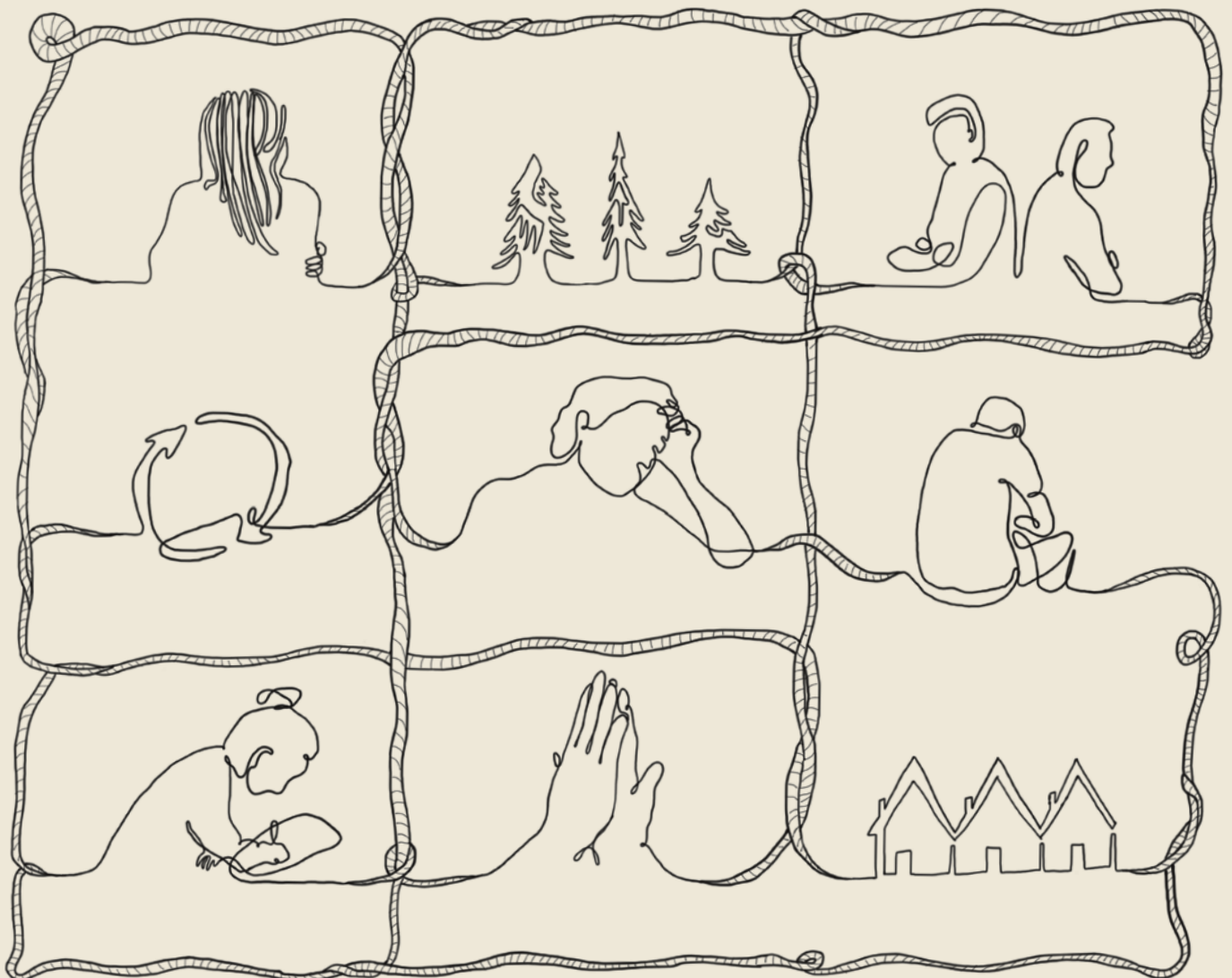


MY STORY

Our Future

A project based on 14 people's
narratives about living with psychosis



Alison Faulkner, Dolly Sen and Rose Thompson



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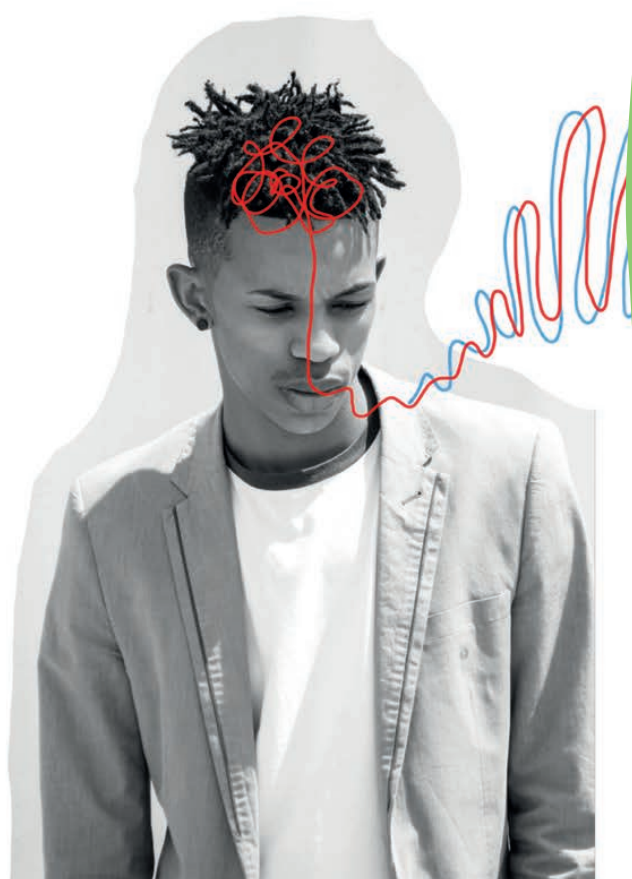
It was amended in July 2022 to anonymise at the request of one of the authors - XXXX

THE BEFORE

My Story: Our Future is a project about living with psychosis. It is told by 14 individuals – the storytellers – and the project team.

The written word is very powerful. So too are pictures. We use both to illustrate the stories we heard, and the points we hope you, as readers, will reflect on alongside us.

We start with one of the storytellers. They raise an important point to carry with us through this work. Everyone has a before, a story about how they came to be where they are now.



“

I was a humble person. I didn't make trouble or stuff like that. I felt trapped, I didn't want to be there.

I wanted to be in the suburb somewhere. I would prefer that my mum moved away. I would prefer to be somewhere else.

Then after some time, yes, it did have an influence on me but I didn't get in trouble so I can't say it took over and it made me a different person but it does change you. The neighbourhood does change you. You see things that change you. You see things that get to you. There's a lot of what you see you don't talk about here. There's a lot of, "No, you can't do that, it won't work out for you." People just constantly make others behave in a certain way that they don't want to. If you're not being yourself, after some time you say to yourself, "Why is this? I want to be a different way," and you can't until you're an adult.

I see people that used to be in a gang but now they're hippies, now they're hipsters and that's really great because music has brought them out, or friendship has brought them out or work friends have brought them out of what they were doing before. But they've messed up their lives at some point. I'm not saying messed up their lives but they had a record before.

There is always, "What were you like before?" people make reference to. You might have £1m, you might have nothing but people will talk about you before, whether you're homeless or you make it. Before is really important.

”

Storyteller 6

HOW TO READ THIS REPORT

My Story: Our Future isn't a traditional research project – deliberately so. At every stage, we, the research team, carefully considered what approach felt most appropriate, amending our plans as we went.

We believe that this journey and our reflections on it are an important part of the process; they are an important part of the story of this project. This means that this write-up doesn't follow traditional reporting conventions.

It also means that it is long. You are invited to read it cover to cover if that feels worthwhile, but it has also been written and designed so that you can dip into it.

If you are interested in our methodological process and its evolution, it would be worth starting with the first part 'Our beginnings'.

Readers who want to jump straight to the stories will find them organised into chapters that address different themes (see the Contents page opposite for a list). In the third part, we attempt to draw together commonalities and notable absences across the stories.

This is the part to check out if you are most interested in the key findings from the project or the storytellers' experience of services. Turn to page 89 if you want to read our recommendations.

Although the entire report is written in a reflective style, look out at for individual reflections and perspectives from our research team – the green boxes dotted throughout the report.



CONTENTS

ACKNOWLEDGEMENTS

THE BEGINNING

Our starting points

Early Intervention in Psychosis services	8
Getting started: the story of this project	10
Building a research team	10
Gathering life stories	11
Inviting people to take part	14
Interviewers and storytellers	15
Mapping stories	15
Recording stories	17
Making sense of the stories	18

THE END

Our learning and recommendations

Key messages	81
Thinking about feelings	82
Storyteller's experiences of services	86
Recommendations	89

THE MIDDLE

The storytellers and the stories

First impressions	25
Story themes...	
1. Stories of stress and coping	26
2. Seeking a home, a place to belong	32
3. A story of losing trust	40
4. A story of rediscovering trust	46
5. Feeling trapped in a vicious circle	50
6. A story of loss and searching	54
7. The frustration of negotiating services	58
8. A story of resourcefulness: creativity, faith, family and nature	66
9. Stories of loneliness and isolation	70
10. A story of positive relationships	76

POSTSCRIPT

Reflections from the research team	91
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This project has only been possible because of the support and patience of a lot of people.

We would like to thank the steering group members for their guidance, motivation and ongoing encouragement. We list members here with affiliations at the time of their steering group membership: Sarah Joy Dawoud (Lived experience mental health consultant), Nicholas Campbell-Watts (Certitude), Claude Jousselin (South London and Maudsley NHS Trust), Simon Clark (Barnet, Enfield & Haringey Mental Health NHS Trust), Victoria Glen-Day (NHS England), Peter Kohn (London Office of CCGs), Denis O'Rourke (Lambeth NHS), David Monk (Symmetric Partnership).

There have been several staff at the McPin Foundation who have assisted the project and the production of this report and the accompanying podcast: Agnes Hann (Senior Researcher, original project manager), Karen James (Research manager, assisted with research ethics application), Vanessa Pinfold (Research Director, has been involved throughout), Kathryn Watson (Communications Officer, providing report and resource illustrations), Cassandre Greenberg (Communications Officer, producing the podcast), Jessica Bond (Communications Manager, assisting with editing final report).

One of the original peer researchers left the project part way through and we thank them for all their input in helping us shape the study and beginning the process with us including developing project materials.

Finally, we thank everyone who shared their stories and time with us.

Alison Dolly Rose



THE BEGINNING

Our starting points

This work was commissioned by the Office of London Clinical Commissioning Groups, the mental health support charity Certitude and South London and Maudsley NHS Foundation Trust in order to better understand the experiences of people who have psychosis. Specifically, they sought to understand the experiences of people who use Early Intervention in Psychosis services in three south London boroughs: Lambeth, Southwark and Lewisham, to support the development of those services. Later the study was opened to people using Early Intervention in Psychosis services in Barnet, Enfield and Haringey.

The McPin Foundation were commissioned to conduct an in-depth qualitative study exploring the experiences of people who have used local Early Intervention in Psychosis services and the experiences of their carers. We called the project *My Story: Our Future*, a title that came out of discussions with our team and the project steering group.

EARLY INTERVENTION IN PSYCHOSIS SERVICES

Over the last 15 years, the NHS has developed services for people between the ages of 14 and 35 who are experiencing their first episode of psychosis (Pinfold et al. 2007). These Early Intervention in Psychosis services focus on the early detection and treatment of symptoms. Studies have shown the services lead to better long-term clinical outcomes for service users compared with generic community or inpatient mental health care (Singh, 2010) and they now form an integral part of the community mental health offering in England.

However, few in-depth qualitative studies have explored the experiences of people with psychosis. Much of the existing work is restricted to people's experiences of using psychosis services (Rhodes, 2015; Sebergson, 2014; Tindall et al., 2015; van Schalkwyk, 2015) or their pathways into care (Jansen et al., 2015). There is less published research that explores the broader context of people's lives and the situations and events that may have contributed to people who use services needing them

in the first place, although exceptions to this includes work by the Exploring Psychosis Together group (2012) and Thornhill, et al. (2016).

With this in mind, *My Story: Our Future* adopted an approach that deliberately sought to look beyond people's experiences as a 'service user' or 'carer'. We set out to hear people's life stories to see if they could help us identify and understand important events or experiences which have had an impact on their mental health.

People seeking help from mental health services are constantly asked to tell their stories to psychiatric professionals. However, this is usually within the restrictions of a psychiatric assessment. They are rarely given the space to tell their story on their own terms and as Morgan notes in *Values and Ethics*

in Mental Health: An exploration for practice, "Little space is to be found here for engaging with personal meaning making...". Telling our stories is one way in which we "make sense of our lives, our identities and our worlds" (Morgan et al, 2016).

To do this work, we looked to techniques used in the collection of oral histories. Oral history is a method of gathering, preserving and interpreting the voices, memories, feelings and attitudes of people and communities (Lummis, 1987). Oral histories enable people and communities to narrate their experiences in their own words, voices that might not otherwise be heard and are often marginalised or invisible within mainstream history. People and communities are enabled to provide first-hand accounts of the past that can enhance, or even challenge, dominant historical accounts (Frisch, 1990).

We were drawn to this approach as a way of complementing the wealth of quantitative literature about early intervention services and the demographic profiles of the people using them. Our aim was to listen to the life stories of people who use Early Intervention in Psychosis services, or care for someone who does, to understand their experiences of managing psychosis within and beyond formal services.

We wanted to give people a voice to tell their own stories and give their own accounts of psychosis within the context of their lives. We have learnt a lot from doing this project as a team and took a lot longer over the work than planned to ensure that we worked with people's stories carefully, consistently and thoughtfully throughout.

WHY DO OUR STUDY THIS WAY?

Dolly's perspective

“As a service user, I accessed my patient notes for a book I was writing. It was quite a shocking, dehumanising experience. All I could see was the pathology of me or the observable data of unobservable worlds.

It did not show the truth of me. You do not see the Dollyness of Dolly in my psychiatric notes. You do not see the XXXXness of XXXX in his. This is what this study aims to do: to decipher the human being behind the patient notes, to see their life beyond the consulting room, the hospital, the community mental health team.

”

GETTING STARTED: THE STORY OF THIS PROJECT

Before we begin to introduce peoples' stories, it is important that we also 'tell the story' of this research project and particularly of the survivor researchers who conducted it.

We were initially approached by the charity Certitude in July 2015 with a brief to gather the stories of people who had been using Early Intervention in Psychosis services in Lambeth, Lewisham and Southwark.

During those early discussions we decided that it would be essential to recruit researchers who had lived in the local area and who had themselves experienced psychosis and used mental health services.

We were successful in recruiting three researchers, two of whom, remained with the project from start to finish including Dolly Sen. We asked them to select their preferred term to describe their role and they chose 'survivor researcher', which we use throughout.

Throughout this report you will encounter writing from XXXX and Dolly in which they reflect on what they heard from the people who participated in this study and how the stories related to their own experiences of psychosis and encounters with services.



BUILDING A RESEARCH TEAM

Dolly, XXXX and a third researcher who wishes to remain anonymous worked together to develop *My Story: Our Future*. It was coordinated by two members of staff from the McPin Foundation.

Initially, Agnes Hann worked with the survivor researchers to decide how the study would run, design the study protocol and study materials, and to gain ethical approval. She also coordinated the recruitment of participants in the early stages and conducted interviews with the survivor researchers.

The coordination was later passed to Rose Thompson, who co-led many of the interviews and coordinated the analysis and study write up. During this time, one of the original survivor researchers left the study to pursue other opportunities.

Our team was completed by Alison Faulkner, a survivor researcher, who has experience of using mental health services but not of psychosis. Alison worked with us in an advisory capacity throughout and worked with us to analyse the life stories and write sections of this report.

WHY GET INVOLVED?

Alison's perspective

“ I was attracted to this project because of its focus on hearing people's stories. I have been a survivor researcher for many years, having had my own experience of using mental health services, and worked on many different research projects and consultations.

Rarely do we have the time in research to really listen to people's stories. In mental health services, our story often becomes obscured by professionals who need us to fit into their model of what mental distress represents.

I believe that it is through telling our own stories that we come to understand our mental distress within the context in which we are living and have been living and will go on living.

It is an active process and a way we can help and support each other to understand mental distress – if we are allowed the space to tell our stories, we can begin to open up the space for understanding.

As one of our participants said: 'It is a very special experience which people go through and they need more support for it and be able to talk to more and more people who have also gone through that [...].'

You still need that safe environment where you feel accepted and not being laughed at and understood.

”

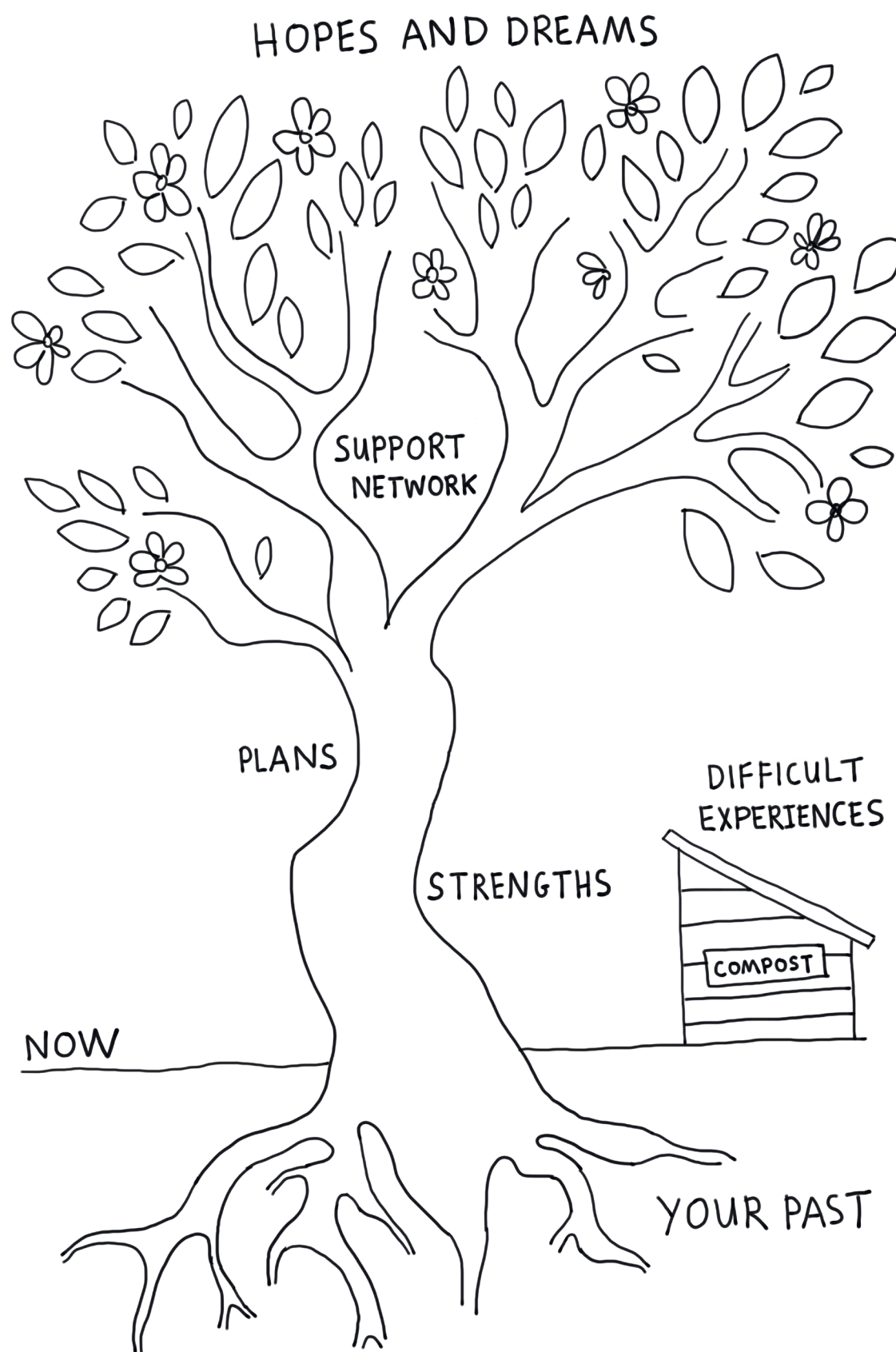
GATHERING LIFE STORIES

In the early stages of the study, Agnes undertook training in a research method called 'Oral History interviewing'. This is a kind of interview that historians use to collect the stories of people who were alive during important times in recent history.

