



Hospital to Home: Birmingham Stories

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Foreword

Changing Our Lives has a strong and proud history of working with people who find themselves stripped of the most basic human rights, often those people with a learning disability and/or autistic people in inpatient units. Our work is always shaped by a recognition that people themselves are in the best position to know what works for them. So, hearing first hand from people with a learning disability and autistic people about their experiences was the obvious approach to highlighting what needs to be done to make sure that people no longer get stuck in modern day asylums, but live ordinary lives in the community.

This collection of stories describes three people's unique journey from hospital to home. These stories, of Liam, Zeze and James, honour the courage of each person and celebrate their achievements. They highlight the essence of what has helped them along the way and show what is possible when people are put centre stage of their own lives. Their real experiences show first hand that no one is too disabled or too affected by mental health problems to live an ordinary life.

Thanks to Liam, Zeze and James for sharing their stories. Thanks also to the staff at Aspirations Care and Precious Homes for their help.

Jackie Taylor

Senior Development Officer

Liam's story



Liam lives in his own flat, loves travelling to London to see rock gigs, has an impressive DVD collection, and is planning a trip to Cardiff to watch the Snooker Welsh Open. He is a thoughtful, insightful man, with a lively sense of humour. Staff who support Liam talk highly of him, "He's a fair man who gives everyone a chance."

Liam is happy and has settled into a new flat, where he is supported by Precious Homes, but he has walked a difficult path to get to where he is today.

Desperate for help

A few years ago Liam was living independently in Worcestershire, with 6 hours a week of support, but he began to feel like his mental health was declining and he got to the point where he was struggling to cope. Although he went to his local crisis team for help, and his mum was pleading with professionals for help, Liam was left without any support from the mental health crisis team. After an attempt on his own life he ended up in A&E. In desperation, it was Liam's mum who eventually found him a bed at a private secure unit in Cardiff, for people with autism and behaviour labelled as challenging.

False starts

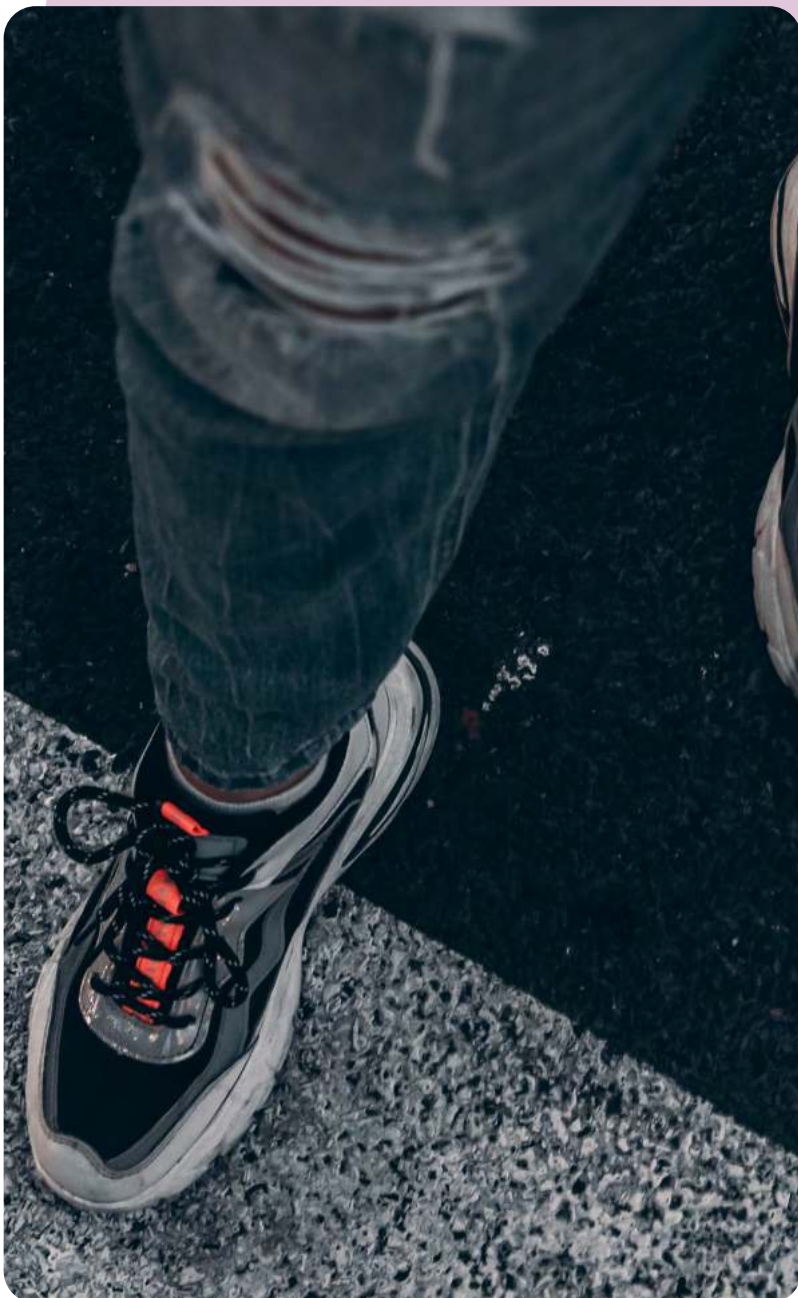
Liam spent the next 3 years going in and out of that hospital.

