

WAITING FOR SOMETHING BETTER

Stories of adversity, resilience,
mental health and **hope**

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WAITING FOR SOMETHING BETTER
is funded by:



About Living Well UK

Living Well UK is a three year programme that is creating new systems of mental health support across the UK, inspired by a model developed in Lambeth, South London.

The Living Well UK programme has been awarded £3.4 million in The National Lottery Community Fund funding to support new local partnerships in Edinburgh, Luton, Salford, and Tameside & Glossop that will each develop their own version of a Living Well system.

The aim is that these new Living Well systems will become leading, internationally recognised examples of an innovative ways to help people achieve good mental health in community and primary care settings. They will have the potential to be scaled across the NHS in the UK, transforming current provision offered by GPs and community and mental health teams.



About Innovation Unit

Innovation Unit is a social enterprise based in the UK, Australia, and New Zealand that grows new solutions to complex social challenges.

By making innovation happen we help create a world where more people belong and contribute to thriving societies. We build alliances with ambitious places, organisations and systems around the world to adapt, adopt and scale innovations that deliver lasting impact and reduce costs.

Design by Ellie Hegarty

Introduction

Good mental health matters to everyone, but collectively, across the UK, it is getting worse. There are many suggested explanations for this, including historic underinvestment in NHS services, stigma and discrimination that make it difficult for people to ask for help, the negative influence of social media, especially on the young, and unhealthy, stressed lifestyles associated with work pressure and social isolation.

The World Health Organisation (WHO) defines mental health as ‘a state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her own community.’ Increasingly, our society is recognising how hard it is to live out this idealization. More and more people are publicly sharing personal struggles with depression, anxiety and other emotional states. We are gradually coming to terms with the reality understood by many cultural and religious traditions for a very long time - that life comes with suffering.

How hard it is to feel mentally healthy in an age when the protective factors for good mental health - such as strong relationships, economic security and good housing - seem so threadbare.

And how hard we find it to make sense of our own mental health at a moment in history when we are puzzling out the language, meanings and responses to mental ill health with unprecedented depth, enquiry and argument. Am I unwell? Do my feelings make sense, given my experience? What will help me most to feel better? Will people understand?

Added to this we now have the challenge of a pandemic, a virus that has thrown the majority of the world into very different ways of living. Covid-19 has changed our routines and activities immeasurably. Research from the WHO shows that it has caused elevated levels of stress and anxiety across the population. Increased degrees of distress and levels of depression and insomnia are being recorded along with symptoms of denial, anger and fear. This at a time when services are harder to access, counselling and therapies put on hold or their format changed to online.

The power of stories

This is a book of, and about, stories, collected through close observation and 'being with' storytellers themselves. The stories presented here capture the lived experience of 'mental health', but in an important sense they are not stories of mental health - that is too narrow. They are, more accurately, stories of adversity, and the ways in which it affects life experience and outcomes, including mental health.

Through these stories we can start to see how mental health is currently 'done' - in other words how it is described, how mental health services and systems are designed, how power and resources are distributed, and the practices that shape how people receive, interpret and experience care and support. Practices that include:

- Focusing too narrowly on clinical treatment that blocks an understanding of the impact of wider social determinants of mental health.
- Putting pressure on people to translate their experiences of grief, loneliness, despair and fear into the language of 'mental health'.
- Asking people to wait and wait for an assessment that might not lead to actual help, or to help that is ineffective even though well intentioned, and retained as 'business as usual'.
- Asking people to repeat their stories to different practitioners, or to select only parts of their story to relay to specific practitioners.
- Denying people help because they have other, seemingly conflicting, needs (for example substance misuse issues).
- Creating gaps between services because people are considered 'not sick enough', or 'too sick', to qualify.
- Discharging, signposting and 'handing off' - as techniques for rationing services, managing demand, and resisting engagement with the 'whole person'.
- Relying on learnt assumptions about who is, and who is not, responsible for helping.

Thinking about how people 'live through', 'live out' and 'live around' mental health is important; it allows us to more clearly see that what may appear as a 'single' factor is in fact a multitude of factors, often spread across the life course. All the stories we have gathered capture a person, or a family, struggling to maintain mental health equilibrium. Each person's struggle comprises a different matrix of factors - even though they may share the same diagnosis and are offered the same medication. For example, the factors of 'depression' for one person with a partner with Borderline Personality Disorder and three sons with Autism Spectrum Disorder(s), will not be the same as the factors of 'depression' for a single man battling with alcohol addiction.

As a society, as individuals, we are rarely exposed to the full complexity of a person's life course. How might we use a deep understanding of complexity to see the ways in which social, institutional, clinical, political and other forces collectively impact upon a person's ability to get better and stay well?

Living Well UK

This Story Book is funded by The National Lottery Community Fund, through the Living Well UK programme. The programme is working to create a new approach to mental health, and is inspired by a collaboration of carers, people who use services, staff, managers and leaders in Lambeth, South London, to redesign the local mental health system around the voice of lived experience.

Only by drawing insight and inspiration from lived experience can we draw out the multitude of practices, and the ways in which the inter-relationship of those practices, affects people's experience of services and support.

Effective services and systems of support can't be designed in the abstract. The lived experience of people affected by mental health needs is the only genuine starting point and source of insight about what needs to be changed, what needs to be done. We need to create, through practice, a different set of responses shaped by the insights that come from hearing people's accounts of themselves and what matters to them.

Asking questions

Yet stories alone do not provide answers, instead they are an invitation to engage, to ask questions. They trigger compassionate empathy, an ability to connect with what people are living through and, crucially, to either take, or help them to take action to feel better and live well.

Human lives are complex. They lack predictability. They appear full of contradiction, and are lived out through intricately designed relationships. It is this complexity that we must explore. As we travel through the complexity we highlight themes that emerge, especially those that surface in more than one story. We ask questions and make suggestions about how 'doing' mental health differently could improve lives.

Our aim is to avoid oversimplification and generalisation. We don't think it is easy to create a robust and accurate analysis of complex lives and systems. Instead we see stories as prompts for sensing and responding.

Our analysis

Towards the end of this book we offer an analysis of the stories. Our analysis represents the collective reflections of a group of people with diverse perspectives who came together to bear witness to the stories and to surface shared understanding:

- An experienced mental health practitioner
- A senior mental health commissioner
- A sociologist
- Service designers
- People with lived experience (many of us)

The conversation we had is the analysis presented.

We would like to invite you to 'join in' with the conversation. We want the stories to be a living resource that does not simply reinforce or evidence the positions we set out in the analysis - but, by contrast, are used by collaborative groups with diverse perspectives to help generate new meaning, new questions, and ultimately move towards new forms of collective action.

The stories here were gathered before Covid-19 struck. Since then it is becoming clear that the crisis is forging space for change. We see social movements garnering strength with people demanding social, economic and political equality. The intense difficulties and dangers that we are facing are allowing us to re-imagine our way of being. In short we have an opportunity to make positive changes to how we live in ways we could not have contemplated before. To this end we want these stories to inspire new kinds of conversations and the shared pursuit of new and better solutions.

"If you are not like everybody else, then you are abnormal, if you are abnormal, then you are sick. These three categories, not being like everybody else, not being normal and being sick are in fact very different but have been reduced to the same thing".

Michel Foucault in interview, 1975

Content warning

Some people think it is helpful to include 'trigger' warnings at the beginning of potentially distressing stories, others don't. Because we wish to promote inclusivity in mental health, we feel it right to share with you that there are elements of these stories that you may find upsetting and, by so doing, give you the choice to continue, or not, or to read at another time. We would also hope that you find the stories helpful and even inspiring.

Stories of Lived Experience

We would like to thank our storytellers for generously, and bravely, sharing their life stories. Each storyteller has a unique reason for sharing, and many told us just how important it was for them to have their stories heard and shared widely.

All storytellers have given their consent to share their stories and have co-crafted their final words with us. We have anonymised key details (including people's names) to protect identities.

"There is no greater agony than bearing an untold story inside you."

Maya Angelou,
'I Know Why the Caged Bird Sings'

May

We meet May at a local support centre on the outskirts of London. Her first concern is whether we will have access to counsellors after hearing her story. This level of thoughtfulness and consideration is deeply embedded in May's very being. She thinks of other people rather than herself and throughout the day she refers to feeling she has always had to look after others.

May has never before told anybody her full story, partly she tells us because her generation 'never talked about things'. Handing us a typed list of her experiences she explains that she wrote it after going to see a therapist. Within 10 minutes of meeting May had, in her words "clamped up" - she didn't feel she was believed.

"I left the place feeling worse. I went home and wrote the list as well as a suicide note. You're told through your life to keep quiet, you hide things and then when you do try to get help nobody believes you! And I thought, if a professional doesn't believe me, who is going to believe me?"

This thread of not being believed, of hiding what has happened, of the consequences of actions, of putting others first, of feeling others think you are 'pulling a fast one' is embedded in May's experiences. She tells us about turning up for a benefits assessment with freshly washed hair and "being looked at as if you're not believed and you just want to tell them that you don't want to be here! They make it worse - they make me want to go home and take the tablets more ... Because, every so often I have a stash of tablets and when things get too much I sit down and look at it ... at the moment my little dog is keeping me here. If my dog passed away tomorrow then that would be a big thing, whether I would want to continue".



The beginning

May's story begins with her brother and herself in care – she doesn't know why – but she does remember having a bad time.

She tells us her foster mother didn't like her and shows us a scar from boiling water being poured on her leg – she doesn't know what she had done. This physical abuse was replaced by sexual abuse when she was back home. May knows she was still under five as, "I hadn't started big school yet".

The first time she was kept back from going with her brother to the seaside.

"I didn't know what I had done, I didn't know why I wasn't allowed to go". Her stepfather gave her sweets afterwards. *"I didn't know it wasn't supposed to happen".*

"I used to go to church when I was little – and I would pray to God to make it stop. I didn't know what was happening, but I knew I didn't like it. I used to think I was awful because He didn't listen to me and He didn't stop it. The church used to say that if you had sins you would burn in hell, and so I thought I would burn in hell, because I was asking for something to stop and perhaps I shouldn't be. I didn't know the abuse was wrong until I got into secondary school and it was "Does your Dad do this?" and it wasn't until I listened to the other girls that I knew their Dads didn't do what my Dad had been doing".

Later, following a row in which her Mum had dragged her upstairs by her hair May tells us *"I told her he'd been messing around with me and she said 'I'm going to ring the police!' She thought I'd said it in anger. I*



couldn't even tell [the police] everything. At one point, when the police weren't with me, my Mum came in and told me if I carried on my brother and sisters would be put in care, so I told them I was lying. I got a thrashing off [in trouble with] the police. I don't think she even told my Stepdad ... and then it was just back to normal".

As a consequence, when May experienced rape as a teenager – scared stiff she would be killed afterwards – she was terrified of going to the police in case they wouldn't believe her. She was interviewed by two male police officers. The offender admitted six other offences and got eighteen months.

"Was that all I and six other women were worth – just eighteen months!" At the time it happened, May's Mum was away with her second Stepdad. They often left May as a young teenager in charge of her siblings, feeding, clearing up, and getting them to school. May tells us after the rape, *"Mum never sorted a lawyer out for me or got me therapy. The only thing I got told was 'go to the doctors and make sure you don't have a STD or are pregnant.' It was like, just get on with it".*

May's relationship with her Mum and siblings is now difficult. As she says *"Mum didn't believe me all those years ago, what's going to make her believe me now.*

My sister doesn't believe me". Her brother with whom she is the closest wasn't aware of any of it. *"I didn't want him to see the list, but I got to such a point I had to tell him. But my sister-in-law has asked that we don't discuss it – basically she doesn't want him fucked-up like me, which hurts ... again, I've got it to myself again. I've not spoken to my Mum for [...] years because I can't handle her".*

"If a professional doesn't believe me, who is going to believe me?"

Leaving home

When May moved away from home it was with her best friend. She tells us of being caught up in what today would probably be called a sex ring but then they called 'sugar daddies'. She and her friend used to look after each other, protect each other.

"It's like all my life I must have had this sign across my head saying vulnerable idiot!" They were more frightened of his wife than him - what would happen if people found out! He gave her a job with people he knew. The men there used to sexually harass her too. Whilst there, May's best friend took her own life - May was so angry with her. She tells us that they had agreed to do it together. May's Mum didn't want to know, wouldn't talk about it. She has subsequently told her that people who kill themselves are very selfish. *"Well, you've got a very selfish daughter sat here because I've been trying to kill myself for years but never taken enough tablets"*.

Receiving the wrong sort of advances from men has continued throughout her life. She says that she can't have relationships now *"my head is so messed up"*. During a quiet moment, May divulges that she feels very confused about the place of sex in relationships. She swings from not wanting to be touched to wanting love and the physical relationship that goes with it.

May does have a grown up son. He has been diagnosed with depression and anxiety. May gets upset, worrying if she caused this because of the way she brought him up. She hasn't seen him in years - he sends her the odd message. She misses him so much. He doesn't know anything about May's background. May tells us that when he was growing up he 'grounded her' - now he isn't with her, she feels adrift.

The present

Recently, May has been diagnosed with arthritis. She has had symptoms for over eighteen years but it was put down to increasing age, her physical job as an occupational therapist and mental health issues.

Flare-ups are now every week. She takes codeine. They took the Tramadol off her. She also has terrible nightmares *"I'm constantly being chased in my dreams, I'm being tortured, I'm being raped, I save everybody else except for myself, and I can never find my way home"*. Ironically, when her arthritis is at its worst she does not suffer from the nightmares - the reverse is

also true. When the pain gets really bad she takes extra painkillers and drinks spirits. She feels it is the only way she can cope and tells us she often gets to the point where she is just fed up with *"the pain, the pressure to try to get well"*. Triggers are particularly difficult. Just recently, contact from her Mum caused her massive anxiety. Feeling she was *"going to explode"*, she went into the bathroom and in tears took scissors to her long, dark, curly hair and cut it short. She tells us she has a *"war wound"* caused by her taking a Stanley knife to her thigh. *"I went out, spent money I couldn't afford on a new knife. The cut sprung open and I bled and bled"*. This needed hospital attention but the fear of telling people what had happened stopped May going.