It is designed to allow people to tell their experiences of complex events in their own words. Agnes incorporated learning from this type of interviewing into our study protocol.

She also trained the survivor researchers in the approach and together they developed a plan for how they would carry out the interviews with the 'storytellers' – as we now began to think of our participants.

The researchers created a set of visual resources including visual life maps and timelines that storytellers could use (see Tree of Life diagram overleaf). These resources would allow storytellers time to think about what parts of their story they would like to tell and what parts they would like to keep private.



Mapping resource: Tree of Life (adapted from Ncube, 2006)

DIFFICULTIES WITH RECRUITMENT

Rose's reflection

“ I have been working in research for about 10 years and I actually found this study quite difficult to recruit to. I think we spoke to about 4 people for every person who decided to take part. I think there are a number of reasons for this.

The most significant obstacle was the kind of Research and Development Approval we were able to get (the permission we needed to begin). We received something called Patient Identification Centre approval, which meant that while we could identify potential participants through services, we were not able to conduct research activities on NHS Trust premises. This meant that we were unable to spend much time in services and so did not become familiar to the staff or the people using the services.

Early Intervention in Psychosis services are very busy, often pressured places, and the clinical staff may not have had much time to talk to the people they worked with about our study. If we had been visible, we would have been able to develop more trusting relationships and be on hand to explain more about the study. However, I also think that this was not the right study for some people. Many people were still making sense of what had happened to them and were not at the right point in that journey to be able to tell their story.

If we were to conduct a similar study again, it may be better to try to recruit people who are approaching discharge or have recently been discharged.

”

Dolly's perspective

“ I found the recruitment so frustrating. We couldn't relate to people as fellow human beings and had to go through hoops and procedures and trust overworked care coordinators to do their part.

It felt like an 'othering' process too, which I didn't feel comfortable with, causing a separation between myself and the participants that wasn't there when we started.

”

INVITING PEOPLE TO TAKE PART IN THE STUDY

We found our storytellers by asking staff at Early Intervention in Psychosis services to advertise *My Story: Our Future* and to talk to people about it. When staff spoke to potential storytellers they would explain a little bit about what would happen. Potential storytellers could then either contact us directly or they could pass their contact details to us through a member of staff at their service.

We would then meet with people to talk to them about the study. We did this so that potential storytellers could connect with us and find out about what we were like as a research team. They could also ask questions about what would happen during the sessions with us. People then decided whether they wanted to take part or not; we encouraged them to take time in making this decision.

Relatives and people who cared for someone using Early Intervention in Psychosis services were approached through carers' groups. The survivor researchers attended these groups and explained what the study was about. People who were interested then spoke to them during the group about the study, and if they were happy to take part, gave us their contact details. We then contacted them to arrange an interview.

By the end of the study, we had heard the stories of people from Enfield who were or had been under the care of Barnet, Enfield & Haringey Mental Health NHS Trust (BEH), and from Lambeth, Lewisham and Southwark, who were or had been under the care of South London and Maudsley NHS Foundation Trust (SLaM).



WHY DID THE STORYTELLERS TAKE PART?

XXXX and Dolly in conversation

XXXX: I think the majority of them just wanted to be heard. They've been dismissed so many times by the services and talked down to, they wanted to get their views across. Some of them hoped to make services better for others in the future by sharing what they have with us.

Dolly: That's the impression I got as well, that they were just waiting to tell their story and they had the chance to do it. But we tried to think how many people have not had their chance to tell their story. Maybe that's one way services can improve – by giving people that chance. I mean one guy said that he wants people not to go through what he went through and that the services will treat others in a better way. I hope the project will have that impact and it will honour that intention, I think.

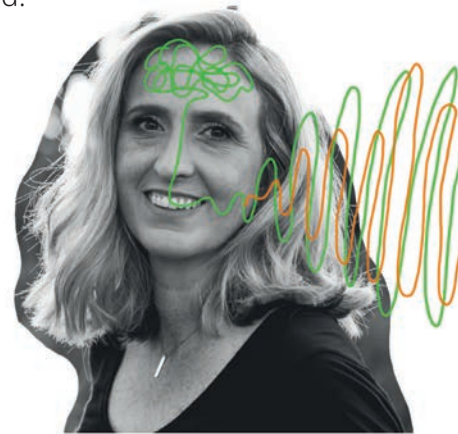
INTERVIEWERS AND STORYTELLERS

Storytellers were usually interviewed by two or more researchers. In most cases, one or more of the survivor researchers, Dolly or XXXX, would be paired with one of the study coordinators, Agnes or Rose, to do the interview. Dolly and XXXX both have experience of psychosis and had used mental health services. Dolly had some experience of interviewing before, whilst XXXX was relatively new to research when he joined our team.

When Dolly or XXXX were in the room, the storytellers knew that they were talking to someone who had been through a similar experience to them and who knew a bit about how it feels to use mental health services.

We hoped that this would enable storytellers to feel more at ease with the process and more comfortable when telling their story, as at least one of the interviewers would have an 'insider' understanding of what they had been through.

In contrast, neither Agnes nor Rose had any experience of psychosis or of using services for psychosis but both had a lot of experience of conducting interviews. This meant that they could offer support to XXXX and Dolly during the interviews and take the lead in asking questions as required.



MAPPING STORIES

We conducted interviews in a number of stages. Once people had agreed to take part, we invited them to come to the McPin Foundation to take part in a mapping meeting. Storytellers were shown the visual resources we had developed and were able to choose between the different options.

The idea was that they would be able to spend some time thinking about how they wanted to tell their story and potentially to create a visual 'map' to use through the interviews.

While we spent some time with all interviewees going through this mapping process, some were comfortable simply beginning their story. For these storytellers, it was easier to tell their story in a free-flowing conversation than it was to try to pin down their story using the visual resources. Others brought their own visual resources with them.

One storyteller had made a film based on his experiences and brought his storyboard¹ for us to see. A second person asked if we were able to bring a keyboard to the interview, which we did, so that she could play some music for us. A third person brought documents and certificates for us to look at while he was talking.

1. A storyboard is a graphic display with illustrations or images in sequence for the purpose of presenting the visual story of a film or animation.

MAPPING RESOURCE: LIFE COURSE MAP

CHILDHOOD

FIRST DIAGNOSIS



WHERE I AM NOW

YOUNG ADULT

ADULT

RECORDING STORIES

Once we had discussed mapping with the participants, we invited them to begin a recorded interview. For some, this meant beginning to tell their story while still in the process of looking at the mapping materials, as thoughts naturally occurred to them.

For others, it meant having a careful discussion over the mapping materials in one session, and then beginning the recorded interview in a later session after they had had time to think about their maps and to decide on which parts they would like to talk to us about.

We took a deliberately flexible approach in which we tried to work with storytellers to enable them to tell their stories in a way that was comfortable for them. This meant that some people attended a single interview, while others talked to us on as many as four separate occasions.

While we had some questions that we could ask during the interviews to help storytellers tell their stories, we did not have a rigid interview schedule.

Instead we discussed with them what we would ask in the interviews before they began, and together agreed a strategy about how we would go forward. It had been our plan to try to co-produce interview questions with storytellers, but most found this idea difficult and preferred that we ask questions that were responsive to the story they were telling in the moment. We audio-recorded and transcribed all the stories.

When interviewing storytellers with caring responsibilities, we did not go through a lengthy mapping process as many of these storytellers had limited time available for the study.

WHY GET INVOLVED?

Dolly's perspective

“ The first thing that attracted me was my own experience of being in the psychiatric hospital. People were making decisions for me and talking about me. Nobody was actually asking me, as if I didn't really exist. I felt like I was just a piece of merchandise.

They were listening more to my family than me and making decisions based on other people's version of events. I think it's really helpful for people to come in and talk about what they need to talk about. ”

MAKING SENSE OF THE STORIES

When we began trying to make sense of the stories, one thing became clear quite quickly. Storytellers did not tell us their stories in neat, linear ways. Instead their stories often moved back and forwards in time, as they thought more carefully about different themes and events in their lives.

When we as a research team came together, we realised that carrying out a traditional thematic analysis alone would mean chopping up these stories into themes, which risked truncating them and losing the essence of storytelling and the oral history approach.

We did not want to lose the sense of the narratives and possibly, the important message contained within the whole story. However, we were also aware of patterns emerging across the stories of different storytellers and wanted to ensure that we did not lose these.

For this reason, we took a slightly unconventional, four stage approach to understanding these narratives.



1. STORIES AND PICTURES: MAKING COLLAGES

At the beginning of our analysis process, we found the richness of the stories we had heard overwhelming and, in some ways, difficult to make sense of. We decided that attempting to use a systematic approach to the data would be unproductive. Instead we used a creative, more intuitive approach.

We brought flipchart paper, pens, scissors, glue and magazines into the analysis meeting and began to make collages. We cut out images from the magazines and arranged them on the paper, sometimes talking about our choices and sometimes doing it in silence. After some rearrangement, we glued the images down. We made some notes by the images to capture what we were thinking about when we placed them together. We allowed ourselves to be led creatively by the aspects of the stories that spoke most powerfully to us.

Over a number of sessions, we created 7 collages on themes such as home and housing, relationships, emotions, medication and trying to access services. These collages enabled us to pinpoint some of the most important messages in the data, which we then incorporated in later stages of our analysis.

THE BENEFITS OF WORKING CREATIVELY

Rose's reflection

“ Using collage in this way is probably not a traditional ‘academic’ approach to working with qualitative data. Whilst I have ‘academic’ training and over 10 years of experience in using traditional research methods, I probably do not comfortably fit within the ‘academic researcher’ box. I have been making things and pictures since I was very young.

It felt very natural to me when I began working on the stories with Dolly, XXXX and Alison, who are also creative people, to try to make pictures about our data. The first time we tried this approach I remember that all four of us, for different reasons, were feeling quite flat and tired. Faced with the richness of the different stories, we found it difficult to digest and verbalise everything that was there.

When we began working together visually it was like we switched to a different part of our brains and began to work together very fluidly to unlock the stories and their meaning. I noticed that we worked very quietly together and there was little discussion while we were making the collages.

Each of us were drawn to different things. I tended to favour images, while for XXXX, it was headlines or phrases. Dolly produced a ‘found’ poem from words in the magazines. Alison at times preferred to draw rather than to use images from magazines.

Once the collages were made, they were a great focus for the discussions that followed, both around what we had captured and also what we may have missed.

”

2. UNDERSTANDING CORE NARRATIVES

At the same time as working together on the collages, Dolly, XXXX and Alison were also conducting a mini narrative analysis in which they looked at each story to identify the core 'genre' and the key 'emotional tone' of the stories.

Alison created a proforma and this helped us to identify the ways in which the narratives felt and sounded, as well as the core themes running through them.

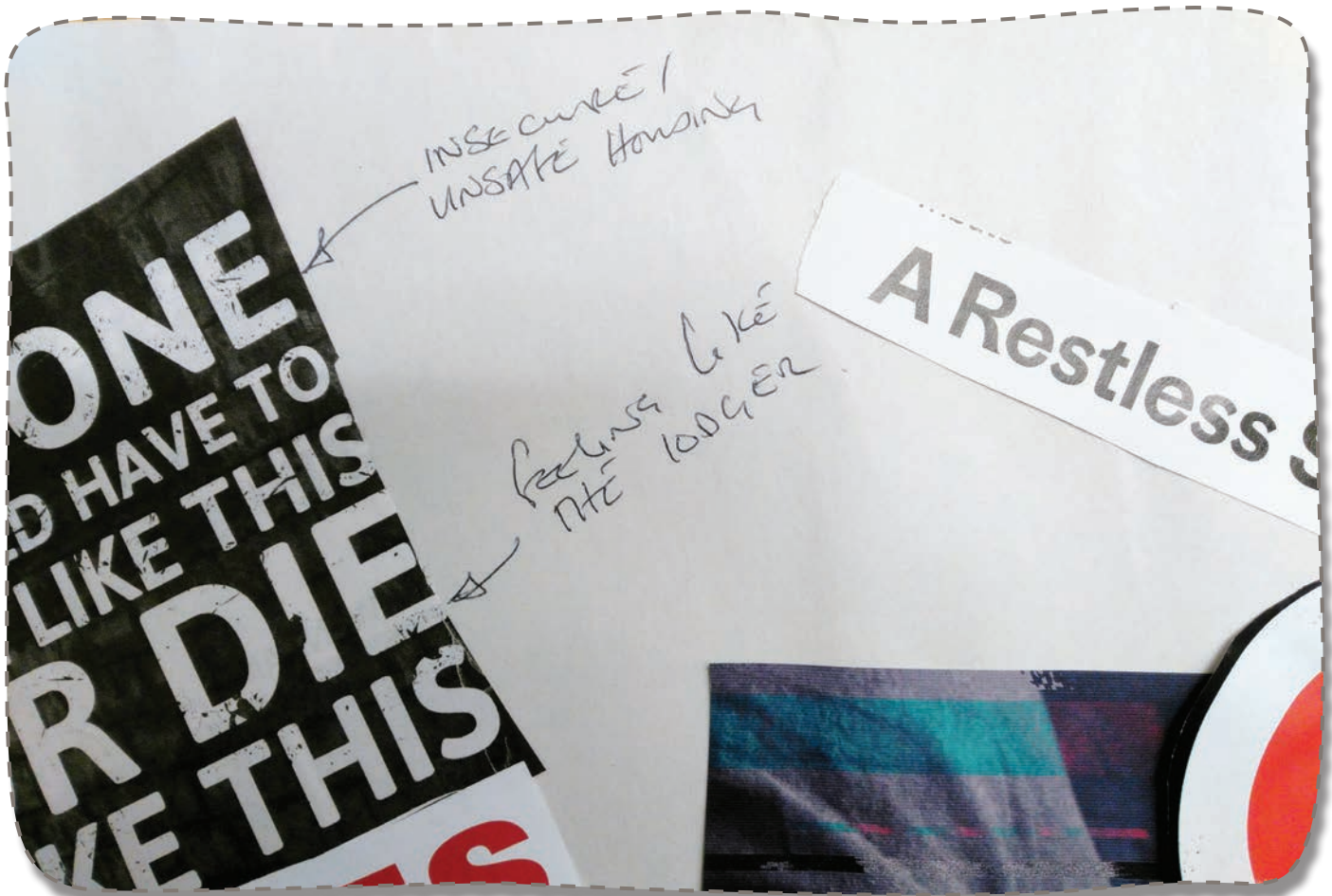
3. DECIDING ON THEMES

After we had completed the collages, we worked together to decide which themes we should write about in our report. A theme was an important thread in the stories of some or all of our storytellers.

In total, we identified 10 themes. Examples include shared experiences like difficult early life events, difficult relationships, insecure housing or homelessness, and loneliness or isolation. We then wrote short sections about these themes. Each of us took the lead in writing half a page on a small number of themes.

We then circulated our writing and commented on each other's work. Alison also wrote some sections in which she tried to capture a single story from one storyteller. We then brought these together and Rose edited all the sections together to create a single document.





4. THEMES AS STORIES

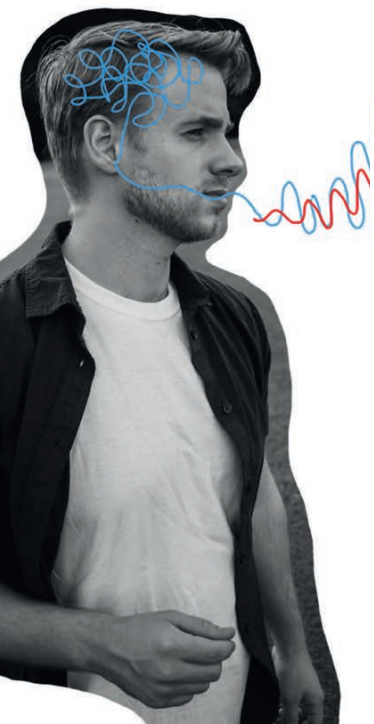
When we read our first draft, we found that by presenting the narratives as themes we had gone too far in the direction of 'chopping up the stories'. This meant that when we used quotes from the interviews, they were no longer connected to the whole story and their power was lost.

We showed some of these sections to our steering group and they also felt that by chopping up the narratives to create themes, we had lost the essence of the stories. At this point we came back together as a research team and talked about how we could write our account in a way that invited readers to gain a better sense of each person's story, while highlighting important

themes and issues arising across the data. We decided to write about just one or two of the stories to illustrate each theme, in this way retaining whole stories within the context of a theme.

Once we had done this, we then went back through the narratives and tried to 'cross reference' all the different stories so that we could bring attention to some of the patterns that ran across some or all.

We hope we have achieved a successful balance with this approach; we certainly took time and care to work on it together. As a result, this account is a collective effort between all of the team members.





THE MIDDLE

The storytellers and the stories

To avoid reducing the storytellers to a sterile list of demographics, we have resisted the temptation to 'describe our sample' as a list of characteristics and numbers, as is traditionally done in research. Instead we give a short taste of the biographies of each of our 14 storytellers.

SERVICE USERS

- A white British man in his mid-thirties who is an award-winning creative professional; when we met, he was doing some freelance work. In the past he has run his own business. He also has creative hobbies and describes himself as having always been close to his family.
- A black British woman in her early twenties who lives alone in council accommodation. She is close to her grandparents and very musical.
- A black British man in his early twenties who lives with his mother and who enjoys football. He was working towards a vocational career at the time of the interview.
- A man in his early thirties who had emigrated to the UK from a South American country as a young adolescent to join family here. He lives in council accommodation and would like to work in the creative industries.
- A white British man in his late thirties who, at the time of the interview, had stopped working as an office-based professional and was thinking about how to change careers. He lives alone and had been diagnosed with a chronic health condition in his mid-thirties.
- A man in his early twenties who is interested in computing and music. Both of his parents had migrated to the UK from Africa.
- A woman in her thirties who had migrated to the UK from India as a young adult. She lives with her husband and child and runs her own business.
- A white British man who had spent some time living nomadically in the last few years.
- A white British woman who grew up in a rural area and spent time in her early twenties travelling and learning languages. She had previously worked for a trade union.

CARERS

- A white British woman in her early sixties who looks after both her husband and child. She has worked in the charity sector for much of her career.
- A father of eight children who migrated from Africa to Europe in his twenties. He cares for one of his adult children. He has worked in several industries but was not working at the time of the interview.
- A woman with children and a partner, who loves animals. She described herself as having disabilities. She had worked in the creative industries in the past but was not working at the time of the interview. She did not want to disclose specific details about the person she cared for.
- A black woman with a busy professional career who is married and who cares for her adult child who is under the care of Early Intervention in Psychosis services.
- An Asian woman who is married with adult children, who lives with extended family and who migrated to the UK from South America. She cares for one of her children.



