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Listening to People's Voices

North Staffordshire Mental Health Inquiry Report June 2014

*"We are of the North, outwardly brusque, stoical,
undemonstrative, scornful of the impulsive;
inwardly, all sentiment and crushed tenderness."*

Arnold Bennett



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Acknowledgements

We would like to thank everyone who has taken part in the Inquiry for their support and contributions, particularly those people who have taken time to share their stories and experiences. Without them this report would not be possible.

We would also like to thank Lifeworks, North Staffs Users Group, The Carers Time-Out Service, Recovery is Out There and Level 5 Staffordshire University Social Work students on placement with Brighter Futures. Their offer of time and a listening ear during consultation empowered so many people to tell their story.

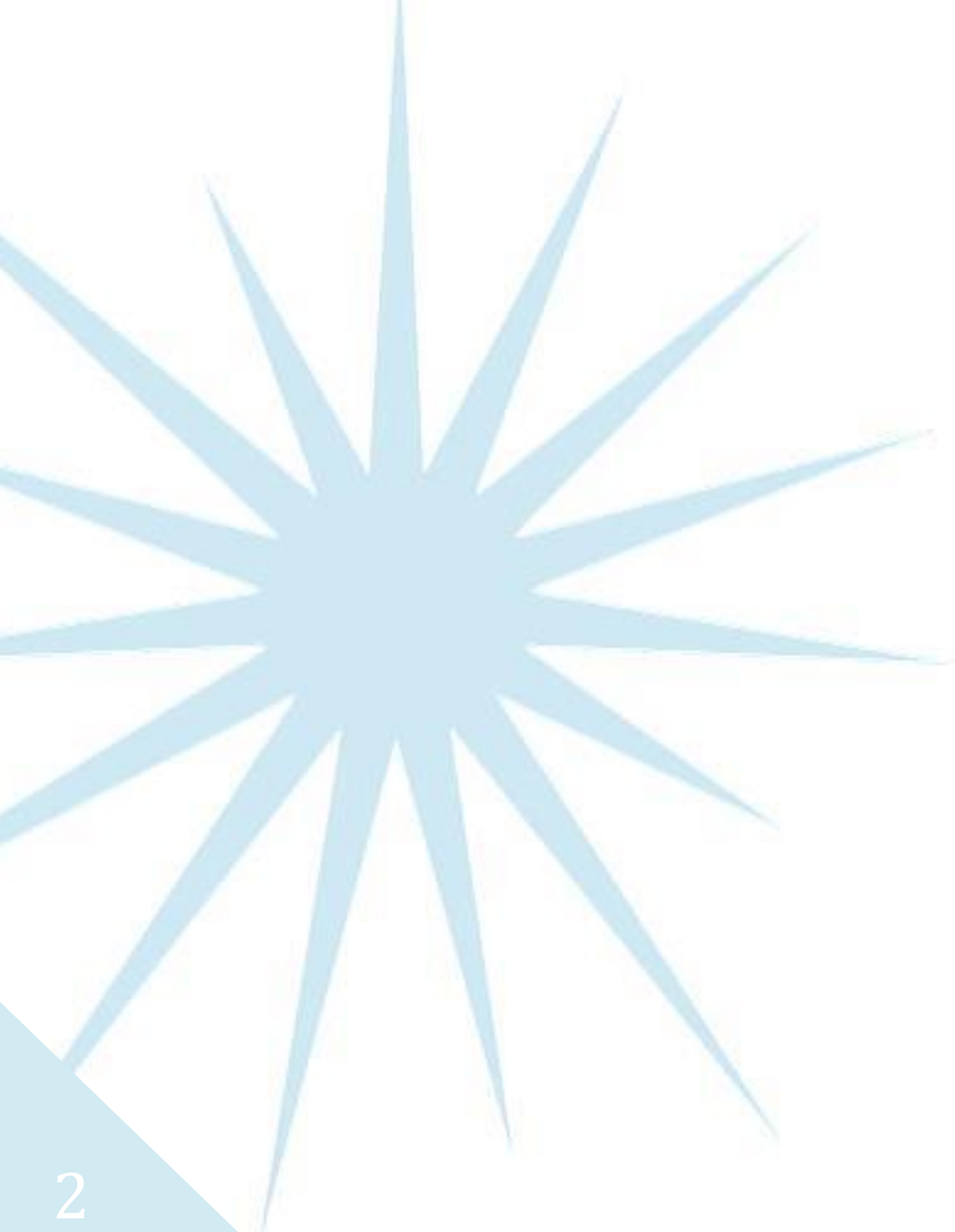
Inquiry members

Brighter Futures (lead organisation), Bishop of Stafford, Carers Time-Out Group, Keele University, Kevin Raftery, Lesley Haines (Independent Psychiatrist), Lifeworks, North Staffordshire Combined Healthcare NHS Trust, North Staffs Mind, North Staffs Users Group, Recovery Is Out There, Ron Daley on behalf of GP Paul Unyolo, Sarah Hill, Stoke Expert Citizens, Stoke-on-Trent Citizens Advice Bureau.



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A Walk in the Woods

It's like a walk in the woods with a guide.

I've been that way before, but she points out things as we go along.

I understand things better, see things more clearly,

I notice the sun shining more brightly, feeling its warmth on my face;

Smell the flowers, learn; learn to relax and enjoy; learn to love more again,

Believe in myself, have the courage to say what I see,

And the confidence to stride forwards.

But ahead of us, getting closer, the path divides

And I have to go one way and she will go the other; and I feel puzzled

Because I wanted her to point out every tree and branch, every leaf,

Each bird, each path; and I feel a bit strange

Worried, disappointed.

My step falters, but I keep walking, thinking; and in time I realise,

She has shown me the most important trees,

The people I walked past who are behind me, the fir cones at my feet,

The way ahead, and the beautiful hills in the distance.

And most importantly, that I don't have to see everything to

Understand or to enjoy.

I go my way and she goes hers.

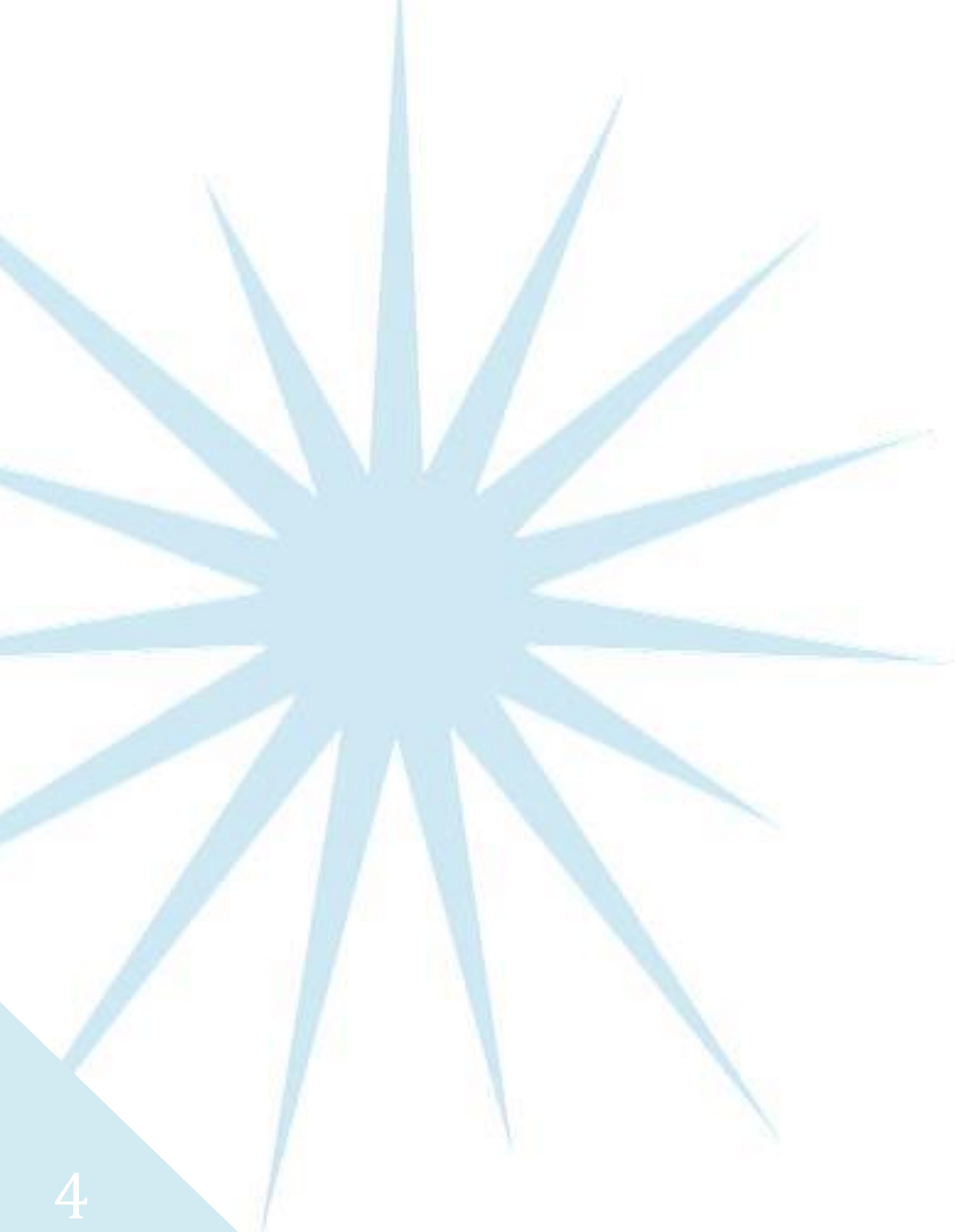
I walk on alone, carrying the knowledge she gave me, with me

by D.S.Bleakley (Inquiry contributor)



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Foreword

You may find it difficult to imagine what it is like to feel quite unable to get out of bed in the morning. Not just to enjoy a “naughty but nice” lie in, but being prevented from leaving your bed when you really want to get up to do something that you want to do. You may not be able to conceive being so anxious about meeting people that you reject invitations to social occasions or family celebrations. You may not know what it would be like to hear voices inside your head telling you to do things of which you would not normally dream.

Despite the fact that many of us find it hard to imagine them, these are all symptoms of mental ill health. Astonishingly, in view of our shared ignorance about its symptoms, mental ill health will affect about a third of us at some time in our lives.