The invisibility of May's pain hurts her so much *"It's like if you've got cancer or a leg missing people can understand, but when you look normal and you're absolutely screaming inside with pain and scared stiff of everything and everyone - people don't see that until you break down. I'm told I'm too poorly for Mind and I had CBT a while back and was told I was too ill for them ... but I'm not poorly enough for other stuff, how poorly have I got to be?"*

At the time we spoke to May she had been waiting nearly a year and a half for therapy. She has been told she does not meet the criteria to see a Psychiatrist, although nobody has ever explained what that criterion is.



Throughout May's story we see the insidious effect of childhood sexual abuse and the resulting trauma. We hear too the manner in which the effect of her early experiences continues to ripple out into her future with ongoing physical, emotional and psychological harm.

Her words capture how her experiences have devalued her self-esteem and disempowered her, leaving her fighting to cope each day. Throughout, of greatest importance to May, is to be genuinely listened to and believed, for people to see beyond surface appearance, to hear and acknowledge the truth and the effect of that truth.

May's story invites us to ask many questions, including, how can we make it possible for people to develop their ability to care for themselves with kindness and compassion, and how can we recognise people's skills and talents, and use them to rebuild confidence, identity and purpose? In the story that follows we once again see the destructive effect of childhood abuse and the pressure that society places on people to appear and function as 'normal' despite suffering from trauma. For Sabita this was compounded by inadequate recognition of her vulnerability as she moved from child to adulthood.

Sabita

Born into an Asian family in the North of England, viewed as middle-class, well educated, well spoken and successful with money and status, Sabita was encouraged to present herself in a certain way, to “put a face on”, a “show of happiness”.

This outer appearance of respectability hid what Sabita tells us was a “*dysfunctional and closed family, with religion in the background. Praying every week just for my stepmother to prove she was a good person ... And shame – things you don't talk about*”. There was no love or care. Her father, who had arrived in the 1960's from the Indian subcontinent, was married by arrangement to her mother. Sabita remembers her father being “*very focused on work, money and being quite cold*”.

Growing up

When Sabita was 3, with siblings between the ages of 4 and 15, her mother, only just in her 30s, took her life. “*She was in and out of a mental health unit all her life in England*”. Sabita feels that her father's coldness to his family “*made my mother more ill*”, especially as she also felt isolated and alone with her illness speaking very little English. She had one Asian friend. “*They both had mental health problems and were shunned by our Asian community as they were seen as crazy*”.

When Sabita was 3, her mother took them back to her place of birth in order to end her life in a place she called home. She is buried in an unmarked grave. From that moment on, the family has never talked about her mother or her death, “*Like it never happened*”. It was only when Sabita turned 25 that her eldest sister started briefly talking about their mother's death.

Within weeks Sabita's father married a relative on her mother's side who was just 16. He was 41. For two to three years her stepmother was threatened with deportation. Because of the family's status in the community this triggered frequent media responses. It was in the local press and Sabita remembers TV appearances, photographs in the newspapers of her and her siblings looking confused and the airing of “*sordid things*” about her family, and the threat of her siblings possibly being put into care. She still has the press cuttings.



Within three years following Sabita's mother's death her stepmother went on to have three children of her own with Sabita's father and as Sabita grew up she was increasingly neglected, physically and emotionally abused.

In her own words, *"It became more physical. I would be stamped upon, punched, my hair ripped out, boiling hot water poured upon me. Once my stepmother had her own kids we were given little food, or only [given] leftovers. We did not know how to say how we felt. We had no social or communication skills, we were not taught them. There was no heating and there were mice coming up at night in the attic where we slept. Everyday as a teenager my stepmother would put me down saying I was mad, crazy, criticising everything I said, saying I should get out of her house - a house my mother had left to her own children after she ended her life. My Dad ignored all the abuse and I thought it was normal".* It was a friend who noticed the bruising while Sabita was at school, but as Sabita says, *"she was a child too - she didn't know what to do. At school I would constantly arrive with bruises and nothing would be said".*

Sexual abuse, focused on Sabita's sisters, was taking place, although Sabita only learnt of this as an adult. She feels she may have escaped because she was intuitively defiant. However, she was therefore subjected to more physical abuse. When she was a young teenager she told her Dad that men outside the home had sexually assaulted her. He ignored it. The same way he ignored her sisters' abuse. She feels he was an acceptor of it. She believes this affected her relationships with men when she left home.

Retrospectively Sabita realises that she was depressed from thirteen and feels that if she had known her mother's condition it would have helped her enormously.

"It would have helped explain why I tried to take my life, with my first attempt at twenty-one. And then why I had the same turmoil with mixed mood states, and hell in my mental health every time I was pregnant, where I wanted to kill myself and my unborn baby. And feeling scared that I could not cope, as I had no parental role models or idea of how a person functions in this world having never learnt them as a child.

And I still find it difficult to trust people now, or build lasting relationships as an adult".

Sabita now has no children due to the loss of pregnancies. As an adult, years later Sabita reported her stepmother for abuse. She tells us her stepmother was questioned, but nothing was done about it.

Leaving home - the Hostel

At seventeen, when Sabita was at sixth Form College she left home, eventually moving into a female hostel. She lived there for eighteen months. And then moved frequently to different places over the next few years.

She describes the complexity of the social world she found herself in at the hostel, discovering the line between a vulnerable person and a criminal.

"Everyone around me had been physically or sexually abused. So were doing crime, drugs, alcohol to deal with these issues and our mental health. The girls were groomed for prostitution and became addicted to heroin for life by the time they turned 18. I became aware again that something wasn't right, like when I left home. These men around us were being abusive and locking us up, and boyfriends started to want to share you or introduce you to people. I now realise they were pimps and grooming gangs. I was sexually assaulted in a car park, but back then it wasn't classed as rape ... So, yes, I was raped, but I couldn't talk about these things ... you build up the same life as in your childhood, patterns of control - sometimes it wasn't explicit, but the control was there". Sabita adds that all of the above issues are *"covered up in the homelessness world".*

The hostel did help Sabita get some support from their charity workers, but some of them she describes as *"doing their duty, but not really knowing what was going on ... they were turning a blind eye to the heroin issue, and the normalizing of rape and domestic violence of the young women in the hostel, even when the women were pregnant at the same time."*

The police also ignored them *“like we were filth and scum. When we were just young people abused as children by our Mums, Dads and siblings, with no home and surrounded by bad and dangerous criminals, and trapped in poverty. Even now it feels like a normal default to see Class A drugs when I had them all around me as an answer to mental health. It wasn't seen as dangerous. It was just normal. We didn't know any better. Despite the drugs, crime, abuse and prostitution the older people made us feel safe. Even though they were probably manipulative and controlling at the time – they were looking after us. During my time at the hostel, I was also dealing with issues that were happening at home, again written about in the local papers”*.

During this period Sabita saw a counsellor at her college for a few weeks – but she did not seek to ask Sabita the *“right questions.”* It felt more like the counsellor's focus was ensuring Sabita could complete her studies, rather than asking her what was happening at the hostel, and talking about her family history in order to support her.

Whilst at the hostel she feels she saw the signs of mental ill-health coming such as walking for hours at night alone, disassociating, and engaging in risky behaviour. But Sabita could not understand what was going on as she had no knowledge of mental ill-health at the time, so she just ignored it and never spoke to anyone about it.

University and a career

Following the stay at the hostel Sabita moved to another city to go to University, and to move away from the pressure of the drugs in the homeless community that made her feel trapped in that life.

Sabita felt increasingly depressed in her final year, but continued her studies struggling with no support for her mental health. She had lost contact with all her family at that time too, due to the problems she had experienced since childhood. After University she moved back to her hometown, and later into the small town in which she now lives.

“You build up the same life as in your childhood, patterns of control – sometimes it wasn't explicit, but the control was there.”

She worked in the corporate world, becoming increasingly successful with her career over the years. During this period, in her early twenties, Sabita was diagnosed with depression. Struggling to cope, she was put on antidepressants – which she took for six years, regularly, believing in them and following the mantra of *“if you have a social life, go to the gym, you will get better”*. Over the years there was some person-centred counselling and CBT, however the greatest help was regularly seeing a GP who took a holistic approach.

Eventually after suffering years of bullying at work, and with her mental health not getting any better with medication, Sabita chose to go to a private Psychiatrist, private because she felt scared of *“the system”*.

“I told them my Mum had Bipolar, committed suicide and there was abuse. The Psychiatrist just said ‘you're stressed’. But I knew ... my Mum had Bipolar”.

She felt the response of experts was *‘wait till you're at your worst’*. *“You have to tell them the symptoms, not the early warning signs. You can't tell them what you think you have. You have to wait till you've got the actual symptom in the manual. The warnings, signs and patterns are ignored”*.

“I just wanted to start screaming and break things. I felt I was going to get violent. I was managing my depression but I was getting more anxiety, hearing more voices, seeing things. I was constantly self-harming, cutting myself on my arms for years just to cope at work, and to deal with all my pain and memories from my childhood and the hostel.”

Despite the mantra of *“just carry on”* Sabita had to leave her job at this point and go on benefits due to a mental health breakdown. She managed to get Art Psychotherapy for eighteen months that helped enormously. But a week before her father, who had been terminally ill for two years, died the therapy stopped.

“It was literally my Dad's going to die next week, but we have to stop therapy due to a lack of resources. I wish there was possibly even a Peer Support worker at the time, just to express how I was feeling”.

The death of her father

Sabita's mental health deteriorated and in the Autumn following her father's death she was diagnosed with Bipolar disorder.

He died one and a half hours before New Year's Eve. The trauma of not having seen her Dad and having no relationship with him since she was seventeen, and then seeing him in a coffin triggered Sabita's condition. And Sabita's Dad chose to see all her other siblings on the days before he died, passing on a message through them to Sabita that she deserved all the bad things that happened in her life. Sabita could see the signs – such as playing loud music late at night – her brain felt more manic over the summer months after her Dad's death, until Sabita was referred to the Crisis Team in August, and then received the diagnosis of Bipolar disorder from the Community Mental Health Team in September. Her experience has been that health experts judge you on the way you look, not what you are telling them.

"They don't look at your life experiences, or the fact that your medication may affect other parts of your life. Such as I have an underactive thyroid which affects my mood, the side effects if your family has serious health conditions too, and you don't want those. Or that if my Mum had Bipolar, that antidepressants increase my serotonin to possibly make me get Bipolar like my Mum did too".

What helps Sabita now is using an NHS Support Centre and engaging in Service User involvement with her local mental health trust, *"all the things where I have relationships, where I meet other service users. Service users listen to every single thing you are telling them. They understand you. I can also focus on doing something meaningful in my life, which I enjoy too, surrounded by some very caring and hard working staff always looking to improve the service for service users all of the time. Helping others also makes me feel good too".*

As we speak with Sabita we can see her striving to make sense of the different worlds she has experienced and applying this to organisations such as the NHS and how they are not designed to deal with, in her words, *"the other world. Now I just want to help people with complicated issues that many people don't talk about. I am desperate for mental health services to change. To consider why we go around in circles and are stuck in the system for so many years. I've never been put in a ward, even though I have been through A&E, Crisis Teams, and can be constantly suffering, or suicidal, or completely unable to cope in the community with no family contact or social support. I still think I've got problems in a community, we're still suffering just as much, but we're hiding it. Charities have not always been deeply caring and supportive to all of my needs too. And it's like I have a double edged relationship with the NHS, I can see how deeply caring they are, with the staff keeping me going in Service User Involvement work and the creative courses at the Support Centre, but there are bad bits. They are so pressured, so things can go wrong".*



Besides vividly describing the effect of childhood physical abuse, Sabita's story captures complexity in the 'handling' of mental health and in particular the lack of empathy that she experienced.

It highlights our failure to acknowledge people's actual lived experience, including within our institutional structures (for example in Sabita's homeless hostel, where she continued to be exposed to significant risk), and challenges us to explore how we can respond when people's stories have not previously been valued or recognised. Similar questions emerge on hearing Dan's story - that of a young man who looked to society to 'make life better' but who has been left feeling failed and betrayed.

Dan

Dan is in his late twenties. He recalls his history by way of two 'crisis' points in his life. One just after he moved into his permanent flat in Cardiff at around the age of twenty that he refers to as a "nervous breakdown", another approximately two years ago, when a man he met at a food van for the homeless - whom he subsequently offered a bed to - stole from, and rejected him.

At the Support Centre

We arrive at the agreed time to meet with Dan but he is a little late. When the tall young man with tousled jet black hair, lively eyes and an engaging smile walks in (can of energy drink in his hand) the Centre manager Louise asks where he's been.

Dan replies, "*Picked up my money.*" Louise says "*You were meant to take the young ladies with you*". Dan replies, "*Yes ... well.*" Louise changes the subject congratulating him on "*looking so smart!*" He smiles broadly, obviously pleased.

We sit at one of the tables at the Centre but within moments it is clear that remaining still is immensely difficult for Dan. His body is constantly on the go. Movements in his legs, his arms, hands, his head flicking repeatedly to one side, longish hair pushed out of intense blue eyes. Fingers travel up to his face, down his long beard and over and again to one particular spot on his cheek, producing a stroking action before returning to rest, uneasy, on his leg. Dan smiles and tells us he feels very anxious.

We ask if he would like to tell us his story. "*I don't know, I don't know where to begin!*". How about when he was growing up? Emphatically Dan replies, "*Er, not really*". We ascertain later through question and answer that Dan has an older brother who is handicapped and lives in 24-hour care. Dad, an accountant, left Mum when Dan was very young. He also has a stepsister - he has never met her.



School was difficult for Dan, *"They didn't like me much ... 'You can't do any exams', things like that"*. When we ask whether he had many friends he replies, *"Not particularly"*. With depth of feeling he adds, *"I didn't like one thing about it"*. Dan tells us *"Home was a bit much, I don't think I could be my own self, that sort of thing. I wish the situation was different, but that was about it"*. He tells us his relationship with his Mum and Dad was *"hard at times"*.

Dan now lives in a one bedroom flat with a communal garden. He tells us he's been there for eight years, *"it's nice and green"*. He comes to the Centre up to five times a week. He doesn't like being at home, *"I get quite anxious when I'm there - I can't bear being in - it's lonely."*

Dan tries *"to take it one step at a time"*. Taking a sip from his energy drink, he brightens and says it helps him focus.

"It stimulates me to the point that I can actually have a civil conversation. It goes back a while when I was really distressed with life. I found out whenever I had this, I seemed to just calm down, no problem ... I could just focus".

