common ground between the storytellers was the emotional content of their stories and the feelings they elicited in us.

So, we have structured the next section as follows:

- Key messages
- Thinking about feelings
- Observations about services
- Our recommendations

KEY MESSAGES

Many of the stories highlighted the importance of **safe and stable housing** to mental health, and the consequences for people who were subject to unsafe or insecure housing, or who became homeless. The idea of 'home', or rather, of not having a safe place to call home was implicit across all the narratives and spoke to a fundamental need that was not being met. On hearing these stories, we researchers had strong emotional reactions. **We asked ourselves: How can you stay mentally well if your reality is constantly frightening, if you are physically at risk on a regular basis? How can you recover if you do not have a safe place to rest?**

This sense of a lack of safety extended beyond the four walls and a roof that may constitute physical shelter. We heard stories of people **living in situations in which they regularly witnessed violence or crime. Some of our storytellers told us that people around them had died in violent circumstances, through drug overdoses or through exposure while living on the streets.**

The consequences of a lack of a secure home don't have to be this extreme to be damaging: other storytellers told of **not feeling quite like they "fit" at home.** Some described feeling like they were "the lodger" or that the families they lived with didn't understand them, were overly critical or did not want them there. We also heard of **people feeling unable to connect with other people in their communities, of losing friends when they or their loved one became ill, or of being unable to make friends after moving to a new community.**

In a few stories, we heard of people feeling disconnected because they did not fulfil the roles society expected of them:

"As a child I was told not to cry, but I never had a conversation about money, about sex, food, medicine, cooking. There is other stuff as well that, you know, that men, you just don't talk about, and this is normal. But, if you step outside that, and... it's bizarre, really". [Storyteller 8]

Implicit in many of the stories was a deep sense of loneliness and isolation. Some of our storytellers had never met anyone else who had psychosis and were reluctant to explain what they had experienced in case they were laughed at or dismissed.

In these circumstances, **where people may be physically unsafe and socially very isolated, it is not difficult to imagine how our storytellers may have developed psychosis, or how difficult it may be to get better.** Food and shelter are fundamental human needs.

Humans evolved as social animals. Isolation is dangerous and prolonged periods of isolation can cause us to become sick. Despite the importance of these deeply human needs being firmly established by a wealth of biological, psychological and sociological evidence, our society does not currently prioritise ensuring that they are met for all.

These stories give a face to the facts and figures identified by a wealth of other research in this area. Housing, in general, is very expensive and safe social housing is scarce (see Croucher et al., 2018).

Our economic system promotes work lives that are lived away from our families and friends who may provide the social connections that support mental health and mental flourishing. Funding has been cut from programmes that supported everything from early child development (e.g. Sure Start centres, see Cattan et al. 2019), to helping the population live healthy lives, to providing care for people who may be ill or disabled, through to developing, maintaining and deepening our social connections to each other.

Loneliness and the links to mental health is a growing concern to policy makers and academics (Mann et al 2017; Wang et al. 2018).

THINKING ABOUT FEELINGS

Throughout this project we, the research team, have spent considerable time talking about the emotions that the work brought to the surface. We have been aware of the emotions that were, implicitly or explicitly, described by our storytellers and of those they evoked in us. We agreed that it was important for us to write about these emotional experiences, although it was not always clear how.

While these emotions were, for us, clear 'themes' in the stories we heard, they were also so prevalent and expressed so differently in each account, that it was very difficult to select a single narrative to illustrate these emotional experiences. We instead chose to devote some of this section of the

report to thinking about how three emotions in particular – anger, fear and confusion – cut across all the stories that we heard.

Anger

On hearing and reading some of the stories, we experienced strong feelings of anger. When we heard stories in which people had been let down by the system, we found it difficult, at times, to look at the stories objectively.

We heard how one young man had become homeless and had found it immensely difficult to work through the system to access housing support. He was shifted around the hostel system, placed in housing that was unsafe and from which many of his belongings were stolen, and eventually housed far away from his work and social connections.

We also heard of a young woman who, while still quite unwell, was placed in housing that was predominantly occupied by men and who was assaulted. We heard of storytellers who, upon experiencing symptoms of psychosis, found it very difficult to access services because the healthcare professionals they did see did not seem to know where to refer them to, or because they experienced repeated arrests instead of receiving mental health care.

We also heard of a young man who was let down by a system that was unable to deal with the complexity of his autism and bipolar disorder, and who, as a consequence, experienced an assault on the wards and was left to roam the streets all night when a bed could not be found for him.

It was difficult to hear these stories and to know how to process them. For those of us with experiences of negotiating the mental health system, these experiences struck close to home. We are left hoping that by completing this project and by publishing this report, we are able to humanise the facts and figures we hear reported in the news about mental health, and to make it easier for readers to connect with these issues on a more human level. After all, behind the facts and figures are real people with real lives trying to make it through life, as we all are.

