

# DIGITAL ACCELERATOR LIFE STORIES

Bexley residents'  
experiences of diagnosis  
and treatment of severe  
mental ill health



**NHS**  
**South East London**  
Clinical Commissioning Group





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\*Names have been changed to protect identities

# **THE DIGITAL ACCELERATOR PROJECT**

Mind in Bexley (MIB) applied for and won a small bid from the NHS Digital First team in early 2021. This funding was used to identify gaps and better meet the needs of locals with severe mental illness (SMI), through digital and other activities.

The project team consisted of South East London Clinical Commissioning Group (CCG), Digital First, the Bexley Voluntary Sector Council and Mencap.

The project ran from April 2021 to March 2022, under the shadow of Covid.

Despite the challenges, the project was able to deliver on its objectives.

- We established a monthly peer support group aimed at clients with a SMI diagnosis
- We created the infrastructure to deliver an annual health check service to MIB clients with SMI within the supported environment of the monthly service user group
- We recruited and trained a team of 4 Digital Skills Training Volunteers to deliver training to clients one-to-one
- We improved the existing referral pathway to Mind in Bexley's Recovery College for clients as well as set up a new, easier referral pathway in to the project for local GPs via their DSX platform
- We put all of our Bexley Social Prescribers through the 2-day Mental Health First Aid training program
- We also offered every GP practice in Bexley one free place on the Mental Health First Aid training to be taken up in 2022
- We established a monthly peer support network for accredited Mental Health First Aiders and Mental Health Champions in Bexley
- And we invited some of our clients to reflect on their experience of poor mental health in this compilation, the Digital Accelerator Life Stories.

Here is what they had to say.

## **Laura Rey**

OPERATIONS MANAGER  
MIND IN BEXLEY

# INTRODUCTION

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The Digital Accelerator project was keen to shine a light on the needs of clients with SMI and to explore new ways to address gaps in their care, through digital and other means.

As part of the project we wanted to provide an opportunity for these often voiceless individuals to be heard. We invited them to share their lived experience as well as suggest lessons to be learned and recommendations for future advancements.

The stories that follow are brief accounts of their experiences, over many years, from their points of view. These are not linear, detailed or verified. They are recorded, as recalled, by our generous participants and we thank them for sharing their often times difficult experiences with us.

Our aim was not to blame or finger point or judge. The aim of this exercise was simply to listen, reflect, learn and share this information to support future work.

We hope that this record serves to remind us of who we serve and how we can continue to improve our offer so we can better meet the needs of those who need us most.

For more information on the Digital Accelerator programme please visit [www.mindinbexley.org.uk/smi](http://www.mindinbexley.org.uk/smi).

# MICHAEL

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**Male**

**Mid 40s**

**Part-time self-employed**

**Supported by partner and both parents**

Michael has experienced mental health issues since his teens. When depression first hit he was prescribed anti-depressants and advised by his GP to approach Mind.

At the time he felt like he didn't quite understand the diagnosis, the treatment and the support available to him. This would be a recurring theme over the next 20 years. At 19 he had his first "breakdown". He was hospitalised in Surrey for 2 weeks, "possibly" diagnosed with Bipolar and sent on his way with little more than his medication. Again, he felt unsure of his diagnosis, his treatment and the support available.

### **"Nothing was set in stone. Tell me so I can deal with it"**

He continued to struggle on for years but often found himself being bounced between his GP and A&E. He felt like if he wasn't in crisis he didn't get support, even though he knew that without intervention, a crisis was inevitable.

### **"If you're not in crisis you won't get support"**

He felt that over time he learned the only way to get support was to escalate his behaviour. This led to incidents of self-harm and a number of attempts to take his own life.

His most recent attempt saw him end up in the Woodlands unit in Bexley for 5 weeks. This was a turning point. There he met two people who would help change his trajectory.

The first was an advocacy officer from Mind who was visiting the ward. She approached him and simply asked "Do you need any help?". They spoke for 1.5 hours. When she left he had a pack of information that he could refer back to. After he was discharged he went through the pack and for the first time he was able to see himself in the literature. He finally felt he had an idea of what was happening to him and how to move forward.

During that discussion, she also identified that he was eligible for both Universal Credit and PIP. He'd been signed off, unable to work for years. He was financially supported by his parents and partner, but still wanted to support his children. Now he could.

The second person to help was a doctor. This doctor took the time to talk to Michael, to understand his concerns about the medication he was on and adjusted them in collaboration with him.