Dan likes coming to the Support Centre as well as being out and about and going to the gym, *"[it's] pretty much all I do"* he tells us. Although he adds that he's taking this week off, *"I think I'm going to have a bloody mental breakdown by the end of the week"*. He's just come off cigarettes, having smoked for nearly four years.

"It was the only thing that seemed to block out a lot of the emotions that I was feeling at the time. I don't think I was ever stable enough to stop until now. If I tried to give up smoking before I would lash out. I'd probably be getting my fists up [...], things like that".



'Out and about'

We head out to walk the streets. As Dan leads us along the roads he becomes confident and assured, guiding us across busy streets, negotiating traffic, telling us about the geography of the area and beyond, historical facts, train routes and destinations; interesting quirky stories spilling out in an articulate, enthusiastic, smart and quick-witted manner.

We talk about the appointment this morning to collect his benefits. The statutory services term Dan as 'vulnerable and at risk of exploitation' and maintain control over his money. He receives £90 on two separate days, just two days apart. We ask Dan what he thinks and feels about having to collect his money like this.

"Counting out the money in front of me, in front of everybody else, makes me feel more vulnerable. It's actually quite horrible".

Dan goes quiet, his face set, impassive. He tells us he also has to ask for extra money every time he needs larger essentials, such as a new coat.

Being friendly and being betrayed

Dan talks about a *"really bad time ... Well, I was trying to be ... silly me, typical me, I was trying to be friendly to people maybe I shouldn't have."*

"I picked somebody up who was not what they seemed and it went wrong, it went wrong. They stole some of my good clothes and I'd just got myself a new phone. They took that".

Dan stops speaking, averts his face, yet again his expression becomes impassive and the tics and tremors appear. He was outraged when a member of a voluntary organisation intervened in the situation.

"They were trying to contact my social worker, trying to explain this person's behaviour toward me and she was immediately on their side ... I think he [the person who stole from him] found me a bit difficult, I don't know why, but ... He was pretty open about taking my stuff, but they were making out he was so sorry and he really wasn't!"

Social Workers

"Well, I've had a social worker in the past, but I don't think I need them anymore ... They're not always aware of the full situation. I think she said at one point that I needed a bit more discipline in my life. What! I don't think so! She couldn't explain it very well either. I completely disagreed with her".

Talking of Social Workers brings Dan to talk about his Mum and the troubles he has had with her in the past. *"Before, we'd get into arguments. I think in the past she got into a bit of trouble - she was hanging around with some wrong'uns, problems with the law as well. During that time I was going to her a lot. Because of the bloody social worker, I've not always had this amount of money coming in so I was asking Mum to bail me out".*

"When things were tough, it was tough in the head primarily as well. There were a lot of mental health issues going on as well. It was horrible; I had some kind of breakdown ... I checked in with the manager at my accommodation. We went to my GP and he made the referral to a psychiatrist. It was actually me who suggested ADHD to the GP, but it was quite late to be diagnosed - bloody hell!"

We talk about ADHD and Dan tells us that for him it's *"just continuously being restless ... They put me on Ritalin. I went on it for about a year and after that I found I could concentrate a lot better, to the point I didn't need it".*

We ask Dan if he would like to go back to the psychiatrist and he says, *"Maybe ... it's quite a complex thing. Quite often, whenever a problem comes up, by the time you've got to see a Psychiatrist, sometimes the problem has passed".*

"Quite often, whenever a problem comes up, by the time you've got to see a Psychiatrist, sometimes the problem has passed".

An unexpected history

Dan suddenly tells us that the first diagnosis he had, which was for Autism, was when he was three.

"So, I got diagnosed at three and again at twelve. Apparently, I went through a brief stage in care and the foster family I was with said there was some ... in the words of this bloody report ... 'inexplicable behaviour' ... basically an unrecognised condition".

He was in care for a year. *"I found out by myself ... my GP gave me this report and it had my history." He was twenty-six when he learnt all of this. "Yeah - fuck it! It just said on my file, 'developmental disorder'. I read the thing for myself! I just read it ... And it was all there!" Laughing - "and I never knew! Fucking hell!"*

Dan went to his Mum to ask questions. *"It was basically because she wasn't coping. She'd just moved away from my Dad's. She had her own social worker and Mum just said to her, 'I need a break'".*

A place Dan cannot avoid

As we walk we come to where Dan collects his benefit money.

"That's it here" he says pointing to a door. As he speaks he's moving away from the building. We ask if we can go in. Dan gives a resounding *"No!"*

"It's full of homeless people and things like that and I'm not homeless. Rough people, people on the streets trying to get accommodation, whatever, it's not the best of situations".

Dan tells us that the police are often called to deal with people in the payment centre. We can see it makes Dan uneasy and uncomfortable. He's made his concerns about having to attend this location clear to his Social Workers, but apparently with all the branches closing there's no way of putting him anywhere else.

The Food Van

We arrive at Dan's gym and his demeanour is completely different. The sense of humour, clipped by being near the payment centre, re-appears.

With a cheeky smile he asks if we should get lunch? When we tell him lunch is on us he laughs out loud and chooses a branch of a well-known chain restaurant. As we choose our food he says *"I take it the expenses are paid for you by your head-office!"* Dan laughs, *"I could get to like this. Can we meet up everyday, please?"*

As we sit having lunch we talk about celebrating Birthdays and Christmas. This Christmas, he tells us he was with his Mum and they had Venison from Lidl. Dan shows us a photo. He's obviously proud and talks us through what he did. We talk about Dan's friends; Jamie, about twenty years older than Dan, and Robert who is nearer his age. Robert was recently evicted and is now staying with Dan *"until further notice"*. We ask how Dan met them.

"From the homeless scene. When you're absolutely out of food you have to use the food van, food banks. I'd been going on and off for about three to four years. Things were really tight - 2014. I don't go now. Things like stopping smoking have made a difference - a packet of fags was the difference between affording to live comfortably and living on the breadline. Going there became hard - I was quite depressed ... obviously you see quite a lot of hard people there".

Dan looks away and says to nobody in particular, *"but it was an experience I went through in life and that was it!"*

We walk back to the Centre and start to go through Dan's timeline; living with Mum and Dad, being put into care, back home with Mum, hating school, wandering the streets as a teenager, few friends. Moving into temporary accommodation during his late teens. Not liking it, being shouted at by the other men. Moving back to Mum's and that not working out and moving back into the same temporary accommodation. A support worker recommending an organisation that turned out to be for *"low, sad people; riff-raff. The worst decision I've ever made"*. Dan's face becomes completely set, his jaw clenched.

Later, at a second meeting Dan chooses to go into more detail about this period of his life. He talks about the sexual abuse, telling us that he was abused, *"played around with"*. His hands scan down his body past his waist, *"down there."*

Referring to Support Workers he says, *"they were supposed to give me a better life, they didn't, they gave me a worse life. They introduced me to a nonce! They got me raped!"*

Anger is etched on his face and he talks about *"systems supposedly being there to protect"*. He also talks about subsequent sexual encounters, alluding to his confusion and uncertainty about the acceptability of relationships with men. As we talk Dan makes it very plain that he particularly wants this part of his story to be known; *"I want the truth to be revealed! I want people to know"*, and he repeats, *"they were supposed to give me a better life, and they didn't, they gave me a worse life!"*

There was a point in Dan's life, following the *'nervous breakdown'*, just as Dan moved into his permanent flat, when he asked himself, *"where am I going, where is life going, which direction should I go in?"*

He tells us he still needs time to heal from the trauma of the relationships in the temporary accommodation and our second meeting illustrates this - he is drinking again. There has also been a short break in his visits to the Centre following a disagreement, but he is now back and, as Dan puts it the *"gradual cure, something better, toward emotional stability"* can hopefully continue.



Dan's story is an example of the brittle fragility of some peoples' lives. From his childhood, through his teens to his twenties, his autism and ADHD have not been considered to be sufficiently disruptive to warrant focused care.

As a consequence he has lived an existence 'on the edge', barely coping. To help him through each day he puts in place rituals and self medicates – be it an energy drink or alcohol. He feels that those who have had power over him, from his childhood through to today, have failed him. How do we work with people who feel they have never been recognised, listened to, understood, done right by, or fully informed by people in power? And how do we recognise the collective impact of multiple challenges in people's daily lives? In our next story, Megan's experience also reflects the interconnectedness of challenges as they build from childhood through to adulthood and on to motherhood and the knock-on effect within her life.

Megan

Megan arrives to share her day with us concerned that she is late. Her bright personality is reflected in her warm smile, the beautifully bright tattoo on her neck and the Cornish sunshine. Once we are settled in comfy chairs in the quiet room at the Centre we ask whether she would like to tell us a little about her childhood. She trips over her words, an aftermath she later tells us of her abuse as a child. "I think I've had depression since I was about 8 - I think it was a nature, nurture thing - the way I was brought up influenced how I thought of myself."

Stepdad

When Megan was six months old her Mum and Dad split up and her Mum, pregnant with her little brother, got together with her Stepdad.

"My Stepdad wasn't the nicest guy, he was physically, mentally and emotionally abusive. He would tell us often that we were worthless. Punishments were being stood in front of the front door, or at the bottom of the stairs for hours. You had to stand straight; you had to have your feet together. He would growl at you and say you were lucky to even be alive. So this is why I am in the mental state I am - he was telling me I wasn't even human, I was some alien - like he could snap his fingers at any moment and anything could happen and I had to be grateful for him.

I remember one morning I got up a bit early so I read a book in bed. He saw me reading and he pulled me out of my bunk bed and he was like, 'you'll wake up when I tell you to'. He made me stand at the front door and I was tired and in my pyjamas and I think because I hadn't eaten and I was standing up for hours I fainted and fell back and hit my head against the corner of the radiator. I had a fit and woke up to find him over me screaming to get up. I remember that I sat next to my brother on the stairs and he said 'Megan's bleeding' and my Stepdad threw me like a fizzy drink and a chocolate biscuit and he was even growling about that like, 'you can't do anything!' They found out shortly after that that I was anaemic, so nothing was said about the standing ... nobody knew".



Megan tells us she used her anaemia to try to reduce punishments – and then he would say, 'Okay, but get back up in two minutes!'

"He would sit in the living room behind you watching. You would end up counting the steps, the crumbs on the steps, you'd sing in your head, you couldn't hum, you couldn't do anything. When he walked past he would stand behind you and growl and say 'stand up straight' – I haven't told anybody this, like in detail, but ... you could only move when you were going to school or if you were going to the toilet. It was like when you tried to move your feet to go up the stairs your legs would be locked. I remember I would stay on the toilet just to sit down for a bit".

Megan's Mum had moved out when she was six. *"She left me and all my brothers and sisters with my Stepdad. She was in an abusive relationship, she got herself out ... I don't hate her for it, but she still beats herself up about it. Up until I was about twelve I was with my Stepdad. My Mum fought for the six years to get us back – my sister and I would see her one weekend and my Dad the next. But Mum and Dad couldn't do anything to get us out of it apparently".*

Depression

Returning to feeling depressed at eight Megan tells us, *"I remember having to go to the shop for the bread and I had to go across this bridge and I saw this shard of glass on the floor and kind-of carried it around with me and I would scratch my arm with it. I remember thinking I don't know how to do it and I don't know how hard to do it."*

Thinking about those years Megan says, *"I don't think anybody questioned it – It was one of those horrible things – they are one person behind closed doors, but to everybody else they are this lovely person who can never do any wrong ... What got us out of it ... my brother was going for a bath – he's just under a year younger than me – and my Stepdad hit him and he fell and hit his head. He went to school with a big purple eye and told the school everything and the social worker got involved. My Stepdad went to court, but I*

don't think anything happened, he never got time for it. His sons said it was an accident. Then I went to Mum's for two weeks of the school holidays and after like, two months Mum said we were never going back".

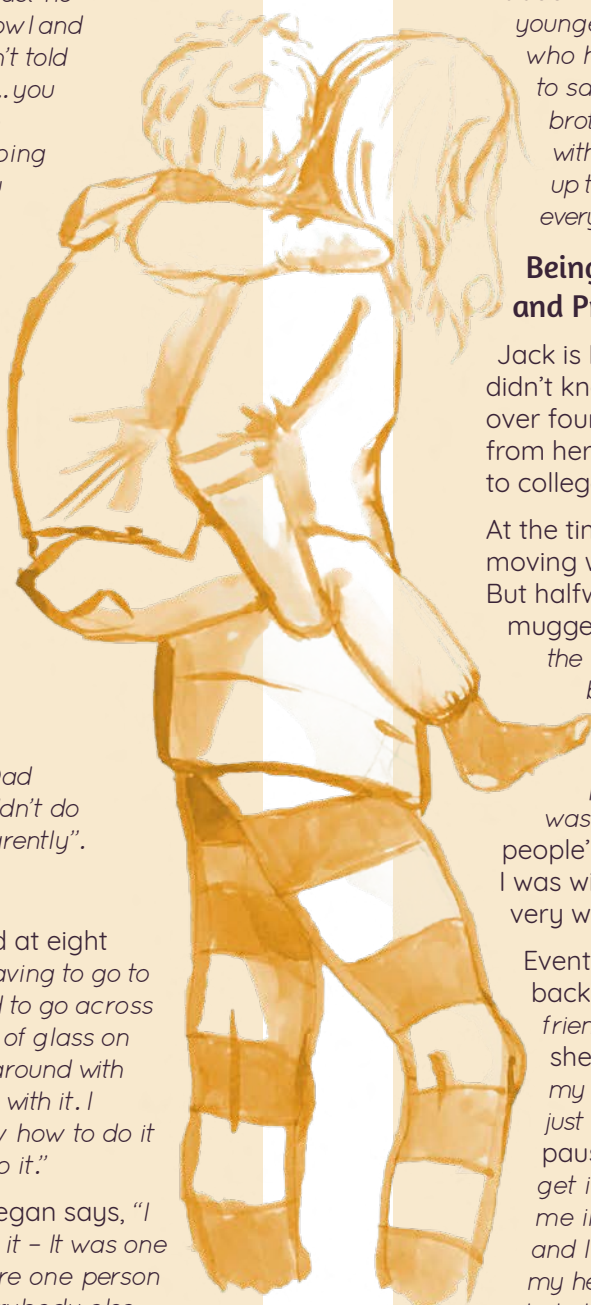
Megan tells us that all the children suffered. For her sister, it was 'fears' until she was about nineteen. *"So she had me and my younger siblings. She had to be that person who had to fight for us and basically try to say 'No' to him. Two out of my three brothers fight a lot – none have contact with him. That's why I want to bring Jack up to know that nobody is worthless, everybody is worth something".*

Being Mugged, Assaulted and Pregnancy

Jack is Megan's seven year old son. She didn't know she was expecting until she was over four months. She had moved away from her Mum's when she was sixteen to go to college in Plymouth.