Fear

Fear is an emotion we all know. It is a feeling that is caused by danger or threat, real or perceived. Our brains are hardwired to respond with a fight-flight-or-freeze response when we encounter or perceive a frightening experience. Fear can be hard to live with if it infiltrates every part of life. It is hard to imagine what it might be like for your fear to be labelled as pathological, a symptom of mental illness. It isolates you from everyone else. It can make the person seem different to the rest of the world and less knowable to others. But looking back at certain stories told in this project, some examples of paranoia are understandable and it is sometimes possible to trace it back to the person's past or current living environment.

Take the storyteller we met in the Chapter 2. Fear pervaded his life, impacting on his housing situation, his relationships and his mental health. We heard how this young man had multiple experiences of homelessness. He was eventually housed in accommodation that was repeatedly broken into, and where he witnessed violent incidents and saw vulnerable people being exploited and hurt.

It seems this storyteller had nowhere to turn to find safety. You sense from his story that he was let down on multiple occasions by services and that indifference on the part of others exacerbated the situation and unfurled poor mental health like a road he needn't have gone down. We can sense his frustration with his housing provider in this extract:

So, yes, like all these things added up to a case for me to go to the housing association and be like, "Look, I'm not safe there. Your facilities are not making it helpful for me to deal with things like that." [Storyteller 4]

As researchers, we found it difficult to understand what it feels like to never feel safe, but this young man described a life in which this feeling was 'normal'.

So, it's always been around me, though... I could have been killed...

When he finally became unwell, the voices and sounds he heard were another source of fear. It is not difficult to see a direct link between the content of these experiences and the violent things he had seen and experienced in his life.

I get to the serious things because I could not only hear my friends, people that I know, people that I will know, and, like, their family members. I could hear them being tortured and murdered and that and that's exactly why I broke down and I lost it because I thought, "What am I meant to do for this to stop?" Because I was by myself in my house, you know, and I can hear all this stuff and I've never gone through these things, ever, ever, ever, ever in my entire life. It's been bad where I've felt like killing myself but I've never heard things.

Accessing mental health services was another fearful experience for this storyteller. He was frightened by the heavy sedation he saw in fellow patients who could barely function as a result. He felt he could not trust medication and so had to rely on his personal resourcefulness and inner strength to come out the other side of pain and fear.

While some of our storytellers didn't have as difficult lives as the storyteller above, their fear came with the first stirrings of psychosis. For example, in Chapter 4 we heard the story of a successful professional. His first experiences of fear, or "paranoia", emerged when he won a large contract at work. This made him think that he needed to prepare for a life of success, which included protecting his reputation by isolating himself from his friends.

Also, when you go to some of these networking events, they're a bit odd, a bit creepy and so all these little seeds were beginning to be planted in my brain at the time. So the first sort of paranoia, paranoia was I started thinking that my friends were trying to set me up and trying to frame me... So I started cutting off friends because there was a whole trust thing. I was losing trust basically so I started rejecting friends and increasing my isolation. [Storyteller 1]

For this storyteller, hospitalisation did not provide relief or feel like a place of safety. He described vividly an experience in which he was forced to take medication, which resulted in dramatic side effects, frightening him further.

They forced me drugs and the drugs paralysed my legs so I couldn't walk. It scared me so much that I cried and phoned my dad and said, "I need help, please come and help me."

Fortunately, this storyteller had his medication changed and he recovered enough to reestablish family connections and return to his work. Looking back, he was aware the isolation had prolonged his psychosis but also understood that being in the midst of psychosis is like being in quicksand. It's all-consuming and hard to see beyond.

Confusion

Our experiences of collecting these stories was not linear. Many of the storytellers dipped in and out of their stories, and at times it was clear that they were trying to understand what had happened to them even as we were listening to them speak. People's stories and lives do not follow logical storylines, much as we might like them to.

As listeners, we are often drawn to make sense of someone's story by trying to fit it into a neat narrative. We tried not to do this.

This did leave us with a challenge. While it was our job to help the storytellers describe the many aspects of their stories, it was not always easy to do so. We had prepared materials to help people 'map out' the points in their lives they would like to talk to us about, but these materials sometimes introduced confusion. It was clear that some people did not really want to engage in a mapping exercise – they wanted someone to listen while they talked and tried to make sense of their own story.

For most of the storytellers, we emerged from this process – both the mapping and the interview – with some sense of the narrative threads that made up their story.

There was an exception – one storyteller whose story we could not make sense of. This person did not find the mapping materials helpful. In part, we are unsure whether he felt able to trust us. During the discussion before the interview and during the interview itself, he expressed concern about whether he should or should not tell us certain things.