# MICHAEL

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Other aspects of his stay at Woodlands were less positive. Knowing how the system works he was adamant he wanted a named care co-ordinator before he was discharged. He refused to leave until he was given one and staged a 6-hour protest opposite the staff cubicle. When he followed up with the name he was eventually given, there was no referral made and the named person was on leave for two weeks. He felt lied to.

He was however picked up by Hawthorne's Home Care Team after his discharge. They provided him with a lot of information and support and most importantly, they did what they said they would when they said they would do it. They never let him down.

**"If they say they're going to do something they do it."**

While Michael continues to struggle with his mental health he currently seems to be more satisfied with his medication and is actively engaging with services like Mind in Bexley.

In our discussions Michael made the following recommendations for services:

**1) Improve training for GPs and staff around mental health in general**

- He said "How you speak to people matters". He also emphasised the need to really listen to patients. He didn't feel heard for a very long time and when he was, it made a difference.

**2) Improve information at point of discharge**

- He felt it would be useful to receive a leaflet or some sort of discharge pack which listed local support services. He also wanted a clearer idea of what the referral pathway looked like. Where was he in the journey? Where did he go to next? If he understood the options he would have felt more empowered. A named contact on release would also have been helpful.

**3) Question the efficacy of your communication and look at how that can be improved**

- He felt unclear about what his diagnosis was for a very long time and hoped medical professionals could think about how and when they communicated this.
- More broadly, local service websites also had a responsibility to make their offerings more accessible. Are services online or in-person? What happens once the referral form is filled in? Who is the service actually aimed at? More work is needed to help service users find the best solutions for them.

# KIM

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**Female**  
**Mid 40s**  
**Unemployed**  
**Currently in supported housing**

Kim's life has been characterised by trauma and abuse. She grew up on a "rough" estate in south east London. Her father was a violent alcoholic and her mother emotionally absent. She was "sent back out to fight" everyday.

After her parents divorced she was bounced between the US and the UK, branded a "naughty child" and eventually excluded from schools in both countries. Her and her brother were abused by an Uncle and she started using marijuana at 12, moving on to crack cocaine by just 13. She was pimped out to older women to pay for her drug use and only gave up drugs for short periods when she was pregnant.

By just 13 she had been abused, exploited and neglected, and the chaos continued for decades.

Around 5 years ago Kim hit breaking point. Her best friend died, she became homeless and she had a hysterectomy. She decided to turn things around and trying to get clean was one of her first steps.

She was referred to Nexus for support with substance abuse, but found this service intrusive and says they were always phoning and checking the house.

Feeling exhausted she eventually found herself at Woodlands for 6 weeks where she was diagnosed with Borderline Personality Disorder and Bipolar Disorder. She didn't have a clear idea about what this meant and she didn't know who to ask.

Referred in to Erith Centre shortly thereafter she participated in an outpatient group, but this was no help. She was unhappy with the group leaders and often felt they were bored. When one of the participants took his own life the group was disbanded with no explanation or ongoing support for already vulnerable group members.

She was put on anti-psychotic medication, which she later removed herself from, and has since battled to get an appointment with a psychiatrist to get her back on it. Kim's GP is doing her best to support Kim while she waits.

Kim has also received support from Pier Road and at last feels like she is making progress. She's been drug-free for 3 years and has cut down on her drinking. But things are still a struggle.

**"I thought I would feel normal without drugs"**

# KIM

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For now she continues to engage with services.

Kim adores her grandchildren and they are a protective factor in her life that keep her moving forward, despite the obstacles, every day.

In our discussions Kim made the following recommendations for services:

**1) Always question if contact is useful and necessary or just plain intrusive**

- Kim feels services need to step back and think about how they contact clients and the frequency of that contact. Calls and emails can be overwhelming. Automating communications, as is the case with email event reminders, can be intimidating rather than helpful.

**2) Do not offer online interventions at the expense of in-person initiatives. There is a need for both**

- Kim prefers face-to-face services and will not engage in online groups and workshops. She has found that Covid has limited the selection of support she's been able to engage with and she hopes that further consideration is given to those who are unable to engage with online services for whatever reason.

**3) Question the efficacy of your communication and look at how that can be improved**

- This bears repeating. Similar to Michael's experiences, Kim was confused and overwhelmed by her diagnosis and unclear on where to get more information. More thought can be given to how a diagnosis is communicated and what tools can be provided to support the client/patient at that time. Communication is key!