At the time it seemed like a great idea – moving with her boyfriend and friends. But halfway through the year Megan got mugged. *"I had borrowed money for the rent ... the mugging turned out to be from the very people I actually trusted, that I had built friendships with – they had arranged it. The police showed me pictures and it was like 'do you recognise any of these people' and it was like 'that's my friend I was with' and the police said 'Yeah he's very well known for things like this.'"*

Eventually, later in the year Megan went back to college but *"I stayed with a friend."* Here Megan stops – we ask if she is okay. She says *"I can talk about my childhood and everything else, it's just that ... I stayed with this friend [long pause] – I was sleeping and ... I'll not get into it ... basically he tried to assault me in my sleep ... all this was happening and I was going through a lot kind of in my head ... I wasn't really getting any help because of stuff that was going on ... and I couldn't trust anybody. I was in this vicious cycle – what do I do – I don't have the money and I can't do college and I can't do this and I can't do anything, everyone's out to get me like everyone is wanting to hurt me. I just didn't see the point in anything ... and I was just making bad decisions as well ... I was*



drinking more and I wasn't talking to anybody and amongst all this, at seventeen, I found out I was pregnant. It was basically then 'this is the worst thing that can happen.' I was terrified ... and then I went along for the scan. In my head I was thinking 'I can't do this, I can't look after myself let alone ...' but it was one of the best days of my life – I just seen him, waving – he was almost a fully formed person, and I remember seeing him and crying. It's ever since seeing him that I have something to live for, somebody who needs me, that's a nice feeling. I tell everybody he's the reason I'm alive and he's the reason I keep fighting. He is the one solid in my life right now". Megan laughs, "he stresses the hell out of me too!"

Postnatal Depression

When Jack was born Megan had postnatal depression. "I was telling everybody that everything was fine, but it wasn't. I went to a party and found myself just standing there screaming at Jack to shut up. I felt awful because everybody was staring at me, I cried for hours. I ended up getting counselling to deal with things I wasn't dealing with. I got diagnosed when I saw my GP". Her GP put her on Citalopram. "My mother at the time was like, 'you don't need that, you're fine' so I came off cold turkey".

Jack

Jack has his own issues and Megan says that although he may not be the cause of her stress "sometimes he is the straw on the camel's back". Megan smiles and shows us pictures, "He's got the cheesiest grin!" Jack struggles in school to focus. He doesn't have an official diagnosis yet but there has been a suggestion he has an Autistic Spectrum Disorder and possibly ADHD. "He had Echolalia as well at one point and the Doctor said he has anxiety. You don't want to hear that a six or seven year old has anxiety, like he shouldn't have anxiety at that age".

Between Jack being aged five and seven Megan went back to work as a teaching assistant – she found the children were a great distraction, "but as soon as I left the room I would just want to cry".

"I was afraid to even tell anybody how I was feeling because ... they would come and take Jack away"

"A lot was going on with Jack as well, he was struggling with my working. I tried to work more hours to make more money - but it just turned into a vicious cycle".

"I ended up losing my job because I took sick time off because I couldn't cope, so I got fired, so I was getting less money. I got to a point where I thought, you know what, I need to concentrate on [Jack]. But afterwards I went for about 6 months without any money – I got into rent arrears – I was trying to get money from everywhere else and pay it toward rent and that's when everything started to crumble, I wasn't going out, I wasn't opening my letters, I wasn't getting any money in. The house was getting into a state ... I've not been diagnosed with either, not official, but I've been called a hoarder and a kleptomaniac. I take like shiny little trinkets, completely useless stuff. My house got like one of those 'Hoarders from Hell'".

The school had put Megan in touch with Barnardo's – everybody was trying to get Megan help for Jack but Megan tells us, "I don't think it was until actually anyone came in the house that they were like 'you need some help'. When a woman from Barnardo's did come round she was very shocked about the house, so she got in touch with Social Services".

"That was like the kick up the bum that I needed. Social Services scare the living daylights out of me ... I was afraid to even tell anybody how I was feeling because I was terrified that if I tell them I can't look after myself they will come and take Jack away ... and I've not done it in over a year, but I was harming myself as well."

Megan tells us that she and Barnardo's came to an agreement that they would come around once a week and more people would get involved. She hasn't seen Social Services since or heard anything from them.

Megan tells us that when Jack gets his diagnosis that the school and she will be able to move forward with stuff.

"There are loads of things that are just in limbo at the moment. For example I can't claim to be a carer for additional needs until he has a diagnosis – so that's stressful". Megan tells us that it is also hard to get childcare. "Trying to find someone is stressful and if you do find somewhere they charge a lot ... So I speak to them before they take him; what triggers him, what calms him down, would you be okay with that and sometimes they say 'that's okay' and then after a couple of weeks they say he's a bit too much. He

has been let go from groups because they don't have the support for him. Like an after school group – they didn't have the money for a one-on-one so they said they were sorry they had to let him go because they don't have the money. So because he doesn't have a diagnosis and support he can't go to that group. Ninety other children and no one to do one-on-one with him”.

“Since things were bad last year I have the Centre which is my support, and I did have counselling and I go to group counselling at my GP ... and I talk to friends more, at the same time you can't talk to friends and family like you can to a counsellor”. Megan also has a befriender from a local organisation who comes to see her once a week. They go for something to eat – she says it is somebody to speak to who doesn't judge her. “It's just nice to have somebody to talk about the little things, somebody to have a laugh with”.

Megan also goes to a mental health 'station' – “You can talk to people, there are stalls with money management, self help, etc. But it's walking in and talking to people ... I just don't know where to start – this is where I struggle and need help. It's all a jungle – I've got stressed about not working, I've got stressed about money, I've got stressed about him and his mental health and my mental health that goes up and down everyday with my medication”. Megan has been struggling with her medication, Sertraline:

it has been “up-and-down.” It makes her tired or produces insomnia. If she can't sleep she has nightmares. She has also been forgetting to renew her prescription – although she has recently sorted that out.

Financially, things aren't easy. She is on Personal Independence Payment, £200 a month, Mum is helping out with bills, and she is on Universal Credit. The woman at the job centre is fantastic, makes her laugh; “I stress out – I go in and think they are going to be angry because I'm not working”. Megan got an advance payment – when it came through she says she didn't recognise her bank account – it had never had that much in it before. She has put around £600 aside for a rainy day.

Mum takes Jack on holiday to Majorca every year – she wants Megan to use some of her savings to go this year to help. “Mum just wants to go somewhere warm , Jack wants to go swimming and I just want to go somewhere to sleep.” Megan has only ever been on holiday once – to Canada for around ten days. A friend she met online bought her passport and flew her over to Australia using his air miles.

At present Megan is just focusing on the next six weeks “I don't know how this summer holidays are going to be – whether I put myself on the 'back burner'. I don't know how I am going to do six weeks”.



Megan's story captures a myriad of complexity, from physical and psychological abuse as a child, to sexual abuse as a teenager, through to being a single Mum with a child with special needs.

We see the pain of no longer feeling like a contributing member of society and the anxiety caused by fear of those in power. People's experiences of mental health are deeply connected into the wider context of their life, from their housing, to their personal relationships to the stage of life they are in. Failing to recognise this context leads to people feeling judged and misunderstood, and to efforts to support them failing to have a positive impact. This is also the case for Peter and his family, who struggle with life in difficult circumstances, held back by formal support that only leaves them barely managing from one day to the next.

Peter

Peter meets us at the door of his three-bedroom home in Devon with his arms full of folded washing. He invites us into a warm and homely sitting room and apologises for the “mess”.

The room is spilling over with the hallmarks of a family with three children. Toys and washing vie for space with art materials and lots of ornamental elephants. Peter explains that they would like to build an extension but cannot afford it. *“We own our home and although Social Services say we are overcrowded they cannot offer any solution for improving the situation”*.

At present the two older boys, Tom and Timmy, have their own rooms and Lennon at seven shares with Peter and Angela. *“Not ideal”* Peter says. They would like to have a bit more privacy. He and Angela don't get to go out much either, *“[it would] be nice to just have a bit of time together, or for myself”*.

Struggling everyday

We go through to the kitchen where Peter tells us how much he struggles to keep the house tidy and functional – small things like the bins not being emptied every week means that mess stays in the house making life more difficult. The garage has been leaking too and valuable belongings in danger of getting wet are now also crowded into the kitchen. For years he has been trying to redecorate. He tells us, *“ten minutes a day is all I can find, if I'm lucky”*.

Life hasn't always been like this. Eight years ago before Angela was diagnosed with Borderline Personality Disorder, PTSD, Agoraphobia and Clinical Depression they both worked. Now he is her carer and also looks after the children all of whom have an Autistic Spectrum Disorder. Tom cannot work and spends most of his time in his room. Occasionally, encouraged by Peter, he will go to a local sport centre to play skittles and sometimes goes to see a gig with his Mum. Timmy is at present at a high school that caters for pupils with Autism. The school placement was meant to be temporary but he's been there for nearly four years. Lennon is at the local primary. They are waiting for him to receive a diagnosis for Autism.



We move back into the sitting room, Peter taking up his usual chair at a small desk, cluttered with paperwork, situated at the entrance to the kitchen. Each person has their place in the room. Angela has her chair in the opposite corner to Peter, surrounded by her art materials with her laptop and music within reach. Since 2017 she has been producing textile art and she is clearly talented.

Invasion of their home

Peter tells us that eight months ago their home was invaded by drug dealers. *"They burst in demanding to know where the drugs were – I was like, 'what are you talking about!'"* It is clear that the event has left Peter traumatised. A clearly identified suspect was arrested, but for some reason not charged, now Peter is scared to leave the family. He tells us, *"life was hard enough before, but now ..."*

Peter was diagnosed with clinical depression several years ago – he also thinks he may have ADHD. Passionate about football as a young man he used to be extremely good, but as a result of a footballing injury he now has problems with his ankle and knee, which *"pops out"*. He used to like to run and take the dog for a walk, but he can't do either now. He also used to like to play darts like Tom, but stopped because of the house invasion. Now he only goes out for essential things, like taking and picking up Lennon from school, getting the shopping and going to appointments. Angela has to be accompanied to supermarkets because they cause her high levels of stress, and shopping has to be by taxi because, although they have a car, Peter can't drive it. His licence expired and it has been so difficult to organise what is needed to renew it, finding his passport for example.



Just recently Peter has made a couple of new friends. He tells us that in the past friends have let him down, or have been overpowering. *"I've not really had a great time with friends ... makes me wonder if I've ever had a proper friend until recently ... I'm always too eager to help people"*. For example he has loaned friends money, *"then they have just disappeared"*. Peter says he is too easily manipulated and led.

At present, when he can, he plays games online with his friends. He built his own computer from scratch and Tom is very good at programming.

The post arrives and with it a letter informing them of a change in their dentist. Peter is clearly worried as changes in routine affect all the boys. Tom in particular has just gotten used to their present dentist.

As Peter talks the door opens and in comes Barnabus, the family's much-loved old dog. Peter tells us he was a rescue. Not long after Angela follows, settles in her chair and Peter immediately brings her porridge, tea and medication. We talk about her art, her elephants and the house invasion. Angela is deeply angry with the Police. *"They came in here accusing us whilst my husband was in the back of an ambulance!"* We hear that the dealers used pepper spray and attacked Peter, leaving him concussed with head injuries.

Angela

Angela has had dealings with the Police before. As a child she suffered sexual abuse at the hands of her stepfather who turned out to be a relative. As a consequence, at the age of sixteen she was constantly moving to avoid being located. Eventually she made a 'historical accusation'. The relative was brought in for questioning, denied the accusation and no

further action was taken. Angela feels deeply, deeply aggrieved, pointing out that his brothers have all been accused of sexual abuse with one now locked up inside. Following the failure of her attempt to achieve what she sees as justice, Angela had a 'breakdown' and was hospitalised for nine weeks. Now she has mood swings and she tells us *"I'll tell Peter 'I love you, you're wonderful – now fuck off!"*

Angela has one or two good friends locally and very occasionally sees some of her family, but getting about is difficult because of the lack of transport. Her time is mostly spent working with textiles and listening to her music and she follows some online mental health groups.

Timmy

As we chat, Barnabus at Angela's feet, one of the family's cats wanders in followed by Timmy. He is much earlier than expected. Articulate and smart, Timmy is classed as high functioning and was today trying out a new school for his GCSEs. When he first visited the facility he had been impressed, especially as there was the opportunity to do a hands-on element such as horticulture, mechanics or hairdressing. Now he says he won't be going. When he was there the school pointed out the CCTV cameras and was locking doors behind pupils. He saw a number of students having meltdowns and was told he may get "threatened" on going into the main building. Peter confides later that he himself had been in tears the night before as Timmy changing schools would mean he would lose his support network, people who understand what he is going through. We have since heard that Timmy has gone to the new school, a necessary move if he is to have any chance of passing his GCSEs.

Support Services

As the afternoon wears on Peter chats about Support Services. Social Services are about to close off Lennon's case and Timmy does not have a Social Worker now. Peter tells us that the Social Services have so many "emergencies," that appointments are often cancelled. When they do meet he does not feel they are helpful. "Instead of feeling like they are there to help us it feels more like we are there to tell them things ... so, Social Workers? It's not worth the agro".

"You just get into a routine and things are getting better and then they take them off you and you're sinking back into the sand again."

Concerning any respite for himself as a carer he has been told, "We would pay for a hotel or caravan for yourself.' *But when I ask ... 'How do I get there?' it is 'Oh, you've got to fund that yourself.' 'And what do I do about everybody else that I look after? 'Oh, well, we don't sort that out'".*

With regard to his carers budget, six years ago they told him he had an amount to spend. "I chose to get a laptop but it was a nightmare - it was 'wouldn't you rather have this, that or the other - a gym pass?' - I'm not going to get the opportunity to go out to the gym! When I got offered it the next year ... No!... it created so much stress for me. That many strings and conditions - jump through so many hoops and I can't get the things I need".

