

Bringing Lived Experience Into the Conversation



In a world increasingly driven by statistics and data, the power of personal stories is often underestimated. Yet, the voices of those who have directly lived through social challenges or difficult experiences offer a perspective that numbers alone cannot capture. Lived experience – those firsthand accounts of navigating life’s challenges – provides a unique lens through which we can better understand and address the issues facing our communities.

Lived experience is about more than just anecdotal evidence; it is about bringing real human experiences into the conversation, ensuring that policies, services and solutions are rooted in reality.

Damian is a lived experience volunteer supporting the Safe Havens (mental health crisis services) across Kent & Medway. He is a resident of Thanet and knows firsthand how important preventative mental health services are:



“My daughter has EUPD, complex PTSD, autism and chronic anxiety. For about two years, she was constantly just being pinged from her GP to The Beacon Community Mental Health Centre, back to her GP, back to The Beacon Centre, and so on. But nobody was talking to her. She would just be told, ‘No, we’ve referred you to here,’ ‘No, you’ve been referred back to there.’ It got to the point where nobody was doing anything to actually help her.

“During the pandemic, she joined a PERDI (PERsonality Disorder) group run by Speak Up CIC here in Margate. She finds groups very hard, but Speak Up CIC got her into a group with people who understood her perfectly, whose personalities meshed with hers and made things a lot easier. She loved the group so much and for the first time actually felt listened to.

“I am a big advocate of Speak Up. They have the magic touch and are the most caring people you could meet; they want people to get better. They want people to not be living on the edge of crisis all the time and they will support you however they can.

“Seeing the difference that it made to my daughter, I decided to get involved with Speak Up myself by going to their creative writing group. I have chronic depression and anxiety related to a physical condition, and I have chronic fibromyalgia. That’s when I started to hear all of the horror stories of the mental health services that other people have experienced. I got to the point where I couldn’t just sit back and listen anymore. I had to find some way of helping to get mental health services that actually work for people.

“Seeing the difference that it made to my daughter, I decided to get involved with Speak Up myself by going to their creative writing group. I have chronic depression and anxiety related to a physical condition, and I have chronic fibromyalgia. That’s when I started to hear all of the horror stories of the mental health services that other people have experienced. I got to the point where I couldn’t just sit back and listen anymore. I had to find some way of helping to get mental health services that actually work for people.

“I started to represent Speak Up as a lived experience volunteer. I was writing letters to our local MP, getting in contact with Mental Health Matters (who operate the Thanet Safe Haven), and taking my experiences and the experiences of those at Speak Up to anyone who would listen. This is when I came into contact with EK360. They understood my views and shared my belief in making change.

“In November of last year, I found out through a newspaper article that the Safe Haven in Thanet was being moved into a very clinical environment for a non-clinical service. It was awful to find out in this way, and I know it triggered a lot of problems for people. I spoke to EK360, who told me that Mental Health Matters were looking for someone to share their mental health experiences and keep the service designed for people, rather than in spite of people.

“I got the chance to sit down with Mental Health Matters and find out what was really going on. Then I could see how the newspaper story was a mistake and shouldn’t have come out; it made a flashpoint where there didn’t need to be one. It was handled badly, and you could see that Mental Health Matters were really hurt by the way the news had come out.

“The move of the Safe Haven to the new location was actually a really good idea, just handled in the wrong way. I’ve met with a lot of the Mental Health Matters area managers and leads working on this project. They are really lovely people and are looking at this as, ‘This is your service – how would you like it to run?’ which is the complete opposite of everything you’re used to when you’re dealing with mental health services. They’re listening to what people need and they are very passionate about this working. It’s the same sort of passion you’d see from groups like Speak Up CIC and EK360. They want something that will work properly, to provide a service that is needed, rather than just to say that it’s being done.

“Now I’m working closely with Mental Health Matters and KMPT. I don’t like being critical if I can’t offer a possible solution to something; I’d rather offer constructive criticism than just say, ‘No, that’s a bad idea.’ Everybody that I’ve spoken to has said the Safe Havens are doing what they say they’re going to do. They’re actually providing a place where you can de-escalate. If you need someone to talk to, there will be someone to talk to. If you just need to be left sat alone in a calm environment where you can stay calm, you can do that too. It’s all based around what a person needs, and they’re getting good reports from everybody who is going.