Brighter Futures has decided to produce this report because we believe that a better understanding of mental ill health is essential to each of us because at some time in our lives we will certainly either suffer ourselves or come across someone who does. Over the last 40 years Brighter Futures has seen many people return to productive engagement with local communities as a result of the mental health services we have provided. We know that Stoke on Trent and North Staffordshire cannot afford the loss of talent which would result from ignoring this issue.

Mental ill health is different from physical disease in two ways. First of all it is usually hidden and kept secret. Secondly, people who suffer mental ill health also suffer the added burden of societal prejudice. Much of this prejudice is based on ignorance. We believe that the ignorance which surrounds mental ill health is best countered by telling the real life stories of those who suffer from it. This report seeks to tell the stories of local people whose lives have been touched and sometimes overwhelmed by mental ill health. These are people just like you or me.

This report is about listening to people’s voices. Many sufferers have no choice other than to hear voices as a symptom of their illness. We believe that they and everyone who suffers from mental ill health deserves to be listened to. We must learn from the voice of their experience and to act against the scourge that will affect so many of us.



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We hope that in retelling these stories we will encourage individuals, communities and service providers to gain a new understanding of the suffering of their fellow humans. We hope that where there is now prejudice and ignorance there will be compassion and understanding.



Mike Wolfe

Mike Wolfe
Chair
Brighter Futures



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Introduction

Positive mental health, wellbeing and resilience are at the heart of a healthy society, provide the foundation for healthy communities and enable people to be active citizens within the areas they live. There is a clear association between good mental health and better outcomes across a number of areas. These include years of life, physical health, and educational achievement, criminality, maintaining a home and employment status.¹

Mental ill health accounts for over a third of all illness in Britain and 40% of all disability. In any one year 1 in 4 British adults will experience at least one episode of mental ill health with 1 in 6 adults experiencing a mental ill health at any one time.² Approximately 1 in 5 General Practitioners (G.P.) consultations are about common mental health disorders.³ Depression and anxiety are the most widespread conditions,⁴ however both often remain undiagnosed.

Sadly, the percentage of the population living with mental ill health in Stoke on Trent is higher than the national average. Data for Stoke on Trent and North Staffordshire suggests there are between 77,347 and 87,547 people living with mental ill health in the area.⁵ This is a problem that we can no longer afford to ignore.

The North Staffordshire Mental Health Inquiry set out to talk to people in Stoke-on-Trent and North Staffordshire who have experienced mental ill health or who care for someone who has mental ill-health. We asked people to tell us about their experiences of living with mental ill health and using services.

Over a four month period we listened to the real life stories of over 140 people, including carers. People's experiences highlighted the existence of 12 common themes that fell naturally into two

¹ New Horizons, P8

² Adult Psychiatric Morbidity in England - 2007, Results of a household survey, National Centre for Social Research, J

³ "Adult psychiatric morbidity in England, (2007): results of a household survey, NHS Information Centre for health and social care, p27

⁴ The Fundamental facts, Mental Health Foundation, 2007

⁵ Stoke-on-Trent Director of Public Health Annual Report 2012; Newcastle-under-Lyme Health and wellbeing Strategy 2013 to 2018, Consultation Draft Text Version; Staffordshire Moorlands District Profile 2013.



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main areas: the way in which people's mental ill health affected their lives on a day to day basis and the impact of the outside world upon people living with mental ill-health.

We invited representatives from a number of local organisations across Stoke on Trent and North Staffordshire to join the Inquiry Panel. Membership was intended to bring together a group of people who would be able to bring knowledge and expertise of specific groups within the overall mental health community. Invitations were extended to people from mental health service user and carers groups, Fulfilling Lives Expert Citizen Core Group, minority ethnic groups, faith groups, higher education, mental health service providers and providers of other services thought to bear relevance to the purpose of the Inquiry.

During this time we promoted the Inquiry using local media such as Radio Stoke and The Sentinel. In addition we sent information out about the Inquiry via e-mail and in paper form to over 30 organisations, all of whom had been contacted in advance of this.

We held four group consultation sessions. All of these were hosted by service user led groups who offered an open invite to their members to come along and talk to members of the Inquiry Panel about their experiences.

The majority of people who contributed to the Inquiry shared their stories and experiences with us by completing a standard form which had been pre agreed and trialled by Steering Group members in advance of the main consultation.

We also captured feedback from people via telephone interviews. This enabled us to include people who felt unable to engage in one to one sessions face to face or who told us they preferred to talk to us about their experience rather than write it down.

The report identifies two distinct areas that people talked about: the ways in which the symptoms of mental ill health affect people and how they live their lives on a day to day basis and the impact of the outside world, particularly family, communities and services.

Chapter 1 of the report describes people's experience of their illness. This includes triggers and symptoms of which we may have knowledge but the stories describe many ways in which apparently separate facets of illness join up in real life.



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Chapter 2 describes how the medical profession and other services as well as society at large impact on an ill person's life. These effects can, as we will see, be either positive or negative.

The stories people have shared demonstrate a spectrum of experiences that range from very positive to very negative. Some people talked about how they lived with their mental ill health day to day, other people described how their illness put their life on hold – preventing them from doing even the most basic tasks. Some people said that services had been helpful and aided the process of recovery, others told us they had created more problems than they had resolved. In some cases they had contributed to a deterioration in mental ill health rather than an improvement.

Twelve major themes emerged from our evidence. Somewhat depressingly, these are all issues that have been identified by policy makers and Governments for more than a decade as being the main areas for action if services are to better meet the needs of the people who use them.

Stigma and oppression, dignity and respect and choice and control are perhaps the most subtle but frequently mentioned amongst the themes highlighted. The single biggest issue for people was “navigating the system”. Over 60 people talked specifically about the mind boggling complexity created by the mixture of agencies, services, processes and information (or lack of). People said that at best this made getting help difficult, at its worst it prevented them from getting the help they needed when they needed it. The role of General Practitioners (GPs) as either gateways to or gatekeepers keeping people from services also featured prominently in many peoples stories.

The purpose of the Inquiry was to give a voice to a group of people who are often silenced or dismissed as a result of stigma and oppression created by the ignorance and prejudice of many in society. We have achieved what we set out to do, we have listened to peoples voices and, through this report, are sharing these stories with the wider world of people, communities and service providers.



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The Inquiry has created an opportunity for people to develop a better understanding of mental ill health and its impact on those people who live with it daily. We hope that in the longer term this unique source of real life evidence will be the basis of better mental health services in Stoke-on-Trent and North Staffordshire.

Sarah Hill

Sarah Hill
Inquiry Chair



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Chapter 1

What people told us about their illness

1. Triggers

People told us that their mental ill health has been affected by a wide variety of social, environmental and economic factors. Many people have told us that their mental wellbeing has been affected by a combination of events over time, the final one of which was a “trigger” and tipped them beyond the point of being able to cope any more. In other cases the triggers were more specific.

1.1 Multiple triggers

“John” told us his story that demonstrates the common experience of a life that contained many triggers. He says:

‘I first became unwell at the age of 21 (I was diagnosed with clinical depression by my GP). Although I can’t pin-point exactly what triggered my depression, I can say that I was having trouble at work, my relationship with my girlfriend had ended due to her terminating a pregnancy. My father was also putting pressure on me to leave home.

Eventually I became homeless and began to drink heavily, my confidence was rock bottom. I remained homeless for two years. At first I did not know where to seek help, as my illness prevented me, then when I got in trouble with the Police I consulted a doctor who admitted me to hospital.

When I was discharged I received no help with benefits or accommodation. In my thirties my life consisted of hospital admissions and short spells of paid work. I was admitted to hospital again where I was treated for schizophrenia. It was at this point that I was housed by Brighter Futures and my life improved. I am pleased with my treatment by all those concerned and this year I am starting a course at university and possibly some voluntary work.

I now live in a quiet street with no problems with my neighbours. I remain stable mentally with my last admission being 15 years ago.’



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“Liam” told us that many things had caused his mental illness. His jumble of misfortune is perhaps typical of the kind of multiple disasters that many people face before becoming ill.

Liam met his partner at university. The couple moved to Stoke because his partner was pregnant and wished to be closer to her family. Due to family pressure they settled for accommodation next door to his partner’s parents. Liam thought the standard of the accommodation was poor, however his partner’s family dismissed his concerns. His partner didn’t seem to want to contradict her parents’ wishes.

Liam set up his own photography business. He had studied this at University and wanted to become a professional photographer. His business failed. He describes himself as working in a “dead-end” job after this.

Liam focussed on getting the landlord to carry out the repairs required to the property; heating; hot water; doors and windows that fitted and closed properly, were safe and kept warmth in. The landlord did some of the repairs but wasn’t forthcoming. Liam felt everything was an uphill battle. His partner didn’t want to cause any problems with the landlord and kept undermining him when he challenged the landlord over the conditions of the property. When his partner gave birth to their daughter the conditions at the property weren’t much better.

Liam’s relationship with his partner was becoming difficult. Her family were taking over her life and this was driving a wedge between them. Liam found a flat that was warm, dry and clean. However his partner wouldn’t move in because it wasn’t close to her parents.

Things came to a head, Liam and his partner split up and he moved to the new flat. During his first week in the flat he was burgled. He found out afterwards the landlord hadn’t had the keys back from the former tenants nor had he changed the locks. The police took a statement but did nothing else. During a visit to his family in Lancashire Liam had his wallet stolen.

This was the final incident that pushed him over the edge. Liam finished work unable to cope with anything else. He was unable to wash, eat, dress and struggled to focus on anything. Liam states he “was unable to put one foot in front of the other” and mentally he was “numb”. He “felt sad, as though everything had gone into slow motion and he was living in a different world” and felt “unable to comprehend the simplest of things, everyday life was too much to bear.”



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In “Cheryl’s” story a brain tumour becomes just one of a list of misfortunes.