Over that period of time, although he says he had "good days and bad days", Liam gradually became more depressed and institutionalised from living in a secure unit. He went further into self-harming and attempted suicide again. At this time, leaving hospital became uppermost in Liam's mind. "I would have moved to Northern Ireland, anywhere."

Liam was willing to try anything and tried several placements, which sadly broke down.

"I was desperate to move on, so I papered over the cracks." On one occasion, Liam was in the car on his way to move into a new flat when he had a phone call saying the new provider had decided they couldn't support him after all. Liam was crushed. He says he felt like his freedom had been taken away. "I needed a break from the whole system."

Eventually, Liam found Precious Homes, where he now lives. "This was the right decision," he says.



Moving at my pace

The first thing Liam asked the manager at his new home was "Is it like Winterbourne?"

Although Liam hadn't lived at Winterbourne, he had previously lived in a Care Home that was closed suddenly in the wake of the Castlebeck scandal. It was very important for Liam to know that his new home would be safe and that staff would be respectful. Liam describes the fear that held him back, "My heart was saying go with Precious Homes, my head was saying 'Am I ready? Have I got the mental courage to start again or shall I stay in hospital forever?' I couldn't see life."

Those honest conversations with the manager at Precious Homes were what finally convinced him to take the plunge. "I asked her, 'How long until I have to move again?' She said, 'You don't have to do anything. We're going at your pace.'" In the past people had always made decisions for Liam, and he feels like that was a big factor in the breakdown of support from previous providers. This time, Liam was in control.

"I was scared about the outside world. I was used to not having to do everything. I knew there was hard work to do and I was happy to put that work in." He talks about the process of becoming independent. "You wouldn't build a house from the top down. You'd lay the foundation first and build it up from there."

My life, my staff, my decisions

Liam has been in his new flat for 4 months and now gets 13 hours a day of 1:1 support. Liam enjoys working with staff who are 'firm but fair'. He says: "Life is a learning curve. People need help to develop their lives. "Decisions are totally made with me. 100%." Staff agree and say that this has helped Liam to respect them, and as a consequence he is less angry. They say "It's Liam's life." Liam feels that this has helped him to trust his staff, something he has always found difficult.

Liam interviews for his new staff and when they start supporting him, he sometimes asks for extra shadowing sessions to give them more time get to know each other.