A PROJECT OF VOICES

Dolly and XXXX in conversation

Dolly: ...this is a project of voices, it's a project of that person's voice. It's a project about what their voice is that they hear, the voices of people around them, so like the services but also our voices in here as well, in the questions we ask, in the way we understand what they say as well.

So yes, I think this is a project of voices.

XXXX: It is definitely, yes. Individualism where the person is more important than the voices is vital.

Dolly: What is multiple voices? Not a cacophony, a multitude? I don't know.

XXXX: A symphony of voices.

Dolly: Yes. This is what this project is, a symphony of voices. Nobody has the right to say those voices shouldn't be heard.

FIRST IMPRESSIONS

We spoke to a range of people with different life experiences and varied experiences of psychosis.

Far from there being a single 'typical' life story that emerged, what we found was a picture of people negotiating their experiences in a variety of ways. Thus, our first impression of the stories is that we spoke to 14 people dealing with different, but very human, situations.

These individuals, who faced specific challenges, spoke of individual skills, abilities and strengths, and held different hopes and aspirations for the future.

A REFLECTION ON THE GROUP

Dolly's perspective

“ I am really glad we got a diverse mix of people to participate, one that reflected the population of where the services are based. I have heard that some research projects find it difficult to recruit from BAME communities, but we put the work in to ensure they felt they could take part.

It was also helped by the fact that at the start of the project, we had a black survivor researcher on the team. ”

STORY THEMES

After spending some time looking at the stories, we were able to identify points within the storytellers' lives at which some, or all, of their stories converged. As such, some common themes or experiences did emerge when we looked at the life stories together.

As described in the previous section, we explored the different themes by presenting the experience of one or a couple storytellers as an illustration of each.

We relate the stories in the following order:

1. **Stress and trying to cope**
2. **Seeking a home, a place to belong**
3. **A story of losing trust**
4. **A story of rediscovering trust**
5. **Feeling trapped in a vicious circle**
6. **Stories of loss and searching**
7. **Carer stress of negotiating services**
8. **Resourcefulness: creativity, faith, family and nature**
9. **Stories of loneliness and isolation**
10. **A story of positive relationships**

Each of the sections are about 5 pages long.

We have tried to balance detail and depth with readability and a focus around the theme.

#1 Stories of stress and coping



A few of the people we spoke to talked about experiencing high levels of stress in their lives, through school, work or due to their personal circumstances. The sense of feeling under pressure, and of that pressure not being understood by key people around them – family, friends and teachers – was palpable in some of the stories we heard. Some of the young people we spoke to explained that they had felt pressure to take subjects at school that they did not enjoy, or that they were pushed to take exams or study at university before they felt ready. Others were attempting to manage multiple stressful situations at the same time.

The story of one young woman characterises the kind of journey some of our younger storytellers had been through. Throughout her early life this storyteller had a difficult home situation. Her mother was at times unwell with a mental health problem and, consequently, she lived with her grandmother from an early age.

Her mother did not always respond well to this situation, which led to a complicated situation at home and with local authorities.

[Storyteller's mother] was calling the police and making accusations about me being locked up in the house by my nan and granddad and she would [say I was locked in] the basement sometimes. Obviously the police would come by and I would get annoyed by police now whenever I see them because they were like, "Are you alright? We have just got to check. We are just doing a job."

At the end of the day, from however many years ago from then to now, I have tried to contact the police [from the local area] just to say, "If my mum calls or makes allegations saying that I am missing..." She used to say I am missing as well. I said, "Don't take it on. Try and block it if you can. Put a note on your system to say call me." I wanted them to check. [Storyteller 2]

Throughout her narrative she describes a complicated family situation, involving a history of mental health difficulties on both sides of the family. At times, we felt a sense of her feeling quite alone both within her family and at school, and of needing to take responsibility for herself at a young age.

In her early school years our storyteller spoke about feeling clever and doing well. She felt supported in her school environment and did well on assignments and in exams. This situation began to deteriorate as she approached her GCSE and A-level exams, and this sense of being left alone to cope with difficult things was again present in her story.

In primary school, my teachers knew that I was a young carer, so they looked out for me. In secondary school, my teachers knew that I was smart, so they pushed me. In sixth form, they didn't give a shit – sorry for the language, but they really didn't.

Around this time she also found herself distracted by pursuing relationships with men, which she describes as contributing to a loss of interest in her education.

[...] All of those hormones really made me focus on men and I wasn't really thinking about my education. Because I was naturally smart, I just thought I would ace the maths and I did ace the maths. I didn't even do any revision and I still got an A. I thought I would be able to do that in all of my subjects, me being big-headed. Plus, I had just won Student of the Year for Key Stage 3. [...] I wanted to put that in. That is

an achievement. [...] Yes. I decided to do it again thinking I could get A and then get A in every other subject. I was predicted at least three As, apart from maths. [...] Yes. I got a B in my physics. I got a B in all of my exams but I got an E in my coursework and at the time, when I was doing my physics coursework I was in a relationship and he was very controlling.*

She felt support was not provided to her through the later stages of her education, potentially due to a lack of understanding on the part of her teachers. This had an impact on her ability to succeed in the subjects she was studying.

...my teachers weren't really helpful – they didn't really understand or, maybe because I wasn't diagnosed or had a learning disability, or learning difficulty should I say, sorry, they didn't see anything. They thought "you know, this girl got twelve/eleven A-C grades; she is capable of doing A-levels, we don't need to help her, let her do the work". So, that is what I'm thinking, so that must be what they're thinking as well. At the end, when I finished the first year of sixth form, I didn't – because I failed the whole year, I thought "no, I have put all my time, all my effort into it. I don't bunk". I started bunking near the end, because I was just like, "no, they're not helpful and it's like no-one understands".

So, because no-one understood what I was going through, I didn't even understand what I was going through, so I didn't have any help like that, so I guess I definitely developed the psychosis, and they diagnosed me with anxiety and severe depression as well.

Our storyteller described how cannabis had been present in her life from a very early age, which may have resulted in drugs feeling like a familiar coping strategy to reach for. She had this in common with a number of storytellers who spoke of using drugs as a way to manage or escape from stress.

She pinpointed a particular moment when she felt that stress resulted in her turning to “weed”:

I tried to do maths at A-level and my sixth form didn't help me. [...] I just wanted to do science and maths and that would have equated to three or four A-levels but they said I had to do Health and Social Care as well which was a BTEC so that is like an extra two A-levels. That would have been me doing six A-levels and everyone else was doing four. They wouldn't allow me to just do the three. [...] I didn't really understand Health and Social Care and I [wasn't] interested. I should have moved school but I liked the head teacher of the sixth form, who was my ex-sociology teacher and I got on with her. Most of my friends were staying there as well and I hadn't been to a lot of schools. I was a bit timid and shy as well and wasn't ready to meet new friends yet. I was just a bit in my own world really. [...] Yes. I think that's where it got stressful. I was getting really agitated. I started smoking weed when I started Health and Social Care.

Like several other storytellers who had used recreational drugs, or who had cared for someone who did, this storyteller explained how her experiences of using drugs had happened around the same time as she felt her mental health was deteriorating and she received a diagnosis of psychosis.

So, yes, I thought I was going mad, but I didn't think it was anything to be brought up about, so I kept it to myself. Obviously, my friends saw because they had me on the Messenger, but I started smoking, after that, when I left school, after my GCSEs, and I lost my concentration in my work, in everything, really, and I guess it was just like a big decrease. Rather than me being elevated and being like, “yeah, I'm studying A-levels now, I'm doing this, I'm doing that”, it was just like neutral, and I felt like I was still in school, just having to do what I have to do, but I didn't really think “this is

PERSPECTIVES ON STRESS AND PRESSURE

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“ I could identify with the experiences of stress and pressure our storytellers talked with us about. Leaving a job which offered little hope for the future gave me hours of unstructured time and I was struggling to survive on benefits. I couldn't afford to feed myself properly and lost a lot of weight. It was around this time that my voices became more frequent. ”

Dolly

“ I can personally relate to the school pressure scenario. I started to hear voices at 14 when both my school and my home life were difficult. The school did not know how to handle it, which added to the pressure, saying things like ‘pull your socks up’ and ‘you are not concentrating hard enough’. You don't get a complimentary pair of socks when you enter the mental health system. ”

another big step, I need to focus on it". I just took it for granted, and I think that is – the smoking as well; the smoking makes me lazy. [...] Yes, so I started smoking weed between when the GCSEs finished and my A-levels started, and I think that whole gap was where it kind of escalated, the whole poor mental health – that got poorer.

She explained to us that she had been unaware of the connection between cannabis and psychosis and that she needed more support to understand the link than was on offer.

I think that, if I knew that it was the weed that made me into that state, in the first place, I wouldn't have picked it up. If I had someone telling me, assuring me, "don't smoke the weed; it's not good for you, it's bad for you, that's why you had this episode, it will do it again", but I got – someone said 'psychosis' and I got a print-out, that had some symptoms on it. At the time, my concentration was very, very, very poor.

Immediately after her diagnosis she was cared for at home by her grandmother, and the home treatment team. She had a relatively good experience with the home treatment team, who helped her adjust her medication.

The home treatment team came to do a referred review and they asked me how I was feeling. They always ask that. The first time they came I said, "I am not feeling well." I felt so much better because I was actually able to talk without stuttering. I said I was having hallucinations and didn't know what was going on and they said maybe it was the medication. They changed the medication and it got better. The hallucinations stopped and I am on the same medication now. It's quite good.

However, during this time she was encouraged to move out of her home to live independently. The process through which this happened remains unclear to her and has left her with feelings of rejection.

I had my own room and stuff, so it wasn't like I was in the front room or – I was living there for twelve years, maybe, then my Nan asked me if I wanted to leave and I didn't know what I said, but I must have said yes, because she – I don't know, whatever happened, my care-coordinator was telling me that if I wanted to go to the housing, or something – something happened, I don't know, but, anyway, I went in housing and they put me in emergency accommodation and, reflecting on it – not thinking, at the time, but reflecting on it, I thought that my family didn't want me, but I've talked to them and stuff and that's not the case, but the fact that they asked me to leave, I thought "what's wrong with me? Am I turning into my mum?", because my mum has severe mental difficulties; she is severely mentally challenged, and I think that's where I get it from, from that gene or that inheritance of DNA or whatever.

There was also a sense of further 'aloneness' and isolation in her narrative as she talked about her new housing situation, which felt unfriendly, and at times unsafe.

I have just been looking after myself. I have got other problems, like rent arrears and my neighbours chatting, saying that I'm – complaining about me, but they are false allegations. So, they are all males, in my block, in my flat, and two of them have – one said that – there are three people, A, B and C, and I'm C – so, A, B, D, should I say.

A said that B likes me, then A said that A likes me, and then D had his friend over that tried to do something to me, and I told the police about it – a bit late though. I only told them this year and it happened like a year and a half ago, but I didn't think anything of it. So, now that I have told my housing officer and she started getting on to me about people saying that they're complaining, or whatever, it's like everyone is trying to make up stuff against me now. So, some underneath me are saying that I'm stamping on the floor every night and banging and I broke his ceiling light, by stamping on the floor, so I don't understand how that is possible.

This situation was compounded by a breach of confidentiality by her housing officer, who disclosed something that she had told them to one of her neighbours. This disclosure had negative consequences for her relationship with that person. She also described difficulty in securing further support, which may have been partly due to a lack of understanding on the part of the housing authorities of the impact of her mental health on her.

My Nan came with me to see my care-coordinator, to book an appointment. My Nan told my care-coordinator what was happening, and that breach of confidentiality and stuff, so she – I don't remember, now. [...] She said she was going to make an appointment and then she was going to call my Nan. She still hasn't called my Nan, and we're supposed to go – I want to book an appointment, so that she can come and we can go to book a housing appointment, so they can talk, because they are supposed to know that I am under mental health and stuff, the housing, but they don't take that into

consideration, because if they knew I had psychosis, they would understand that I might do things that – like hallucinate or shout, at one point, and not realise that I'm shouting, or just, if I'm depressed, I'll start screaming – not screaming, but shouting or crying loudly, or whatever. It's just that I'm trying to calm myself down, you know? So, it's not anyone killing me in the property, it's just me, by myself, but then again, I know that I have to take neighbours into consideration, and stuff, but all the things that I'm being accused of, it's not even me that's doing it, it's the other neighbours.

Under these stressful housing conditions, it is perhaps not surprising that at the time of the interview, the storyteller was still smoking cannabis, despite wanting to stop.

Yeah, because it's like – not like you're taking oxygen, but like you're meditating, kind of, when you smoke, like you're taking deep breaths and you can see it coming out and it's like – I think that is what got me hooked onto smoking, as well, was me feeling it going in and out of my lungs and thinking "this is a nice feeling". Not nice effects, long-term effects, but it's a nice feeling, at the time. I don't know. Yeah, so I should be recovered soon, hopefully.

This storyteller described to us her determination to stop smoking and move on. She said that she had taken an active role in researching services that might support her. This suggests a resourcefulness that she shares with many of the storytellers we spoke to. When we met here, she was about to start with a new service that supports people to stop taking drugs.

Yes, so there is a group on Wednesdays. I'm going to go tomorrow. I signed up last week, when I had my assessment, and I passed it because I had high THC levels and, yes, that was the only thing present, which should have been the right thing. Yes, I'm going to go tomorrow and see what they say, because it's like a support group and stuff, where they talk and stuff, so I thought, "yeah, why not", I might go there and let out some feelings. That's what they're for, you know? [...]

I was googling and I was looking for – because, recently, I've been looking for detox clinic and things like that, because I really want to stop the smoking, but I go to my GP and they're not really very helpful. So, I don't know, I called the – I self-referred myself, came in for an assessment and they gave me a leaflet with a timetable of all the groups, for the whole week, and the woman circled the cannabis stuff and they have yoga, as well. So, yes, that was like self-referral and I'm going to go there tomorrow and see how it goes.

Despite all the challenges this storyteller was facing at the time of the interview, she remained positive and had clear plans for the future, even if it was still a struggle to remain motivated at times.

Yes, so I'm starting college again in September. [...] Doing ICT, or IT. Yes, that's like a foundation year, so I'm going to do that and then go to university, but university is where I want to be and what I want to do, specialising in cyber security, mobile forensics, digital forensics, because I've actually got a forensic science level three, but just half of it, but it's still classed as a pass-pass. Yes, it's the

equivalent to one and half A-levels, that's it. So, I want to use that because I know that it's not a waste of my life, so use that forensics, go into IT and make my dream and lots of money. [...] I think that's why I'm depressed, because money doesn't solve all problems, but it solves many problems and I know that there are so many problems that affect me directly and indirectly, that could be solved with money.

So, I'm just trying to say that I have this mindset, where I think, "if I'm doing this, to get to here, to get to there, to be this", so that is my motivation, but it's not always motivational, because I'm just thinking "it's another day, I'm still here".

PERSPECTIVES ON CANNABIS

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“ In my own experience, weed made me 'come back to life' when the medication I was taking was numbing me completely and I saw no point in living. It became a survival tactic. However, the marijuana that was available when I was a user was nowhere near as potent as the Class B skunk that is around now. Any user, for whatever reason, can always become psychologically addicted. ”

Dolly

“ My personal experience of marijuana was instant paranoia so I didn't pursue it. I had had the experience of psychosis beforehand but smoking made it immediately worse. ”

#2 Seeking a home, a place to belong



The need for a place that feels like home was a strong, even urgent, issue for many of the storytellers. For some, the feeling that they did not belong or fit in at home was a poignant theme running through their stories. Some storytellers experienced this feeling as an inability to feel at home within a different country or culture to the one they were born into. Others spoke of being or feeling physically unsafe at home, or of losing their homes and becoming homeless.

The journey of one of our storytellers embodies many of these aspects within a single story. This storyteller was born in a South American country and was left at birth with his grandmother. He describes his early life with her as a time of mutual support, where she cooked for him and he helped her, but also as a time of poverty and hunger. He lived with his grandmother until her death when he was still a child.

Yes, I was going to primary school and, obviously, she couldn't fend for herself at the time [because of a broken hip], so, there were some food banks that were giving us what we needed to survive and get by and that. So, yes, we were supported by that and she was old and, sometimes, in the winter, the weather wasn't good and she got this sickness, like bronchitis. Then, from there, she got worse because we didn't have enough funds for her to get checked at the hospital. So, it was left and it was the wrong thing to do because it got worse and then she caught some pneumonia, some pulmonary disease or whatever and she passed away from that. [Storyteller 4]

So, I was left on my own to fend for myself, and, I was very young, until my father got informed of it because he wasn't around at the time, so, he didn't know what was happening. Yes, so that was what happened in my childhood and I was forced to grow up quite fast.

This storyteller told us of being with his grandmother when she died, and of being left alone to deal with the immediate aftermath of her death. This early event seems to have been a turning point, and for much of the rest of his story there is a sense of him being left alone to deal with difficult things.

So, it took a while because he didn't know she had passed away, so, it took about two weeks. Most of the community chipped in to give her a nice burial, so, it was a community thing to say thank you to her because she was a community person. So, when they all chipped in, it was a very good thing and that included the people from the market who chipped a bit in, so, that showed a bit of respect for her. [...] So, if you can imagine, the whole community carrying this coffin and blocking off the road and no-one is beeping because they know what is happening, so, it wouldn't set off a riot.

So, all this was happening and I had to handle it and at the time I took it hard because I knew that I wouldn't see her again or speak to her but because I was young, I wasn't really focusing on things at the time even though I felt hurt. It wasn't phasing me, though, and since then it seems that she was the only person there who would show me support and stuff. It was just that little bit difficult to deal with, you know? [...] I felt like the people that really needed to come, weren't there and I didn't realise that until years after.

He spoke about trying to take responsibility for their home after her death, and how this was difficult for him to do. Eventually he moved to live with a

local family while he waited for his father to return from England to look after him. This was the first of many experiences of having to leave a home and start again.

He waited for some time to be reunited with his father, with whom he had had little contact since he was very young. Our storyteller then travelled to England with his father.

I had met my Dad before that, but, he was in the military, he was a military man, so, sometimes, he wasn't able to be there and left me and Nan to deal with things. [...] Eventually, after I was living with these people, this family, yes, I was able to go and meet my parents, or, meet my Dad. It was kind of like, you can't really hit a reset button on a human being and say, "Let's reset it or reboot it."

You can't do that, so, it was difficult for me to come to another place, let alone, another language, another people, another culture; how the food is, how the weather is. So, it was like a big reset for me, innit? So, I come and I had to fly by myself, and, that, in itself, was a journey, innit? The most I'd ever been in was a van, or a car, like a taxi, so, to get on a plane, for how many hours, on your own when you're only twelve or thirteen. So, it was a big journey, for that alone, innit?

On moving to England there were many aspects of the culture that he found very different from his home country, and these differences were exacerbated by a language barrier. At times this led to frustrations at school as he was unable to keep up with some of the lessons.

Storyteller: So, from me knowing things a little bit in advance, I would say that education is better here because in [name of South American country,] it's tough. I was already learning algebra and I hadn't even left primary. So, when I was in Year 9 [in the UK], they were just touching algebra and I was like, "Oh, I just remember this." So, in my head, I'm thinking, "What's happening? Am I in front or am I behind?" [...] I was way ahead in a way but my language barrier set me back a little bit and I was falling behind a bit in the stages of life and stuff.