“I had post-traumatic stress disorder following the birth of my child. This led to post-natal depression. Things were getting better then both of my sons were diagnosed with autism and we had to fight for schools. My husband was made redundant and we were worrying about money and then I was diagnosed with a brain tumour”

1.2 Housing and safety

Many people have told us that where they live and the quality of their housing is important to their wellbeing. Becoming homeless or living somewhere that is not safe has had a significant impact upon a number of people who responded to the Inquiry. “Gemma” told us how her housing affects her wellbeing:

“I don't go out at night alone, I don't feel safe. There are a few "hoodies". This makes me feel nervous and frightened”

Thirty six (26%) people made reference to their accommodation at some point when telling us their story. Nina told us how where she lived helped her stay well:

“My flat makes me feel better. It is lovely and warm and it's in a nice quiet street. I can see trees from my kitchen window and I go for walks in the country which is only 5 minutes away”

Nine people described living in poor quality housing. The descriptions included living without heating and hot water, having doors and windows that didn't close properly, mould growing on walls and ceilings and faulty electrics. Six of the nine people also described “battling with” and “constantly chasing up” landlords who were slow to respond or who in some cases did not respond at all.



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The way in which poor quality accommodation featured in people's stories is also worth noting. A number of people moved into their accommodation at a point where they were in the middle of a series of devastating life events. The impact of this being the need to find housing fast to avoid becoming homeless, therefore time and choice were not on their side.

Eight of the nine moved into their accommodation at a point when they were in mental health crisis. For some people the impact of this seems to have been that the quality of the accommodation was almost irrelevant. Either because they felt they deserved no better, the accommodation was as bad as everything else in their life or at that point or it was simply a roof over their head beyond which nothing else mattered. Other people described themselves as "not having the energy or strength" or being "too ill" to keep asking the landlord to carry out the repairs he had promised when they moved into their house. This is what people told us:

"The house wasn't in very good condition when I went to look at it. It was dirty, there was rubbish in the back yard and the walls were damp (I realised when I moved in this was because the heating didn't work). But I was desperate and just needed somewhere to live. The landlord never bothered with anything to do with the property" Mark

"After my marriage broke up stayed in a flat for several months where there was no heating or hot water. I contacted Brighter Futures and they got me out of there" Ella

"The house was a mess, but I didn't care. I felt so low and depressed I just wasn't bothered. I think I lived without heating and hot water for over six months and I slept on a sofa in the living room, I didn't have a bed" Tanya

"The woman who showed me around said the landlord knew about the things that needed repairing and they would be done in the next week or so. The landlord never showed up. I had to keep ringing and chasing the agent to see what was happening. After three weeks the boiler and the front door got fixed, but that was it. I gave up after that, I didn't have the energy to keep ringing about the other things" Saul



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For many the poor conditions and lack of safety and security contributed significantly to the deterioration of their mental health or inability to recover.

“From the frying pan into the fire. I had left one set of problems that were making me unwell and then I moved here. The house was a hell-hole and I felt trapped with nowhere to go. The landlord didn’t respond when I reported things were broken. My depression was getting worse and I had no way of finding somewhere else and moving out”.

Several people described moving out of poor housing, streets or neighbourhoods as a turning point in their life from which they describe things as starting to get better.

“I moved into supported housing in a new area and things started to get better straight away. My neighbours didn’t bother me, it was a quiet area and I felt safe.”

Anti-social behaviour was also a large issue for people with mental ill-health. “Alan” told us he had moved several times because kids gave him trouble and he felt unsafe”. Other people also told us they had moved to a different area in order to feel safe.

“Louise” and “Liam” told us that they used alcohol as a way of coping with their anxiety relating to the area in which they live.

“I started drinking alcohol to manage my anxiety about the area I lived in. This led to me and my girlfriend splitting up. We had been together for over 20 years.”
Liam

“I don’t like being at home alone especially at night. Groups of teenagers hang in the street I live in and I don’t feel safe. It makes me feel anxious and that is why I drink.” Louise



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Neighbour issues featured in over 15 case studies with every single person describing the way in which problematic neighbours had made them feel unsafe and anxious in their own home and where they lived. This in turn had impacted negatively upon their mental health either causing mental ill health or making existing ill-health worse. People described having neighbours who were noisy, aggressive and threatening.

“My neighbours were loud and intimidating - that scared me. I was frightened in my own home”.

Two people told us they had been directly targeted by their neighbours.

“Within 18 months as a vulnerable adult living alone, I began to experience verbal abuse and harassment from my nearest neighbour, which I believe tipped me over the edge”.

In Emma’s case the abuse got worse after she reported it and she ended up moving to get away from her neighbours.

“I got on well with my old neighbours but when they left and new people moved in I started to have problems. They played loud music until late at night and would stare at me and make loud comments when they saw me. I reported this to the housing officer in my area who said she would talk to the family. I was anxious about this because of what they might say. I knew when they had been spoken to because from then on it got worse. I didn't report it again because I was frightened of what they would do next. I moved somewhere else, it wasn't as nice as my flat but at least I felt safe”.



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Some people acknowledged that they felt more paranoid when they were unwell and recognised that the impact of their neighbours' behaviour was greater than it would have been when they were well. However, people told us that whether the source of their fear or distress was rooted fully in fact or partly in delusion or paranoid thought it was real for them at the time. On this basis it would have been helpful if services had taken them more seriously and shown more empathy. This particular issue is one of many that demonstrates the vulnerability of people living with mental ill health and how this can increase and decrease over time in response to wellbeing and circumstance.

"Sylvia" shared her experience with us:

"One night I couldn't cope with my neighbours being noisy. I got into a taxi and went to Harplands for help. They didn't help much and wouldn't give me a bed. The crisis team took me home - they were very good, they tried to settle me in and made me some food, but when they left I couldn't stay in my house. I was scared because how I was feeling made me scared of the neighbours - I thought they wanted to kill me."



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1.3 Childbirth and parenting

Childbirth and becoming a parent is a positive and happy life event for many people. For others it can be a traumatic event or one that is overshadowed by an often late or misdiagnosis of postnatal depression⁶. “Cheryl” and “Barbara” shared their experiences with us:

“Until eleven years ago I had no problems. I was a very positive person. The birth of my second child was very traumatic – made worse by the response of the professionals to the situation at the time. I nearly died. I developed post-traumatic stress disorder and this led to postnatal depression. Afterwards I felt I was being treated with a one size fits all approach and that my views were trivialised and dismissed.”

“I struggled to look after my child, people didn’t listen when I asked for help. I think, looking back that I had postnatal depression that wasn’t diagnosed.” Barbara

There are some similarities between the experiences of the two women in that both attribute part of the trauma of their experience to the professionals involved at the time and the ways in which they responded. “Louise” also talked about not being listened to as she described the impact of being sectioned under the Mental Health Act after the birth of her child:

“I had postnatal depression and was sectioned so I had no choice or say in anything and was separated from my baby which has affected my bonding with my child.”
Louise

⁶ Suffering in Silence, 4Children, September 2011, p4



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Each woman developed long term mental ill health following their experience. “Barbara” and “Louise” also suffered the additional devastating impact on their relationship with their children.

Eleven (8%) people told the Inquiry that their children had difficulties themselves and needed support. The impact of supporting their children to cope with their additional difficulties and continue with everyday parenting was, for many, immense. Nine people told us that this had led to them developing mental ill health themselves.

1.4 Bereavement

Nine people (6%) attributed their mental ill health to the death of key people in their life. This was predominantly parents, however people also talked about the loss of their grandparents and best friends as having a significant impact. A number of people, including “Sarah” and “Linda” described the loss of several key people within a short period of time being too much to cope with.

“I lost my Mum, Granddad and Step Father all in the same year and then my cousin took his life the year after. This triggered my depression. I took an overdose and was told I was heading towards a nervous breakdown.” Linda

“I came into mental health services after the death of my Mother and best friend close together. I was unable to cope and have been unwell since.”

Other people acknowledge the trigger point being the loss of their second parent – even if their first parent had died many years previously. “Mark” said:

“I lived with my parents. When I was 25 my Mum passed away. I carried on living at my parents’ home with my father till he passed away five years later. After he died I had a nervous breakdown and was admitted to hospital. I stayed there for a year.”



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1.5 Childhood trauma

Some people (10) described their mental ill health being a result of events that took place during their childhood, including specific mention of the impact of living in the care of the Local Authority. People referred to “things not being great at home” or “something that happened” or being abused when they were a child. “Amy” was living in Local Authority care when she was abused. Emma told us how debilitating the care system was and the damaging impact it has had on her life and wellbeing:

“I think I started to have mental health problems in Primary School. Things weren’t good at home and I was diagnosed with ADHD. My family put me in care at 12 years old and I lived in various children’s homes. I don’t have any contact with my family now. I had a very poor education and I left with no qualifications. I think living in care affected my education and in fact my whole life. I haven’t ever really had a proper job and haven’t worked for five years. I feel let down by everyone.”



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1.6 Work

Thirty-four (24%) people talked about the impact of work upon their mental health. Most people said that they had been unable to work or had to finish work because their mental ill health prevented them from doing their job or their employers weren't supportive.

"My depression along with my physical disability have prevented me from ever contemplating returning to work. I previously had my own business for over 30 years. I had to start to employ other people to cover me due to the onset of my depression." Alan

"I am unable to work because I am unable to leave the house some days and even if I got there I might have a panic attack." Kerry

"I have tried to work, but I struggle to concentrate and so had to give up my last job, my employer wasn't very helpful." Cherie

"When I was well work was OK, but when I was unwell things got difficult, my boss didn't understand and it got more and more difficult to have time off." Tim

"I kept having time off work because my mental health wasn't great. I have since being diagnosed with anxiety and depression. My employer wasn't very helpful and I lost my job." Steven



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“Ian” told us he lost his job due to his mental ill health and this was a cause of great distress to him.

“Frank” and “Sheila” said that losing their jobs had triggered their illness:

“I lost my job and then had a mental health relapse. I felt useless that I was unable to work.” Frank

“Losing my job led to me developing depression and anxiety.” Sheila

A significant number of carers also reported that they had had to stop work as a result of their caring role. This was due to needing lots of time off and being unable to cope with the combined demands of work and caring.

“I finished work early due to caring needing me to have lots of time off.” Ann

“Work gave me a chance to get away from my caring role. However they weren’t understanding at all of my role as a carer for my disabled son. I resigned in the end, I could take no more of how they treated me.” Agnes

1.7 Family and relationships

Seventy (50%) people talked to us about the link between their mental wellbeing and family and relationships. Nineteen people stated that their family was the direct cause of their mental illness or a contributing factor. “Jim” told us that his family don’t understand his mental ill health and make him feel worthless by making him feel like he should “get on with life”.