As Liam says "If staff weren't good it would be useless for me." A key skill for Liam's staff is being prepared to learn. Liam doesn't share his support time with anyone, so staff are able to help him deal with problems early before they escalate. Staff notice the signs of Liam's frustration early and take him away from stressful situations to calm down. His staff know when he needs space and when he needs closer support.

Liam is seen as an expert in his care. He tells the story of a new member of staff who was unsuitable for him, and who was then disrespectful towards him during a mediation meeting. This person failed their probation period and was asked to leave. Another member of staff didn't get on well with Liam, but staff say they spotted how this person could work better with someone else, and they were moved from Liam's team. It's crucial that Liam is listened to, and he really feels that staff want the best for him. He says "This is the first care company who have put me first. Support here is about more than just money."

*"You wouldn't build a house from the top down.
You'd lay the foundation first and build it up from there"*

Liam

Looking forward

Sometimes Liam thinks back to life in the hospital and how difficult it was.

His advice to others is to: "Take it one day at a time", "See what each day brings. If you think too far ahead, you'll go doolally." Overall, Liam has strong feelings about how mental health needs are met by society. "The whole system should be looked at," he says, "Mental health doesn't get the attention it needs."

His staff feel that his big achievements in the first four months have been choosing and moulding his staff team, settling in and starting to look for jobs. All of this has helped him to gradually put his difficult experiences behind him. Liam and his staff agree that another sign that he is comfortable and settled is that he is always planning ahead for new things to do, especially his big passion, going to music concerts. For Liam, the real positives at his new home are more freedom, being in control and making decisions for himself. He feels proud that now he tries things that are outside his comfort zone. "My motto has always been, 'We'll win this war one day at a time.'"



Zeze's story



You could say I've had a busy year!

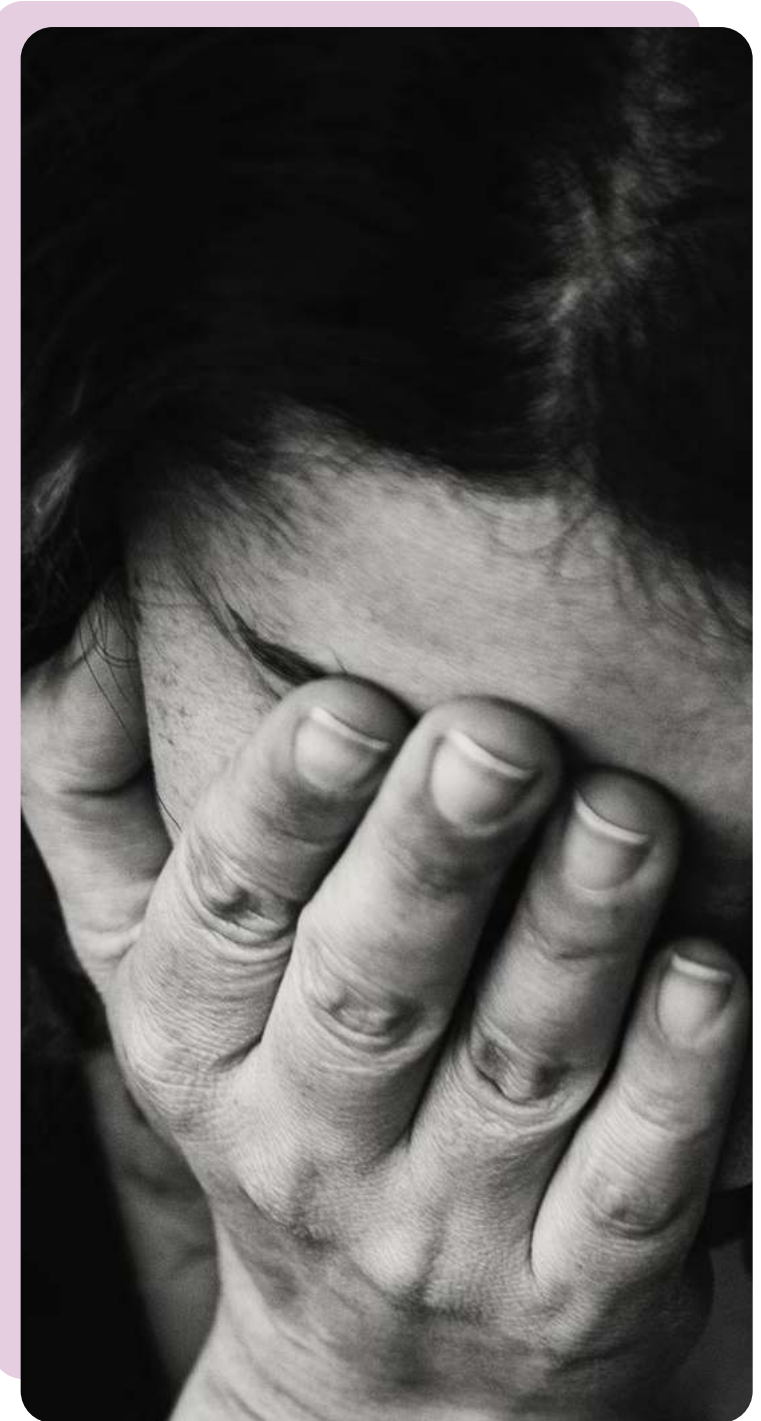
Just seven months ago I moved into my new flat, I've started my A-Levels, become a student ambassador and an Expert by Experience in Youth Mental Health, and I've published and launched my first book. Not too bad for someone who before moving here had spent 4 years in different mental health units.