Interviewer: So, you said you got a little bit of extra help; was that help actually helping?

Storyteller: [...] I remember [name of teacher,] oh my days, he was my first support teacher, after the [language] tutor, and I had to miss some lessons because I didn't know the language and things like geography and history. So, things that would involve a lot more language, I would miss and I would go into the library to see [name of teacher] and we'd do our own things and learn from other things and stuff.

So, I remember [name of teacher] as well, he was a cool guy. So, in between that, I was always in some sort of support stuff and I felt that that, kind of, helped, as well, with my progress and stuff.

The transition to a new home with his father, who had a new family, was also difficult for him. At this point in his story, like in the stories of other storytellers, we picked up on a strong sense of him feeling like he did not 'fit in' at home, or at school.

[...] I felt like a lodger at the time, not because my Dad didn't like me or don't want me, but because of the rest of the things. He already had his family and he was already married to someone else and I didn't know this person. Like, coming from where I come from, my experience of things, it was difficult for me to get on with things around that area, innit? It seemed difficult for someone who is not my Mum, to tell me things and to tell me what to do and stuff and it was a more equality thing because they already had a kid.

So, everything that the kid did, and you know there are going to be fights, normal things, but it was more of a thing to me, like, "What are you doing?" Like, I was always wrong even though it wasn't me. Or things over my personal things, "Don't touch them." You know, things like that? [...] So, obviously, when my Dad came back from work, he would get the lowdown off his wife and it would make me feel bad and it was every time and I was like, "Oh, my days!" And I was like, "You always think it's going to be me."

So, it caused a friction between me and my Dad, whether it was a jealousy thing, I don't know but to me it felt like I wasn't fitting in. I'll always not fit in, I'll always be an outsider. So, yes, that's probably what kicked off that rebellious stage and it showed in the school, innit? Now, I know what ticked me off but at the time, it was just like one of those kids, innit? Yes, and they say the older you get the wiser you get, so, it's learning those things but I did get to a point where I'd just had enough and I was coming to school and was starving through the meal periods and that's maybe why the kids used to bully me. Kids can sometimes be evil and I was just kind of wasting away through the

pain because kids used to stare if I was eating a little bit faster.

Disagreements with his father escalated into physical fights and he found himself leaving a home again, this time to stay with a friend.

Yes, and there was traffic, and somebody got out of their car and saw little old me being chased and they see how my Dad is behaving and they came and said, "Are you alright?" And there was a family member and they took me upstairs and they gave me that option of, "Do you want to go and stay somewhere for the moment?" And I said, "Alright." And there was a period between finishing school and starting college and this is when it was happening, so, I went there and I stayed there for a bit like a month, a couple of months. So, then it got back to me and Dad trying to deal with things but I had a new mate from college, who I stayed with, who lived with his mum and dad and we were doing the same course.

After that I couldn't get a job and couldn't keep up with things, so, I had to sign on and stuff. But there's something in between all that and I still feel like it's not where I should be, it's not where I'm meant to be, you know and I suppose that feeling kind of dragged me down a little bit more, every day, to the point where I just snapped somewhere down the line.

He attributes this feeling of not having a place to be, of not fitting in, as leading directly to his psychosis. He shares this aspect of his story, of feeling dislocated, of not being where he should be, with some of the other storytellers. When reading these narratives, we, the research team, got a sense of a kind of

spiritual restlessness or homelessness, which in this narrative eventually led to real homelessness.

I fell out with my friend over a girl. So, I left home and my friends and I literally became rough sleeping, homeless.

At this point in his story, he finds himself moving from place to place, living between hostels and staying with friends. He describes having little control over where he lives or how he is able to live in those places. He was eloquent about the emotional response he has to this situation, describing deep feelings of fear, anger, and pain.

I was kind of falling into that system where I was just going into a loop and they were moving me from one hostel to another hostel, the same part of the thing, innit? It just felt it was building up, the frustration, the anger, the sadness, the fear, everything was building up inside of me and me trying to project it a certain way wasn't helping me at the time. I couldn't project it and lay it all out, so, it just sounded like I was an angry man and they had no time for things like that. So, it was like I was a dog, barking at a wall, and people couldn't see where it was coming from.

They were using people, not just me, other people that were already institutionalised because that felt like prison to me. Like, the prison, the cells, and where I was at the time, some were changing but they were still communal and the people that lived there, the people they were bringing. Things like that and eventually, you just fall down and they don't help you, so, it's like quicksand you just deal with that kind of lifestyle. I was probably living in them for ten years plus.

The situation made it difficult for him to gain employment or to hold down a job.

Somehow, I found myself an interview at Sainsbury's and Sainsbury's gave me the job. So, I was working at Sainsbury's for a little bit, mainly a month, two at the most but I literally became homeless because I fell out with my friend. So, the manager saw what was happening, he didn't know but he was suspicious because my clothes weren't clean. What can I do? I'm homeless, I can't wash them and I was trying to go into bookies and wash myself, places like that, trying to survive, innit? Yes, the fella said, "Is there something wrong?"

And that's when I laid it all out to him and he said, "You know what, I'm not going to fire you but if you want, you can resign and then that gives you the option to always come back." So, that just means you write something and then I resigned and I gave it to him. I suppose that left it open if I wanted to go back but at the time, there wasn't much for me, like stacking shelves and stuff.

While he spoke of feeling grateful for the help and support he received in the hostels, he described a life that felt more and more difficult to sustain. He lived alongside people who were heavy drug users and this created situations in which he was exposed to more difficult experiences.

The only downfall that I would probably say is that they were dealing mostly with people who used to take hard drugs and drink, alcoholics and stuff like that. I made friends with a couple of them and I even witnessed a couple of them dying in front of me because they had too much or whatever and probably, the cold.

He talked about seeking help from different people and finding many doors closed. At times he described feeling overwhelmed: "I just thought it was like a big monster that I was fighting, and once you take out one, there's another one and then there's another one down here, you know what I mean?" Like other storytellers we spoke to, he describes turning to drugs to cope with his difficulties.

Yes, that's why I got into the drugs, I started smoking weed and it was like a vicious circle and I was being sucked into all these things that were happening, innit? So, it just felt like there was nothing else for me to do apart from that, so, I'm doing things like that.

He describes how living in hostel accommodation placed him in close proximity with people who were involved in criminal activities. These people would allow other people involved in crime into the hostel. Through this close contact, the storyteller found himself associating with people who were violent. During this part of his story he describes a life that feels increasingly violent and dangerous, from which he finds it very difficult to remove himself.

It came down to the thing of opportunity because people like me probably don't have enough opportunity and support around it to follow it through, you know? People are different, you know what I mean? Some people bloom late, so, I was kind of left in that predicament.

Through these associations, he himself became involved in violent events and came to the attention of the police, and on occasion was arrested. At

the same time, he describes being a victim of crime and of having his room repeatedly burgled, possibly by other residents of the hostel.

His girlfriend's upstairs on the top floor, my girlfriend's friend is down there just having it all out. His dog has come downstairs and my girl had a little baby in her arms. This is why I switched, yeh? The main issue that I had was he lobbed an iron that was in the laundry room. He picked up the iron and he lobbed it beneath the frame and he hit the baby that she was holding. So, that's what made me see red and that's why I did what I did. The dog's come downstairs trying to bark off and my girl's already afraid of dogs as it is, yeh? Now, he's using the dog, the girlfriend's upstairs using the dog against me.

So, I gave the dog a good kick and the guy's like, "What are you doing to my dog?" And I'm like, "Take your dog away." At that precise moment I felt like I was going to do something with the dog. So, within minutes, and it was like it was all planned, it was all rehearsed. It felt like that because within minutes the police were there and they usually take an hour to 45 minutes to get from [name of police station] to here but they were there within two minutes. And they were there and they were taking me away and it was, "Right, okay. I'm the bad guy, innit?" So, I just said to them, "Just, please, just get on with it." Because there was nothing else to say, there was a little bit of bants and that.

During this part of his story it is extremely hard to describe the places he was living in as home; they were often physically insecure and accommodated people who are involved in drug use or violent activities.

After I left that place, as people would say, "from the frying pan into the fire", into that place where I was getting burgled left, right and centre. There's nothing to say and I was going to simple places, like the shop and I'm waiting in the shop and I come back and somebody's broken in and taken this and taken that. It started with small things. I got myself a PS3 after that and finding out that that's gone and all the games and that's the first time. The first, second time, third, fourth, fifth, sixth, seventh. It just got to a point where, third time, I said, "It's someone who lives here." So, I started knocking on everyone's door, I started doing the police's job because they wouldn't want to know, they wouldn't even do that. They would have a laugh about it and they would have the plastic police.

He spoke of feeling a constant sense of struggle and described finding it difficult to manage the difficult emotions that came with that. Hearing and reading this story, we found it difficult to understand how someone living in such conditions could begin to manage difficult emotions, or indeed, stay mentally well.

He was eventually moved from this environment into new accommodation in a safer area. But moving to this area brought a new aspect of dislocation to his story. His new accommodation was a long way from the places that he had previously been employed or volunteering. Around this time he discovered an interest in photography, which he began to see as a way out of the cycles of violence and rootlessness that he had been caught in. At the time of interview, he was trying to pursue this interest through applying to courses. However, being so far from the centre

of London initially made pursuing this interest difficult.

So, nothing works but then I saw as my salvation, this thing, that was kind of ongoing but they didn't tell me, "Yes." But they didn't tell me, "No." But I felt that that was another step for me to get out of [name of county] because I was left in the middle of nowhere and even though there were people around and the area was nice and they were trying to help me with things, I felt like I wasn't meant to be there, you know? So, I said to them this is what's happened; I've got family, I've got friends that live in London. Not only that, hopefully, I'm going to follow through this journalism thing and follow through photography because that was the main thing, to get through the journalism.

So, I said, "That's my side of the bargain; could you please put me back in London." And it took two years and this is what I'm saying, the woman that was assigned to see me. Every time she came in, she saw it and the last time she saw it she was like, and I could overhear it because it's so quiet up in the country, that when she went outside, you could hear the woman saying, "Bless him, he literally has nothing. Move him back."

This storyteller was eventually moved back into London, where he was placed in a flat that he felt was secure, and where he was able to feel comfortable. However, by this time, years of moving from place to place and living in unsafe housing had taken its toll. He began hearing voices and had what he described as a breakdown, during which he was hospitalised. He described feeling like he was still carrying these

difficult experiences with him when he began using Early Intervention in Psychosis services.

So, I came to [Early Intervention in Psychosis service], with all these things in my head, so, I knew that something was being done on these things that were happening to me. So, it wasn't just all happening because of my fault, I mean, I made it happen. It wasn't just me, it was a whole team of people that was left in front, on the way, to make it carry on and carry on. So, even up 'til now, I still think it's a carrying on because things, like, if I want to follow a certain path, it will eventually just mess up for me. Not because of my own fault but because of certain people.

I suppose I would like to be independent. So many people don't even own their own house. I think I would like to somewhere down the line be able to afford a home. A house is a house but a home is a home. I would like to try to be more settled and try to help my family, the ones who are in a worse situation. It's difficult because you know there are people who are worse off. You tend to feel a bit bad but that's life. It's the roll of the dice. Some people are born into it and others are successful at things and then there are people who are born into the dark side of things. I think I would like to have a place to call my own and not worry about bills and stuff. I would like a little business. It doesn't have to be here. It could be abroad. It's easier and more manageable here. I suppose that is what I would like to be. I would like to be that person who doesn't worry about certain things like, "Where is my food coming from? Or, "What do I have to do to have a decent living?" That's what I would like to be.

THE IMPORTANCE OF A SAFE HOME BASE

Dolly

“ When I was young, school was my sanctuary away from a difficult home life. But then I was bullied at school. I could not relax at home and I could not relax at school. I had nowhere to rest. Without a safe place to call home, your mind cannot rest.

Insecure housing had plagued my mental health for at least two decades. When I lived in an abusive family home, my then psychiatrist said it was not his job to help me find a safe place to live, despite it affecting my mental health fundamentally. It is only when I had my own place that I could call home, I found my mind and emotions could settle too. ”

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“ When I was in a large psychiatric hostel due to homelessness some of the other residents were using heroin and regularly offering to get some for me. I was insecure and depressed at the time and was afraid that one day I would accept their offer in order to feel better.

I managed to get an interview at a smaller hostel run by Mind and they offered me a room, which put me out of the danger zone. I was one of the lucky ones to get away in time. ”

#3 A story of losing trust



Issues around trust and mistrust were recurring themes in the stories: the problem of knowing who could be trusted to talk to, or who could be trusted to help.

One story in particular is a strong example of how breakdown in trust between people, and between people and services, could result in the deterioration of a situation when someone was experiencing psychosis. The reluctance of this family to work with or involve the police because of racism – and the consequent lack of trust in the police – was also an issue in this story.

Our storyteller is a mother who spoke to us about her son's descent into paranoia and psychosis. She described how she experienced him change from being a well behaved and caring child, who did well at school and further education. By sharing her story, she was piecing together the events that happened and how her son changed so drastically.

He was a really good child, very quiet, a nice kid. He did everything. He cooked, cleaned, whatever. He was a really good kid. He finished school, finished uni. I had no worries about him. All my friends were having problems. I was worried about teenage problems, nothing at all like that. [Storyteller 13]

The son she had raised, knew and trusted gradually became a person who was difficult to understand and communicate with. At times he seemed to be an angry shadow of the person he used to be. Eventually the relationships he had with his mother's partner, his godfather and his mum appeared to break down through instances of misunderstanding and mistrust. In this story, in particular, a number of the characters appeared not to trust each other or believe each other's version of events.

The first clear incidence of this mistrust was when the family home was broken into; only her son's room was targeted, and all of his things were stolen.

He lost valuable possessions and his artwork, which could not be replaced, while the rest of the house remained untouched. She described how her son became extremely mistrustful and suspicious after this event, and pinpoints this incident as the beginning of him becoming unwell.

It was definitely somebody he knew because he was having all these people in the house. They cleaned his room out, proper, everything out, including all his artwork because he's an artist. All of his work, they took his computer which had all his work from uni and from school because he got an A at art in his A-levels. So they cleaned out all of his work, took even his hard drive. So even though we could replace the equipment, you couldn't replace all the work, plus all his music as well because they were doing... he had a lot of beats and stuff on it.

So all of that I think really is where it started because then he became really paranoid, suspicious of everyone, couldn't trust anyone. I think that's, for me, where it all... well I mean we didn't think anything of it. I didn't think it was that serious anyway but I think that's where it started.

She described thinking that the burglar probably had inside knowledge of the layout of the house and planned exactly what they wanted steal. It appeared to her son that the person who robbed his room must have been one of his friends. This resulted in him cutting off contact from many of his social circle and becoming isolated. He stopped trusting the people he knew.

But like I said, the whole point is the effect it had on him. This is where I think this psychosis came from because he was going to every single shop [looking for his things], he was being suspicious of everybody. He banned some of his friends. He even banned... he had his really good Chinese or Korean friend and he thought it was him who broke into the house so he just banned him from coming to the house. He stopped speaking to him.

Perhaps the betrayal of trust was as hurtful as the loss of material goods. It was later revealed the person who had robbed his room was not one of his friends but a relative, bringing a new level of mistrust into the story. While her son believed he knew the identity of the thief, our storyteller did not believe him; she put her trust in the family, which was in turn betrayed.

Yes, after that robbery, I think that's where it really affected him and we didn't know. The reality is, we later found out, the police contacted [son] about a year after the robbery because his passport was stolen, money, everything as well. So we were all scared about identity theft but it later turned out it was my brother's son who broke in the house and he had the same name as [son]. [Son] was suspicious of him and I'm saying, "No, I don't think he would have done it." So it was only when they found the passport, the police found the passport when my brother's son was arrested. The thing is, my brother is a [name of profession] so that was a shock to him so he phoned [son] to see if [son] had given him the passport. [Son] goes, "No, it was stolen," so then we knew.

Then [son] phoned me to say, "See, I told you it was [brother's son] who broke into the house.

The robbery happened at a time when a breakdown of trust was a feature of a number of relationships that are central to this story. Our storyteller believed that her son's godfather, a longstanding friend, had a negative effect on her son's perceptions of her new husband. She described how the godfather changed in the way he related to her and her son, and suggested this may have been because he was jealous of her new partner. This caused her to question how a close friend, who she trusted enough to appoint as godfather, could do something so spiteful. It appears the son may have been used as a pawn for this man's hurt feelings.

Then [godfather] started influencing my son negatively. My son was okay with my husband, my partner at the time, but once we got married my friend switched, then he totally twisted my son. My son wasn't speaking to me for a while.

The situation deteriorated significantly over time. While our storyteller was working abroad, her son was sharing her house with her partner. There were arguments between the two men that were impossible to resolve. The two men's stories of the conflict were very different so the storyteller was unsure who she should believe, her son or her husband.

So [husband] was in the loft, [son] had the whole house to himself. He keeps going up to [husband] to harass him and started getting really rude. Even his cousins would notice how rude he was getting to [husband] to the point of snatching [husband's] phone away, this and that and the other. He was getting more and more aggressive.

After more disagreements between the two men, the situation got so bad that her husband was talking about divorce. The situation could not continue, and the two men could not find a way to live peacefully in the house with each other.

[Husband] was chatting about is, "I want a divorce. I'm not living like this forever." Then [son] is telling me about the altercation, he's not saying what happened, "The guy's a loser," "He's this and that". But what turned out, what I found out from [husband] was [son] went up there with an afro comb and grabbing his phone, he was chatting on the phone, grabbing his phone saying that he'd disrespected me.

[Son's] story is that [husband] was on the phone disrespecting me, or he heard [husband] disrespecting me so he went up there to ask him why is he dissing his mum and then... but [husband] story is he's chatting to his friend, because they're both into music, chatting about music. [Son] comes up there and started shouting at the phone, "You stink of..." and really being disrespectful and shouting so that the person on the phone could hear. Anyway, so yes, he came up to attack him and [husband] goes, "Yes okay, come."

It seems the son was hostile and unable to get along with any members of his family. Our storyteller could not allow her son to move back into her house. She was becoming increasingly concerned about her son's behaviour. The police were called to the house again and her partner made it clear that he could not live in the same house as our storyteller's son. Our storyteller described concerns about being a black woman and having a black son. She, and other members of her

family, did not trust the police following experiences of working with them in a professional capacity in the past:

I know, dealing with the police, I'm a black woman... The thing is, as a black person, the police come to the house to remove one person, they take two black men. I know, I've worked with the police and they are proper racist.

Our storyteller described various events that put a strain on her relationship with her son, including renting out the family home, her son's fears around who will inherit the house, her new husband, and her son's unsettled living arrangements.

I don't feel he's [husband] going to kill me. I have told him [son] that. [...] He [son] thinks that [husband] is going to kill me and get the house. I said to him, "okay. Funny your name is on the will and in the will you will get the house, with or without me being married to [husband]. This will goes to you."

At this point our storyteller had agreed to help her son financially so that he was able to rent a place of his own. When he moved out of this accommodation, the landlord informed her there were rent arrears. She discovered that her son had been spending the rent money on cocaine, although he denied this. Once again, her trust was tested.

She described an incident in which her son had been very concerned the police would come into his accommodation – which now made sense.

The correlation between weed and the fed [police] doesn't make any difference to me. But now I realise why he was so concerned about the fed,

because I got an email from one of the other tenants that he was sniffing coke all day and that shook me to the core because for the life of me, I would have never ever guessed that [son] would have been taking coke. Weed, yes, but coke, that was shocking.