Several people, like “Sophie” told us that their mental ill health had led to them no longer having contact with their family. “Sophie” said

“My illness causes arguments with my family and I don’t see anyone anymore. I think they struggle to cope with me being unwell and I find it difficult being around them.” Sophie



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Nineteen carers responded to the Inquiry all of whom described the huge impact their caring role has had on their mental health. Many carers described their day to day life as a battle with constant challenges from the person they care for and the outside world. Some carers told us that their mental ill health is a direct result of them caring.

“Being a carer is a physically and mentally demanding challenge. I continually feel stressed and at times feel so isolated. Even the simplest of tasks is a challenge.”

Diane

“Louise” told us what happened to her:

“Mental ill health has affected my life because of the lack of support from NHS services for my son. Because of this I ended up in crisis myself and needed counselling. Things hit crisis point when my son’s personal budget was withdrawn. I ended up in psychological services due to stresses put on me when support was withdrawn for my son who was a service user. I did try to use Healthy Minds, but as my stress was so high with suicidal feelings, they decided I was at risk and called the Crisis Team” Louise

“Michael” told us how caring for his wife led to him nearly losing his own life:

“I had a heart attack due to the stress of looking after my wife.”



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2. Impact

People consistently talked about the debilitating nature of their mental ill health and how it affected all aspects of their life. This section looks at five areas of a people's lives which we were told are commonly affected by mental ill health.

2.1 Confidence and active citizenship

Many people told us their mental ill health made simple tasks impossible. For some it redefined their role within society from that of active citizen to being dependent upon welfare benefits and support from others to get through each day. "Mark" told us he "felt unable to do most things now because of stress".

"Every day is like trudging through treacle."

"Jean" described how her mental health fluctuated up and down and this determined the degree to which she was able to cope on a day to day basis:

"Most of the time I can cope with the things that are thrown at me. Other times I crumble and feel like the sky is going to collapse around me. Other times I feel really vulnerable and start to panic, not knowing which way to turn."

"Cherie" told the Inquiry how her mental ill health had devastated her life from a young age, affecting her ability to learn as a child and maintain paid work as an adult.

"My mental health affected my life badly for many years. I didn't attend school and couldn't keep a job down."



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Being unable to contribute positively to their community was particularly distressing for some people. The change was often associated with loss of confidence, choice and control. Several people talked about their feelings of guilt at having to claim benefits and being unable to cope without help from family or services. “David” talked about his illness over the last 20 years, telling us how he slept on the sofa day and night and how his confidence was so low when he was depressed he couldn’t leave the house. “Ewan” said

“I am claiming Employment Support Allowance but I feel guilty for claiming benefits and not working.”

“Alison” also told us she was unable to work and that her confidence was so low she felt unable to leave the house some days. She said:

“I have been out of work for three years now. My mental health has affected my confidence, I don’t want to go out. I only go to the Observatory and Greenfields.”



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2.2 Relationships

People also said that their mental ill health had seriously affected their ability to form and maintain friendships and relationships, including with their children. Not being able to trust people was a recurring theme that many seemed to cope with by avoiding close relationships. Fear of being hurt or rejected featured in multiple stories, particularly if people had experienced difficult relationships during childhood. As with trust, people told us they coped with this by avoiding getting close to anyone. “Zoe”, “Dave” and “Ian” told us how their relationships have been affected:

“I push people away if they get too close, I need my own space. I struggle to hold down relationships due to this.” Zoe

“I was diagnosed with bipolar at 19. I didn’t get on very well with my family when I was growing up. I have always found it difficult to get close to people. I worry about whether or not I can trust people and keep waiting for them to let me down. It’s just easier to keep my distance.” Dave

“My depression has put a massive strain on my relationship with my adult children because when I am unwell they look after me.” Ian



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2.3 Education and work

Over 13% of people (18) told us that their mental ill health had impacted negatively upon their education both as children and as adults. Difficulties concentrating, not being able to cope with the social situations created by mainstream learning environments and stress and anxiety caused by coursework and study deadlines were cited as reasons for people having poor educational experiences and outcomes.

“My mental ill health has affected my education. I started courses but couldn't complete because of anxiety.”

Six people said they had had to stop working because of their mental ill health or had never felt able to work. People gave almost identical reasons for being unable to work as those for struggling with their education.

People talked more broadly about the impact of their mental ill health on their education and employment. People talked about feeling so low and depressed they were unable to get out of bed in the morning to go to college or work:

“I stopped working because I became unwell. I couldn't cope with getting up to go to work, let alone doing the job.”

Others described feeling paranoid about what other people thought or said to them and having so little confidence that they didn't think they were capable of learning or doing a good job.

“I finished work because I was being bullied. On reflection I was unwell at the time and couldn't cope with what was actually my workmates having a bit of fun.”



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2.4 Self-harm

Over 25% of the people who talked to us said they had used self-harm as a way of coping with what was happening to them. People told us that they self-harmed by misusing drugs, alcohol and solvents, not eating, cutting and taking overdoses.

"I used to limit what I ate. My life seemed to be done to me rather than with me and this was something I could control."

Several people talked about their self-harm being a way of them asking for help. "Barbara" said:

"I first used services as a teenager after an incident in my life. In more recent times I went to A & E because I had taken an overdose. I wouldn't ask for help but would take tablet overdoses."

A smaller number of people said they had tried to kill themselves because they felt so desperate. However "Susan" and "Harry" told us that this was more a cry for help than a real attempt to end their life.

"I did try to kill myself, it was a cry for help. It helped me get services." Susan



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2.5 Substance misuse

Twenty two per cent of the people who talked to us told us they had misused substances. Contrary to the popular misconception, it should be noted that this substance misuse is not the cause of the problems of the people we talked to, but their attempt to solve it. In many cases we have heard that substances were used to try and make the pain of mental ill health bearable. These are well intentioned attempts at self-medication and as such can be seen as symptoms of the underlying mental distress rather than a cause of it.

“Jack” and “Sue” told us that they had used drugs and alcohol to help cope with their mental ill-health. “Jack” told us he used alcohol and cocaine as a coping mechanism and “Sue” said she used alcohol to reduce her anxiety and calm her nerves.

Some people also told us that they had recognised that this self-medication was in the longer term unhelpful and had created an additional layer of problems for them to deal with. “Paul” said that he no longer drinks because it makes things worse. Sadly, of course, many people don’t have “Paul’s” strength and are already strongly addicted to substances before they realise how ineffective they are as a cure for their mental ill-health.



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Chapter 2

What people told us about the world's response to their illness...

Mental ill health has symptoms which have been described to us but, in addition, as shown in this chapter, it provokes often unhelpful responses from friends, family, neighbours, colleagues, health professionals, carers, other services providers, and the general public. These negative reactions often make the primary symptoms worse.

2.1 Family

People's experience relating to their family was very mixed. Some people described how supportive their family, particularly their parents, had been when they had first become unwell. People said that their family provided emotional support, practical help with shopping and cleaning and in the case of "Jane" and "Michael" somewhere safe to live. "Rosie" told us that her illness had brought her family closer together.

Others told us that though family tried to be supportive and were probably very loving, they became unable to cope with the various symptoms of their illness or the self-help treatments they adopted.

"My parents are very supportive but they get annoyed that I drink."

Other people described their relationship with their family as damaging. Several people told us that their family were the main factor or a contributing factor in their mental ill health. One of the challenges people raised was that family members did not understand their mental health or how it affected them. Several people told us their parents thought they should cope better and not let their mental health impact upon their life. "John", "Lyra" and "Chris" told us the following:



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"I have a difficult relationship with my family. They don't understand and I feel pressure to get on with life." John

"I feel like my family think I am useless." Lyra

"My parents didn't get it, they told me to pull myself together and get on with things."

Chris

Several people told us that the worst thing people had said to them was "pull yourself together". They said the "advice" was unhelpful and made them feel even worse about their illness and about themselves.

Sadly some parents believed the best way of coping was to ignore their child's illness. "Susan" and "Leah" told us their families pretended they didn't have a problem. Both women described this response as damaging and one that prevented them from getting the help they needed when they first became unwell. In "Leah's" case the response of her parents made her feel embarrassed and ashamed about being ill and she started cutting as a way of punishing herself for what was happening.

Eight people said that their marriage or relationship broke down as a result of their mental ill health. This was because their partner was unable or no longer able to cope with their illness or the self-help treatments they had adopted to try and cope themselves. "John" told us that his marriage broke down because his wife couldn't cope with his depression.

About 10% of the people we spoke to had experienced difficulties in getting help for their children when they believed something was wrong. People told us they had raised concerns with their children's school, GP and/ or health visitor over time to no avail. In some cases the parents raising



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concerns were seen as problematic rather than professionals taking time to establish what was causing the parent to worry.

The frustration and desperation felt by the people who talked to us was very evident. For many parents their experience was still raw, even though their child was now getting the help they needed. These are some of the experiences people shared with us.

“Without a diagnosis a parent is not listened to or taken seriously – no action is taken. You are seen as a trouble maker or a bad parent.”

“My son was struggling at school and it didn’t matter what I said – nothing made a difference to the way they treated him or responded to him.”

“I was not listened to when I was repeatedly going to health services about my daughter.”

These experiences were particularly prevalent amongst parents of children later diagnosed with Autistic Spectrum Disorders, although they also relate to people whose children were later diagnosed with mental ill health and dyspraxia.



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2.2 Carers

Nineteen people who responded to the Inquiry were carers and there were several recurring themes. All carers talked about there being a lack of support – both for the person they care for and themselves. Most people talked about there being a need for emotional and practical support to help them cope with the demands of their caring role.

“There isn’t enough support. There needs to be more practical help and respite for when things become overwhelming.”

Having the opportunity to have a break from the person they care for, even if only for a few hours to go shopping or to the gym was described by all carers as essential if they were to be able to continue caring.

“Visits to the Carers Group delivered by Making Space enable me to have a few hours respite each week because my husband attends an NHS recreational group that day. Being able to talk to other carers is helpful and helps put my problems into perspective.”

Everyone described the significant impact of being a carer upon their physical and mental health. People told us this increased if they did not have support or get a break in some way. “Sylvia” said that her son had had his respite reduced and was now only entitled to two weeks a year. “Emma” said that her son had recently had his support reduced and this had resulted in her having to do more. She told us the only way to resolve this was to start paying for the support themselves, which was difficult when they didn’t have much money to start with.