The family no longer have a Support Worker - "they have now decided they can't do much for us. I did find it handy to have somebody to talk to, help with benefits, and give us a lift to the Citizens Advice Bureau, CAB. But they cut the funding. She was taken off us".

Previously they found an outside support worker, Fred, he was excellent, more like a friend. "But you just get into a routine and things are getting better and then they take them off you and you're sinking back into the sand again - you just think what's the point. So now when they offer we ask how long for and if it's only a few weeks or months we say 'Nah - don't bother - you're just going to get to a position where we are comfortable with them and we're actually starting to make a bit of progress and then you take them off us!".

Sadly Peter's Mum is not a support. She has in the past called the Social Services, interfering in their lives. It is a major trigger for Angela so she no longer sees her.

When Peter's GP first diagnosed him with clinical depression he referred the family to a Community Psychiatric Nurse, CPN. They were signed off last year. His GP had said he didn't think Peter was clinically depressed anymore; therefore the CPN discharged the family. Peter tells us "even going to see him once every six months or so gave me somebody to talk to." He can't really talk to his mates, "they don't really get the mental health issues with Angela. It's like 'you've just got to tell her to stop doing that' - it's not that simple!" Peter is still on medication for depression - he says it takes the edge off a bit - he is on the highest dose.

Referring to his GP he says it is a good practice – one GP is good on mental health, another on the physical but he doesn't understand mental health and will just say, "Pull yourself together".

Lennon

We leave to collect Lennon. Peter tells us that mornings can be difficult. Lennon dawdles getting ready which means they are late leaving. If he arrives late then it upsets him for the day, so often Peter will carry him on his shoulders to school. It doesn't do his knee any good.

As we wait in the playground another parent comes up to speak to Peter to tell him that a facility he uses has been axed.

Lennon comes out unhappy, he tends to have meltdowns, and his one-to-one Support Worker tells Peter he has had a bad day in which he hit another child. Lennon is now slouched on the other side of the playground in tears. Peter listens and then very calmly encourages Lennon to come over. We walk out of the playground and within minutes Lennon is on his Dad's shoulders smiling and chatting to us. Peter tells us the school is very good.

Tom

We arrive back to find an amazing light show projected on the wall. Tom appears from the kitchen. A tall young man, a "gentle soul" as Peter describes him, smiles as we tell him how fantastic the light show is. Neglected by his biological father, Tom prefers to be with women – he trusts very few males. Like Timmy he was bullied at the local secondary school and now spends a lot of time in his room – fascinated by electronics. He uses his benefits to buy online and in fact several packages have arrived today. Peter tells us the packaging adds to the problem of home clutter. Tom can have meltdowns. He is very strong. Peter wishes Tom had been around during the house invasion.

As the family engage in their normal activities, Timmy going upstairs to spend time in his room, Tom working out how to set up a box for photographing objects and Lennon on his tablet, we talk about a normal day for Peter – he tells us he tries to sort the house out, but some days he just sleeps, like a couple of days ago, "I came home and fell asleep for the entire day – I was just absolutely exhausted – had bloods tests recently and the doctors are looking for possible diabetes – it's in the family". He eats

little throughout the day, instead just eating with the family in the evening. He would like them to eat at the table, but it is buried under "stuff" and he can never find the time to sort it out, or as quickly as he clears a gap it fills once again.

Left treading water

Before we leave we ask Peter what progress would look like? He smiles his gentle smile, shrugs his shoulders and replies that having help to take the family to appointments would be lovely, otherwise the whole day goes on travel and that is upsetting especially when it is for relatively minor things; it involves so much time and money. He would also like to be effective in clearing the home, making space and to be able to have the luxury of principles, for example recycling to charity shops and caring for the environment.

It is time for us to go. Peter says it would be lovely if we could return – it's nice to have somebody to talk to. As we leave, one of the family's chickens meets us in the front garden. It jumps into Peter's arms and settles, waiting to be stroked.



The story of Peter and his family highlights the impact of different, yet connected, challenges, and the way that formal services are often narrowly focused on risk management and not growth.

These services can often leave people living in circumstances that create a brittle and fragile co-dependence. How can we ensure that support doesn't abandon people at 'just about coping', but helps them grow, develop and achieve change? How can we avoid the mistake of thinking that if things look 'normal', then things are fine? Matt's story draws our attention to how people's mental health is often shaped by the intersection of long-term physical health conditions and complex feelings about personal and social identity.

Matt

Matt arrives exactly on time. Tall with long dark hair and a noticeable tan he is wearing a light T-shirt. He does not feel the cold. We on the other hand are wearing sweaters.

We chat and Matt decides on a 'chronological' approach to his story, although confides he will "*witter – as most people*". Straight away one notices Matt's clear voice, articulation and logical approach.

Growing up, Dad's girlfriends and Diabetes

Matt was born in the late 1980s in Oxfordshire. His parents split up when he was eighteen months old. He is aware that a few months earlier his Mum had gone into, "*what these days would be a Psychiatric hospital, what at the time was an institution*". Matt tells us that his Dad is not good with mental health so he did not cope well. Mum had self-harm and suicidal issues, depression and he knows a lot of stuff from her childhood; she was fostered, eventually adopted, but not by a nice family, "*it was the typical falling down a set of stairs in a bungalow type of thing*".

Dad brought Matt up, although he did see his Mum fairly often in Institutions. "*I remember going through a lot of security barriers and airlock style doors and that was to get to the visitor waiting area*".

When Matt was in his mid teens Mum was released long term. Since then she seems to be basically fine – although physically her health is appalling. She now lives with her new husband.

During his childhood Matt and his Dad moved a lot – later Matt tells us that by the time he was in his early thirties he had moved over thirty times. This included occasionally going back to live with his Dad's parents. Various girlfriends came in and out of Dad's life. When Matt was in primary school his Dad moved in with a long-term girlfriend, which Matt says was horrendous. She has daughters who at the time attended the same school as Matt. "*To be friends at school was fine, because we were both fairly social outcasts at school, normal dealing with bullying and all the rest of it, however, at home, her and her sister were*



the bullies and because Dad was out working one, two, three jobs it was me, the girls and their Mum (Carol). Carol is a difficult person for me to get along with generally. We get on at times these days, but when I was a kid it was a different situation ... everything was my fault - anything I did was wrong, anything that went wrong was me". Matt did have what he calls his 'reprieve' - every weekend he stayed at his Grandparents where he was spoilt and could sit and talk, or not talk and that was fine - whereas at home he wasn't allowed to just sit in his room and read. "They were convinced that children had to be outside".

Being away at the weekend meant that the girls would go into Matt's room and everything would be torn and broken whilst he was away. He confides that life was fairly tortuous.

Eventually Carol got pregnant but not long after the baby was born Carol and his Dad split up. Matt didn't really have anything to do with Carol, the girls or his stepbrother for the next seven years.

Just prior to the split his Dad had decided that Matt's punishment for a now forgotten misdemeanour should be he didn't go to his Grandparents any more - he never ended up following through with it but, "As a kid in the meantime my response was to try to strangle myself, but it didn't work. A few days later I tried to run away - I got as far as the front of the estate. Unfortunately the estate was in the middle of nowhere - I ended up turning round and going back". Matt's Dad was aware of his attempt to run away, but nothing was mentioned, nor has been to this day. Nobody in the family knows about the attempted strangulation.

Dad and Matt moved back to his Grandparents and Matt started secondary school where he continued to be bullied. He tells us that he had some friends, "but I was still in an outcast group; the people that didn't have anybody else to be friends with - no one else would be friends with us so we kind of had to be friends with each other - at least to whatever degree we managed. Occasionally you would end up with people effectively

making it into a social group somewhere and disappearing. I managed to get by in high school by mostly being unnoticed, or not standing out enough to be an issue for anyone. In my school you were picked on for being dumb - so I managed through most of secondary school. I had some issues when Dad got a girlfriend, Olivia, who was nearer my age than his and was doing her teacher training at my secondary school. Awkward! Olivia tried to be motherly - difficult when I was thirteen - she was twenty-two".

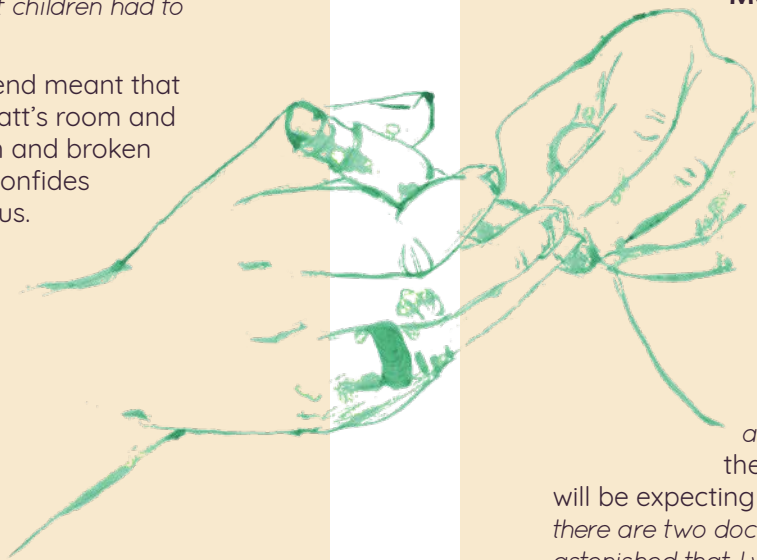
Mental Health with Diabetes

During Matt's early teens he became very ill. He passed out and when they finally did a blood test it showed he was severely diabetic, Type 1 diabetes, "the doorbell rang and there were nurses who had just come off their shift and they had received a call to say 'take him to the hospital right now, they will be expecting you'. We get there and there are two doctors waiting. They were astonished that I walked in of my own accord. Based on my blood tests I should have been unconscious, if still alive".

Because of Matt's age, (fourteen) paediatricians were treating him but with adult medication levels, so things were confusing for him. After the first week he went back and got shouted at because he hadn't adjusted his insulin levels.

Matt was on a form of mixed insulin, long and short term, that meant he had to eat certain amounts at certain times of the day. "So you had to deal with that. And that is basically you being told that is for the rest of your life ... You're supposed to live to a schedule now. So if you do any sort of exercise ... that will bring your sugars down, if you eat anything else that you weren't supposed to, or at the wrong time then ... again you have no control over anything that is going on".

Matt tells us he flunked his way through his GCSEs. "I struggled with dyslexia. I think because I can read and think and explain they didn't get where the problems were".



College and coming out

On receiving his GCSE results Matt says that his Dad, although not showing his anger, did take him down to the local College the next day and say, “‘find something’ – so I was pretty much pushed into doing IT”. By this point he was really struggling with diabetes, which was very badly out of control making him feel ill a lot of the time “I’m still reeling from not having done what I had intended and expected with my GCSEs, as the initial plan had been to do my GCSEs, study the sciences at A level, and go to Oxford”.

Following the IT course Matt switched to Media. That went reasonably well however Matt says he is no good at the people side of it. “Interview techniques I can learn, but when it comes to doing stuff where you have to deal directly with people it doesn’t work very well for me, I’m not good at that”. Matt has a problem with being spoken down to, “It’s one of those things that has come up from time to time, that people have to treat me as they want to be treated”. In the past, Matt has worked for the University, but he found the Professor’s relaxed ways very disturbing. He tells us that he has been accused of being aggressive and argumentative. “I’ve gone like, ‘No, I’m not in the slightest’. It’s a very strange thing – I don’t understand”.

Matt tells us that he had never liked the way he looked and “additionally I had some problems with walking ... Carol had noticed that I walk on my toes ... the doctors tried various things, including a plaster cast. My toes and feet turn in. Because of that my calves are overdeveloped which means that walking a lot is painful and with Diabetes you are gaining weight anyway – and between bullying and my weight P.E. was never a big thing”.

At college Matt was forming more of a friend group. “I managed to sort of ingratiate myself ... a lot of them played a game. [...] I already knew how to play, and had cards that were older than some of them”.

Matt also tells us of incidents of self-harm – scratching, razor blades, “I was always surprised people didn’t notice that my Grandma’s sofa was covered in my blood”.

Matt laughs, “This was however the time that I discovered everybody basically thinks that I am gay! ... I was up at the other campus and somebody there I didn’t know wanted to talk to me ... how they were having those kinds of feelings and how they were dealing with that.”

“Even up to that conversation if they had used the word gay I would not have known what they meant. But because they said they had started to feel attracted to other guys I understood what the concept was and my idea was: ‘is that a problem?’ We ended up having a conversation on the Internet that night and I realised that the reason he had been talking to me was because he thought that I was like that”. Matt tells us this resulted in a long conversation over the next few weeks where Matt came to realise that he did like guys “and I didn’t know!” So on the Internet and with his friends Matt came out as bi. “I spoke to my Auntie Jill about it – she is my favourite Auntie – everyone gets on with Jill – she is always the special one -- very much like my Uncle Joe who is my favourite Uncle. They don’t have kids and treat me as the surrogate kid. The first thing she said was “Are you alright with that? Are you okay?” With his Mum he told her on his eighteenth birthday “I was seeing my Mum. She was buying me trainers and I spoke to her before we went into the shop because I didn’t want her to buy me a present if she wasn’t okay with it – and she said ‘that’s fine, I thought you might be’ – I think by this stage I was saying gay. I told Dad when I went to University. He dropped me off – I waited to tell him as he was about to go. If it was going to be an issue I didn’t want to be anywhere near. He said ‘I guess I’m not having any Grandchildren any time soon’ and I think he gave me a hug and said it was fine”.

At this point Matt had moved out to his Grandparents. Carol with Sam, his stepbrother, were back with Dad. We ask Matt about his relationship with his Dad. “We get on better when we don’t live together. Dad is someone who can get angry at the drop of a hat. [He] isn’t good at dealing with emotions, either his own or anybody else’s. He is someone who we have subsequently decided, whilst he is too old to be tested, is somewhere on the Autism spectrum. This has come about because my half brother is Asperger’s ... they have looked at it and said ‘Yeah we can sort of see this is a genetic thing’ and especially if we go back and look at Granddad a lot of the ways that Granddad behaved ... Yeah again this could all sort of filter down. ... but of course you can’t test past a certain point because you have learnt the social skills to avoid showing your problems”.