“Mental Health Matters have told me that in a way, they’re glad that the newspaper article caused them such problems because it made them step back and think, ‘Are we doing this right? Is there another way we could do this?’ And even now, they’re not stopping but continuing to look at what else they can improve and to make the Safe Havens better.

“I’d like to think I’m making a small difference. I would certainly like to see a lot more lived experience representation in mental health services. It seems that a lot of mental health services are not willing to work with the community and they’re ignoring what people have to say. I’d like to see a mental health system that works. Not for me, but for my daughter. I can’t see me being alive long enough for it to happen because there are so many problems in the system. And people with lived experience aren’t being let in to have their say.”

“EK360 are very passionate and I’m very grateful to them for putting me forward for being able to work with Mental Health Matters. I would encourage more people to get involved and bring their lived experience to where it matters the most. And EK360 know where people can make the most difference. One voice shouting into the wilderness does nothing. But the more voices we have saying the same thing, the more chance there is of change happening. That’s my ultimate hope; that we can get enough people to speak out and actually make a real difference.”

Damian is a great example of the importance of lived experience representation in mental health services. As we grapple with complex societal issues like mental health, inequality and social justice, the importance of lived experience roles becomes ever clearer. Damian has found great respect from those he has shared his story with, including Jacqui Davis, Mental Health Senior Programme Lead at NHS Kent & Medway Integrated Care Board, who said:

“Damian has brought invaluable insight and learning for both the provider and commissioning teams involved with the mobilisation of the Kent & Medway Safe Havens. He has used his personal experience to explain how plans and interventions might be received/experienced by service users of the Safe Havens and generate healthy, positive conversations with the whole mobilisation project group.

“Damian always delivers – above and beyond what he’s committed to do. He really gets the provider thinking about comms and marketing and about how to get the message out to a wider group of people than we probably would have done. He has been a critical friend to the project team and getting us thinking outside the box. It is so important that he voices his opinions and views and has been able to put forward suggestions and solutions.”



These roles bridge the gap between policy and reality, ensuring that decisions made in boardrooms and local government offices are grounded in the real-world challenges that people face every day. The inclusion of lived experience roles is not merely a trend or fad, but is a necessary evolution in how we approach complex social issues. By valuing the expertise of those who have lived through the very challenges we seek to address, we ensure that our solutions are not just theoretically sound, but practically effective. Damian shows us just how lived experience can offer a form of expertise that is essential in driving meaningful change. As **Martyn Cheesman, Lived Experience Lead at EK360**, reminds us, people like Damian are indispensable:

“Damian’s passion for improving the local Safe Havens was immediately clear. He strongly felt that the services weren’t listening to what patients had to say and he himself had a lot to say about how the Safe Havens could be better. He believed that the voices of people who used the service were crucial in making it work effectively. His insights highlighted some serious issues that needed attention.

“When a chance came up to put forward a candidate with lived experience for the Safe Havens, Damian was the obvious choice. His personal experience and determination to make things better made him perfect for the role. Since taking on the position, Damian has done an amazing job; he’s playing a huge part in improving the service, making sure that patient feedback is heard and acted upon. Damian’s journey shows just how important it is to include people with real-life experience in shaping mental health services. His dedication has led to real changes that have made the Safe Haven a better place for everyone who uses it. By sharing his experiences and advocating for others, Damian is making a big difference in the community.”

By elevating the voices of those who have walked the path, we create more empathetic, effective solutions that truly address the needs of our communities. In the end, it is the lived experiences of people like Damian that turn our abstract problems into human stories – stories that have the power to drive lasting change.

If you are interested in volunteering as a Lived Experience Representative, please visit www.ek360.co.uk/volunteer-with-us for more details.

**EK360
The Old Court House,
8 Tufton St,
Ashford TN23 1QN
Kent**

 **hello@ek360.co.uk**

 **EK_360**

 **ek360**

**We engage
We reflect
We improve people’s
lives**