Several carers also talked to us about not feeling valued and often being seen as over protective or neurotic rather than someone who knows the cared for person better than anyone else.

“Professionals showed no empathy and were judgemental. I was classed as an overbearing mum when trying to explain how my son was struggling. I felt disregarded, but when I became proactive and fought they started to listen. Why wouldn't they listen at the beginning instead of letting my son become worse?”



2.3 GPs

Sixty people (42%) who contributed to the Inquiry made reference to or talked in detail about their experience with their GP. It is clear that the attitudes and actions of GPs are a key determinant of mental wellbeing. People told us they had difficulties in getting appointments with their GP and once they had been to see one it was even more difficult getting an appointment to see the same person again. People told us the lack of continuity made it difficult for them to form a relationship with their GP and establish trust. It also frequently results in the retelling of historical information or stories, which then impacts significantly upon the time available to discuss current issues.

People's stories relating to their GP experience identify four distinct aspects of the service/help they received, which are:

- The GP knowledge of mental health
- The GP knowledge of available services
- The relationship between the person and their GP
- GP attitudes to mental health

There is a notable link between the degree to which contact with a GP was positive or not and the four elements people have commented upon. People's experiences can be divided into two camps. Positive experiences where GPs acted as a gateway to other help and support and unhelpful experiences where GPs acted as gatekeepers, preventing or making it more difficult for people to get help and support.

"Alan" and "Jo" told us their GPs were supportive, that they listened to them and referred them to other services including helping them access secondary care:

"I am lucky to have an excellent GP. If my GP hadn't been so supportive I would have definitely taken my own life by now." Alan

"I have a wonderful GP. He listens and has signposted me to other services." Jo



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Sam said that her GP had worked in mental health and that she thought this had been helpful in him being able to understand what she was saying and how her mental ill health was affecting her.

People who described their GP as unhelpful did so on the basis that; they didn't offer any information about relevant mental ill health or services available; they didn't refer them to other services for help, in two cases people said their GP had refused to make referrals; they did not seem to have much knowledge or understanding of mental health; they did not feel their GP listened to, valued or respected them. Three people told us that their treatment preferences were completely ignored; the GP was clock watching and more focused on that than them as a patient. This is what people told us:

"Not all GPs are aware of what's out there and so information between GPs is inconsistent."

"GPs and Mental Health professionals need to be more aware of services and signpost to them better, it seems that people are just expected to know what is out there."

"Our GP was unhelpful – she didn't understand and wasn't helpful referring to other services."

Fifteen people told the Inquiry that their GP had been dismissive of them during appointments. People said that their GP seemed unwilling to do anything when they tried to explain how they were feeling and get help with their mental ill health. These are some of people's comments:

"My GP trivialised what I was saying and what I was feeling."

"I kept seeing my GP because they wouldn't help with my depression. In the end I swapped GPs and now I have a lovely doctor who helps me and doesn't just judge."



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"I saw lots of GPs but felt I wasn't been taken seriously about how bad I felt."

"When I moved to Staffordshire Moorlands I struggled to find a GP who would take my depression seriously or listen properly."

"I had an issue with one GP who called me a hypochondriac. I complained but it wasn't upheld. I changed surgeries."

"When I go to my GP about anything I am always given anti-depressants as my GP thinks it is all in my head. I know it isn't in my head."

Several people who had drug or alcohol problems also said their doctors had been judgemental and dismissive. "Pete" said that in his experience older doctors were worse than younger ones.

"I went to see my GP first. He/she told me I was a useless chronic alcoholic, gave me the tablets and told me to go away."

Seven people specifically commented on the willingness of GPs to prescribe anti-depressants. In two cases they were prescribed even when the people had specifically said they did not want to take them. "Matt" and "Eve" said:

"My GP just keeps prescribing anti-depressants, even when I said I didn't want them and asked if there was anything else available." Matt



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"My GP just wanted to throw pills at me even when I asked for another form of help. I wasn't referred to counselling until I was 19." Eve

"Simon" told us:

"I kept getting repeat prescriptions for anti-depressants. My GP said I shouldn't take them for too long because they are addictive. I have been on them for ages now so I think it's too late"

Some people talked about their experience of doctors being quick to attribute their physical health problems or symptoms to their mental ill health. This has led to major illnesses such as cancer being wrongly diagnosed or not diagnosed at all and left people suffering significant pain and discomfort unnecessarily. "Cheryl", "Paul" and "Rick" told us:

"I have found out time and time again that if my mental health diagnosis is known about I am not taken seriously. My tumour went undiagnosed because my headaches were put down to stress." Cheryl

"When I am seen in the NHS about a physical health problem, I have found time and time again, that if my mental health diagnosis is known about I am not taken seriously".

"My GP responded better to my physical health problems than my mental health. When I asked questions she was very helpful about my physical health, what my options were and what would happen next - less so about my mental health. I was offered anti-depressants and not much else, although she was very nice and did listen to me." Paul



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"I encouraged Martin to go to the doctors because he had been complaining of stomach pains for a long time. He was reluctant to go, but did in the end. His GP dismissed what he was saying and said the pains were in his head. This went on for over a year until Martin eventually went for tests. It turned out he had cancer and it had spread, so there wasn't much they could do. He died four months later." Rick

During one discussion group people said they felt there was often a power imbalance between themselves and their GP. This left them feeling unable to challenge or ask questions, even when they believed they were not being prescribed the correct levels of medication or were being given medication they did not want.

It is, of course, likely that GP attitudes reflect those of the public as a whole in that they range from exemplary to oppressive and problematic. At one end of the spectrum are GPs who demonstrate knowledge, empathy and understanding of mental ill health and related services. At the other end are GPs whose attitudes appear to be prejudiced and inaccurate. Whose actions seem to, at best, make it more difficult for their patients to get the help they need, at worst prevent them from getting any help at all. It is less clear from people's stories whether or not there is a link between GPs knowledge and understanding and the degree to which they are helpful and supportive.

2.4 Respectful relationships

A key theme to emerge from people's stories is the importance of relationships. It would seem that in many situations the success or otherwise of an intervention is more about the effectiveness of the relationship between the person using the service and the person delivering it than the intervention itself. Very often people talked to us about the staff within a service and the relationships they had with them rather than the service being delivered.

Many people told us their mental ill health made it difficult for them to build relationships. People said that having trust and confidence in the professionals supporting them made it easier for them to be open and honest about their life and any problems. People said that being treated with dignity and respect are very important factors in them being able to develop trust and confidence.



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"I don't trust people easily. It takes a long time to build trust."

People described three conditions they believed were necessary for this to happen. This information deserves careful attention coming, as it does, from people who use services and are experts in their own mental wellbeing. People told us that they need:

- To be given time and space to talk
- For professionals to show empathy and that they care
- For professionals to demonstrate that they are really listening.

The frequency and prominence of these within case studies indicates their importance to people using services. The way in which people talk about them also suggests a high level of interdependence between the three. If any one condition was absent it seems that dignity and respect are not created in the mind of the person receiving treatment or support. It is noteworthy that these conditions all require action on the part of the professional. It is not, apparently, enough to assume that the patient will know that the professional cares because the patient's previous negative experiences make such an assumption unrealistic.

Listening was the most frequently mentioned of the three and warrants specific mention because of the significance of this within not only the communication exchange, but whether or not people felt they had choice and control of what was happening within their life. In order for people to recognise they were being listened to, people told us it was important that professionals actively demonstrated they were listening to what was being said through their body language, facial expression and also by acknowledging what was being said and responding to it. Many people had previously had multiple experiences of not being listened to and so the active demonstration of listening to people and responding back was even more important.

People's experiences of using services were varied. Some people told us they were treated with dignity and respect and listened to at all times:

"I was involved in discussions and listened to."

"North Staffs Users Group treats you with dignity and respect."



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"I am happy with all the professionals who have supported me. I feel I have been listened to and treated with dignity and respect."

"My hospital Social Worker helped me get supported housing with Rethink. I would have been dead today if I had not got the help I needed, I used to self-harm very badly. They were great to talk to and would listen for hours, I was involved in my care plan and was treated with respect and dignity. Thank you."

"Staff at the American and Echo listen and treat you with dignity and respect."

"I was treated with respect by Brighter Futures and it was easy to ask questions. Professionals have been very helpful."

"I feel I am treated with dignity and respect as an individual."

"Greenfields and Mind were supportive and understanding. At Brighter Futures I found stability, understanding and accommodation."

Others told us that they were not treated with dignity and respect for the following reasons: staff seemed not to care; very often their opinions were ignored: staff didn't listen; professionals didn't have time. This is what some people told us:



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"It took years to find trust and people who understood."

"I felt like I wasn't listened to or consulted and suggestions I made would be ignored."

"A couple of the staff cared but the vast majority didn't."

"I was treated badly by professionals but after years found good ones. I was treated like a piece of irrelevant meat, by hospital doctors for example."

"People with mental health problems aren't listened to. Opinions are formed before you have had chance to speak."



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2.5 Welfare Benefits

Changes in the welfare benefit system featured prominently within many case studies and people told us that they are worried about how the changes will affect them. It is clear that concern about finances is an extra pressure which contributes to mental ill health in many cases. People told us they are particularly concerned about the bedroom tax and whether or not they will have enough money to live on. Several people simply told us it was a struggle to live on benefits and low income.

A lot of people told us the benefit system was confusing and talked about not understanding the processes around claiming benefits – particularly new benefits.

“It’s difficult to access benefits and there have been times when I was without money for up to a month because of issues around paperwork and trying to explain my situation. I had to attend ATOS again and they declined my benefits. This decision was overturned with help from the CAB. I am still struggling to get help with a crisis loan for a cooker.”

“I had no help with money and they have taken me off benefits which made me struggle.”

People also said worrying about the assessments for Employment Support Allowance or Disability Living Allowance/ Personal Independence Payments affected their mental health negatively. These appointments became a focus for anxiety and stress.

People told us they were concerned about being taken off Disability Living Allowance (DLA) and being told they are well enough to work. “Sheila” told us that even though she had successfully appealed against a decision to stop her DLA and it has now been reinstated she is already worrying about her next assessment.



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“The DWP have stopped my money. They said I hadn't been in contact but I had. Now I'm worried the DWP will take the money I owe from my Disability Living Allowance. I filled in an ATOS form in December but have not heard anything.”