My book is called *Miscellaneous Memoirs of the Mad* and it's all about my journey through Child and Adolescent Mental Health Services (CAMHS) and hospital. It's quite humorous, but it also portrays some of the dark times. Writing the book has been really good for me. It's helped me move on from my past and given me some closure.

A traumatic start

I had adverse childhood experiences, which means multiple traumas before the age of 12. At 11 I was self-harming and having input from CAMHS in the community. At 14, I went into an inpatient unit for the first time, followed by a high dependency unit (HDU), a psychiatric intensive care unit (PICU) and finally a forensic low secure unit. I was quite different then, quite unwell – at times I was suicidal.

At the secure unit I experienced my first floor restraints. I had 13 in one year and each time I was given a rapid tranquiliser by injection. At that time, I was self-harming quite a lot. I was fed with a nasogastric tube because I had stopped eating due to my delusions. I thought the staff were all against me. After one significant self-harm episode something changed and I decided I needed help.



The right support to progress at my pace

My psychologist in the secure unit was amazing. We did schema therapy and I learnt lots about myself as well as developing new coping skills. I made progress and eventually went to a step down unit where I lived for the next 6 months. This was helpful because the jump to living independently in the community would have been massive for me, especially as I find change difficult because of my autism. When I got to the step down unit I was amazed at the freedom. I remember saying "We're allowed a ceramic mug? We can go in any room we want?" It took a while to process, but I got there.

"It was very powerful... I had a big voice in the process."

Zeze

Finding the right home in the community

The progress I made at the step down unit meant I could finally start to look at places to live in the community. I looked at 3 or 4 places before I found Precious Homes. I knew straight away it was 'the one'.

My flat with Precious Homes is my dream place. There's a gym across the road, which is great because using the gym has always been one of my coping mechanisms. I've got my own flat which is perfect as I've always liked my own space. One of the things I always struggled with in hospital was having no time alone. I enjoy my growing independence and go out a lot and use the bus. I'm working up to independent train travel next.