Her son later went to the home of his childhood friend and the police were called. This friend also had no trust in the police but the storyteller advised the friend to get her son to the hospital by whatever means it took. She told him:

"When the police come, use the opportunity. Talk to the police and tell them to take him to the hospital. Just tell them he's had a mental breakdown. Whatever means tell them because he's telling the police people are chasing him with guns and somebody pulled a gun at him. Just tell the police he's had a mental breakdown."

Her son's friend could see how much his friend had changed and he went to the hospital with him. Although our storyteller's son denied hearing voices, his friend suggested that he was experiencing hallucinations. The son saw a psychiatrist in the hospital A&E. He was put on a Section 2 (which allows people to be detained for 28 days for assessment and short-term treatment) and then a Section 3 (which allows people to be detained for 6 months for longer term treatment). Her son responded to medication and although he is much better, our storyteller is still unable to trust him enough for him to move back into the family home.

It's really sad because I would love to give him back his key but I don't want him there when I'm not there and then he's never going to leave.

MISTRUST AND THE CONFLICT OF DISTRACTIONS

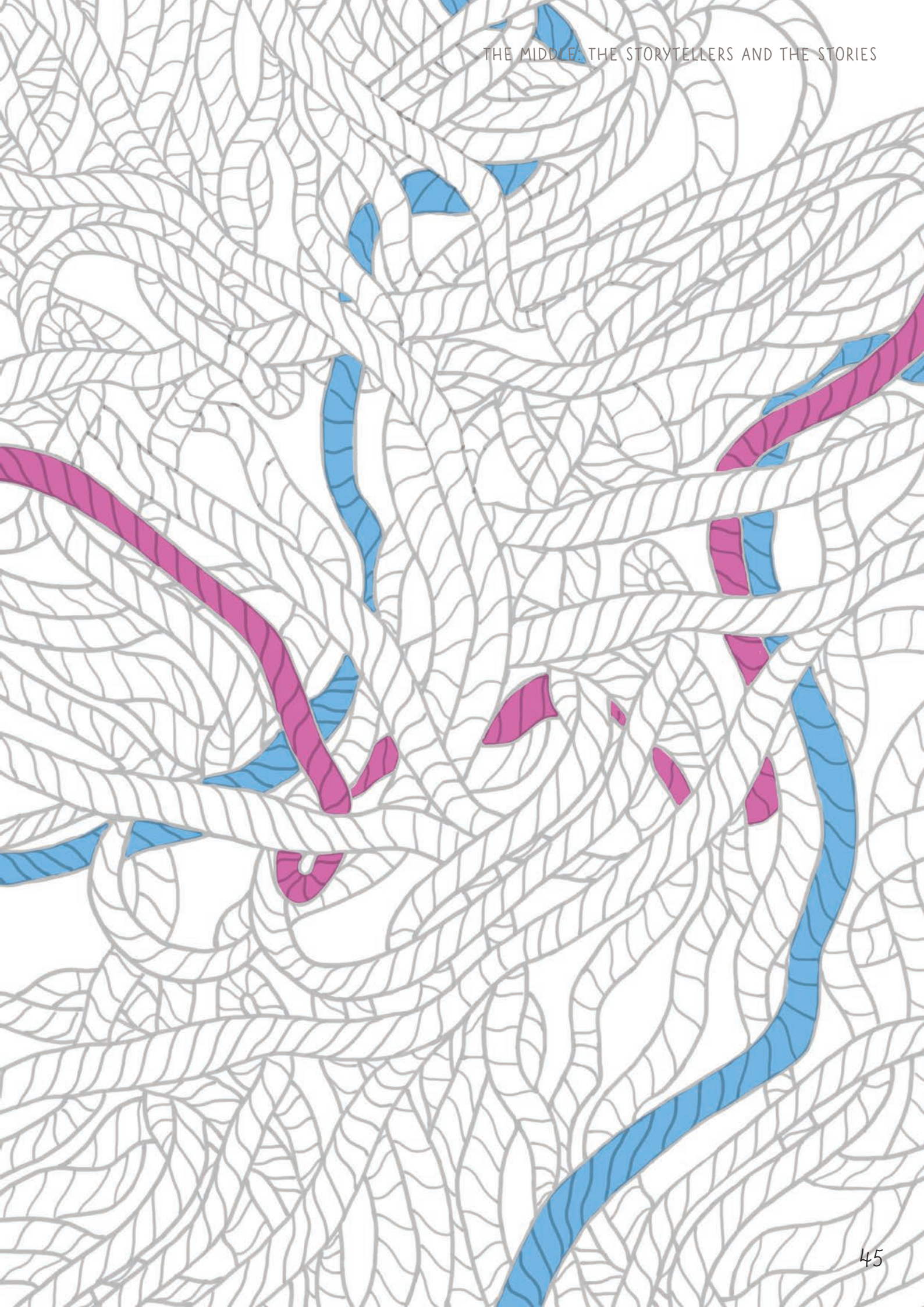
X's reflection

“ It feels like the breakdown in trust across a number of relationships may have hindered the storyteller's understanding of what was happening to her son and her ability to get him help.

While he was displaying erratic and aggressive behaviour, it was difficult for this storyteller to make sense of the situation. It seems that the involvement of multiple people making accusations against each other, may have made it difficult for her to recognise that the changes in her son's character were related to mental ill health, rather than due to a confusing and fractious set of personal relationships.

Mistrust in the police, due to fears of racist behaviour, may have resulted in missed opportunities to get help for her son.

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#4 A story of rediscovering trust

Some storytellers talked about losing trust in themselves, their family and their social circle. Others said that they did not trust mental health services or other authorities such as the police. Conversely, a key component of some stories was finding trust after losing it or developing it for the first time. Several storytellers talked to us about finding people they could talk openly to and put trust in.

One storyteller, with a good career, told us how he had left his job to freelance and how he stopped having contact with his family and friends after winning a big contract. After isolating himself, he eventually became unwell.

I won quite a big job with a lot of money, so I was financially secure, but I started to believe that because I was given all this money, that people were working in the background to build a platform to launch me as somebody very successful. [Storyteller 1]

This really is the beginning of the seeds of fear because I also had a non-executive director who talked about being involved with the Russian Mafia and stuff.

He believed he was destined to become a celebrity in his field of work and therefore wanted to protect his professional reputation. He stopped trusting his social circle, feeling suspicious of other people's motives. He also became mistrusting of the public, believing people had ulterior motives.

So, the first sort of paranoia, "Paranoia One" we called it, was I started to think that my friends were trying to frame me. I was very conscious of it, if I was going to be a celebrity, to have my reputation protected. So, I started cutting off friends and increasing my isolation. I couldn't get any more work, so I got frustrated and went to Brazil for six weeks because I hadn't been on holiday for years, so I went to Brazil and travelled around.

But wherever I went, I felt that there were people following me and I even said to a girl I was with that I felt people wanted my blood, as it were.

On reflection, the storyteller could understand that his fears were a part of being unwell, but differentiating between reality and paranoia was difficult when he first became ill. He spent a lot of time alone at home writing screenplays. The work of creating screenplays took over his life.

So, I wrote my first screenplay and since then I wrote 34 screenplays. That gave me the relationships I was missing with people, with humans, that I was having with my screenplay characters. So, it filled a hole in my life.

During his illness he lost contact with his family, which was uncharacteristic as he was close to them, and lost trust in all relationships. He spent more time alone and as his fears progressed, he began to think there were hidden messages that only he was able to recognise. He refused to see family and believed his behaviour at home was being filmed. His family became concerned when he refused to see them.

When I left the house, I recorded my flat because I thought it had cameras installed in the lights. I thought I was being constantly recorded all the time in my flat. So it was amazingly intense really. So, what have we got here? So, then what happened was I turned my parents away and by the time I turned my parents away at Christmas, they came to take me home, because they go home at Christmas and I just slammed the door in their face.

The storyteller's family managed to get him sectioned. While in hospital, he refused to talk to the other patients and doctors, not trusting anybody and keeping himself to himself. He had previously been very close to his parents, so this period was difficult for all of them. After getting over the shock of being sectioned and an incident where he describes being forced to take medication that had frightening side effects, the storyteller began to re-engage with his family. This appeared to be a turning point for him to start rebuilding relationships of trust.

So, I've always been very close to my parents and I pretty much ring them every weekend. I did when I was ill, ring them. It was only at the end that I then stopped ringing them and so they realised something was a bit odd. So now I'm healthy again I ring them every weekend again, and so does my sister. So, we usually speak for a couple of hours. Yes we've always been very close and [they've been] very supportive of me and everything. So I think they were very scared. My dad cried because he was scared that I disowned them. I did say that I'd disowned them when I was in hospital and they were upset because they thought that by putting me in hospital that I'd never speak to them again, which fortunately hasn't happened. But yes, I've never seen my dad cry really so it was obviously very traumatic for them, very stressful for them to go through.

Having rebuilt his relationship with his parents, he went back to work. He was uncertain whether he'd be able to manage but he slowly began to build up trust in himself again.

REFLECTIONS ON SUSPICION

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“An early sign of my own mental ill health was when I began to believe everyone who tried to contact me, family or friends, had motivations for their own benefit. I wanted to be alone. I was feeling very inspired with my creative writing and just wanted to write.

Every knock at the door was intrusive. Doctors and the police came and put me in the hospital. I felt a grudge towards everyone.”

Having been through psychosis, our storyteller was aware of the events and actions that had caused him to become unwell.

So, it's just being more aware of the triggers, being aware of my vulnerabilities and the triggers that cause my paranoia. So, the fact that I cut myself down, isolating myself. Now I'm much more... like making the film, going to meet-up groups to go and see movies and stuff like that to keep myself socially active.

Having no previous knowledge of psychosis and being unaware of the Mental Health Act and the laws around sectioning, it had been a shock for him to find his civil liberties taken away. It was difficult for him to trust the hospital system.

I'd never heard of sectioning. I couldn't believe they could take my freedom away. I was shocked. I was horrified. I had no awareness that they were able to do that to people, so it was all new to me, so whenever you've been through it, you're like, "Well I bloody well don't want that to happen again".

Looking back, he says that things may have been easier if he had shared with others what he was going through, rather than hiding his psychosis and making out everything was alright.

I just wonder if the more people I had around me, whether I'd have ever admitted these strange things that were going on. I'm not sure I would but I'm just saying that the more opportunities you have to open up and be honest about your situation, the better. I'd reduced it down to such a narrow point of contact that I was able to keep up this front that everything was okay when it wasn't.

Having come to terms with his mental illness, he says he is now willing to talk to other people about the experience.

My attitude is that I was ill, I'm always happy to be a poster boy for psychosis, it doesn't bother me. I'm happy to talk about it. I don't have stigma. For me, it doesn't have a stigma attached to it. I had an illness, I've dealt with it and it's just like having a cold or something like that, you get ill. I haven't had any stigma problems associated with it but also, I don't feel... like I don't like holding back. I'd much rather just be honest.

So I think this public awareness, and that's part of the reason for making the film, it's this whole public awareness of mental illness that there's all about just getting people to talk and not letting people isolate themselves because it's not healthy. I think it's too easy to... like I said, I'd never heard of psychosis.

He has returned to work and regained his social life, which he sees as a way of staying well. He is open about his experience of psychosis with his friends and has regained trust with his family and social circle.

Well I've got a girlfriend so that helps, human interaction with people, talking to my parents regularly, work. I felt a lot happier when I was at work so work is very important. I'm very focused on getting some work. Yes, and socialising. So I was quite lucky at the last place I went to, we used to go down to the pub on a Friday, which was quite nice. Nobody knows I'm ill. They're shocked when they discover I was ill because I'm quite normal now. So yes, I quite enjoy being social, which is the side effect of not isolating myself. I make an effort.

This man's difficult journey through psychosis seems to have made him stronger. He regained good health and has recovered trusting relationships with his family and friends.



#5 Feeling trapped in a vicious circle



A couple of people talked of feeling caught in a cycle of difficulties, and of searching for a way out. Both described how drug use sustained the cycle.

The first of these, a young Black man, talked of an unstable childhood with a father who was often absent for long periods. His parents came to the UK from a country in Africa and his early life was affected by this move because his father had to keep returning to Africa due to immigration problems. He talked of the instability of his family life, living with different family members and his parents having different partners.

She was married twice that I know of, and the same with my dad, you know? I've been living with dad before, I've been living with my mum before. I've lived with my uncle before, I've lived with my aunt, I've lived with my cousins. I've moved around quite a lot and that's just because I didn't feel okay and they didn't feel okay with me, you know? So, moving around,

you're not stable. You're sometimes in a place where you know you're becoming a burden but you can't do much. If you had the money you would do different. But, you can't. It was kind of a rollercoaster ride for some years. [Storyteller 6]

He also described a culture clash caused by not belonging in either place: "So, growing up here and being kind of like you're from back home, sometimes having to bring back home here, and going back home and they don't get you."

His parents split up when he was seven and he described them as telling different – but misaligned – stories about what was going on. As a teenager, he spent a lot of time with friends who got up to "a lot of mischief" but he did not join in with this at first. There was an overall sense that he did not fit in with his friends and peers. He talked of liking jazz but peer pressure discouraged him from enjoying this. He liked indoor sports but "it just wasn't cool".

He began using cannabis at school and eventually it became a habit. He was thrown out of his home and became homeless. He entered a cycle of repeated arrests and hospitalisations that he found hard to break out of.

I was becoming aggressive to some people. I was going to places I shouldn't and being picked up by the police. Once it becomes where you have legal problems and some social economic problems at the same time, you find yourself in trouble. And, I kept getting in trouble and it kept flagging as he's unwell. He needs to be sectioned. So, I would go back to my mum's place and I wasn't welcome. I would be... like kind of... the police would be called by the neighbours because I wasn't supposed to be there. The police would be called by my mum and then the police would just keep sectioning me and taking me to hospital. So, that's why it's happened so many times. Not that I've been unwell repeatedly. But, just that I'd been in some places where I shouldn't be.

I believed I was going crazy and nobody would know what was going on and that I would just be on drugs forever and they would be giving me all kind of concoctions and I would never leave the system. You know, it was a cycle where I would keep getting arrested. The police would keep bringing me to hospital. It was just not stopping. You know, it kept happening. The sectioning kept happening, the arrests kept happening. I went to jail a few times and they remanded me a few times. It was just a cycle that wouldn't stop until I met [name of service]...

Finding the Early Intervention in Psychosis service was a kind of breakthrough. He managed to move himself to a different place in his life with their support. The service gave him practical support as well as the opportunity to talk to a psychologist, which he found reassuring: "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." They also helped the family to understand what was going on for him.

Finally, he felt that he was breaking out of the cycle of repeated arrests and hospital admissions.

I've met some very helpful people. They have made me feel welcome at the service and I've moved on with my life in a good way. They helped me when I had no other person to go to that was like a professional, to get help from.

And, really, what they did for me is, when I entered the community again to have someone to go to, to go and see. To have people around me that could follow-up my progress and it was all about me not going back into what I was in before and making sure it was not a recurring cycle and making sure that if I need any help with employment or housing or financially, that I would get it.

Looking back, he was able to take responsibility for some of his mistakes as well as appreciate the opportunities that the service had given him. He also described having one good, loyal friend and finding an appreciation of his own skills. Music was a great help: "I don't know how to explain but when I listen to

music I feel more okay in myself, listening to the right song at the right time."

Reflecting on his start in life, he was able to understand the peer pressures that had influenced him and to also re-connect with his younger self and the hobbies and interests that he once enjoyed.

They just hang around and smoke with people or make trouble with people. They want to do the typical young black guy stuff. I didn't like all the young black guy stuff, is what I'm saying. I didn't feel comfortable stepping out of there until a few years recently. What it was like, you sit by yourself, you have an opportunity to talk to different people and you say, "This is not me." I just kept saying to myself, "This is not me. What is me?" I had a notebook there and I wrote down stuff in the notebook and I would show people. You meet people and you talk to people and they want to know about you. There was not much to say about myself so I knew I had to pick up some hobbies. I knew I liked stuff before so that helped me draw a conclusion that I should get into what I liked before, as an adult. It's not too late. Galleries I will visit.

He expanded on this by describing how the environment in which he grew up had limited his and other people's expectations, and the extra effort it took to break out of that.

But over time influence takes its toll on some people. So they can't do exactly what they should do. They can't behave in the way they ought to. It's like a step backwards. So what they want to do and the way they want to behave is fine and dandy, they can if they want to but it's more difficult for them. Home is difficult, the estate is difficult, school

is difficult. There's a lot of obstacles placed in front of them that make life a little bit where they have to work twice as hard. They might want to be a certain profession they can't do because there's no support. They may want to help people and it's not cool to help people. A lot of stuff is frowned upon and a lot of stuff is just really difficult for them.

There was a sense in his story that finally he had found his place in the world. He was volunteering with homeless people and had been on a training course. He was also considering going back to study, as he had left school with poor GCSEs. He described himself as "submersed in the music culture" and had recently brought a drum machine.

I see myself as being a lot more stable. Before I was very inconsistent in what I did. I would start stuff halfway and leave it. I would have interests in one field and just kind of hopping from one place to another. A lot of bouncing around is what I did over the years. I wasn't settled. I wasn't consistent. I wasn't showing signs of someone that is dedicated to anything. So, now I've become interested in what I'm interested in and I take it seriously and there's been no problems.

All these things together led him to feel that he was currently in "a great place".

...with the support for me. So, these kinds of things don't happen again. I've become a lot older, this was a few years ago. And, I've matured. It's helped me mature, you know? Having a long time to think, having my own place, being financially independent, working with people who have problems like myself, but maybe more so than myself.



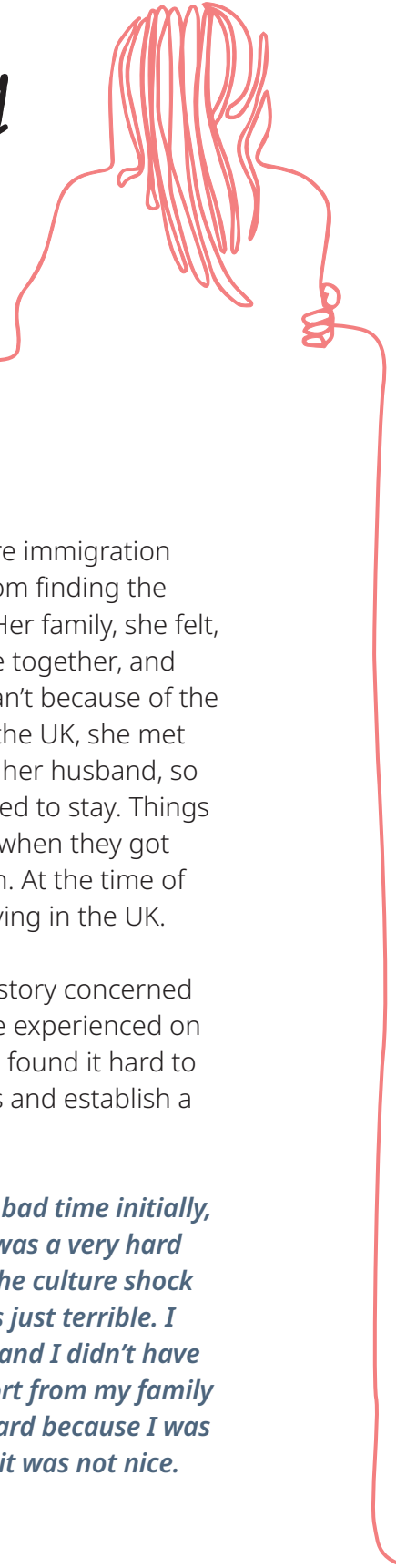
THE VICIOUS CYCLE OF MEDS

A joint reflection from XXXX and Dolly

“ Our own experience of a vicious circle is around medication. They give you anti-psychotic medication to stop the voices. Anti-psychotic medications have a sedative effect – they take away your sense of self and your ability to do things that are meaningful to you. You feel disconnected from the world. So you become depressed, and then you are given anti-depressants.