People also described the devastating impact of lengthy processes and unhelpful decisions to reduce or stop benefits, which for many resulted in having no income for several weeks. Employment Support Allowance featured prominently amongst the concerns people raised.

“Being reassessed for Employment Support Allowance is stressful.”

“My Employment Support Allowance has stopped. I have applied for a Personal Independent Payment but not heard back yet. It is a struggle without my own money – I am relying on family to be here to make sure I eat.”

In some cases the facilities provided for claimants were patently inadequate and could make access to a persons' entitlement impossible. For instance “Wayne” described the additional stresses of trying to claim benefits for him in relation to both his physical and mental health:

“I am being messed about with my Employment Support Allowance at the moment and I don't know what's going on. There are no loos at the dole in Hanley and I have continence problems, so have had to cancel appointments in the past – I may lose money. Lots of different rules for different things, sometimes I feel like a prisoner. I am being forced to go on courses where I may meet people who don't understand mental illness. I feel threatened by being sent on courses.”



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2.6 Education and work

Many people who responded to the Inquiry told us they had worked or been studying before they became unwell. Whether or not people had previously worked or studied, a large number of people told us that they wanted to work, volunteer or learn new things.

"I volunteer with Brighter Futures and am trying very hard to get a paid job. I studied at University but had a breakdown due to the stress of coursework and exams."

Many people told us they didn't think there were enough opportunities to work or study that would be sensitive to and supportive of their mental ill health. People wishing to return to work stated that employers seemed less willing to employ them if they knew about their mental ill health, even if they had the required skills and experience.

"I had good job but had to give up due to depression. I am looking for work now but struggling to get anything. The Job Centre are not helpful with supporting people with mental illness and I have found it difficult to get information about the support available."

People shared similar stories about the impact of their mental ill health on their education. "Neil" told us he was unable to attend mainstream school because teachers couldn't cope with his behaviour. This resulted in him leaving school without any qualifications.



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2.7 Other services

2.7.1 Cuts

Lots of the people who responded to the Inquiry said they were concerned about services being cut as a result of Government cuts to health and local authority spending. People told us that funding cuts had so far resulted in there being fewer community-based day services and those that remained offered less than they used to. People told us they have fewer options of where to go during the day and told us that positive activities such as day trips had been reduced or stopped.

“People with mental ill health need more choices, not less. Places like the American, which is brilliant, can't do everything.”

People also described the closure of the Mental Health Resource Centres as a significant loss of day services:

“I felt great benefit from services at the Ashcombe Centre and was devastated when it closed down.”

A number of people commented on service reductions impacting negatively on the ability of services to respond to individual need and how “one size fits all” approaches to service delivery are unhelpful and frustrating for all concerned. “Peter” stated he thought the NHS seem increasingly reliant on charities such as Mind, Changes and Brighter Futures. Services such as these give people a safe place in which to relate to other people and to regain the habit of engagement or creativity. These are places in which self-esteem can start to grow again and trust be rebuilt. They are, according to the people we have talked to, key to recovery from mental ill health.

Six people talked about the loss of community beds and the negative impact this has had upon their health. People told us that when their mental health has deteriorated they now have to go into Harplands when they would previously have used the resource centres. For some this has not been a positive experience. “Ken” and “Iris” told us:



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"I used to stay in the Bennett Centre bungalow when I was unwell. Since it closed I have stayed in Harplands twice, both times I had a bad experience and ended up coming out feeling worse than when I went in." Ken

"It is much more difficult to get the help I need since the Resource Centres have closed. It is particularly difficult out of hours now." Iris

Other comments relating to service cuts included the way this devalues the people who need and use the services, the need for more supported housing to help people live independently and the imbalance of service provision between Stoke and North Staffordshire.

"The way money is being pulled makes us feel unworthy and long waiting lists only increase our problems."

"Service changes have resulted in everything moving to Stoke and very little being left in the Staffordshire Moorlands."



2.7.2 Continuity and retelling the story

“Simon” stated that cohesive care with continuity of support staff was vital to successful support planning and recovery. Whilst other people described this in different ways it was a recurrent theme within the Inquiry.

Over 30 people made specific reference to having to continually retell their story. People gave various reasons for this: having lots of different support workers over a short period of time due to sickness or staff shortages; poor staff handover; poor information sharing between the same or different agencies; staff not bothering to read case notes in advance of meetings.

“I had several Community Psychiatric Nurses in a short space of time which was unhelpful.”

People said they were unhappy at having to re-tell their story because going over old ground took up valuable time from already time limited support or consultation sessions. It also devalued them and made them feel like staff couldn't be bothered to find out about them or their current circumstances. Other people found it upsetting because it involved re-living experiences and events that were often painful and distressing. “Sam” and “Hayley” said that retelling the story had raised such painful memories that they had self-harmed after support sessions as a way of coping with their feelings.

People commented on the impact that staff turnover and multiple staff contact had on service quality:

“Frequent changes of staff affect the effectiveness of input and treatment.”

People also stated it made it difficult for them to form relationships and build trust with the professionals supporting them.

“I got on well with my previous psychiatrist and CPN but now I get confused about who I am seeing and why.”



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"I feel let down by services. Currently I am engaging with Lymebrook but feel like am being passed around from one to the next and that I am some sort of training programme for mental health workers"

This in turn made it difficult for them to open up and be honest about what was happening in their life and how they were feeling at a given point in time. People told us:

"It's difficult to open up and trust people. It makes it difficult to tell people how I am really feeling."

2.7.3 Lack of knowledge and understanding of Autism Spectrum Disorder

Eight people who responded to the Inquiry have an Autism Spectrum Disorder or care for someone who does. Everyone said there is a need for all services, including GPs and hospitals to improve their knowledge of Autism Spectrum Disorders in order to be able to recognise and more effectively support people on the spectrum. Parents and carers described their experiences of trying to get their loved ones the help they needed as being so traumatic and distressing it led to them becoming physically or mentally unwell themselves.

People told us that the lack of knowledge and understanding by professionals often resulted in people being misdiagnosed or dismissed as difficult or unwilling to engage with services and support.

Several people also flagged up that people on the Autism Spectrum often have significant difficulties forming relationships and coping in social situations. Both of these are barriers to people using many mainstream mental health services, often due to the types of services being offered and also the settings in which they are delivered. "Mel" and "Joan" said:

"I am frustrated at the continued lack of progress in services for people on the Autistic Spectrum" Mel

"Mental health charities need to accommodate the realities of Autistic Spectrum conditions, where people can't cope with social situations but need one to one daily support." Joan



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When looking at people's experiences more broadly it is possible to identify this as part of a wider issue relating to the poor response of services to people with complex needs. Many of the people with complex needs who talked to the Inquiry seemed to have less positive responses from services.

Several people talked specifically about the services currently available not working for them or excluding them because of the particular presentation of their mental illness or the additional complexity created by the self-help treatments they had adopted as a way of coping with their illness. The evidence suggests that this is the case for people with a dual diagnosis of mental health and substance misuse and people with personality disorder as well as those people on the Autism Spectrum.

2.7.4 Psychological therapies

There was a mixed response from people relating to the impact of psychological therapies. People generally said they found these helpful, however markedly less so when they were not delivered face to face.

"I had cognitive behavioural therapy over the phone. I didn't realise it would be over the phone – I wasn't impressed. I have been passed to someone for face to face support but they haven't been in touch. Another therapist has given me a number to contact but don't feel like ringing it."

2.7.5 Personalisation and choice

A number of people talked about services still adopting "one size fits all" approaches to support. The need for personalised support was highlighted frequently by people who have responded to the Inquiry. People told us very clearly that things that work for other people don't necessarily work for them. One person specifically raised concerns that the social models of support adopted by many services create a barrier for people who find social situations and relationships difficult.

People told us having their opinions and preferences listened to and having a say in how they are supported is important. This helps rebuild confidence and self-esteem and enables people to take control of their journey of recovery over time.



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"I haven't always felt involved in my care planning – decisions have been made for me instead of with me. It did improve when I complained."

The number of people have told us that their support plans did reflect their individual needs and preferences and who thought that services listened more now than they had previously was small. The majority of respondents who talked about this told us that they still weren't properly consulted or listened to.

"I did not feel listened to. I felt that it was my fault that I wasn't getting better and that I was a failure."

Their experiences suggest that many services still struggle to operate with the flexibility necessary to provide people with truly individual packages of support delivered in ways that best suit them at a given point in time. This would seem to indicate that overall services still have some way to go in order to truly embrace personalisation.

One aspect of choice and control worth noting was that many people talked about feeling unable or unwilling to ask questions about their medication or care plan. Several people said that it simply hadn't occurred to them to ask questions at the time. Other people told us that they didn't because they feared the response would have been either defensive or evasive and therefore unhelpful. Even more worryingly, people said they feared there would be a negative consequence of them asking questions – and that either their medication or support would be stopped.

2.7.6 Out of hours/crisis provision

People's stories highlighted very different experiences of using out of ours or crisis services. Several people told us that the closure of the mental health resource centre community beds had reduced the support available out of hours. For some people the impact of this has been that the service options now available make them feel worse rather than better.



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Several people made reference to the Crisis Team, some people had found the service very helpful and supportive. Sylvia told us:

"I have used the Crisis Team when I was feeling suicidal and they were very helpful and understanding."

Several people told us they found it difficult to get help from the Crisis Team. "John" told us he had called several times on different occasions, but had never managed to get help because his problem was always the wrong type of problem. "Bella" told us:

"I have tried to get help from the Crisis Team but never managed it. Whenever I have needed help I have never been able to get any, including when I was saying I wanted to commit suicide."

Others described feeling frustrated by the type of support available from the Crisis Team. "Lisa" said that she felt the support she got from them wasn't enough:

"I am not always happy with out of hours support. I only get a 20 minute call from the Crisis Team - it's not enough. I want face to face support."

"Paula" told us she thought that the Crisis Team did not intervene early enough to avoid a crisis. She also raises the issue of risk from the perspective of both the service provider and service user in a way that suggests an unsatisfactory response from the provider and also a differing viewpoint of the degree of risk in her situation.

"It's a waste of time because when I need the Crisis Team I am already in crisis and have cut myself or taken an overdose and they won't come out because I have a history of violence - although never to workers."