Having choice and control

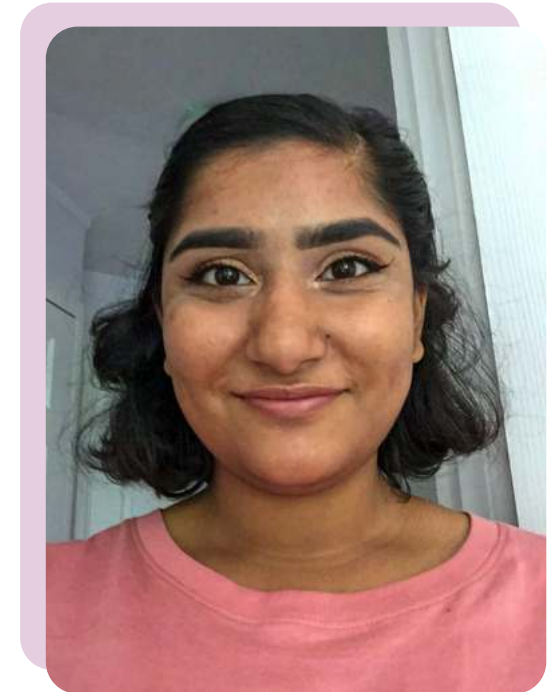
I had lots of control over the process of moving here. When I first saw the care planning paperwork, I knew I would be able to fill it in myself, and that's what I did, asking the staff for advice when I needed it. Everything here is agreed with me, not for me. I chose how long my transition period was - as quick as possible! Even so, it was very powerful that they said they could wait for me. I had a big voice in the process.

Helping myself by helping others

Being an expert by experience has been really helpful; it's given me a purpose and some focus. I struggle with my self-worth, so doing things for myself was never a motivator for me. As harsh as it sounds, now I don't have to live for myself, I can live for others. I am co-chair of a group called Think4Brum which is a coproduction steering group. I was the research lead previously, which meant linking in with the universities about research on mental health. We do all sorts like interviewing service managers and doing walkabouts of youth mental health services. I'm currently starting some work with people who live in one of the secure settings I used to be in, collecting survivor stories.

I sit on the scientific advisory committee for the National Institute for Health Research, I work with the University of Birmingham and Birmingham City University advising on research proposals in youth mental health and lecturing on their social work, mental health nursing and general nursing courses. I've recently started as a Young Ambassador for the National Autistic Society.

My expert by experience work has given me a great social network too. In the secure unit we all used to pull together through some really difficult experiences. Being in a coproduction group is similar, but in a much more positive way because we're doing it to make change.



Plans for the future

I have a lot of plans for the future. For now, I'm focussing on finishing college and keeping up my coproduction work. Eventually I want to go to university to do biomedical science or psychology. I want to be a researcher, but I know that's precarious so I'm going to do a masters as a physician's associate. I want to be a physician's associate in a mental health unit. I want to use my experience to help people in similar situations.

I want to do my own piece of independent research before I go to university. Eventually I want to travel and see how different mental health settings work outside the UK. For now, I'm working on my second book, which is about moving on and mental health in general.

Advice to others

My advice to anyone who's earlier on in their journey than me is there is a life after all this. What helped me was engaging with my therapy and working on my embedded problems. You can have a good life after hospital.

Find something that gives you a sense of belonging, that could be a hobby or being part of an expert by experience group. Find yourself a coping strategy that works for you, both in hospital and when you get out into the community. It could be yoga, the gym, it's different for everyone.

Most importantly, don't be afraid to have a voice in your care. It's not cocky, it's sensible.



James's story



James is a 31-year-old Stoke City fan who lives in his own flat with support. James' home is one of a block of supported flats for people who have learning disabilities and experience of mental health difficulties. His life now looks just like anyone else's: he volunteers as a landscape gardener, likes to stay looking sharp - he's a regular at the local barber - and he can usually be found in the social club on a Friday night where he is a fully paid up member.

Life hasn't always been this ordinary for James, and for a long time it was very bleak. He grew up in Stoke but moved to a residential home in Birmingham as a young adult when he was struggling with drink and drugs. James thrives on structure and boundaries, so when a Deprivation of Liberty Safeguard (DoLS) was lifted in his twenties, James says "I completely lost it." It triggered James to increase his drinking and drug taking and to spend more time with friends who were getting involved in criminal activity. Eventually, he was arrested and was detained under the Mental Health Act.