Interviewer: *We can carry on a little bit today, then you go away, have a think and come back, we can definitely do that, and spend a bit of time with this process, if that's what you would like to do?*

Storyteller: *Um, I feel I've said too much if I'm honest.*

Interviewer: *Yeah?*

Storyteller: *Yeah.*

Interviewer: *So, we can delete the recording, or bits of the recording...*

Storyteller: *No, I'm happy, yeah, yeah." [Storyteller 8]*

Unlike for other storytellers, we were unable to create a trusting environment in which he could tell his whole story. Instead, he offered small scraps of his experience while trying to work out the extent to which it was safe to tell us things. Through small windows into his experience, we gained a sense of someone who was deeply connected to nature and who had a spiritual understanding of the things that were happening to him.

He told us of a kind of spiritual awakening that he had been through, how he was in the process of rejecting some of society's expectations of men to embrace more emotional, feminine aspects of himself, and how difficult this could be at times. Through the small insights we gained, we got a strong sense that his story made sense to him, but we could not piece his whole narrative together.

We found it difficult to know how to support him to tell his story more fully or to create the trust and safety that might have helped.

This story of confusion may resonate with others who have tried to understand the internal experiences of another person, standing on the outside and looking in. Indeed, the carers we interviewed also described this kind of confusion, and to a far greater extent than we experienced. Family members told us how difficult it was to make sense of what was happening, watching people they thought they knew change in ways that felt alien and, at times, dangerous.

They shared these feelings of confusion even if they could not fully understand their loved one's story.



STORYTELLERS' EXPERIENCES WITH SERVICES

One of the reflections we had as a research team was how, in the majority of the stories, we learnt very little about services. Indeed, during the interviews, we sometimes found ourselves asking specifically about storytellers' experiences with services as the project had been commissioned by mental health service providers.

These questions frequently did not yield long or complicated answers, unless the storyteller's experience had been difficult or complicated. It remains our overwhelming impression that the majority of the stories we heard were not about use of services.

Our storytellers were far more focused on telling us about the important or pressing issues in their lives. Because of the limited way in which most storytellers talked to us about services, we are unable to come to substantive conclusions on how people experienced them. We do, however, want to share our thoughts on the following aspects of care:

Early Intervention in Psychosis services

Many people found the Early Intervention in Psychosis services helpful. In particular, the experience of talking to a psychologist was highlighted.

Having someone listening and having someone to talk to. Some people might not relate to what you are saying but at least if they are listening you know what you are saying is being taken on

board. They aren't just seeing you like a client or a service user. You are a person. [Storyteller 4]

One person talked of feeling reassured by their service. It had helped him understand that his problem was common, that it could be treated and that they would help him to move forward – "and they have". He also found the psychologist helpful:

[Talking to a psychologist] went very well... it was an outlet for me. It made me look in on myself. It gave me someone to bounce around ideas with. After talking to the psychologist I felt reassured in myself that what I was doing was right. Before that I didn't really talk about my situation with anyone... [Storyteller 6]

For another person, the service had opened up opportunities, enabling him to attend a film and media course, which was something he had long been interested in.

Hospital

Although a couple of people found being admitted to hospital a helpful or, at least, a neutral experience, several found it harsh and shocking. One likened it to a prison and said that people were not looked after. The environment was described as one of conflict:

They were trying to force me to take pills and I was putting them across because I knew this was not what I'm ending up in. Things like, they started troubling me, trying to get me into a screech mode, an angry mode so that they could force feed me tablets. So, they did it to me a couple of times, they're trying to force me and trying to lock me in my room. Any normal guy

MY EXPERIENCE OF HOSPITAL

Gary's reflection

““ When I was in the psychiatric hospital, I felt forced to conform. I had a tribunal hearing and they were talking about me. I might as well have not been there. A woman was saying to the doctor, “Is he a danger to himself or others?” They didn't ask me if I felt I was a danger to myself or others. They just ignored me.

When the doctor said, “No,” his booming voice demanded compliance to what he thought was best, but he was making decisions on my life and my mind and overpowering me. I felt it was aggressive and violent in a very sly way, put across in an educated, authoritarian way. My perception was that the system was against me.

””

that's going through that, they're going to eventually go nuts. [Storyteller 4]

One person was shocked to be sectioned under the Mental Health Act; they had not realised it was possible to be detained against their will. For another, this loss of freedom was devastating:

... after that my trust broke down so then I wouldn't speak to anybody. [Storyteller 1]

Medication

One woman was very critical of the medication she was prescribed. She felt that her compliance with medication was monitored by social services – that this became the sole prism through which her recovery was viewed. She was very eloquent about the limitations of this.

You feel like you're a rat, science rat kind of thing. They're giving you

different medications to know which one is good and which one is not. I think I had a relapse this year as well so again, the whole process of how much medication to give, it goes on. [Storyteller 7]

Accessing services: help and information

There was a common thread of storytellers not being able to find somewhere to go when their problems first began, or of finding a service (usually the Early Intervention in Psychosis service) too late.