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“Melanie” described the response from the Team as unhelpful and said that she didn’t feel they listened to her or believed what she was saying, with dire consequences in her case:

“I sometimes feel that services don’t take me seriously. I felt let down by the Crisis Team as they didn’t respond to, saying that I was going to take my own life. I did as a result jump off the Midway car park.”

Some people talked about using Harplands Hospital and, with the exception of one person, described their experience as scary and/ or unhelpful. People told us:

“One night I went to Harplands for help - I was having a breakdown. They weren't helpful. They left me waiting on a chair all night, wouldn't give me a bed and discharged me. They kept bringing me magazines and wanted me to eat. I didn't feel like reading or eating I was depressed, having a crisis and just wanted to sleep.”

“I found being in Harplands very difficult, it was scary and I felt alone.”

“I was in Harplands for a few weeks when I was unwell. I was safe and people treated me well.”

Five people described the “discovery” of the Brighter Futures Safe Spaces Network as life changing.

“The turning point in my recovery was accessing Brighter Futures Safe Spaces Network. I was briefly in Harplands but felt scared by some of the actions of others. I have also accessed the Crisis Team on a weekend which really helped me as it prevented me from taking another overdose.”



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"In the end I was offered Brunswick House (part of Brighter Futures Safe Spaces Network), which was the best thing I had ever been offered in all the years I'd been seeing doctors and nurses."

Three people talked about their frustrations at not being able to get a bed space when they needed one.

"The best place for out of hours support is the Safe Spaces Network, although sometimes you can't get in."

People said that the Safe Spaces Network offered them somewhere safe to stay where there was always someone available to talk to and who would listen – at any time of the night and day.

"Beverly" and "Tony" said:

"Being able to get away from my problems, relax and have a good sleep makes life bearable again."

"I used Safe Spaces at the weekend. It was very helpful because it gave me someone to talk to and helped me de-stress. They have helped when I have been in crisis."

Nine people told us they used the (Brighter Futures) Telephone Helpline and that it provided them with a lifeline and helped them to cope with life on a day to day basis or when things got particularly tough.

"The only out of hours support I have is the (Brighter Futures) Telephone Helpline, there is no one else to call - nobody there out of hours. I call the helpline almost every night. If I didn't have the helpline I think I would have ended my life by now. They support me and the information they give is very good."



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Two people described the problems they faced in accessing out of hours services due to having used drugs or alcohol.

"I have tried to get help from the Crisis Team twice now and they wouldn't come out to me because I had had a drink."

People told us they often misused substances when they felt particularly unwell or anxious, however on occasions when their mental health had deteriorated further it had then become a barrier to them getting the extra help they needed. People described an apparent unwillingness of mental health services to respond in person, despite on one occasion having being asked to undertake a mental health assessment by a GP. When combined with mixed responses from the Police, people told us this resulted in them being left in potentially high risk situations without support when they were particularly vulnerable.

Several people talked about using emergency services out of hours because in their experience this was the only way, or best way, to get help. "Dan" told us that he called paramedics when he was in crisis because there was no one else available. "Anna" told us that she could only get telephone support out of hours and so went to A & E if she wanted to see someone face to face.

2.7.7 Self-harm

Thirty-five people told us that they self-harmed as a way of coping with the problems in their life. People told us that Echo, delivered by Brighter Futures, was the only service available that provided support to people who self-harm.

"There isn't much help apart from (Brighter Futures) Echo."

With the exception of Echo, people consistently told us they had been treated badly by professionals – particularly those within health services. People described rude and judgemental attitudes from doctors and nurses when they had presented for treatment for their injuries. The attitudes some



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people had encountered had led to them feeling so guilty and ashamed about their self-harm they had not sought medical attention on other occasions when they would have done so otherwise.

"Professionals reject you because you are harming your own body. I thought it was only me but once at Echo I gained trust and respect - they gave me hope. Services shouldn't write off people who self-harm or who have addictions."

"People treat you differently when you self-harm, they look down on you and make you feel you are wasting their time because you have done it yourself."

"Self-harmers are treated badly across the board - even Brighter Futures."

People talked about there being a general lack of knowledge and understanding of self-harm amongst professionals within health, mental health and other services. This made it difficult for them to talk about how they were feeling and therefore get the help they needed, particularly in times of crisis. Many people said that there had been very little or no follow-up support following incidents of self-harm, even when their actions had led to them presenting to primary health care services or A & E requiring medical attention.

2.7.8 Complaints

Eight people talked to us about making a complaint. Only two of the eight people said they had received a response from the service they complained about. "Steven" said the outcome from his complaint was positive and the service improved as a result. "John" said he was told his complaint had not been upheld and that he felt very frustrated because he felt he hadn't been taken seriously because of his mental ill health.

A further nine people talked to us about being unhappy about the way they had been treated or the services they had received. Four people told us they hadn't bothered to complain because they



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didn't think it would make any difference. "Ann" told us she had complained about a service previously and nothing had happened so she hadn't bothered since. "Martin" told us that staff had treated him differently after he had complained. Staff became unfriendly and unhelpful and he wished he had kept it to himself.

Two people said they hadn't complained because they didn't know how to and another two people said they hadn't complained because they were worried they would be made to look stupid. "Jim" told us he hadn't complained because he was "just glad the episode was over and he had no desire to revisit the issue."

2.7.9 Positive feedback

It is often easy to focus on the negatives and talk about where services need to improve. However over 28 (20%) people told us their experience of using services has been a positive one.

"I have only had positive experiences of mental health services and genuinely believe that I wouldn't be here today without them."

"If it wasn't for the services of Brighter Futures I could have been dead now or living on the streets."

"The services I use have made my life a lot better."

Many people told us that they thought services had got better over time and they felt much more involved in their support planning than they had previously.

"I have trouble asking for help. It's easier now. I have used lots of services and they are helpful."



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People also stated they thought that professionals were more understanding than they had been in times gone by and were more responsive to their needs.

"I think they (professionals) listen and take more notice than they used to."

2.8 Navigating the system

The majority of people we spoke to described feeling frustrated, confused, anxious, isolated and overwhelmed when they tried to get help. Lots of people told us that they found asking for help difficult. People said having to talk about what was happening and how they were feeling was often distressing. This was made worse when they had to talk to complete strangers about very personal and private things, they may not have even shared with the people close to them. Several people attributed the difficulty they had in asking for help to the fact that by asking for help they had to admit they had a problem and also that they were unable to deal with the problem themselves.

"I find it hard seeing different professionals because it's hard to trust/open up to people."

People said that getting help was difficult and stressful because they didn't know what services were available or how to use them. This was made worse by the fact that there wasn't a single place or service to go to for help or advice. We were told:

"It's hard getting into services by myself - I need help with that."

"I would have welcomed advocacy from someone who understands the system who could guide us and access to a Hub for the services available."

"It's difficult to know what's out there, who provides it and for how long."



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The more problems people had, the more difficult it was to get the help they needed. People told us that having to negotiate their way through multiple information sources and systems was at times almost impossible. “Jean” told us that she gave up asking for help in the end because she didn’t have the energy to try and understand how things worked or do the things she needed to do to “join, register or get referred in”. “Simon” and “Linda” told us:

“Getting help is like walking through a minefield.” Simon

“NHS mental health services are not easy to use or navigate and I would have struggled without Lifeworks to fight my case. It's harder to get help for mental health than for physical health, even harder again if you have an Autism Spectrum Condition.” Linda

The degree of difficulty people experienced in getting the help they needed seems to be very dependent upon the degree to which the first service or person they make contact with is knowledgeable and willing to help. Attempts to get help were further complicated by inconsistent responses from professionals within the same organisation and at times the same service.

“I have to fight for help and it is making me ill. I feel let down by services.”

People with a dual diagnosis of mental ill health and substance misuse consistently described the difficulties they experienced trying to get help from mental health or drug or alcohol services. People told us that they had been passed between services on multiple occasions. None of the services they needed seemed willing to offer any form of help or support until the other issue (either mental ill health or substance misuse dependent upon the service the person was talking to at the time) had been resolved. Several people told us they had also experienced issues with the prescribing of medication. Poor communication between substance misuse and mental health services has resulted in people not being prescribed the medication they needed for one or both elements of their ill health. Other people told us this had resulted in delays to them getting the



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correct medication and one person said their prescription for their mental health medication had been stopped due to a mix up in communication between services.

Numerous people talked to us about being let down by services as a result of professionals not doing the things they said they would. This included making referrals, providing information and booking and attending appointments. Lots of people told us that they had had to constantly chase people up to see if they had done the things they had agreed to and to find out what was happening. People found this particularly difficult because more often than not they were trying to get help because they were struggling or feeling unwell and therefore lacked the motivation and resilience needed to keep chasing people. People told us:

“The social worker offered me help but didn't follow it up.”

“Communication between services and departments is poor and I was forever having to follow people up only to find out people hadn't made the calls they said they would or that information had not been received”

Seven people talked specifically about professionals “passing the buck” in relation to actions within their care or support plan.

“It has deteriorated over last 5 years - it can be impossible to contact professionals because no-one answers, but with the new system you are charged for the call.”

People said that there is often a long time between referrals being made and them getting a service. This is very unhelpful when people are struggling and need help straight away. This issue is made worse by the fact that people are often not given information about the processes relating to the services they have been referred in to and are not kept informed about what is happening, for example how their referral is progressing and when support is likely to start. “Mike,” “Anne” and “Jane” shared their stories with us:



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"I was directed to Rethink. There was a waiting time of about 6 weeks, which in my situation felt like a lifetime. I referred myself into Mind, but again there was a long waiting list and I didn't get the sort of help I was hoping for. I saw different doctors but didn't feel they took me seriously about how bad I felt. I was given a property in Staffordshire Moorlands and was transferred to a different Rethink, which I found more helpful. I felt understood and taken seriously regarding my mental state. Some professionals were understanding, but it all depended upon the circumstances I found myself in at a particular moment in time." Mike

"I had to wait for over 11 weeks to get counselling with Mind and although I was referred in to (Brighter Futures) Safe Spaces Network quite quickly by my GP it was three weeks before I got a place". I was also referred in for housing support and I had to wait over eight weeks before I heard anything. Waiting for help was very stressful and made me feel worse than I had before the referrals had been made. I wasn't in control and no-one told me what was happening or how long things would take. I started to wonder whether there was something wrong with me that people didn't want to help." Anne

"It's a minefield out there and often the help only surfaces by the time a person is in crisis and damage has already been done." Jane



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One group of people discussed the transitions between services as being particularly lengthy, inconsistent and problematic with appointments being missed, repeatedly rearranged and on occasions cancelled with no follow up. “Susan” and “Neil” told us:

“Waiting lists are extremely lengthy and I have often found that appointments are forgotten about due to the length of time since assessments (by professionals not myself).” Susan

“The time between referral and assessment is generally no-man’s land and nothing is in place to help. It is often the charities that pick up the slack though vital funding is taken away from this. As an NHS service user I feel forgotten and insignificant.” Neil

Several people talked very positively about Brighter Futures Clubhouse Network and Mental Health Telephone Helpline. They did so on the basis that they were easy to use – just ring or turn up and no referral needed.