Being in hospital

James spent the next 2 and a half years in hospital. James describes the lack of privacy in hospital and the awful experience of being restrained, "If you don't keep yourself calm, you get pinned on the floor." He talks about how hard it was to "keep your head focussed" when living with other people who were having their own difficulties. James was determined to make a fresh start though, and he worked hard towards being ready for discharge. He does have some fond memories of individual members of staff at hospital, and says that they taught him to be respectful and made a big difference in his journey to being free from alcohol and drugs.

James says he spent "too long" in hospital. In fact, he was there for about a year more than he needed to be because of difficulties finding him the right support to leave. A string of providers turned James down for support in the community because of the problems he'd had in his last home. Eventually James met the team from Aspirations and began the journey to his current flat, part of a new community development which offers people who have been labelled as having complex needs or behaviour that challenges their own home and support from a team of skilled staff. During the assessment process, Aspirations learned about James and over the course of a substantial transition period they were able to create and tweak a staff team that fits well with him, his interests and his needs.

In charge of my own future

From the start, James has been fully involved in creating a care plan that is meaningful to him. James was keen for his new home to be a new start. He set himself ambitious goals including getting a voluntary placement, which he has now achieved. James continues to set himself goals and works towards these with support, as he is in charge of his own reviews. Staff around James say that part of what makes him stick to his support plan is seeing how the setup in his new home allows him to achieve what he wants to do.

Being treated with dignity and respect

Even though James' staff team never restrain a person on the floor, it was important for him to have this explicitly specified in his plan when he moved in. It gives James security to know that this will never happen to him in his new home.

James says that it is important to him to know that he has staff who are always ready to listen when he is unhappy or things get tough. When he feels frustrated with the challenges of life or comes across a problem, he knows he will be given the time to talk through his options, understand his rights and decide the right course of action for him.

Staff who support him recognise that James' flat is his home first and foremost. They respect this as they would any other person's home in the community.

James is proud of the progress he has made and his growing independence, which has meant he has gradually needed less support from staff over time. James is supported to take healthy risks, to try new things and to work towards bigger goals step by step. James says he enjoys the freedom he has now and can do more of the things that are important to him, such as going home to visit his family in Stoke on his own.

Setting my own boundaries

James is really proud of the steps he has taken to put his own boundaries in place. Unlike the strict routine of hospital, this is a structure that James has built for himself. He says "I've done loads of big steps." At the moment he feels safer with a Community Treatment Order in place so he requested that this would happen when he left hospital, and staff say he sticks to it "to the letter".

Last year James felt he was struggling to handle his emotions so he referred himself for anger management. He's even taken the brave step of asking the bar staff at the social club never to serve him alcohol. This doesn't stop him having fun though, and on New Years' Eve he and a staff member were there past 2am. Now James manages his own medication, organises his own health appointments, handles his online shopping, and cleans his flat with staff. "I need to start ironing again though!" he says.



"I've done loads of big steps. I'm so proud of myself."

James



Focussing on the future

James was the first person to move into his block of flats, and he has been keen to show his new neighbours the ropes. Now James is taking it one step further by speaking about his journey in front of audiences, something he had never done before. Last year he spoke in front of 50 people at an Aspirations conference. He also spoke at an event celebrating 100 years of Learning Disability Nursing, which was live-streamed on Twitter. He's made a video about his experiences and has another one in the pipeline. James says, "I'm so proud of myself."

James isn't one to stand still so the next part of his lifelong plan is to move out of his current flat and increase his independence with a new support provider. As he looks back on his journey, his advice for people still in assessment and treatment is "Keep your head focussed and calm. Let staff talk to you and help you." When James is asked to describe the feeling of moving out of hospital and into the community for the first time he smiles. "Freedom!" he says.



**No one is too disabled,
or too affected by
mental health difficulties,
to lead an ordinary life**

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