We ask Matt if he was ever scared of his Dad, “This is before hitting children wasn’t allowed – it’s just one of those things. People often say you always love your parents – I

think you might always respect your parents, but you don't necessarily love them. I completely love my Grandma - with Dad I care about him but ... my relationship with Dad is complicated ... I'm aware I only talk to him about interests we share - I don't talk to him about anything that is going on in my life. My life? He has no idea - it's completely irrelevant to him".

The time has come to go out to lunch. When we arrive Matt takes his insulin. He tells us his Diabetes is terribly controlled and a lot of that is mental health problems.

Eating and rituals

Apparently Matt has always eaten his food in order. He was not aware of it until after he became diabetic. His Dad had noticed it before. We watch Matt do this with his lunch. *"The difficulty is when you get it to the degree I am where if you do something out of order it is a problem".* Matt tells us that sometime ago he was feeling comfortable enough to try something out of order on purpose. He did it but then didn't eat for two days because of the thought of it. Matt says it made him feel like *"everything's wrong ... everything stopped making sense ... you get confused about where you are and what's going on".*

Up until he was thirteen Matt had a ritual whereby if he hurt himself on one side of his body he had to replicate it 'accidentally' on the other. If he got it wrong or wasn't convinced it wasn't an 'accident' then it would become part of a sequence, *"I could get stuck for ages doing stupid stuff like going up and down the library stairs trying to bang my big toe on the third step".* That ritual broke the day he broke his arm. He tells us that he still occasionally gets a little stuck on stuff - he tries not to think about it because the more he thinks about it the more he does it. In 2016 he was diagnosed with Obsessive Compulsive Tendencies - although he is close to it being a 'Disorder,' not just Tendencies. This was at a mental health facility where Matt says, *"you go there and there are Psychologists and Psychiatrists".* He had a Key Worker that he would see every few weeks.

University

Following College Matt went to University. During the third year Matt's mental health took *"a tremendous dive"* and he ended up leaving. He tells us a lot of it was his insomnia, which got worse, causing him to skip an entire semester on one particular class. He had what he terms a *"breakdown"* about it. Matt had no support at University. He initially moved back with his Grandparents but they couldn't really understand why he had left and it was *"just get a job"* so he went and moved in with Mum and her fiancé at the time. He lived with them for six months. He then went locally to finish his degree, but sadly failed. Matt says a lot of it is still his dealing with people and he sort of wonders if it is possible to teach somebody how to make friends once they are not a child.

Support

Since leaving University Matt has moved around a lot. His mental health has been very poor at times. On one occasion he *'lost'* six weeks. He spent time in several house shares, sofa surfing for up to six months. Diagnosed with depression he has accessed various mental health services at various locations. They have offered CBT. Matt succinctly outlines that he needs to be in a job to have CBT that will make a difference. The life he has at present does not require CBT - that is why he is choosing to live it. *"you need to be in the situation"*. One of his ongoing problems is that he appears competent and therefore, at say the Job Centre, he gets put forward for things he cannot cope with.

He feels that Talking Therapy last year helped, also his GP seeing him every month or so - *"how are you, what's going on? Arguably a waste of time, but arguably not because there isn't anybody else doing it. Ideally I should be trying to stabilise my mental health by getting into more of a routine, finding the right job, carrying on with my studies. That is something that means I have to make sure I have the right CV, find the right things to be applying for and sit down*

"I don't know how to go about going out to make friends because it always seems like a false thing."

and do it. Whilst I know this, I know I am not going to be doing it because I worry that it will go wrong; I worry that if it goes right what happens at the next bit? I worry that if I have to go on Universal Credits I will then have no idea what will happen to my money. On top of that I have to manage my diabetes, I'm trying to lose weight as I have body image issues and I have been single for many years, so that weighs on me. But because I don't go out and meet people and make friends that becomes more of a problem. But equally I don't know how to go about going out to make friends because it always seems like a false thing. Are people being nice because they are being nice, or because they are humouring you, or is it just a joke to them?"

A while ago they encouraged Matt to find out what people really thought of him by asking them - "I have the kind of friends who will just be totally honest - and the nicest thing anybody said was 'that I was very distant'".

Having wandered back to the Centre we then go for a coffee. Matt carefully and with great attention to detail fills in pages in the Notebook. Toward the very end of our meeting Matt talks a little about more personal things. He feels he is gender neutral. He would rather he was more feminine than he is, presenting as androgynous is how he feels most comfortable.

He hasn't had a relationship in a while - six or seven years - once he is in a relationship he is told he is very good at it "the other person matters and I am completely irrelevant", which he acknowledges is not very good in the long term.

Just before we leave Matt also reveals that his first girlfriend may have led him into situations where there was "inappropriate behaviour - her encouraging me to get involved in the wrong things when I was about eight or nine, she was ten or eleven and at the start of secondary school. She had older male friends who were encouraging certain actions because they thought it was fun to do those kinds of things with a kid."

Remembering a certain location Matt says, "I do remember [...] I was encouraged to get naked and I remember there was a lot of stuff - things that, whilst nobody ever said anything, I was discouraged to go down there in the future by adults in general".

Matt tells us that he feels most comfortable when he is someone else - "when I'm reading, or playing a game or watching a film because then I am the person in the story. I'm not anywhere else". Matt agrees that he sees this as living vicariously.



Matt's story encourages us to think about the impact of interconnecting life experiences and challenges - in this case family bullying, physical ill health, body image and sexual identity - and how much energy is needed to achieve a sense of self and find a place in society.

How do we help people find greater emotional wellbeing by supporting them to work through significant struggles, including finding and accepting their true identities and coming to terms with long-term physical health conditions? In our last story, we see the impact of extreme and extraordinary childhood experiences and the impact it has on a person's ability to turn their life around.

Tom

Tom arrives at the Centre in Essex promptly, very neat, with striking blond hair and looking much younger than his thirty-nine years despite the noticeable scar above his right eye, the result of defending a good friend.

Almost before he has sat down one of the Centre managers knocks on the door, in her hand a list of jobs. It is clear that Tom is a much-valued member of the Centre, providing help as and where he can, be it with IT or painting .

"I'm either at the flat, or work, or at the Centre – and they always find something for me to do, so I'm not sat twiddling my thumbs. It's either that or I'm on the Pool table. I can take my anger out on the table – hit the ball as hard as I like".

Tom has missed work today to meet with us and the opportunity of earning £70. When he talks about his work he lights up and during our day he often shares snippets, from talking about the firm he works for to the kindness of his boss and his family. He feels they trust him, *"I actually think of them as friends"*. The construction company is made up of just five people. If the group were bigger he says he would end up arguing with everybody. Not having a phone at present means that every other morning Tom walks down to the office to see whether they need his skills as a plasterer or not that day. Being able to work is a very important factor in his life and Tom tells us he would happily do it seven days a week.

Managing his anxiety, depression and anger are significant issues and Tom is very aware of this. At present a dependence on alcohol determines a pattern to his day, but he is fighting hard to reduce his reliance. He has been to see an Alcohol Liaison Nurse, is keeping a diary and is attempting to reduce his consumption. *"Alcohol is the closest thing I've got to a rock basically. A can is closer to me than anything 'cos it can take my mind away from everything else. But I know it can make me even worse 'cos it can make me start thinking about stuff - that's why I just drink until I fall asleep - then I wake up and start fresh"*. On a Sunday Tom will take more Mirtazapine just to *"get rid of the day"*. He will put himself in 'tick' for drink. *"I know*



where all the alcohol shops are, what time they open. If it's there I'll drink it". Tom's food comes from a local food bank.

Early Years

Tom grew up in Wales with his three older sisters, he now lives in Barnet. We ask if he went to school around here and he replies, "Well, I can't say I went to school. I left for school in the morning, but I didn't go to school". As a young teenager he "hated" the area, but "Now I've grown to love it again". We ask Tom to tell us more about his childhood but he hesitates, "No, you don't want to know about that. I don't want to go through that, no, 'cos that will send my head west". Later in our conversation he refers to one thing that happened when he was thirteen that "is proper personal, and I've not managed to deal with it, if you know what I mean. I'm still waiting for the mental health team to help me out with this one." He doesn't want to bring it all up and then "walk out in a foul mood". He has been waiting months and months to be referred.

Never knowing his biological father, Tom was raised by his stepfather. As a small boy he grew up with chickens, ducks and dogs in a family with aunts and uncles, biological and otherwise, all living close by. Granddad - his Mum's Dad - was a very important part of his life. Tom remembers spending every weekend with him, being regularly taken to the pub on a Sunday. "It would be a packet of crisps, a game of pool and a pint of Guinness - put a lining on your stomach. We'd be home for three o'clock, have a Sunday dinner then both of us on the settee for an afternoon nap. Just good memories. They're the only ones I've got to be honest - all the others are just me getting fucking high as a kite and getting arrested everyday".

When he was nine his Granddad died. A year later his stepfather lost his leg in an accident. "After he lost his leg, he started drinking and the relationship with Mum just fell apart. When he lost the house in a game of poker Mum was like 'fuck it - divorce'. He brought me up - we called him Dad. Everything just went wrong. Me Dad had always been on construction - now he was going out everyday getting pissed - he

couldn't work. It were proper hard for him - I get that now".

We ask if his sisters looked after him. "No!". "Look after yourself - that's how it was when I were brought up. So I brought myself up - that's all I can say really".

Tom tells us we won't see emotion from him, "I bottle it - that's the problem with me, I need to learn how to deal with my emotions. I basically brought myself up from thirteen.

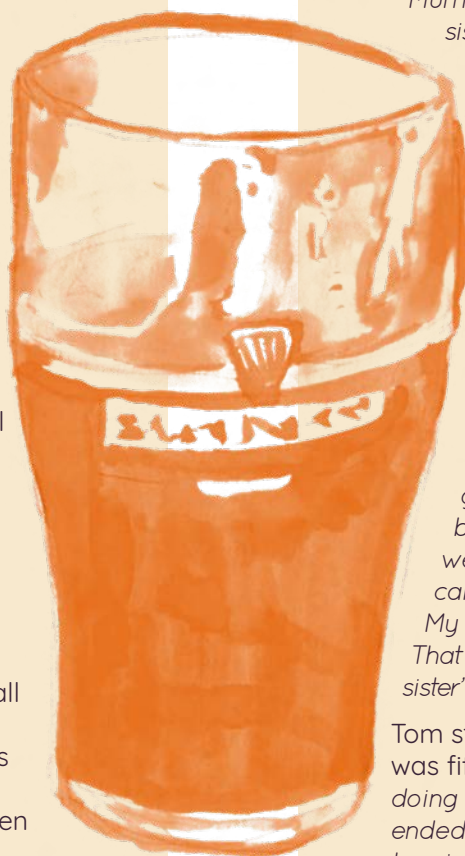
Mum tried putting me into care and my sister, Lizzie, was like 'I'm not having that. I'm old enough now to be his legal guardian', and my sister took me over. She was eighteen. She'd just come out of care the week before. And that was when everything went fucking wrong for me. I lost everything basically. My structure collapsed - my family's life core collapsed - that's when I went off the rails".

We ask what life was like with his sister. "So, different people lived there - I'd leave to go to school, sign in and go back home. Just get stoned in the bedroom with mates. As long as we weren't doing anything criminal nobody cared, as long as we kept our heads down. My sister was smoking weed, taking 'Es'. That's how I got into drugs, through my sister".

Tom started taking class A drugs when he was fifteen. He tells us, "The weed wasn't doing anything. I made myself homeless, ended up on the streets. So I was taking heroin to black out why I was homeless and to live on the street - makes you feel numb so you've got no emotions. Only problem is after that you've got to find your next fucking fix. So I was committing crime then, at fifteen I was a prolific offender".

We ask if there was any support, "I was in and out of hostels but I couldn't live in them without getting stressed and angry ... snapping and fighting with people, so I would get evicted. My family disowned me because I stole off them ... I lost contact for many years".

When Tom was in his twenties he started a relationship with a Social Worker. He tells us she was amazing, they were together for over five years. "But I fucked it up, through my paranoia and everything". Tom shrugs -



sadness etched on his face, *“there’s nothing you can do ... It was coming off the drugs, the paranoia, I just kept putting it on to her and basically she’d had enough of it”*.

Tom can remember the month and year when he walked into the chemist and said *‘I don’t want the Methadone’*. He weaned himself off, reducing the dose by one milliliter a week. Now he sees his old drug associates around town – he still knows where most of the smack dealers are – and they are all *‘look at you!’*. *“But they’re always putting me down because they can’t get where I am”*. Now he says he just needs to get off the drink.

Family

Tom tells us a little more about his relationship with his family. He has lots of nieces and nephews and speaks about them with love and pride. Yet despite his love for his family Tom says he has periods where he doesn’t visit because his head’s *“just not been there”*. Ironically when he last went he came back to find he had been burgled. *“so my head’s a bit more fucking west. I thought, yeah, I can go up and see them, I feel alright. Went up, had a couple of spliffs [...] when the kids were in bed, [...] and when I came back to the flat I’d been fucking burgled! Police came out – no fingerprints”*. Tom was involved in burglary when he was a kid and ruefully sees being burgled himself as a form of ‘karma’.

When his head is in the right space he will go over to one of his siblings. They used to always have Christmas dinner together, but Tom hasn’t been for the last few years. Tom’s Mum has a restraining order out against him for threatening to kill her new husband, Mike. Tom tells us Mike was bullying his Mum, and then *“he fucking tried to start bullying me, but I won’t stand for a bully”*. When Tom was living with his Mum in 2014 Mike would get up at half-nine in the morning, *“not even have a brew, go out, come back at tea-time pissed out of his head saying ‘where’s me fucking tea’ and speaking to my Mum like shit”*.

Tom looks down and examines his hands, *“She’s chosen an alcoholic over her own son and that’s the second time she’s done it now. ‘Cos she chose my first Stepdad over me last*

“My structure collapsed - my family’s life core collapsed - that’s when I went off the rails”.

time, that’s why they were trying to put me in care. Instead of fucking dealing with the alcoholism and dealing with me – ‘cos I was fucking running weed. Life was hard when I was growing up. If I were late the back doors would be locked. I’d break into the caravan on the drive to sleep and then get a beating for breaking into the caravan”.

Tom won’t be celebrating his Mum’s Birthday with the family this year. *“I’ll just sit in the flat”*. Tom adds, *“I don’t go out, don’t do nothing, don’t socialise – and that’s basically my life. I don’t go out after midnight anymore. My life’s been shit, but I’m hoping it will get better”*.