The depression feeds into your psychosis, into the negative voices. So you have more anti-psychotics. These come with side effects, such as dribbling, obesity, diabetes and a lack of motivation, so you feel more unwell than when you were only hearing voices. ”

#6 A story of loss and searching



We have written elsewhere of strong themes running through many of the stories – of loss, immigration and unstable housing, and the implications of being homeless and rootless. For a couple of people, this connected with a narrative theme of searching – for a home, for understanding, for meaning and a sense of belonging.

One woman, born in India, moved to the UK in search of work, a home and family. She began her tale of searching with the loss of her father when she was very young:

That's why you keep looking for a father figure in your life, mentors or things like that and people who might be just like him a little bit. You keep looking for it in your life. [Storyteller 7]

She lived in another country for a while, where she had wanted to settle, before coming to the UK as a second choice.

Even after arriving here immigration laws prevented her from finding the security she needed. Her family, she felt, wanted them all to live together, and she told us that “we can’t because of the immigration laws”. In the UK, she met the man who became her husband, so she was more motivated to stay. Things became more settled when they got married and had a son. At the time of interview, they were living in the UK.

A major theme in her story concerned the “culture shock” she experienced on coming to the UK; she found it hard to form good friendships and establish a sense of belonging.

I did have a very, very bad time initially, from 2006 to 2008. It was a very hard time for me because the culture shock was quite huge. It was just terrible. I was almost homeless and I didn't have any money, any support from my family as well. It was quite hard because I was in a new country. Yes, it was not nice.

She found people in the UK to be “very busy and... very individualistic”, focused on their self-development, their own goals and achievements, to the exclusion of what she described as “the social bit”. She saw mental health facilities as the only way she could find someone to confide in. In her own country, she said:

Building a friendship is quite easy and there are just so many people, you never feel isolated because there's just so many people all around you all the time, you don't have time to think about yourself. Whereas here, you have a lot of time to think about yourself, to introspect and to think about yourself but that's a bit too much I feel.

She compared this to the individualistic culture in the UK, where people are not expected to talk to strangers.

Here, I feel sometimes it's almost like everybody is so quiet and everybody is made to be so quiet that it's almost like you're killing people by the quietness. You're killing people by not letting them speak, I mean on the tube or on the buses, it's just like I feel like we are humans, we're supposed to socialise, we're supposed to speak out but the culture is such that I can't go against the culture I feel. I have to adapt and I feel maybe the adapting has taken its toll.

The trigger for her period of psychosis was a falling out with a friend, a not insignificant incident in the context of her search for human connection. At the time, she was tired from a lack of sleep due to having a young child. She began to see things and to hear voices.

Not all these manifestations were negative. One of the voices was her father: “It's a good voice” – and she experienced some of what she went through as a form of spiritual awakening in which she was channelling information from other beings, some of whom she described as coming from the future. She began a new search: for meaning and understanding in relation to her mental health and her spiritual awakening, but also for someone to talk to about what was happening to her.

She demonstrated a sophisticated understanding of the culture and attitudes surrounding mental health in this country. She was clearly aware that she needed to keep her spiritual explanations to herself at times but was also critical of a system that relied on medication as the main form of treatment. She described her experiences with her psychiatrist as frustrating and said that she had wanted to talk to them about her experiences but found they were unreceptive. This had an impact on her ability to make sense of her experience.

It makes you feel, I don't know what's the word, lonely or isolated or whatever. It just makes you feel not happy because you've gone through this incredible crazy experience and you want to share it with somebody and you want to maybe sit down and just try and understand it. In some ways it might be true, who knows. It might be true that maybe there is a race of aliens and they tried to contact me, I don't know. I should be able to say that, that's my point of view, without being laughed at, without feeling... at least I should be able to think that way or at least have that freedom to think this.

She felt obliged to take medication to prevent her son being taken away by social services – she felt that social services were only interested in whether she was complying: “you’re taking medication because you’re putting everybody at ease”. This further compounded her sense that she could not talk to people about her experiences, making it difficult for her to make sense of them.

She finally found someone to talk to at the mental health service when she was referred to a psychologist – someone who did not dismiss her search for meaning within a spiritual framework. She had spent time and energy seeking an understanding of her own experiences and had finally found a person to share this with.

I just don't want to be labelled because of my viewpoints, to be crazy because if I've gone through this experience, I can say... I don't call it a spiritual awakening, nor do I call it a mental health problem, I just say it's an experience because at the end of it, it's just an experience. You're going through that sort of experience which is different, which is not normal. It makes you do things differently. It can be ultimate reality, it can be several different things. But I should be able to voice my opinion and be able to talk to people. I think that's what is needed in mental health facilities.

Her observations about mental health services included the need for people to find someone on their wavelength to talk to early on, before professionals leap to medication or diagnosis. She also spoke of needing to go somewhere quiet to begin to make sense of things.

She described the language of mental illness and diagnosis as creating stigma. She suggested that regarding it as a “special experience” might encourage more people to talk about their experiences and others to listen.

There should be a place where, without thinking, without making them... firstly, the whole mental thing is debatable, whether it is something you should consider as a stigma because the word mental health itself is wrong I feel. You are saying that this person's mental health has broken down.

I think that's why it creates the stigma. If you called it more experience or whatever, special experience. It is a very special experience which people go through and they need more support for it and be able to talk to more and more people who have also gone through that.

...you still need people to talk to about your theories and the things that you've experienced even though how crazy and far-fetched they sound. You still need that safe environment where you feel accepted and not being laughed at and understood.

She felt that without the freedom to talk about the experiences she had been through and her beliefs about them, she was at risk of losing her identity. In her own culture, her beliefs might have been understood alongside “gods and goddesses, stories where people were flying. We have that culture of having those things, whereas here you have to be a bit mental.”

The moment I say it, people laugh at it and you're like, "Okay, am I not supposed to think that way." So at least you should have that freedom to say, "Yes, it might be possible." If it was possible then I should be able to think more about it. But whereas I feel here, because you're laughed at, you stop doing that. You ignore it and you have to live this bleak life which doesn't... you're not supposed to think about God. I mean sometimes also people laugh at religion.

Interviewer: *So you're having to deny a part of yourself almost?*

Storyteller: *Yes. You're kind of losing your identity.*

Her story ended with her intending to continue her search by moving to another country with her husband and child – somewhere new to both of them that might start them off on a more equal footing.

I'm hoping that the next place I go to is a lot more friendlier and easy for me to make friends too and people who I can confide in and can build that relationship where I don't have to feel as if I don't belong.

Looking back on her story, she said:

I'm afraid that what has happened to me is due to not having that support and not having that family and not having the friendships which I'm looking for.

The interviewer described the tone of her interview as sad but spiritual: "I get a sense of restlessness in her, a seeking of peace and home."

A SPACE TO EXPLORE MEANING

Dolly's perspective

“ I mourn the spaces that psychiatry doesn't want to provide – a place to explore truth, meaning, trauma and pain with someone who has got your back instead of trying to pathologise everything, and pretending none of it is normal for a human to do.

Where can we have difficult and uncomfortable conversations without coercion censoring people in the most demeaning of ways?

”

#7 The frustration of negotiating services

Many of the storytellers talked of the difficulties they faced when trying to access services or negotiate care across services. One of the stories in particular, told to us by a woman about her son's care, demonstrates how inappropriate care and difficulties accessing services can cause distress both to the service user and to the person who cares for them.

This storyteller described a series of difficult experiences trying to secure appropriate care for her son, who has both Asperger's syndrome and bipolar disorder. She described experiences with services that were very mixed.

At the outset, she spoke with high regard for her son's care co-ordinator and Early Intervention in Psychosis services, as they appeared to have understood the complexity of her son's situation.

We thought he was well, very well, better than he had been for over a year but then he had another relapse just two weeks after that. In both relapses, me and his care coordinator with the Early Intervention Team, who is fantastic by the way. She is absolutely marvellous and the doctors are marvellous. [Storyteller 10]

However, when her son needed to be hospitalised, she described a very different experience. During these times, she identified staff's lack of understanding of Asperger's syndrome as contributing to difficulties in securing appropriate care for him.

They offered some support to the staff on the ward because code of practice says that if they lack the expertise, that they have to call in and get professional advice. I understand that [unit] did go and offer advice on how to deal with patients with autism and in her words, she said, "Well, some of the staff were receptive but others just thought it

was a waste of time." I can understand that. Not everybody wants... if you don't know anything about autism and you've got somebody who is in their 20s but actually their emotional age is about 12 then they can just seem irritating. We're always blamed for bad parenting.

On at least one occasion she and her son experienced a significant failure of care. She described the staff's lack of understanding and their resulting failure to appreciate his vulnerability as contributing directly to a sexual assault on the wards.

He's also gay. While he was on the ward he was groomed by another patient who'd been there for about a day and a half. They knew this. They chased [son] out of the other guy's room at one point and then the guy persuaded [son]. [Son] was consensual to start with and then as it went on, he said, "No." Staff intervened because they found them, they could hear them in the wet room. They called the police. The police came and they asked [son] whether it was consensual and he said, "Yes," so the police went away. The police then forgot to write a report about that so the [name of unit] didn't get it until two and a half days later.

[...] So between the police and the hospital, they failed to keep him safe. [...] They were negligent and this again comes back to what I was saying about the lack of communication, that the serious incident investigation report from the highly redecorated version that we saw, makes it plain that the other guy was a risk factor, that he had a history of sexual offences. This information was buried too far down the notes so that staff were not aware of it.

Throughout her story, a lack of resources and a lack of beds, in particular, were identified as causing problems for her son, putting him in a number of unsafe situations. For example, following his assault, he was left to spend more time with the perpetrator as there was nowhere else for that person to go.

So the first time [son] was sent to [name of hospital and area] was when he was assaulted by this other patient, and I call it an assault even though the hospital call it a relationship. The other patient remained on the same ward for 48 hours afterwards. Son was being told not to speak to him although the guy was trying to engage with him in the corridors and communal areas. I mean it was just quite outrageous. [Son] phoned me at one point saying that one of the nurses had threatened to take his leave away if he spoke to this other guy again. I went and asked that nurse about it and they said no they would never have done that. They might have said he would be timed out to his room. Anyway, so that guy had to stay on the same ward for 48 hours because there was no bed available in the trust for them to move him to.

On another occasion when her son was very unwell and they went to hospital, there were no beds across the country which meant that he was sent home from A&E rather than being admitted for care.

When we got to A&E, triage saw us very quickly and then we went to sit in the psychiatric liaison waiting room. [...] Then we saw the psychiatric liaison nurse after about an hour, which was good. She said, "There are no beds available anywhere, nationally, not even in the private sector. Take him

home. Get some over the counter Promethazine". It's an antihistamine in fact but it also helps you sleep and is often used for psychiatric patients to help them sleep, "Get some over the counter Promethazine and I'm sure he'll sleep." I said, "Can I talk to the duty psychiatrist?" and was told, "The duty psychiatrist will tell you exactly the same thing, there are no beds available nationally, not even in the private sector." If he'd been brought in under a Section 136, we'd have got to stay but because he came voluntarily, ill as he was, and he was obviously ill.

After he was sent home from A&E the situation deteriorated significantly. Antihistamines were an inappropriate response to the situation, and as our storyteller had expected, they did not work.

Anyway, so we went back home, got the Promethazine, it didn't work. He didn't sleep. [...] So he went out about 7:30 in the evening. He kept in touch with me on the phone. Then the last I heard of him before his phone ran out of battery was 11:30 in the evening when he said he was on a train to Watford. So I called the police. I said, "He's not very well and he's in danger of getting himself into situations that could be harmful to him." They couldn't do anything but they took a missing person report. Anyway, he disappeared all night, came back under his own steam at about 7:30 the next morning, very distressed, very agitated, babbling complete nonsense. [...] A guy had invited him into his flat, total stranger, and tried to steal his boots off him, chucked him out. Then he approached a taxi driver who got a baseball bat out of his cab and threatened [son] with it. It's kind of a blessing really that he was quite as manic as he was. I think

people wouldn't come too close. [...] So he could have come to quite serious harm during that night. He could have done serious harm because he was so out of it.

The storyteller described her efforts to get her son appropriate care in a safe environment. The stress she was under is palpable throughout, as was her frustration trying to negotiate with healthcare staff who were, at times, very unhelpful. Her negotiations sometimes revealed conflict within the teams who were supporting her son.

But the biggest problem I have is that the teams don't talk to each other enough, they don't spend enough time on the individual. Or if they do, they're arguing amongst each other and that I found most dispiriting, to be in a ward-round meeting where the psychiatrist in charge of [son] has almost shouted at the care coordinator who was doing her best to try and get these forms filled in for the replacement and him almost shouting at her, "It's your job, you do it." She couldn't do it because the nursing staff wouldn't do it.

At other times problems emerged where staff in different services did not talk with each other, or with her. This had a disruptive effect on the care he received.

See now [we] think we've got it sorted out by trial and error that he has medication of the very strong kind that we can apply either as a family or the care home if ever he looks as though he's on the binge of not sleeping. He goes up so fast, two nights without sleep and that will be it. So we did that. That was a learning lesson that any team would have had to try and I understand that psychiatry is a fine art. You try something, see

how it works, try something else, see how it works. If you've already tried something in the hospital, noting take Clonazepam away too fast or any Benzodiazepine for him, take it away too fast and he'll start going up again. It's visible within two days. Now, if the hospital knew that, how come the outpatient team didn't know that when they reduced his Risperidone? How can we get no information about what exactly was being given to him in terms of benzos while he was at [name of hospital]? The liaison isn't sufficient. If they're going to put people out from them into the private sector, they have to have much better liaisons.

She also described problems that occurred when her son was admitted to a hospital that was out of the local area. When he was placed outside of his 'home' service's catchment area, the local team were no longer inputting into his overall care or being informed of any ongoing treatment. Staff at the out of area hospital refused to talk to her about his care over the phone, which meant that it became difficult for her to understand what was happening to him.

The care coordinator couldn't go and visit [son] while he was out of area, not allowed to. Her manager won't let her because it's too far away. So while [son] is out of area, the care coordinator doesn't know what's been given to [son]. I don't know what's been given to [son] because if I ring up the place down at [name of the out of area hospital], they say, "We can't give that information out over the telephone. You'll have to come and visit. Talk to the doctor." So I have to take a day off work because the doctor is not there at the weekend. £40 travel as well on a Sunday because you have to have taxis from [name of place] to this place.

What would have been better there is more communication. I just think it is a big problem that the teams are not communicating effectively with each other. There are too many team rivalries, that the hospital staff, lots and lots of them are fantastic. There's a few bloody-minded jobsworth but you get them in any profession.

At times, she experienced behaviour from staff that was discriminatory towards her son. Staff assumed that her son did not have capacity to consent to sharing information with her or other services, rather than assessing his capacity to consent. This storyteller was aware of her son's rights under the Mental Capacity Act (2005), in which the emphasis is on assuming that someone has capacity unless proven otherwise.

A few days after [son] was assaulted, I went charging in there furious to the ward manager, demanding to know how on earth this could have happened while [son] was detained under section on their ward for his own safety and they couldn't keep him safe. Now, instead of just telling me, "There's an enquiry under way and we'll be able to tell you more, we don't know the full facts yet, we will find out and let you know," I would have gone away. Instead, what he said was, "Oh well, there's not much I can tell you because [son] hasn't given his informed consent to share information with you."

So I produced, out of my bag, the informed consent form that I'd already done when I'd previously claimed for some lost property so there was the form. The ward manager said, "Well things are not quite so simple as that because there's also the issue of whether he has capacity to give consent." This is what I'm pursuing as a

complaint because there's absolute... I mean that's a cavalier way of using the legislation, legislation that's supposed to protect somebody whose interests might be overridden by unscrupulous or overzealous staff and family.

It's supposed to be individual decision based. It's not supposed to be a blanket assumption that this person has no capacity. I don't know the law in detail but I've read enough about it to know that each thing has got to be done as a decision based thing with the proper support and the proper explanations.

Our storyteller explained that his capacity had not been formally assessed, and she felt that the staff were working on an assumption that he would not have capacity to make decisions (contrary to the Mental Health Act). She felt angry about this because if they assumed he did not have capacity to make decisions, he would be denied the ability to make choices about his own care.

But to use it in that way, as a cloak, "You're not going to come past this because we're not going to give you information because it's confidential even though this person has said that they're happy to share the information with their mother, nearest relative, no, you still can't. You still can't because he lacks capacity." So they seem to be hovering around this assumption that [son] lacks capacity for anything. I mean where does that leave people who are locked on wards? I'm still outraged by it.

A number of times, she felt that her own experiences of caring for her son and the expertise she had gained through doing that were ignored or belittled.

But there is a kind of ethos at the [name of hospital], not on triage, we've now sampled three of the four wards, a kind of ethos on certainly [ward], where [son] was ten months, that carers are an unnecessary intrusion. The involvement of carers I know is part of the triangle of care, it's part of the Trust's policy [...] No, it doesn't happen. It happens with the community team because the community care coordinators are fantastic but they're overworked.

So for example, one thing that I suggested to them, because they kept saying, "[Son], don't do this. [Son], don't do that. [Son], if you want to come off one to one, you've got to stop doing blah, blah, blah." I said, "Look, why not give [him] a list of three things or five things that you would like him to do every day. If he succeeds in doing it, give him a reward." "We can't give rewards here."

I said, "Well look, he likes poetry, just Google a poem and print it out. That will take 30 seconds and he'll take it away and read it." They did it for about two days. It's alright, I kept doing it. I sent him a text poem every day. But you would have thought just finding something that an individual patient actually likes, showing that you're actually paying attention, that you care, could actually alleviate half an hour's worth of struggle.

Several times in her narrative she explained that because her son's situation was complicated, a flexible approach that was able to take into account his Asperger's syndrome would have been best for him. In particular, she identified points in her son's treatment in which staff were unwilling to see him as an individual and insisted

on applying strict rules to him which were likely to exacerbate, rather than calm, the situation.

...if you're on one-to-one [observation] on that particular ward in the [hospital], that particular ward follows [hospital] policy to the letter. If you're on one to one, you're not allowed off the end of the ward, not even down to the garden, not even with an escort. You have an escort stuck to you 3ft away and yet they kept him in there 32 days. [...] No fresh air at all in the hottest time of the year. No fresh air and no exercise. There's a gym in the basement but no. It took four and a half months to get the referral for [son] to go to the gym but you can't go to the gym if you're on one-to-one. You can't go to the garden if you're on one-to-one even though the garden is enclosed now. It's absolutely shocking.

I kept saying, "What [son] needs is... look, you've got somebody who is there on one-to-one with him for his protection, not because he's getting violent." Well, maybe he did because fights did break out but, "You've got one person who's assigned to him, why can that one person not take him down to the garden? Why can that person not take him down to the gym?" "Oh no, this is the policy and if you start bending the rules..." This is what the nurses told me.