# ELLEN

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**Female  
Early 60s  
Unemployed  
Lives with a parent**

Ellen was 25 when she first got ill. She was living with her mum and dad at the time and her behaviour became increasingly erratic. She believed herself invincible and says she walked into roads thinking she couldn't die. "If I cross here, I'm winning the battle". She also had terrifying delusions that her brother and father were going to hurt her and kept a knife in her room to defend herself. Her parents became more and more concerned with her behaviour and eventually managed to bundle her in to a taxi and take her to Hackney Hospital.

At the time, Ellen didn't want help. She thought she was fine. In hospital she refused to eat, drink or wash. At one stage there was even talk of sending her off to the countryside to a facility better able to manage her challenging behaviour. Her parents resisted and Ellen acclimatised to the facility, even making friends with the patients and nurses.

Once she started to feel less frightened she became more trusting of the help and when she started to take the tablets she says they worked "like a miracle". She stabilised quickly and was sent home, this episode considered a breakdown and nothing more.

But as the medication was tapered off her behaviour escalated again. She didn't want to be sectioned again, but was, and her job she'd been temping in had to be left behind for a second time.

Again, the moment she started taking medication her symptoms lessened. She realised that medication was "[ok for her](#)" and she was able to sleep and relax.

**"It was a lovely feeling, to think you're normal again. I was so happy."**

But again, no one spoke to her about a diagnosis. She was told about the "disintegration of her personality" but didn't understand what that really meant. Instead, it was her parents who were told she had schizophrenia.

As she stabilised on her medication she was able to return to work, but the working environment became more challenging as she cycled in and out of periods of good and ill health. Eventually she was made redundant.

She said that things went well in her private life for a time and she was in a happy relationship for a couple of years. "He made a fuss of me", but he was a heavy drinker and died from stomach cancer in 2009.

Soon after her partner passed she lost her job after suffering another "breakdown". Ellen's parents had since moved to Bexley and when she lost her job she decided to follow them.

# ELLEN

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Again, things settled for a while, but when the drug she was on stopped being produced the replacement medication gave Ellen severe headaches. As a result dosages had to be reduced and when that happened “everything twisted up in my mind”. It took some time to stabilise again.

Looking back on her experiences Ellen describes herself as having matured a lot and has stopped punishing herself for the things that have happened. She also speaks very kindly of her interactions with the medical profession.

## **“You can’t fault the doctors or nurses”**

When asked about what helped her in her journey Ellen spoke very highly of the counselling she received. She also says that social services stepped in with additional support when her father became ill. She says she always felt listened to.

In Bexley her psychologist signposted her to Mind in Bexley’s Recovery College where she was able to participate in various courses. She attended courses on anxiety and depression and says she really enjoyed meeting people. She’s taken part in keep fit classes and computer classes amongst others, and describes the support in this borough as “better here”.

She says her biggest barrier to getting support has been access to GPs and Psychiatrists. Reception often act as the gatekeepers and she felt it was at times hard to get the attention she needed.

Ellen currently lives with her mum who is in her 90s and appears to be suffering from dementia. Her brother and her now act as mum’s carers and Ellen continues to engage with services.

In our discussions Ellen made the following recommendations for services:

### **1) Don’t underestimate the power of counselling**

- Ellen says the counselling she received was very rewarding for her and that the insights she gained from that, together with a bit of time and maturity, have given her perspective on her journey so far

### **2) Improved access to GPs and Psychologists for people who need it most**

- Ellen stressed the importance of access to specialists and was very much aware of how that had worsened with the onset of the Covid pandemic. Resource constraints should not be ignored.

### **3) Make sure your gatekeepers have the training and support they need to filter clients appropriately**

- Ellen also thought we shouldn’t underestimate the responsibility of the gatekeepers, like GP receptionists, who often were the deciding factor on whether a patient was seen or not.

# JANET

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**Female  
Mid 30s  
Unemployed  
Lives alone in flat**

Janet has been in and out of care since she was just a child. She was bullied mercilessly at school from age 5 and by 7 was experiencing suicidal thoughts. The doctors got involved. Her behaviour was challenging in general and as a result she started the first of many school changes at age 11. She recalls being told she had Aspergers at around this time.

**"I thought it was a death sentence, like cancer or something".**

Her fears about her diagnosis were not addressed and the family were given family therapy as support. This didn't seem particularly helpful to her as she recalls being made to sit in a circle with the family to talk. Everyone was asked how they were feeling, but her.

By the end of year 8 she was moved to another school. She describes things as bad at home and school and says she felt she couldn't cope anymore. At 13 she started to self-harm. She had to move schools again, this time to a boarding school aimed at children with behavioural problems. On viewing the school she said she absolutely hated it "but no-one was listening". She was forced to join and as a result did everything she could to get kicked out. Eventually she was.