GP and primary care services did not come out of this very well. One person felt frustrated at having to go through their GP to access services; he perceived this gatekeeping to be powerfully linked to records held about him and feared the stigma “that's going to go into everything in the future”. Another talked of telling his story over and over again in an effort to get help:

It felt that sometimes you were walking away not knowing whether anything could be done and you'd rehashed your story again another five times. It was just draining that you're having to tell it again. [Storyteller 5]

People talked of needing an easily accessible service where you could get information and advice – an alternative to the GP.

In the early stages, there didn't seem to be people who could refer me to someone else who might know... so just to have maybe that general service at the start that has quite a broad bank of knowledge. [Storyteller 5]

This person gave the example of the Terrence Higgins Trust as a helpful source of advice and information. Similarly, one person found it frustrating when he was expected to claim benefits on leaving hospital, and had no idea how to go about it.

More talking therapies, listening and understanding

Storytellers that we talked to who had been able to access talking therapies, or who had found someone in services that they could talk to, told us that this had been positive and had helped them make sense of their experiences. A couple of people regretted finding a psychologist or someone to talk to in a meaningful way late on in their journey, or wished they had had counselling earlier in their lives.

Yes, there could have been counselling or something, but there was no counselling. I was a young carer... I think more counselling would – because I know you have to be on a waiting list or something, to be counselled, and more counsellors are needed. [Storyteller 2]

One person found it frustrating that neither the psychiatrist nor the care coordinator wanted to talk about what the psychosis meant to her. She was critical of mental health services being too clinical and not giving space to different understandings of mental health difficulties.

They all wanted to be just like get on with your life kind of thing and not to think about those thoughts. It wasn't very nice. It makes you feel, I don't know what's the word, lonely or isolated or whatever. [Storyteller 7]

She felt that there should be less emphasis on medication and quicker and easier access to a quiet place in a crisis as well as to a psychologist.

Other services

One person had recently referred herself to an addiction service to seek support with stopping smoking cannabis. She had not found her GP helpful and had found the service herself online. She was also critical of housing services:

Housing don't take the mental health into account because if they knew I had psychosis, they would understand that I might do things that – like hallucinate or shout, at one point, and... [Storyteller 2]

We provide these observations about services so that this material is not 'lost'. This was a lens that interested the commissioners of our work at the beginning, but as time passed it became less of a focus in the steering group meetings. Services were asked about less frequently and the interest was life events and how we went about 'telling the stories'.

RECOMMENDATIONS

From our project, *'My Story: Our Future'* we make the following recommendations:

For policy makers, commissioners, service providers

It is important to acknowledge that **mental health services cannot prevent people from developing psychosis and that they alone cannot help people recover from psychosis and other significant mental health problems.**

The comparatively little time our storytellers spent telling us about services speaks to this. One of the strongest take-home messages from our work is the extent to which **a person's social and economic environment is intertwined with their mental health.** We know this from quantitative research and epidemiological studies but this project gives a powerful voice to the facts and figures identified elsewhere, which we hope will be harder to ignore.

We **urge much greater inter-agency working**, so that social housing, mental and physical health services, social services and the police develop strong transparent partnerships through which they can fully support people experiencing psychosis and other mental health problems. People who are in insecure or unsafe housing, or who are homeless have no safe base to recover in, cannot be expected to respond well to mental health care. People should not be repeatedly arrested instead of receiving mental health support, as happened for two of our storytellers.

We urge **much greater investment in services and community projects that support people across the lifespan**, both to try to prevent people developing mental health problems in the first instance, and to support people adequately when they do.

Therefore, we **urge policymakers to commit to addressing the socioeconomic determinants of**

mental ill-health. In particular, we urge policymakers to acknowledge and address the link between mental ill health and poor housing, and **invest in good quality, safe and truly accessible housing.**

Having social connections and a community network outside of services is fundamental to people's mental health. To support this, we urge policymakers to fund grassroots community groups who will be able to respond to what their community needs. It is in the community where people are likely to build positive, authentic relationships with other people, and to be able to find ways to contribute to the world in a way that is meaningful to them. As one of our survivor researchers has written in this report, **we need to feel part of the world to have the fight to rejoin it.**

For people working in mental health services

For **practitioners** reading this report, we hope that our approach has demonstrated how valuable **an understanding of the whole of a person's experience** is and how it can reveal factors that may impact an individual's journey towards better mental health. To facilitate the transfer of this learning, we have developed a storytelling toolkit for practitioners, which is available at mcpin.org/mystoryourfuture/.

For academics and service development leads

A final recommendation is for **researchers and service developers to work with survivor researchers whenever they can.** This project has benefitted immensely from being conducted by a group of researchers with expertise by experience working alongside researchers with expertise by profession.