The attack

Tom doesn’t go out at night after being mugged for a few pounds very close to his flat. He shows us the scars on his face from being hit with a crowbar. He tells us they left him for dead *“in a big pool of blood in the middle of the road”*. It’s the second time he’s been attacked, the first time when he was in his late teens. They seriously damaged his jaw. Tom spent weeks in hospital with surgical devices to rebuild his jaw. He also has visible, significant damage to one hand. Tom tells us he doesn’t know how it happened – he says probably fighting. He takes painkillers every day.

We ask Tom about his experience with mental health services. He tells us *“The local rapid response mental health team are crap. I was in hospital – after the mugging – and I asked to speak to them due to my mental illness, because that’s what I suffered from before it happened – depression – and they still didn’t come and see me. I’ve been to A&E – I’ve told them ‘honestly I feel like topping myself’ sat in A&E and still no one’s come four hours later. Even when you get to speak to somebody and you give them everything you’re still waiting six months down the line to hear from the rapid response team”*.

Tom’s GP has prescribed him Pregabalin, Cocodamol and Mirtazapine and Paramol. Pain from his hand, headaches following the assault, anxiety and depression mean he often isn’t able to sleep. *“I’ve not even had the Mental Health Team come back to me yet for a referral. I’ve been waiting months. I’ll be honest with you, it’s a joke. My GP’s nice to speak to but I’d prefer someone who knows what they’re doing, with my mental health, like.”*

“The GP thinks it’s about my anxiety and anger. I keep my story to myself, but I need to get it out ... Nobody has contacted me ... I

don't even know if I have been referred. I don't speak to my family about anything like this ... they've got their own problems".

On the streets

The morning is slipping by and we suggest lunch. Tom tells us *"I'm going to nip to the shop and get a can [and] go behind the sheds, you can go for your dinner ... I don't want you [with me] whilst I'm stood drinking a can because people walk past and give you dirty looks"*. We try to persuade him that it's okay – we don't mind, but he will have none of it. It is something we observe in Tom throughout the day: his manners, politeness, willingness to help and sense of honour.

He does however agree that we can walk to the local shop with him. We go in and it is obvious he is a 'regular'. He points out the two litre bottles he buys for the evening, but just picks up one can. Instead of us going to dinner we all walk to Tom's flat.

Flat

Tom's flat is just minutes from the Centre. It is part of an old building. Security is an important issue. Having been burgled he is understandably anxious. We go through various locked doors, up two flights of stairs and into a one bedroom flat. Tom's few possessions are spread around the available surfaces with notes to himself pinned to the walls. He has few cooking facilities and his washing is draped around the bedroom to dry. There is a large mark on the ceiling where Tom tells us there was a leak from upstairs. The flat is in need of repair and decoration but the landlord has carried out neither since Tom moved in. Tom tells us *"If I'm not at work or at the Centre I'm here. In the evenings I eat, watch TV and drink until I fall asleep. ... I've always said I'll be dead by the time I'm 40. [...] ... I've got cupboards full of tablets ... but at the moment I'm in a good place with my head"*. He points out where the tablets are stored.

After a while we leave Tom's flat to walk back to the Centre. First we pass by the primary school where his niece and nephew, Maya and Oliver are. Oliver is in the playground. The class are having a cycling lesson. Tom is obviously thrilled to see Oliver, on a bike, riding.

Slowly we walk through the streets to a favourite spot of Tom's. It is slightly protected, a location from which he can see people coming from either direction. *"I come here after work – have a can – sit here and enjoy what I've done, makes me smile a bit 'cos I've made somebody happy"*.

During his life Tom has had run-ins with the police and on many occasions has been in prison, including a Young Offenders Institution. *"It was mostly for theft of motor vehicles, driving. The longest sentence was eight months. It was to support my drug habit. Tom was last inside in 2014, but as recently as 2018 he has been arrested. Frustrated, he tells us this followed a badly set up probation where his appointed CGL (Change Grow Live) supporter was off sick. "I went to ask probation for help and all that happened was I got arrested! Seven counts of Section 5, four probation officers and three police. I was asking for help, but the trouble was I was screaming it. I was irate and anxious and I don't know how to control my anxiety and anger ... They threatened to taser me, I didn't care ... I tried to run through a window, put my head through a glass window"*.

Tom tells us you get more help in Prison than outside, *"The Police, probation, CGL, need to listen more and get more training about mental health. It took me two years before I got any help. It fucked up my CRB and hope of getting a job ... You tell Police you've got mental health issues and it's 'Yeah ... bullshit – get in that cell!'"*. Even the Judge said to me *"we don't know anything about mental health. We are sorry about that"*.

Following Tom's arrest he went to his GP – they just changed his antidepressants. *"I don't think there's any follow-up between the Police and the Doctors. [It] just feels like me in the middle getting slapped about"*.

Tom tells us he's got no strengths, no qualities. *"I've seen some horrible sights ... I dragged myself up. If I could turn my life back it would be before Class As. I just want to be able to work ... find a better place to live – move forwards with my life"*.



Tom's story tells of childhood neglect and the substance abuse that later emerged.

When under pressure, Tom finds himself defaulting to tactics that kept him safe when he was vulnerable and homeless. Sadly these tactics put him into conflict with the justice system, stopping him working and now destroying his hope of 'turning his life around'. How can we help people manage behaviours learned in childhood, or as a response to feeling vulnerable, rather than stigmatising them with labels that actively prevent social inclusion?

These stories provide a glimpse into people's lives. Each person, each family, is one of a kind and as such each story is unique.

Yet individually and collectively they raise issues that are commonplace in today's society, such as the effects of sexual, physical and psychological abuse, addiction, poverty, depression, anxiety and loneliness, to name but a few. They also reveal how people 'live through', 'live with' and 'live around' mental health, how professionals choose to identify and categorise behaviour and symptoms (gathering them under 'diagnoses'), and how this shapes the mental health landscape and the support that gets provided.

Analysis and Insights

The stories in this book reveal the complexity of human life in all its richness and difficulty.

Mental health diagnoses and conditions are organised, in part, according to their own kind of ‘complexity’, and services are offered and rationed according to levels of need. If your need is ‘less complex’, you won’t be eligible for specialist, secondary care help and support. On the whole, the people in these stories don’t qualify for that kind of provision, but their lives are super complex, and their need for help is high. So there is a mismatch between mental health service thresholds and the difficulties with which our storytellers are wrestling. This mismatch generates many of the frustrations people experience with the formal mental health ‘systems’, and explains many of the themes in our analysis below, including: not receiving help at all, being asked to wait to get help over prolonged periods, and only getting help that addresses some, but not all, needs.

The stories in this book are stories of life itself, of living at the edge of survival, of living with and working through at worst punishing, and at best neglectful, relationships and experiences. Most of all, they are stories of human suffering, or, in other words, of pain that cannot be tolerated. They reveal the interconnectedness of people’s problems and the relationships between different challenges in their lives, exposing the threads that weave together whole families, households, and extended families. We have reflected on these stories and offer some insights that we think help to describe and explain key failures in our contemporary response to the many of us who struggle to live well.

As we mentioned in our introduction, these stories were gathered pre Covid 19, pre lockdown. We have been considering how different our storytellers’ lives have been over the past months. Confined to their homes for weeks, perhaps quarantined, socially distanced from extended family, friends and avenues of support. They will have been unable to take their children to school, walk the streets, call into a café or go to their local support centre. Their usual ways of coping, their fragile stability and hopes for recovery will have been challenged. Without assuming that they have been unable to cope we must consider what the consequences of Covid-19 has been for them and for others in similar situations.

A note on language

In the analysis that follows we refer to ‘systems of support’ rather than ‘the mental health system’. We do this for two reasons. First, because there are in fact multiple systems. Most obviously there is the mixed marketplace of statutory and third sector services which is distinct from, but variously interlinked with, much more hyper local systems of family, neighbourhood and community. Second, one of the dominant cultural practices in our contemporary response to mental health is to load the responsibility for helping people in distress onto formal mental health services and the professionals working in them. This obscures the roles that citizens might play - either individually or alongside professionals - within person-centred systems of support that have the potential to draw on a wide and rich variety of knowledge, wisdom and resources.

A note on headings

We open each section of the analysis with a heading. Our headings are intended to be used alongside the stories to help to support conversation and dialogue between and among diverse groups of people who occupy different positions in mental health - carers, people using services, practitioners, managers, commissioners, leaders and campaigners. We hope that the headings help such groups develop their own meaning and interpretations and, critically, inspire new forms of collective action.

1: Complex lives, not complex mental health

1a. People's needs are not being met

Through these stories we have witnessed people experiencing poverty, worrying about money, caring for others whilst balancing their own mental health needs, living with the aftermath of adverse childhood experiences, feeling socially isolated, being victims of crime and not having their needs met. Fundamentally, our storytellers are struggling to work through adversity and its effects. May needs support to overcome past trauma, Dan needs help to deal with the fact that nobody cared he was the victim of crime, Megan is struggling to cope with the birth of her child, Peter requires support to run his household and Matt needs support to apply for universal credit.

What do these stories tell us about the way that systems of support are currently designed? Is our response sufficiently tailored to personal circumstances, and does it sufficiently engage with the adversity that so often drives unhappiness?

Dan: *They were trying to contact my social worker, trying to explain this person's behaviour toward me and she was immediately on their side ...He was pretty open about taking my stuff, but they were making out he was so sorry and he really wasn't!*

Megan: *I had borrowed money for the rent ...the mugging turned out to be from the very people I actually trusted, that I had built friendships with – they had arranged it.*

Matt: *I worry that it will all go wrong. I worry that if I have to go on Universal Credits I will then have no idea what will happen to my money.*

Dan: *I was trying to be friendly to people maybe I shouldn't have. I picked somebody up who was not what they seemed and it went wrong, it went wrong. They stole some of my good clothes and I'd just got myself a new phone. They took that.*

1b. Trauma is omnipresent

Trauma and its impacts on mental health can be understood as the most important thread running through all the stories. It is contextual, perpetuated and made worse by environments. It is often linked to gender power imbalance and abusive male dominance, which manifests in different ways in different cultures.

Importantly, those living with or around victims of abuse, neglect and trauma sometimes deny it in order to protect themselves from pain. What would happen if I accepted my daughter's suffering as real? It might mean facing up to uncomfortable truths about my neglect, or my partner's abuse, or my own suffering. It might risk breaking up the family, or giving someone up to the law. So instead the victim's reality goes unnoticed and, in effect, is denied. The trauma is buried, which in turn leads to further trauma. It becomes a burden. Desperate suffering often goes unnoticed. People can look well on the outside, but inside, and unseen, they are tortured by severe distress, self-harm, and even suicide attempts.

The people in all the stories are unable to break free from the effects of trauma. How far are current systems of support able to recognise and respond to these needs, and to engage meaningfully with the causes and impacts of trauma?

Tom: *I bottle it – that's the problem with me, I need to learn how to deal with my emotions ... Life was hard when I was growing up. ... I basically brought myself up from thirteen.*

May: *I used to go to church when I was little – and I would pray to God to make it stop ... The church used to say that if you had sins you would burn in hell and so I thought I would burn in hell.*

Sabita: *It became more physical. ...We did not know how to say how we felt. We had no social or communication skills, as we were not taught them ... My Dad ignored all the abuse and I thought it was normal.*

Matt: *I was always surprised people didn't notice that my Grandma's sofa was covered in my blood.*

1c. Families and communities, not just individuals

Today's public policy gives too much weight to the individual as problem. When someone is unemployed, for example, we say it's because they need to be more 'resilient' or 'hard working', rather than looking for social and economic causes, including power imbalances that limit personal and collective agency. Or when someone is mentally 'unwell', we look for illness within and inside the person, so that wider, external forces remain invisible.

In a sense, we could argue that individualising (or 'personalising') public services is part of the problem, because it reinforces the idea that the state should work one to one through individuals, rather than more fluidly, equally and holistically with connected groups of individuals, friends, families, neighbourhoods and caregivers. In Peter we see a man struggling to cope with the needs of his family and trying to work against uncoordinated formal support that treats them individually. Megan is too afraid to ask for support for fear of being labelled an inadequate parent.

What would a whole family, relational approach to mental health look like?

Megan: *Social Services scare the living daylights out of me ... I was afraid to even tell anybody how I was feeling because I was terrified that if I tell them I can't look after myself they will come and take Jack away.*

Peter: *But you just get into a routine and things are getting better and then they take them off you and you're sinking back into the sand again - you just think, what's the point.*

1d. The power of the told story

Only through the telling of a person's whole story - and not through the fractured parts called for by different professionals - can we recognise and appreciate the impact of a person's history on their personal life, their work and their family. Yet often a person's whole story is never sought. Indeed there can be pressure from others so that only certain parts are told, and even those have to be 'cleansed', for the truth is often too difficult to share, or to be heard. This is especially true when we consider how systems find out about people. Assessment looks at the 'presenting complaint', at the here and now, but this is only one lens to be considered - not the sum total of a person's life experience. A history untold can be experienced as an ongoing, debilitating burden.

In hearing a person's whole story, the possible root causes of mental health problems can emerge and be shared. How we respond to those stories is vitally important. Too often they are not valued or recognised for the impact they have. Although Psychology teaches that mental health ('good' or 'poor') is not simply a result of what happens to you, but how you interpret what happens to you, no one is indestructible. Extreme and extraordinary events and decisions directly trigger acute trauma, despondency, stress and anxiety. It is hard to imagine our storytellers remaining unscathed, or only mildly irritated, by the repeated and terrible abuse and neglect that runs through the tapestry of their lives. Being believed and understood is very powerful; not being believed is utterly destructive.

How can we support people to share their stories in a safe way? What kinds of practice would be needed to allow this to happen? And where trauma is debilitating, how can we make sure that therapeutic support is easy to access?

Tom: *I keep my story to myself, but I need to get it out ... Nobody has contacted me ... I don't speak to my family about anything like this ... they've got their own problems.*

Sabita: *It would have helped explain why I tried to take my life.*

2: Falling through the gaps

2a. The costs and benefits of a diagnosis

The concept of the clinically informed 'diagnosis' plays a disproportionately powerful role in determining who a person will see, what support they will be offered, and how they will be viewed by society. A diagnosis can open doors and provide care and support – it can also close doors and leave people adrift. Often a person will suffer stigma and intolerance as a consequence of a diagnosis and feel as if society does not accept them the way they are. Many people think that a diagnosis means that a person is defective in some way. It is not generally understood that poor mental health is much more likely to occur as a consequence of adversity. As a result people with poor mental health can feel as if they do not belong.