“The easiest services to get help from was The (Brighter Futures) Clubhouse and Telephone Helpline.. I could pretty much talk to someone straight away. Other services took much longer.”

2.9 Stigma and oppression

Lots of people told us that they thought that knowledge and understanding of mental health was poor within their communities and society more broadly. A small number of people felt safe in their community and described local shop owners and neighbours as part of their network of support, however the majority were much more suspicious and fearful of the responses of others to them in relation to people knowing they had mental ill health. People talked to us about not telling people about their mental ill health for fear of reprisal, being singled out or becoming more vulnerable to harm.



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"People treat you like a leper when they find out you have a mental health problem."

"Mental Health is still taboo in the broader community and not understood. People are to some degree wary of people with mental health problems."

"I only tell people close to me about my mental health because I fear how people will respond."

Worryingly, a significant number of people told us they had not been honest about the extent of their mental ill health for fear of being sectioned under the Mental Health Act or having their children taken away because services decide they are unable to cope.

"I kept my illness to myself because didn't want to be sectioned."

"I was worried about being honest about how I was suffering in case I was locked up in Harplands."

The extent to which people described their oppression is worth noting. People may not have used the word explicitly but a large number of people told us they are unable to talk openly about their mental ill health for fear of the prejudiced and misguided responses of others in society. This gives a clear indication of the continued prevalence of stigma and discrimination towards people with mental ill health. People's experiences indicated that this cut across all areas of their life and society from family, friends and in some cases to work, education, recreation, health and other services.



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"I think I have been struggling with stress and anxiety for over twelve months now and I definitely experience depression, although I think it's quite mild. Have I told anyone? No – I don't think my GP would do anything useful and I don't want it on my medical record. You never know who may ask for it in the future and what impact that information may have. I would never tell my employer, they talk about supporting people and helping them with their wellbeing. The reality is very different, mainly because of people's ignorance to the impact of mental illness.

Also they need the people they employ to be able to go into work each day and do their job. There is no point telling my family. We are very close and supportive of each other in many ways, I talk to my mum on the phone every other day. I'm not honest with her about how I feel though. My partner? He thinks that people who say they have mental health problems should get a grip, stop moaning and get on with it. Stop wasting other people's time basically."

"Amy" felt more positive about her mental ill health and told us:

"I think there will always be stigma about mental health issues - including from people who work in mental health services. I am not ashamed or embarrassed by my depression/anxiety. One in four people have a mental health issue in the UK so there's a lot of it about."

Two people shared experiences that highlighted stigma amongst health professionals towards people misusing substances. Both "Tim" and "Ruth" told the Inquiry that attitudes of health professionals had improved once they developed serious physical health problems. It was as though they now had a "legitimate" illness, even though it was no less "self-inflicted" than their dependence upon substances.



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Appendix A

Participants in the Inquiry

The following organisations have supported the Inquiry:

Addaction, Age UK North Staffordshire, Aquarius, Asist, Disability Solutions, The Dove Service, Embrace, EngAGE Stoke-on-Trent, Healthwatch Stoke-on-Trent, Jubilee Project, Keele University, LGBT Staffordshire, Lifeworks, Making Space, NORSACA, North Staffs Carers Association, North Staffordshire Combined Healthcare NHS Trust, Recovery is Out There, Rethink, Savana, Staffordshire Buddies, Staffordshire Police, St Mark's Church, Stoke Expert Citizens, Stoke-on-Trent Citizens Advice Bureau, Stoke-on-Trent and District Gingerbread, YMCA North Staffordshire.



Appendix B

Data analysis

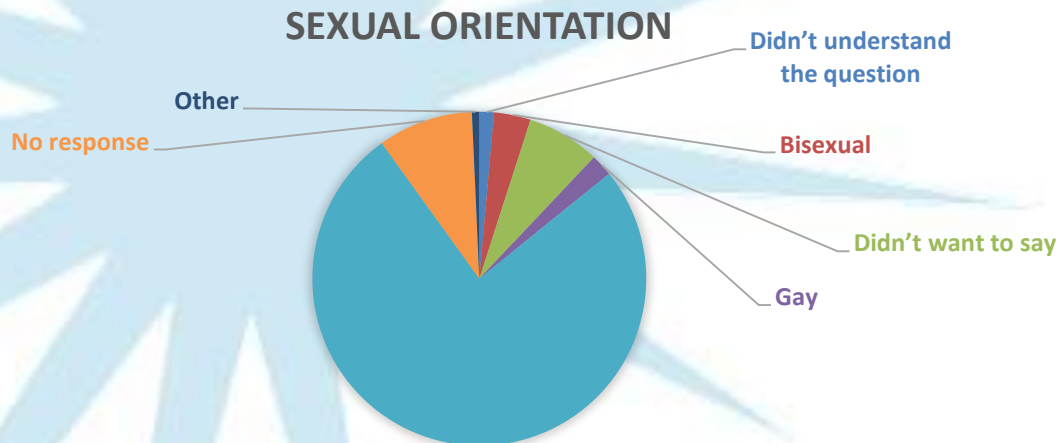
141 people shared their real life stories with the Inquiry. This appendix summarises the demographic profile of participants. Of the people we spoke to:

Gender

41% (58 people) were female and 43% (60) male. 16% (23) did not respond to the question. 84% (118) of those who we spoke to told us they lived in the gender they were born in, 0.7% (1) said they did not and 15.3% (22) did not respond to the question.

Sexual Orientation

When asked about sexuality 20% (28) people didn't answer the question, 3.5% (5) were bisexual, 7% (10) didn't want to say, 2% (3) were gay, 76% (107) were heterosexual, 0.7% (1) described themselves as other.



Ethnic Origin

Participants in the Inquiry were predominantly white British, with only 3 people (2%) describing themselves as having a different ethnic origin. Two people described their ethnic origin as black afro Caribbean and one person as Asian other.



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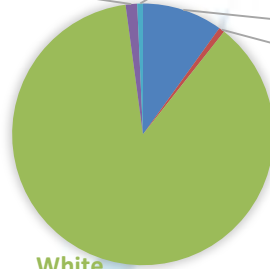
Black Afro
Caribbean

ETHNIC ORIGIN

Didn't
understand
the question

No response

Asian Other



White
British

Age

The majority – 57% (80 people) - of the people who responded were between the ages of 41 and 64. The age group least represented within the contributor profile is 18-25 year range with only 2% (3 people), followed by 31-40 years with only 8% (11) and 11% (16) over 65 years. Four people (3%) did not answer the question.

AGE

No response

18-25

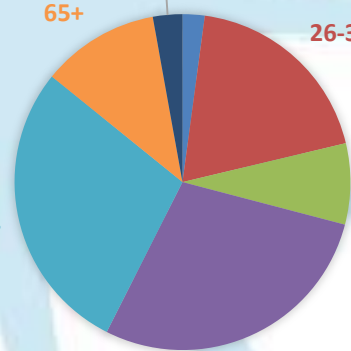
65+

26-30

31-40

51-64

41-50



Disability

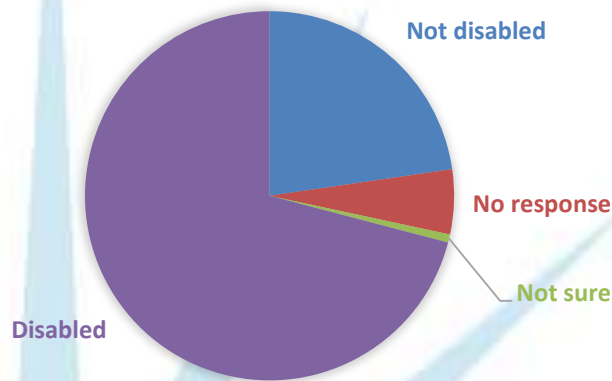
71% (100) of those who responded described themselves as having a disability. 23% (32) said they did not have a disability, 6% (8) did not answer the question. It is worth noting that one person said they did not know whether or not they had a disability due to their GP prescribing anti-depressants for their illness and being reluctant to pursue any other course of action.



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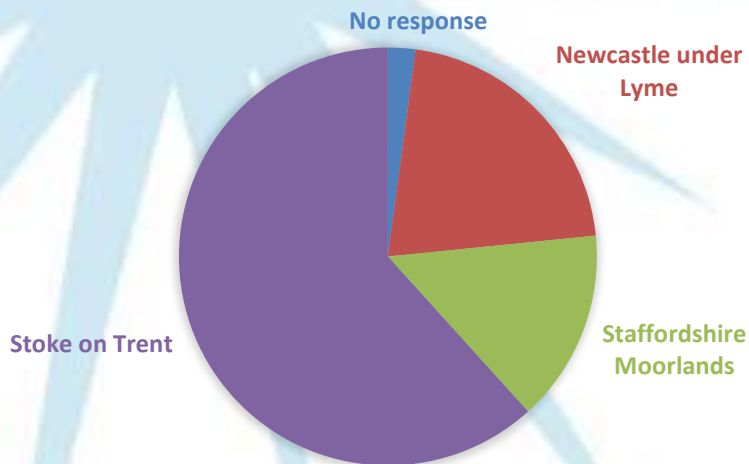
DISABILITY



Geographical Areas

The geographic mix of people was 62% (87) from Stoke-on-Trent, 21% (30) from Newcastle-under-Lyme and 15% (21) from Staffordshire Moorlands. Three people (2%) did not answer the question

GEOGRAPHICAL AREAS



Enquires relating to the data upon which this report is based should be addressed to Sarah Vernon at sarah.vernon@brighter-futures.org.uk