"If you start bending the rules for one patient then you have arguments with every other patient." One size fits all. But what you needed was something in the middle, a part of policy. This is another type of observation.

Through her narrative it was clear that this storyteller has become knowledgeable about many aspects

of mental healthcare, likely as a consequence of needing to negotiate a complicated system while attempting to secure appropriate, safe care for her son. While talking to us she was able to quote figures and findings from official reports on different aspects. For example, she had this to say about hospital beds:

Other things that could help? The CCGs and [Trust] build appropriate hospital accommodation for at least 20 people, if not more because if the Crisp Report is correct and 16% of patients who are currently on acute wards are well enough to be discharged but there isn't anywhere for them to go, then that would alleviate the pressure on the beds if there was somewhere for those patients to be discharged to but that's a political one. I mean it's a huge thing.

The reason why [service] are spending three times as much... the beds at the [private hospital], the ward had 17 patients on it and each of those patients on just that ward was an NHS patient at more than £500 a night. [...] It's only going to get worse but [Trust] could actually make things a lot better for people in the London area by providing the hospital beds that are needed.

So they either have to build a new acute hospital or they have to build the accommodation for that 16% of people who are well enough to be discharged so that they're not at over 100% capacity.

We know that it's over 100% sometimes because occasionally you'll find somebody who hasn't been quite discharged, camping out in one of the sitting rooms because there are no beds.

We felt there was a notable difference in tone to this narrative compared to the others. Elsewhere, there was often a palpable sense of confusion at some points. In contrast, this storyteller spoke with clarity about what should have happened to her son, and a clear sense of anger about what actually happened. She was able to pinpoint where aspects of his care were good and where it was substandard. She was also able to identify parts of the system that do not work well together, which enabled her to locate the source of some of the problems in the care her son received. For example, she had this to say about the impact of stretched resources on her son's care:

So last May there was no psychiatrist because the only psychiatrist with the [name of hospital] early intervention service, his mother had just died so he was on compassionate leave and they hadn't been able to appoint a locum. They'd advertised the job. So this is another problem. 20% of the nursing posts are not filled, even though they've been advertised. So they're working with staff who are overworked. I mean accidents are going to happen. I think we're quite lucky that [son] didn't come to much more serious harm than he did but already, I think that's harmful enough.

From a service point of view, 20% of posts are unfilled, they're already stretched. The staff are doing a quarter of as much [more] work as before so quite understandable that they don't want to spend extra time, spare time, their own time learning about autism. Some of them did. Some of them are fantastic. Some of them, especially the ones with children, understood that anything that you do that gets a five or a six year old or a group of five or six

year olds to actually sit and behave, do what you want them to do, any tricks like that.

Listening to this story, we could not help but feel that this storyteller's experiences – and those of her son – had been traumatic. There was a deep sense of frustration and outrage in her narrative and the impact of these experiences on her family was profound.

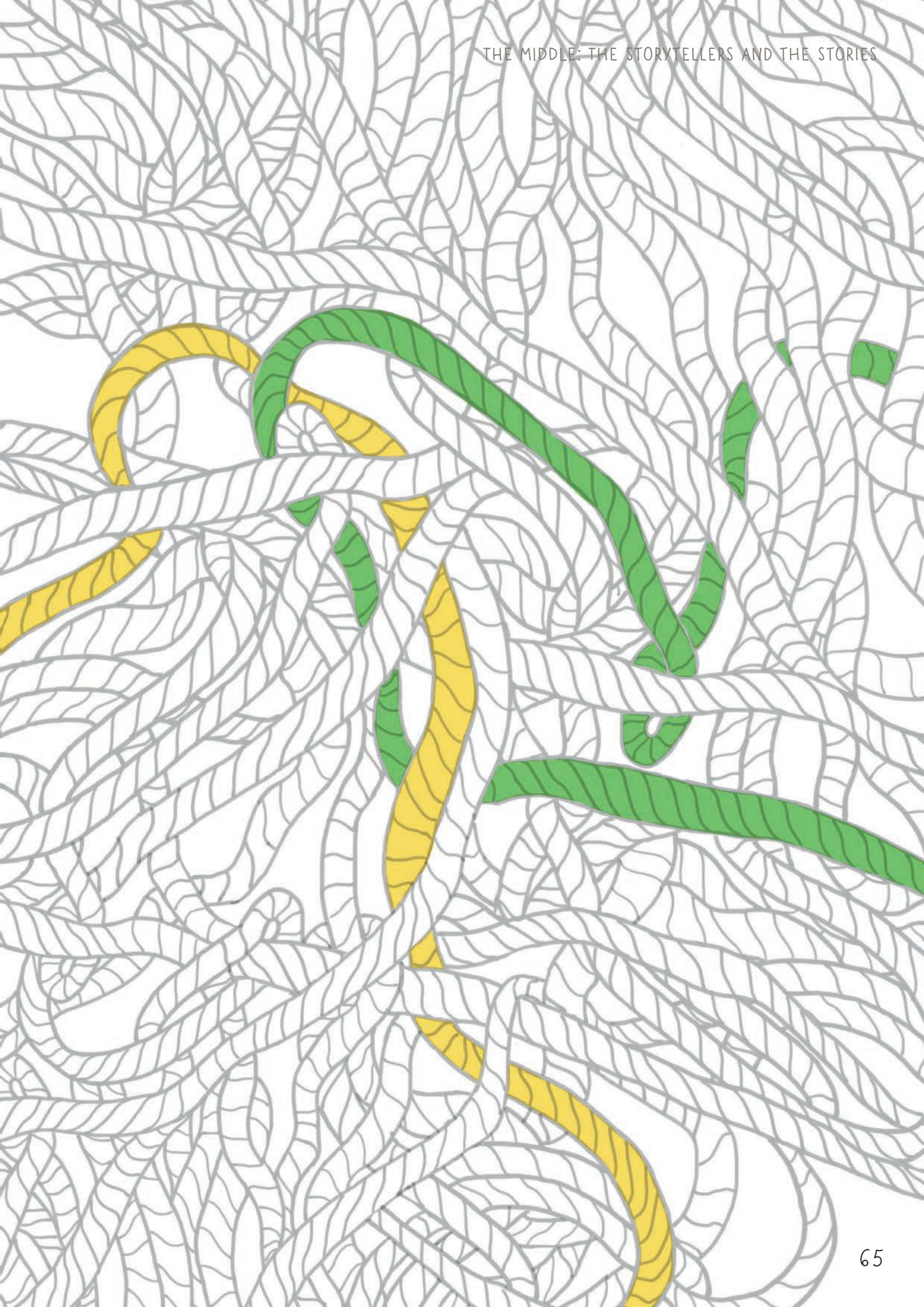
Interviewer: *How has it affected your family situation?*

Storyteller: *Ruined it. But on the one hand, having a kid with ASD, it's already hard work. Lots of relationships don't survive having a child with ASD. The younger one is terribly neglected but he seems to get on with it alright. He's doing pharmacology at UCL. Bad parenting? In his case, yes, lots of neglect but he's just got on with it by himself.*

ANGER AT THE SYSTEM

Dolly's perspective

“Hearing this mother's story made me so angry at how services have let her down. Sadly, this is not a one-off. When will the day come when stories like this don't happen, or happen very rarely? I hope in my lifetime, I hope I don't go to my grave with the system still doing that to people.”



#8 A story of resourcefulness: creativity, faith, family and nature



Many of the storytellers we spoke to were just beginning to live with the implications of a psychosis diagnosis, and some shared the things that they were finding helpful. Different forms of creativity, friends and family, and faith were themes that emerged strongly through these stories. Creativity played an important role in many of our storytellers' lives, helping them make sense of their problems and to remain well. Creative writing and art workshops, often provided by Early Intervention in Psychosis services, were described as a great support to several storytellers.

At our first meeting with a young service user, a shy and softly spoken woman, she created a map of the topics she wanted to talk about. The three main issues important to her were: mental health services, the church and her family. She grew up on a farm with two older brothers and described her younger self as being shy and introverted, with not many friends.

She experienced some bullying from other children. She studied languages at university which she enjoyed greatly, taking the opportunity to study abroad.

I went to East Germany and it was just a year after the reunification. So, it was still quite Eastern bloc. But there was sort of westernisation was just beginning to take root. But it was interesting because it was totally different to what I'd known previously. And yes, so, I really enjoyed it and got to know the East Germany students and got to hear about their experience. And then my second placement was in France, which is the north in the [area], sort of which was nice. But it wasn't so different to what I was used to, a lot of the English-speaking students got lumped together so we all didn't use languages much. Whereas, where I was in [town], there was hardly anybody who spoke English, so I had to practice to get by, and I made a really good friend while I was there and we lived together. [Storyteller 9]

After doing some translation work for a company, she moved on to working in administration for a trade union. This suited her better as she felt she was helping people who needed it.

There was always that sense of satisfaction, in what I was doing, because initially when I was working as a translator, it was just a private company. Their interest was sort of, just making money and that was the only thing. I had some sense of satisfaction from the jobs I was doing, although a lot of the work I've done was temp jobs. It was quite interesting working for the trade unions, sort of thing, so I got to find out about how they operate, and I felt I got to know people – members and representatives.

A lot of it would be people ringing up for advice on their sick pay [laughs] or maternity and that sort of thing, but it was interesting. I enjoyed it and I made some friends, who I am still in touch with, one or two of the friends I've made there. I worked for [council], in Children's Central Care. That was quite rewarding there, in that I was doing something good for the kids, even though I wasn't directly involved in that.

One of her brothers had experienced mental ill-health and died at a young age due to a reaction to the combination of medications he was taking. He was on a life support machine which eventually had to be turned off. There was an inquest into the death, which was extremely upsetting for our storyteller and her family.

After going through the trauma of her brother's death, the storyteller experienced a relationship breakup and had to move home. She then developed depression. She was not well enough to go to work and thought seriously about taking her own life.

The first thing was I'd come back from seeing a friend and I was very, very down and upset and I tried to take an overdose of tablets. I had paracetamols and ibuprofen – I didn't go through with it.

Our storyteller explained that the main reason she changed her mind about taking an overdose was the fact that her parents had already lost a child.

Yeah, yeah. I'm particularly close to my parents and in a way, that's what stopped me from – the main thing that stopped me from taking all the tablets that I had, because I was thinking about my parents and I couldn't put them through that again.

But, well, I sort of started to and stopped midway and I drank about half a bottle of vodka but at the same time... my previous manager phoned me, I think it was the following day, and I was struggling, I was still struggling in the morning and she called an ambulance that came and gave me a check over and she referred me to a, well helped me get a referral, to a counsellor who I saw and talked to for about four sessions [...].

Our storyteller was referred to the crisis team and onto Early Intervention in Psychosis services. She was off sick from work for some time and eventually quit her job as she needed time to deal with her illness.

Yes, that's it. They referred me to a crisis team and a couple of people came round and gave me an interview. My work, I think, referred me to a counsellor, so I had a few sessions with a counsellor, I didn't always... I missed a couple of sessions because I wasn't feeling well enough to go, she said I ought to have gone [laughs], but yes at the time, I didn't.

So, and then, yes, I think the crisis team (over-speaking) then I was sort of assigned to [support worker] [laughs]. And yes, my life changed for the better and I didn't have any idea about what... Well, initially and she was helping me with day-to-day things and encouraging me to go out more and going to college [laughs]. That was a big challenge, as well.

Our storyteller formed a close and trusting relationship with her support worker and brought her along to both interviews with us. The support worker had encouraged her to join creative writing and art classes. Although she was reluctant at first because of her shyness, she now regularly attends and gets a lot of satisfaction from them.

They dragged me to college, yes, and getting home and helping me enrol on the course, which I, yes, I totally enjoyed. I think I was, at first, I found it difficult being with other people at that moment, I was kind of, had all these sort of paranoias, I was really paranoid. [Laughs]. And I was getting paranoid about everything, but I kept going and yes, I enjoyed it. And I've been able to sort of explore my creative side, which I hadn't had the opportunity, or time to do previously. So, I've enjoyed doing that and meeting some of the people.

Although she found the social aspect of attending workshops difficult initially, she persevered and this has become easier. She now gets pleasure from meeting with the other people on the course.

Yes, I'm doing some drawing, which I used to like doing at school and I had to give it up at school because of the option system, but, yes, I've been looking... got into drawing and we've done some painting, as well. And it's a mixture of people, different levels of course, yes. So it's interesting to see, everybody's got different styles.

Art therapy and a creative writing workshop have helped her explore her past, enabling her to make some sense of it and come to terms with the trauma and upset she experienced.

I found the art therapy a useful way to express myself. It mainly focused on my past, I think it associated with my past, what I had been through rather than what I'm feeling now or in the future.

After being unwell, the storyteller described how being out in the open connects her to her childhood growing up in the country and helps her to find her spiritual side.

So I think sort of part of it was growing up in the countryside and now sort of since having depression, it's nice going... I like going out for walks in the park or such things, which is good for my mental health. And I've become more interested in the trees and also my spirituality, I sort of see it in different, slightly different way now.

Appreciating nature, the beauty of trees especially, she found she was looking more at the structures of various trees:

Yes. I think I've been appreciating trees more recently, also doing art as well. They've got some interesting structures, so I'll spend more time looking at the trees than I might at flowers and colourful things. And I got into doing some... got more interested in gardening, when I was living with my former partner and growing things, which I quite enjoyed.

Faith became important too. Being introduced to the church by a friend who had also experienced mental ill-health was helpful. She still attends the services and reads the bible.

I got into my faith, after I started becoming depressed, before I kind of... I was yes, didn't have any faith before, I could appreciate that sort of, how all spirituality benefited people and I went to... going to a village school, lots of them, I'd been to the local church, [...] I had some exposure to Christianity, as a child, but I wasn't really convinced then, I didn't really... and my parents didn't go to church, other than at Christmas, or [laughs] yes, or, for weddings and funerals that kind of thing. But, I'd got a friend, who'd for some time, she's become a born-again Christian, she'd been trying to encourage, influence me in that way, for some time, I didn't think she'd succeed, but she did in the end [laughs] and I think, yes, when I was really at my worst, I didn't think I had a future, and I was really anxious and I always not going out at all. I

got nervous of going out and some of the time I was staying with my friend and she'd also experienced depression, so she had some understanding and yes, she... I think I was more open to believing it, yes, I became more open to it, spirituality and I started... she

CREATIVITY IS A MAP BACK TO ONESELF

Dolly's perspective

“ Luckily, I discovered creativity such as writing and art, which helped me express difficult feelings. I wrote poems about loneliness that made me feel less lonely. I realised I was drawing myself a map that was leading me out of pain and back to myself again. It is the one thing that has consistently helped me in my life and mental health. I think I would still be lost without it. ”

persuaded me to join a fellowship with her friend and we were reading some of the bible and talking about it.

Finding faith in the church gave her hope for the future beyond depression and a sense of belonging. Her support worker encouraged her to keep a dream diary and a journal, which she says she writes in when feeling at her worst.

Thinking about some of the drawings I had done at home, I started off trying to draw some of my dreams and try and represent my depression, thinking about the dreams I have had.

It appears that the art and writing sessions have been a great help to this storyteller, keeping her motivated and helping her to express herself and examine her life. The church and her newfound faith give her a sense of belonging and help her to remain well.

#9 Stories of loneliness and isolation



Many of the storytellers talked about loneliness, isolation or of feeling like an outsider or not fitting in. This was a strong theme throughout the narratives. For some of the storytellers, it was a dominant theme from the outset – loneliness and isolation wove their way through their lives and stories. Rather than picking one person's story to illustrate this theme, we present several facets of isolation and loneliness.

Loneliness and isolation could be a cause or a consequence of mental distress. In Chapter 2, we heard from a man born in South America how the death of his grandmother and his subsequent journey to England to live with his father had led to a homeless and rootless existence. In Chapter 6, we heard from a woman for whom cultural displacement and immigration caused her to be lonely and isolated in the UK.

The storyteller in Chapter 5 talked of losing friends and family when he started to become unwell and began to behave differently. Reflecting on the fact that he did not communicate about what was going on for him at the time, he gave advice to anyone becoming unwell to talk to others and make them aware of what is going on.

I had a lot of friends before my episode and before going to custody and before having issues with the police. But, over time, they hear stories and they don't really understand what's going on and they distance themselves from you and I've lost friends because of bad behaviour. So, I don't blame them. But, I would just say to anyone to make people aware of what is going on the best way you can. I didn't really explain too much, I didn't feel the need to. I just saw it as, "You get what's going on, why are we talking about it, let's not talk about it, can I stay at yours, can I have some money?" And, it's not really normal, you know. [Storyteller 6]

For the storyteller in Chapter 4, distress and isolation coincided as he struggled with paranoia and the idea that other people were following him.

This was really the beginnings of the paranoia where maybe had I discussed it with somebody or talked about it with somebody, maybe the rest of what happened wouldn't have happened but I didn't. I believed everything. When you're in psychosis, once you've been through it, it's easy to then know these are the symptoms but when you're going through it the first time you just believe everything is real. So yes, I believed I was somebody extremely important that was going to be launched as a celebrity and basically my reputation was very important and lots of people were out to get leverage on me. So I was scared. [Storyteller 1]

Consequently, he isolated himself quite deliberately, avoiding contact with people other than his close family.

That started to feed into my second set of paranoia where I started seeing codes everywhere and also, I have an ongoing preoccupation with others having leverage on me so I've really, really now isolated myself completely with only phone conversations to my parents and occasionally seeing them. I've had no friends now for years so it's completely just getting up in the morning, writing, eating, going to bed and I've been doing this for years, in fact five years so it's a very long period of isolation.

He was very clear that isolating himself had not been helpful to his wellbeing, and now had strategies that included remaining in touch with people:

Yes. I won't ever put myself in that isolated position again. I won't ever do the screen writing thing. I have done it now. Hardly any writers have written 34 screen plays so there's no point adding to it. My solution at the time was to cut myself off and write, well, now my solution is to get out there and network.

LONELINESS FOR CARERS AND FAMILY MEMBERS

Carers also talked of facing loneliness with the onset of their relative's mental distress. This was often due to the stigma attached to mental illness, causing friends and family to drop away or making the individual feel they had to keep their distress private. One of the carers we interviewed felt this so strongly in relation to her relative that she barely revealed anything in the interview.

I'm obviously being very careful what I'm saying because I don't want... even though they can't hear me. I could say a lot more but because my loved one is not aware that I'm doing something like this and... for me, the worst thing that could happen is my loved one becomes aware of it. [Storyteller 12]

The most common experience for carers and family members was loneliness caused by loss of support from friends and family, as illustrated by the extract below:

No, they ran away from us. We were lonely because everyone doesn't know what's going on... No, they

don't understand. They just run away, even relatives, they ran away from us... Yes, it's hard, yes. We feel lonely. [Storyteller 11]

A couple of the carers talked of the value of attending carers' groups, where they could talk to other people who were experiencing something similar and feel less alone as a result.

So, I engaged in [carer's group] and then when you start hearing the other carers' experiences, you felt like your problem has been shared, that it's not you alone. So, I find that really helpful because you find that if it's just... you get the feeling, but when you hear the carers that would experience it so, so similar, it's all so similar, you know? [...] because the first time I didn't know anything and one of the parents, when they talked, they told their history of what happened, her experience. I felt like the problem... [was shared] Yes, it's not only you. [Storyteller 15]

ONE STORY OF LONELINESS AND ISOLATION

Here, we share a story in which isolation became a major factor in one man's distress and the onset of his voices. None of the stories we heard fit easily into a single theme, and this man's story clearly illustrates this complexity. His story describes the interplay of threads of loneliness and isolation, stress and drugs, and the 'vicious circle' that resulted from using drugs to manage his distress. In addition, he carries a strong critical voice within him from childhood.