From here she was moved to a school in Somerset, even further away from her family. The timing was difficult. She was raped in the holiday prior to the move. Isolated, abused and angry she started at another school she didn't want to be at. It was here that she started a relationship with a boy who she describes as obsessive. He controlled her activities, verbally abused her and when she fell pregnant at 15, beat her to such an extent that she lost the baby.

Her continued challenging behaviour led to another expulsion, only this time she made a suicide pact with the abusive partner in retaliation. She overdosed on paracetamol and was taken to Queen Elizabeth hospital for assessment. Under CAHMS at this stage she was sent to the Priory. She didn't want to go and had to be sectioned, at first for the weekend, then for 72 hours and finally for 6 months. She hated it and attempted to escape but was forcibly returned. She says "I trashed the place. I wasn't me" and that eventually she was "kicked out" out of the Priory and banned from every Priory in England.

By now she was abusing drugs, drinking and engaging in prostitution. The family had continued to struggle to cope and the behaviour had clearly escalated. She was moved to a high security institution and had to be transported there by ambulance. The circumstances of her transport were particularly difficult for her. She says felt like she was "treated like a criminal". The journey was long and she had to beg staff to pull up at a service station so she could use the facilities. While in the bathroom her mother, who had been following behind in the family car, tried to step forward to comfort her. Janet's mum was restrained from doing so.

# JANET

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On arrival at the institution, Janet was strip searched by a man, despite her long and troubled history of sexual abuse. This was an unhappy start to another unhappy stay.

Janet battled with extreme levels of control and attempted to take her life again. She was there for 18 months until she was moved again. Janet describes her life as being “constantly in care and crisis” and has had to be sectioned a number of times, has been held against her will a number of times and has made numerous attempts on her life.

She is currently living in her own flat and seems happier now that she can make her own decisions. After years of feeling incarcerated she enjoys her freedom but says she sometimes feels like “no one is helping me”, they are “just giving me medication”. That said she is engaged with a social worker and currently participates in peer-led support groups at Mind in Bexley.

In our discussions Janet made the following recommendations for services:

**1) Respect an individual's history. It affects what kind of care can be given and received**

- Janet continues to struggle and has recently been offered a stay at Chapel Hill for respite for a week. She has declined. Her freedom is valuable to her. While she still wants support, anything that reflects any kind of incarceration will not work for her.

**2) Don't criminalise mental illness; not explicitly, not implicitly**

- Being mentally ill is not a crime, but sometimes people who are mentally ill feel like they are treated like criminals. She said “you don't get seen as a human being”. While there are circumstances which require special interventions these should only be reserved for extreme circumstances.

**3) Find what works and do more of that**

- Janet talked about learning coping strategies at one of the places she stayed and said she'd worked with many therapists and counsellors. “Bits can work, but on a bad day I can't think at all”. That said Janet values her freedom and engages in services that allow her to retain that.

# THANK YOU

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We'd like to thank Michael, Kim, Ellen and Janet for participating in the Digital Accelerator life stories research.

We'd also like to extend a big thank you to our other Digital Accelerator clients who participated in the Monthly Peer-led Forum, our quarterly webinar attendees, as well as our Digital Skills Training learners and volunteers.

Thank you for sharing your experiences and allowing these to inform and grow our service.

Thank you to Digital First for the funding, South East London CCG for the project support, Bexley Voluntary Sector Council for the incredible connections and Mencap for sharing your wealth of experience. We are also grateful to Oxleas Trust, local lived-experience groups, Bexley GP practices, Community Connect and everyone else who contributed.

This project will continue to bear fruit. We will continue to deliver digital skills training post project close and we will continue to champion the mental health agenda through training and activism in Bexley.

## **11 things you can do to improve your clients/patients experience of mental ill health**

1. Improve training for GPs and staff around mental health in general
2. Improve information at the point of discharge
3. Question the efficacy of your communications and look at how that can be improved
4. Always question if client contact is useful and necessary or just plain intrusive
5. Do not offer online interventions at the expense of in-person initiatives. There is a need for both
6. Don't underestimate the power of counselling
7. Improve access to GPs and Psychologists for patients who need it most
8. Make sure your gatekeepers have the training and support they need to filter patients/clients appropriately
9. Respect an individual's history. It affects the kind of care can that be given and received
10. Don't criminalise mental illness; not explicitly, not implicitly
11. Find what works and work with that

# NOTES

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