The stories in this book reveal different reactions to the idea that a diagnosis is a 'ticket into the system'. Megan believes a diagnosis will bring her child more support, whereas Tom pleads for help at Probation and ends up in a prison cell.

The practice of using diagnoses to describe and categorise a person's presenting 'condition' medicalises their lived experience. It puts pressure on people to translate their experiences of grief, loneliness, despair and fear into the language of 'mental health'.

Is the true purpose of a diagnosis to ration services or to help people get the right support at the right time? For whom should life experience and adversity be 'ticket' enough to support, instead of a diagnosis?

Megan: *I can't claim to be a carer for additional needs until he has a diagnosis – so that's stressful [and] because he doesn't have a diagnosis and support he can't go to that group.*

Tom: *I went to ask probation for help and all that happened was I got arrested! Seven counts of Section 5, four probation officers and three police. I was asking for the help, but the trouble was I was screaming it.*

May: *Being looked at as if you're not believed and you just want to tell them that you don't want to be here – they make it worse – they make me want to go home and take the tablets more.*

2b. Unseen and unmet needs

Even with a diagnosis, people can fall through the gaps, become lost in the system and be left without support. Certain conditions can be viewed as 'untreatable,' some people can be seen as too chaotic to treat, some symptoms aren't seen as severe enough, or those that present as coping are left to 'just get on with it'. Tom, for example, was not considered eligible to meet with the psychologist he so desperately wanted to see. Matt presents well and seems to be fine. Megan needed to fall to her knees for anyone to listen to her.

But the reality of their existence, the pain and distress they feel, will be every bit as real as somebody with a diagnosis that gives them access to a pathway that leads to careful clinical consideration and support. It is not surprising that they needed to go to such extreme lengths to be noticed, and if they were lucky, supported.

In a stretched system, people can also be connected with support that isn't right for them simply because it is the only offer available. Indeed, we saw this with May who was prescribed CBT, only to be told halfway through that her emotional state was too complex. May receives telephone support which she feels is making her worse, but is too scared to say in case it means she is left with no support at all.

How do we stop others from deciding how bearable our emotions are? Are we providing people with the support that is there, rather than the support that they need? How can we ensure people don't fall through the gaps between services?

Tom: *I've been to A&E – I've told them 'honestly I feel like topping myself' sat in A&E and still no one's come four hours later. Even when you get to speak to somebody and you give them everything you're still waiting six months down the line to hear from the rapid response team.*

May: *I'm told I'm too poorly for Mind and I had CBT a while back and was told I was too ill for them ... but I'm not poorly enough for other stuff, how poorly have I got to be?*

2c. Conflicting systems

Responses to mental ill health vary according to the system that you encounter. When a person's behaviour, triggered by their mental health, moves from the health realm into the realm of policing, the law and the justice system it becomes something 'other'. From behaviour seen as the result of a mental health problem it may be seen as behaviour over which the person is expected to be in full control, that she can contain, that he can stop. It is behaviour that can elicit fines and imprisonment and is carried into the future as a label identifying a 'risky' person.

How far do we push emotionally vulnerable people into mental health services because it is the only place where staff feel confident to respond? How might we align overlapping systems (such as mental health and criminal justice) around a shared understanding and tolerance of mental ill health?

Tom: *The police, probation, CGL, need to listen more and get more training about mental health. It took me two years before I got any help. It fucked up my CRB and hope of getting a job ... You tell Police you've got mental health issues and it's 'Yeah ... bullshit - get in that cell!' Even the Judge said to me, 'We don't know anything about mental health. We are sorry about that'.*

3: Towards caring, strength based systems

3a. Recycling distress

Formal systems of state support run the risk of repeating people's personal experience of not being cared for as children and adults. It is curious that many people in these stories report uncaring responses by public sector agencies, and of provision that keeps them trapped in abusive, neglecting environments. For example, a hostel for vulnerable homeless young people that connects Sabita to abusers is clearly not going to help her recover. This gives rise to what is known as 'systemic trauma', which refers to the contextual features of environments and institutions that give rise to trauma, maintain it, and trigger post-traumatic responses.

How can we ensure services do not replicate and trigger people's past experiences of neglect and abuse? How can we be more aware of, and seek to minimise, the ways in which systems of support trigger even more distress for people seeking support?

Tom: *I don't think there's any follow-up between the Police and the Doctors. Just feels like me in the middle getting slapped about.*

Peter: *Now when they offer we ask how long for and if it's only a few weeks or months we say 'Nah - don't bother - you're just going to get to a position where we are comfortable with them and we're actually starting to make a bit of progress and then you take them off us!'*

3b. Strengths based care

Many services can be poor at recognising people's passions, skills and talents and through these encouraging people to rebuild confidence and purpose, and enabling them to manage the positive and negative aspects of their identity.

Much of the clinical language of mental health is unhelpfully negative: symptom, illness, disease, disorder, problem, remission, relapse, crisis, risk. This negativity at least has the virtue of mirroring the reality of negative life experiences, like the ones in the stories in this book. But it crowds out space for any genuine appreciation of people's strengths, and how they might be harnessed for meaningful productive activity, or be established as the foundation for support and therapeutic change. Talents and skills are often on the sidelines of people's sense of themselves and who they are, and of how others see them, and for this reason are not given the power to help people feel better about themselves, to feel safe and calm, or even fulfilled. This can be exacerbated by the lack of control the system can give people over their lives.

We can see this through Dan having his weekly allowance counted out in front of him and feeling humiliated.

How might we reframe systems of support to engage people in their strengths, ambitions and life goals, to help them grow and develop as individuals and families?

Dan: *Counting out the money in front of me makes me feel more vulnerable. It's actually quite horrible.*

Sabita: *Everyday as a teenager my stepmother would put me down saying I was mad, crazy, criticising everything I said saying I should get out of her house.*

3c. Nurturing the positive

Interwoven through the stories are references to places that provide support and resources, and to individuals who have made a positive difference to lives.

They exist both at the core and on the edge of formal services. For example, the support centre that offers a warm welcome, expert advice and a feeling of belonging; wellbeing courses that nurture hope and the sense of a better future; knowledgeable and empathetic support workers who have had real and positive effects; good GPs who find the time to listen, and caring, hardworking staff across the NHS. These places and people, and others who make a positive difference to day-to-day lives, sit within and outside of the formal 'state' system of publicly-funded services. They need to be nurtured and encouraged.

How do we support more and more carers, friends, family, neighbours and professionals to provide compassionate, people-centred practice?

Tom: *I'm either at the flat, or work, or at the Centre – and they always find something for me to do, so I'm not sat twiddling my thumbs.*

Sabita: *All the things where I have relationships, where I meet other service users. Service users listen to every single thing you are telling them. They understand you. I can also focus on doing something meaningful in my life, which I enjoy too, surrounded by some very caring and hard working staff always looking to improve the service for service users all of the time. Helping others also makes me feel good too.*

Megan: *Since things were bad last year I have the Centre which is my support, and I did have counselling and I go to group counselling at my GP ...and I talk to friends more, at the same time you can't talk to friends and family like you can to a counsellor. It's just nice to have somebody to talk about the little things, somebody to have a laugh with.*

4: From just coping to growing

4a. Discharged but not always landing safely

Support from services can leave people just about coping, with just enough resources to get by. When clinicians, social care or other support workers discharge people from their care, they are doing exactly that – discharging people, not just their duty or care to treat a specific condition.

When someone is no longer deemed to meet thresholds or criteria, because their symptoms have lessened or their life circumstances have slightly improved, it becomes right, in professional terms, to discharge responsibility. And individual professionals are not responsible for the oppression in the wider system, nor should they be.

But there is another reality to this way of organising our system; namely, the desire to discharge and deny the whole person and the wholeness of their suffering, and ignore the system's complicity in it. Tragically this undermines the possibility of change, personal growth and development. Discharging leaves people 'just about ok', and just about coping. It is a tragedy, not only because it leaves people bereft of the care and support that they need right now, but because it perpetuates a system that is not designed to unlock ambition, possibility and aspiration. In its extreme form, discharging can involve a total detaching, with no onward referral or signposting to other services that could help instead.

Why do so many services end their support just at the point at which this kind of growth starts to feel possible? How might we reframe systems of support around a shared interest in supporting personal and familial growth and development?

Dan: *Quite often, whenever a problem comes up, by the time you've got to see a [Psychiatrist] sometimes the problem has passed.*

Peter: *You just get into a routine and things are getting better and then they take them off you and you're sinking back into the sand again - you just think, what's the point?*

4b. Building resilience for the long term

Unless services build resilience for the long term, people will find themselves in need of support repeatedly. Resilience is often thought of as a measure of how well a person can adapt to the events in their life. People with good resilience are able to 'bounce back' more quickly and with less stress than someone whose resilience is less developed. People in these stories often demonstrate high levels of resilience in the face of tragedy, but it is 'brittle'. Poverty of experience and opportunity is a defining feature of the lives of our storytellers. Energy is drained by the near constant struggle with money, childcare, medication, relationships, isolation and anxiety – and victims can be very aware of the 'game' that has to be played, of the 'performance' that has to be maintained in order to retain the slightest semblance of equilibrium. This is exhausting and leaves little strength to focus on the possibility of a better future; it is hard enough just to 'tread water'.

It is impressive how our storytellers find ways to carry on, even when things are really tough, but we worry that their strength might be easily broken, especially when something re-traumatizing happens or when the stresses of life suddenly feel too much to bear. In these stories people are forced to show resilience almost all of the time, rather than occasionally. For this reason we can understand poor mental health as an experience of 'wearing down' or 'wearing out'. This challenges the value of short-term 'mental health' interventions that don't build durable, long-term systems of support around the person that make life easier.

How can we help people to build their emotional resources over the long term?

Dan: *When you're absolutely out of food you have to use the food van, food banks ... Going there became hard - I was quite depressed ... obviously you see quite a lot of hard people there.*

4c. Heroic acts and self-medication

These stories show us how, in these moments, people with mental health needs often develop skilful habits and patterns that help them live and survive. This can include very small choices such as regularly buying the same soft drink, and attributing it to certain restorative or otherwise positive benefits, or more complex survival strategies such as learnt techniques for managing stress or anxiety caused by face-to-face conversations. These small, highly personal acts and thoughts are heroic because they help to sustain life in the face of adverse and threatening circumstances. Even when they involve drugs, alcohol and self-harm they are legitimate and rational responses to unbearable trauma in the moment, even if they are destructive in the long term.

How can we take account of the ways people have had to learn to cope, in order to help them to cope better? And how can we support people to find new ways of coping that genuinely work for them over the longer term?

Tom: *Alcohol is the closest thing I've got to a rock basically. A can is closer to me than anything 'cos it can take my mind away from everything else. But I know it can make me even worse 'cos it can make me start thinking about stuff - that's why I just drink until I fall asleep - then I wake up and start fresh.*

Dan: *It stimulates me to the point that I can actually have a civil conversation. It goes back a while when I was really distressed with life. I found out whenever I had an energy drink, I seemed to just calm down, no problem ... I could just focus.*

May: *When the arthritis gets really bad I take extra painkillers and drink ... I feel it is the only way I can cope.*

Sabita: *I just wanted to start screaming and break things. I felt I was going to get violent. I was managing my depression but I was getting more anxiety, hearing more voices, seeing things. I was constantly self-harming, cutting myself on my arms for years just to cope at work, and to deal with all my pain and memories from my childhood and the hostel.*

5b. Hopeful despite everything

Somewhere in the future, somewhere unknown, some place dimly glimpsed but keenly felt, there is a better life, despite everything. Wanting to get back on her feet, to get her life back, to start to live a little, to be the person she should have been and always wanted to be – there is a tantalizing alternative future that occasionally swings into view before falling away again in the face of the ‘here and now’. This hoping feels unrealistic, almost tragic. Will it ever be realised? It’s sources are many – a new partner who genuinely cares, a mental health service appointment that actually works, different medication that doesn’t make me feel sick or constantly tired.

Despite their heroic perseverance and hopefulness, these storytellers, understandably, seem to lack the internal capability to look after themselves, to wish themselves well, to nurture inside them what is good and valuable and loveable. We notice few feelings of being cared for, connected to others and trusted.

How might we help to build caring systems and people’s self-caring capacities, to grow self esteem and genuine feelings of positive self regard? Fundamentally, how do we help people transform their lives, rather than just giving them something to hope for?

Tom: “Look after yourself” – *that’s how it was when I were brought up. So I brought myself up – that’s all I can say really.*

Megan: *I was terrified ... and then I went along for the scan. In my head I was thinking I can’t do this, I can’t look after myself let alone [someone else] ... but it was one of the best days of my life – I just seen him, waving – he was almost a fully formed person, and I remember seeing him and crying. It’s ever since seeing him that I have something to live for, somebody who needs me, that’s a nice feeling. I tell everybody he’s the reason I’m alive and he’s the reason I keep fighting.*

Conclusion

For many people in the UK it is hard to feel mentally healthy in an age when the protective factors for good mental health are so threadbare.

Services developed in the four sites of the Living Well UK programme meet this difficulty head on. Co-designed out of the voice of lived experience, they offer holistic, person centred support to address wider determinants of mental health (such as housing, welfare and isolation) alongside clinical and medical needs. Delivered by multi-disciplinary teams applying shared practice models, they start with simple questions that empower people to tell their own stories in their own way - "What brought you here today?" "What matters to you, today, tomorrow, next week?"

We think Living Well services are a beacon of hope and a guiding light for how services and systems of support should be designed and delivered into the future. Later in the programme, we will test this claim by gathering another set of stories of people who go on to use the services. We'll want to know what difference they made.

Addressing hard-wired adversity and deep-rooted trauma is challenging. As a society we have a long way to go to nurture good mental health for everyone.

What do you think?

We encourage you to contact others in your local area to engage in open, generative dialogue about these stories. What do they say to you about what needs to change in our contemporary response to mental health? What questions do they inspire for you? Through dialogue about stories of lived experience we hope you and your peers will move towards new forms of collective action, and towards new and better solutions.