This man was the only child of a single parent. He described his mother as critical several times during the interview, although he also appreciated the support she was able to give him despite her own struggles. He felt it was an effort to live up to her expectations, which then morphed into his own.

...my mum wasn't a bad person but sometimes you just need positive reinforcement and you need to feel that what you've done means something to someone. It was just always an uphill struggle. I think that's definitely where that comes from. [Storyteller 5]

He went to a school he didn't choose, a private grammar school, which his mother could only afford because there were reduced fees for single parents. He felt he did not fit in, partly because he was gay but also because the school placed a high premium on academic achievement and sporting prowess, neither of which he excelled at. He said he had low self-esteem and little self-confidence.

I am gay so at the time in an all boy's school, it was quite a formal grammar school that was all about sports achievements and rugby and various bits like that. That was the only recognised way that you would be seen positively almost in the school so you either achieved academically or you achieved in the sporting sense and if not, then you fell in between. So I fell into that bracket really where I felt that I didn't really belong in the environment and the pressure was coming from home to perform in certain ways.

He traced many of his subsequent difficulties back to this beginning.

So that's looking back as where do I think some of my issues in adulthood came from. So it wasn't putting the blame on mum or the time at the school because it was what it was. As a teenager you don't think of it like that but yes, I guess looking back, that could be the start of where I felt that my identity wasn't really what it wanted to be or I didn't feel that I was comfortable in my own skin, but didn't want to say anything or didn't feel that I could do anything about it because of the family unit and just because we're in a small village, that kind of thing.

He experienced a good period between the age of 18 and his early 30s, when he was working and travelling. However, he faced a major turning point when he was diagnosed with HIV in his 30s. This resurfaced the difficult feelings he had experienced as a teenager, causing him to isolate himself.

I think what that did was accelerate some of the negative things from my childhood, couple it with the status and where that then left me in the present day, with feelings such as denial about the diagnosis. For the first couple of years you live in a bubble of just questioning yourself, your place in society, stuff like that. You have this almost self-loathing element.

So the diagnosis just makes you feel very disgusting almost a) that you've got HIV and b) what does that mean for you and contact in the future? It makes you feel very insular again because you go back into your own little world because you wonder what people's reaction is going to be.

The diagnosis caused him to ruminate a great deal about what to do, whether and when to start taking medication, and who to tell. All this fed into the low self-esteem he felt he started with.

I think a lot of the issues to date when the same themes of self-esteem, not thinking very well of yourself, not placing yourself in the world in a decent way, you don't give yourself a break. You're very critical of yourself. All these things that are within yourself, and I'm a deep thinker as well so I go through this chain of not a lot of action but a lot of thinking too much about stuff and that can consume you sometimes.

Following his diagnosis, he also experienced a number of other stresses in his life. He began to take illicit drugs when things became very stressful and he felt the need for escape.

But yes, I think when I got to a point in my life where I'd had, unfortunately, a couple of close family bereavements, work was very stressful, there was some bad things going on at work, then I, at one point, turned to taking drugs. Very light stuff at the start but yes, that in itself is a cry for help I guess that you give because you're seeking something external or you're seeking some kind of release or relief that just takes you away from yourself.

After he began experimenting with illicit drugs his experience of hearing voices also started. During this time, many of his friends, who he had supported in the past, fell away when he reached out to them, leaving him to cope with these experiences alone. He experienced psychosis as isolating, in that he was unsure who to trust, and found it hard to work out what was real and what could be his mind playing tricks

on him. He described the distressing and isolating impact of the voices very eloquently:

So it was very scary stuff. You're not wanting to react to it because you're thinking, "What is this?" and you're also not wanting to let whoever or whatever this is beat you. So, you don't want to react because that gives them the advantage so you're constantly trying to keep one step ahead of something that either is or isn't happening.

Now, if that's in your mind then you're never going to win. This is your life now because whatever it is in your mind that does this to you, it feels like it's always going to be one step ahead because it knows your thoughts, it knows your movements, it knows your conditioning. But because it felt so real and it felt external that people were doing this to me, then I thought that I could get the better of it, I could get control back so it just sent me potty really, that I was doing things to mask what I actually wanted to do to stop them making comments on it. Yes, you could spend hours just doing things that you didn't want to do to create... it's almost like acting within your own home.

Eventually he sought help and was referred to the Early Intervention in Psychosis service. He was appreciative of the opportunity to talk things through and try to understand his experiences. For the first time, he felt able to share his experiences and difficulties with someone – the psychologist.

So she is the only person almost really, in the world that I can sit there and could, if I wanted, say anything to. Is it because she's a neutral person or is

it just because she knows everything that I feel more comfortable? At the end of the day, if I say something to her, I know that the stuff is private and confidential but I know that I can say it and I'm not having to mask a part of the story or act part of it.

Despite having support from a trusted psychologist, he was not yet ready to give up taking drugs so he still felt stuck in a vicious circle that he could not break out of.

The aim is that I want to stop the substance abuse but while I'm stuck in this vicious circle and things aren't, I feel, going right for me, I feel that if I take that away, the only piece of relief, even though it causes me problems, at least I get a moment of relief. If I don't turn to the substance abuse, I feel like there's nothing in my life.

In our interview, he described the ongoing impact of the voices on him, and at times was critical about how he reacted to them.

I still, even though I'm very rational, I'm about 95% at the moment, believing that it's me, it's myself, I'm creating these problems myself or involuntarily creating these problems. But there's still this 5% that when I'm sat in my flat and I hear a voice and it's being aggressive, it still puts the fear of God into me, even though it's only 5% and I'm questioning all the time that 5% but that 5% controls me. It takes away all rationale and in that moment it just panics you, it makes you feel you're going to be sat in a chair for two hours not moving because you think if you're doing something, it's going to get commented on. It just immobilises you. It freezes you. Before you know it, 12 hours have gone by and you haven't

slept, you haven't eaten, you've missed your medication, all these things that then start to have an impact on your life and you're just not doing yourself any good. But where I'm at at the moment is I'm still trying to chase answers to this 5% because when I'm in that moment it feels so real. To me, for it to feel so real, I think to myself, "I can't be making this up. There's got to be something in this that's real," and I'm still chasing that reduction. I want to get myself to the point where I can believe that it's me.

He has found this experience isolating, as outside of his meetings with the psychologist, he felt unable to talk to people about his unusual experiences. At the time of the interview, he had not been able to talk with other people who had had similar experiences, and expressed a need to meet other people who had heard voices.

I think I need to be speaking and be surrounded by people who are experiencing the same things. I think there's some kind of solace in being able to talk to people who can say, "Yes, I experienced that and I know exactly how you feel in that moment."

[...] I think the only thing that can, at the moment for me, take [that feeling] away is speaking to people who have been through it because they know those frustrations, they've felt it. Maybe I can ask them what they did to get beyond it because at the moment, I feel like I don't have the answers.

REFLECTIONS ON ISOLATION

Alison

“For me, this last story illustrates the power of isolation to create or sustain madness, not just from a mental health perspective in this case, but also this man's identity as both gay and HIV positive. The latter exacerbated his low self-worth; a sense of self-disgust had complicated his sense of identity which had fragile origins. There seemed to be an emptiness that he was still filling by using drugs. The story also describes the value (and the absence) of what is often referred to as 'peer support', but which might simply mean meeting other people who share some aspect of your experience through services or groups. He expressed an awareness of this need towards the end of his story. An obvious example of this would be a Hearing Voices Network group, where people share their experiences as well as strategies for managing voices.”

Dolly

“I had no friends for over 15 years due to having psychosis and there being no support to make friends. I remember one time sitting on a bus and seeing people having picnics together in the sun. I started crying because I felt so lonely and jealous. When a mental health coffee morning started up, that was my first step to breaking my isolation and meeting people. Now I am blessed with lots of good friends. When I am at my most distressed, I become paranoid and I have lost friends because I have pushed people away. Those who stuck around realised what was happening and although I pushed them away, they came back to me when I got better. I wish I could find a way to deal with my paranoia so I don't push people away in the first place.”

#10 A story of positive relationships



We have seen from many people's stories that relationships go through immense difficulties when someone experiences psychosis. Almost everyone said some people left their lives when they became unwell, especially friends. It is hard to avoid the negative impact of psychosis on relationships, but there were examples of positive relationships in some of our stories, and how these protected people's sense of self and mental health.

One storyteller was asked who the important people in his life were:

My mum, my brother, even though he didn't believe me at first, he did come and see me in hospital that time. So my brother. My little sister who's autistic. My older sister as well and my older brother. They had a positive impact on me because we talked. My dad as well pretty much. My friends. My two best friends, J and R understood what I was going through and kept on visiting me in hospital, so it wasn't too bad. So there were things that were positive.

They helped me a lot. They brought lots of things for me as well while I was in hospital so I couldn't have asked for better people. It's just when you go through these type of things, depression, psychosis, one thing that should be hammered is that with good people around you, you'll probably get through it. Especially if you have that – it doesn't matter if it's five or six people, if you have one, just that one person, it'll get better. You just need that one person to help you and obviously it gets better. [Storyteller 3]

He cites positive relationships as one of the things you need to get better.

My mum is very important to me. She is my inspiration. She gets all my things and she is the number one woman to me in my life I guess. She helps me through thick and thin and has always been there for me. She took me to my first football game and came to watch me when I was [unwell]. It's stuff like that. It's always the little things that you remember and the big things and all of it can never be replaced I guess.

Then I have got two great friends, J and R. I have known J for about sixteen years so it's a big... he helps me a lot I guess. He is the one who invited me to the football team on Sunday. He is the one that when I got locked out of my house and I left my keys he said, "Come over to my house. I am not going to leave you locked outside. Come round" and I said, "Thanks." He said, "You would do the same for me" and I most definitely would.

Friendship is a two-way thing and this man was able to see what positive things he could provide in a relationship.

I feel I am a good friend. It's a strength I guess... I'm funny and caring. I'm sensitive... I guess I am always there to listen to other people's problems in a way. I don't really judge anyone because you don't know what they are going through so that's why I feel like I am a good friend. I am not being egotistical about it. I am just saying that I wouldn't hate someone just because they are different from me I guess because they are still the same person really. Nothing really changes.

He talks about what he can do for his friends:

What can I do for them I guess? I always invite them to my house. I can cook for them because I can cook so I could cook for them. We will watch something on TV, maybe a movie or a TV show together and if there is football on we will definitely watch football I guess. I think that is pretty much it. If they were in any trouble or had any illness I would honestly help them as well. I would go and see them. It's like a family thing really.

He highlights how his own experience helped him become a better friend.

Interviewer: So if you could meet someone who was going through similar to what you went through, what would your advice to them be?

Storyteller: First of all I would support them and then I would help them... There's one friend who's, kind of, going through a depression but it's not as worse as mine I guess, but I don't know, maybe it is behind closed doors, but it's not as bad as mine. Because I've told her to go to therapies, talk to therapists. I've done a bit of counselling. Told her to do some activities like staying fit and all that stuff. She's been doing that and it's been going okay since I last checked with her.

One of the people who have had the biggest positive impact has been his mum.

I think even when I was ill I thought she had given up on me but she didn't. She said she could never give up on me. She has done a lot for me really. She is always fighting for me. She just wants the best for me. She taught me how to drive as well. Then again I don't know what more to ask for to be honest. She does spoil me a lot. I don't really care about the gifts and all of that. I just care more about her love.

He emphasises the importance of having uplifting friends and protecting himself from negative people to keep well.

I always surround myself with positive people and not people who are bringing me down. If I stayed with

those types of people who are bringing me down, I am only going to go down with them.

When he was in hospital he found a friendship that continued after they were both discharged, one in which they supported each other and wanted the best for each other.

I did meet one good person when I was in hospital. A good friend. I saw her yesterday as well. We spoke a lot actually and we were socialising a lot. We were talking about 'EastEnders' because we both watched it a lot in hospital when we were there. It was nice talking to her. She had gone back to university and so we were just talking. I said, "I hope everything goes well for you as well." She said, "Yes. You are looking healthy and better" and I said, "Yes."

He has an encouraging and reassuring network of family and friends, which he says are essential to his recovery. He also acknowledged the support he got from healthcare professionals.

I also needed to work on myself as well but yes, the help's been great because I've spoken with a psychologist, I've spoken with my care co-ordinator, both of the doctors as well so it's been supportive.

Among all our storytellers, this young man's experience of relationships was the most positive and the beneficial effects were manifold. Having strong relationships reduced isolation and created a sense of connection with other people and the world. They helped keep him engaged with activities such as sport and cooking that filled his time and gave purpose and

structure to his days. Support, care and encouragement were vital in giving a reason to work on getting better and a sense of hope that it was possible. We need to feel part of the world to have the fight to rejoin it.

His story shows the importance of positive relationships when trying to regain a life after an episode of psychosis. It is the flipside of the other stories in our study that demonstrate how negative relationships can aggravate psychosis and make recovery too hard and isolated a journey to begin or stay on. As this storyteller says:

Glad I didn't kill myself. I'd have hurt a lot of people, I guess... I didn't think it would make a big difference but a lot of people said we would miss you.

THE IMPACT OF RELATIONSHIPS GOOD AND BAD

Dolly's perspective

“ When I have been in difficult relationships, whether it be with family, friends or partners, my mental health has suffered; being in supportive relationships has helped my mental health.

Yet relationships are ignored mostly in the mental health system, unless there is a service like Family Intervention on offer. This is the problem with trying to fixate mental distress purely in the brain, when it is more to do with the heart. **”**



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

X'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.



POSTSCRIPT

Reflections from the research team

To finish, the four researchers who have written this report provide their own postscript. Each is fashioned in a very different way. Previously, we reflected how different our fourteen storyteller's stories are, so it is pleasing to end with a similar observation about our team.

X'S STORY

Having left school early with no qualifications, I worked in various unfulfilling jobs until I took my GCSEs at the age of thirty. I went on to complete the Access to Teaching course which got me a place at university. I had no concrete idea whilst studying Education Studies and an MA in Creative Writing where the courses were going to lead me. I trusted the learning would take me towards satisfying and worthwhile employment.

Accepting the position of Researcher at McPin with only minimal research experience was a challenge for me. Working on the *My Story: Our Future* project is most certainly fulfilling work, putting what I learned at university to good use.

Helping service users and carers to share their experiences of the mental health system in order to improve services for future users is such a commendable piece of research. It has been a great honour to hear the stories of the people who took part, they have shared very personal and sensitive information with us. Some interviewees told us they felt a sense of relief from having shared their experiences with us and it is good to know that the work has had a meaningful impact on people's lives.

Many of their stories have similarities with my own journey, having been diagnosed with schizophrenia and depression in my early twenties. Living with mental ill-health has been an ongoing struggle.

Looking back, I don't know how I survived but I believe what I went through has made me a stronger and better person. It feels good to be giving something back to the mental health system through my work as a survivor researcher.

I strongly believe that the involvement of people with lived experience of mental health issues in the project has reaped better results than if it had been run only by professionals. It hopefully meant that the storytellers felt listened to and understood without the threat of being analysed and judged – which is sometimes the feeling one gets when sharing information with mental health professionals.

The work has improved my confidence and senior staff have encouraged me to do more public speaking (my greatest fear) without putting me under pressure. They have also given me help with my application to undertake a PhD in Creative Writing.

I have learned many new skills not directly related to my research role: being on the interview panel for the recruitment of new staff and helping to plan the future direction of McPin, for example. I have also been asked to get involved in other projects. Feeling valued as an employee and having a sense of purpose has had a knock-on effect on my social life as well as my work.

It would have been helpful to me if the *My Story: Our Future* project had been happening when I first developed mental health problems as I had a lot to say but nobody to listen.

THE IMPORTANCE OF DEEP LISTENING

Rose's reflection

“

I took over the coordination of the *My Story: Our Future* project in May 2017, not long after it had received ethical approval.

At that time, the researchers had conducted a number of interviews with people who were carers but were only just beginning to interview people who used early intervention services.

I was fortunate, from this point on, to co-lead the interviews with the survivor researchers. While I am not a researcher with lived experiences of psychosis, during this time I have become increasingly aware of how one aspect of my own experience has influenced this study.

In 2015, I spent a year volunteering at Maytree, a suicide crisis shelter based in London. My role was to talk on the phone or in person to people who were feeling suicidal. The word 'talk' is misleading here. Really my role was to listen, and to listen deeply. Before I began volunteering there, I went through 6 weeks of intensive listening training.

Once there I was surprised by how much people were willing to open up about their lives to me when I put my energies into listening. I feel this experience had a marked influence on the way we conducted the interviews in the *My Story: Our Future* project.

”

THE THING ABOUT LIVED EXPERIENCE

Dolly's reflection

“ That's the thing about lived experience – that we are living a similar experience. We understand the actual living of it. It's not just an academic thing that you can read about. We have felt a lot of the things that people have felt.

We've seen and heard a lot of the things that people, the very act of living, being inside a body that goes through that experience, we've done that, haven't we?

”

A STORY – BY ALISON

I am isolated, lonely.
 I can no longer say
 I have friends, peer support, a home.
 I have moved and changed...
 Caught in a cycle of homelessness
 and
 Trapped by a childhood of abuse and neglect,
 I am frightened by hearing voices, believing things
 nobody else believes,
 I can no longer say
 There is something to look forward to.
 I am worthless, ashamed of my life and my story,
 I no longer feel
 There is hope.

Now read in reverse.

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LET'S TALK ABOUT

turning the tide

A different direction

Sea change

**Turning
the tables**

It has been a long and difficult journey

Connect

Summer 2017

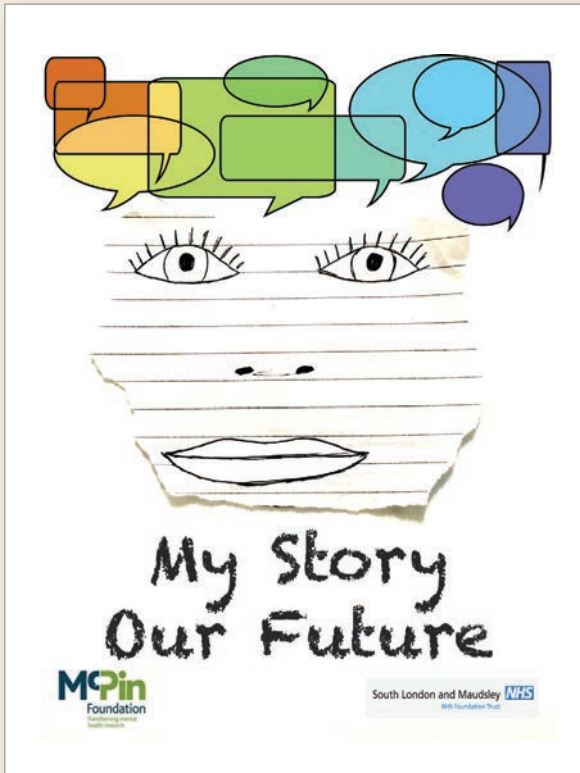
Find your peace

**“You have to take
risks, because
without risks you
are never going to
achieve anything”**

cautiously optimistic about the future.

A found poem by Dolly Sen, created when the research team were using collage to make sense of the data.

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- Delivering high-quality mental health research and evaluations that deploy collaborative methods
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- Working to ensure research achieves positive change

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