

Video transcript: Isaac Samuels lived experience of mental health services

Isaac Samuels: Nobody wants a service. What people want is a good life, but they might need a service to get to a good life. Where it works really, really well is when those that have learned experience - social workers, professionals, psychiatrists - really understand the value of including people, understand that it's about supporting people to see an alternative future after a mental health challenge.

It's about supporting people to find a new identity, find purpose and meaning, supporting people to be as independent as possible.

I was 17, so I'd just got onto an apprenticeship course, I was living in a flat of my own. It was the 90s, so in the 90s there were lots of opportunities and I was involved with so much stuff. So I was doing a Princes Trust, doing the Duke of Edinburgh's, I was travelling, I was studying, I was partying, I was doing everything that somebody at 17 does.

So when I first became unwell, I didn't sleep, became manic, and so that played out as talking really fast, having quite strange thoughts and feelings, being elated and having lots of energy, no inhibitions. Lots and lots of things that are really damaging and unhelpful for your wellbeing. It got to a point where people around me were really concerned, then a doctor was called, and the police were called, and I ended up going via an ambulance to hospital and was sectioned.

I spent a really long time in hospital. It's funny because when you are in hospital you are fighting so much to get out and start living your life. When you are out of hospital you are fighting to get back in because you've become so used to being in an institution. The biggest thing is that you don't know how to live in the world with a different identity, what it means to be unwell, and what 'bi-polar' meant. And I was young as well, I had the added thing of growing up and becoming an adult living with a serious mental health condition.

The hardest bit wasn't actually being in hospital, it was getting back to being Isaac, and what it meant to be a person with mental health challenges, a person in denial, because I really didn't want to accept any of this, a person that would have to do things differently.

So stress and other things that really affect my condition are to be avoided, also being on medication and having a very love/hate relationship with medication...sometimes thinking it was the best thing and sometimes, you know it has lots of side effects, it was adjusting to a new way of being.

I was lucky to access some housing and support provided by a specialist mental health housing provider. I had a small flat and a support worker that would come initially every day. One of the things that was really frustrating over the years was that I'd have really good support and then it would come to an end, and then I would become unwell. So I spent a lot of time in my 20s in and out of hospitals, not breaking that cycle.

I was about 27 when I first got management, a grip, on being able to live independently. I spent years and years of receiving lots of support, and being that person who for services was probably really difficult to work with, to support, and then I had a social worker who suggested that I applied for direct payments.

One of the first things I bought was a dog. I spent a lot of time not being able to get out of my bed, and then I had a dog. For me it was like: 'I don't need to look after myself, but I need to look after the dog.'

So I would get up, feed the dog, walk the dog, it helped me to find a bit of routine, gave me confidence, it made me feel connected.

I'd say I had more people in my life at that point that were paid to be in my life – I didn't have friends, I didn't have contact with my family, things that happen when you become unwell. I was very angry, I was in denial, I didn't have any hopes, I'd listened to some of those earlier messages that you'll never work again, you should just accept that you are mentally unwell, that's your lot. So I had all of that and I believed that.

With this dog I started meeting people, in the local park that were other dog walkers and then that kind of snowballed, you get a sense of connection in your community. The dog was the thing that has been most supportive of my management of recovery back to purpose and meaning.

I spent years and years and years in a cycle of being unwell, being well, being unwell...trying lots of things and failing because of not necessarily understanding that you have to look at the whole person.

There were pockets of really good support and then that would stop because you were doing OK and you didn't need it. But for me I needed a little bit of support all of the time. I think services and social care and housing, all the people didn't necessarily understand that when I was doing well, I didn't mean I didn't need support.

My experience of mental health services is still really traumatic. They are not nice places, there's lots of unwell people, there's lots of unhelpful power dynamics. I'm not the type of person that likes to be told. I like to have my autonomy, I like to be able to make decisions, and often people make decisions about you. Often people have lots of power over your life.

I'd become very institutionalised, so all of the support I received was from services, not from people in my community, not family members and not being connected. I was extremely bored and extremely frustrated that I couldn't use my brain. And so many years wasted.

I became friends with a lady called June. She had two sons with mental health challenges. She said: 'I want you to come Isaac, because I think it would be good for you to talk about your experiences of mental health.' I thought, I've nothing to add. She said: 'Just come for the sandwiches then!'

She persisted so I went to this meeting and started talking about my experiences, and I hadn't realised that was co-production. Through co-production I found real purpose, real meaning. I could make a difference.

At lot of the time doctors and professionals think the absence of negative symptoms such as hearing voices, or mania, is a good life, and for me, a good life is being able to work and being able to love somebody and being able to have your own home. Being able to be well, go to the gym, all those things that most people take for granted are so important to someone like me.

So it was just by chance that I met this kindred spirit on my journey who told me I had some value and I was able to share my negative experiences, my traumatic experiences to make a difference to other people.

She understood that we people with lived experience of mental health challenges can help systems and professionals provide really good care and support.

So I started to share my story, and bear in mind that no one wanted to listen to my story when I was in services, mental health services. No one talked to me, it was de-humanising it was terrible. There was no chance of anyone being in that service recovering to get a life with purpose and meaning.

I found service user involvement and peer support and just started to feel like I had somewhere to go, I had something to offer and that I could make a difference, that I could support other people like me, that I could support services and organisations to understand that if you include the voice of people you'll have services and support that sees people as human beings, not as these unwell people that don't have any hopes and dreams and aspirations.

I needed a lot of support to find me, Isaac, again. I'd lost so much stuff because of mental ill-health. That investment from June and other people along the way, I'm so thankful because without that I wouldn't be the person I am. I'm able to share my skills, I'm able to be in employment, and that's the thing that's helped me most of all on my journey.

I'm married, I have my own home, I have a good life, I have relatively good mental health, because of co-production. It wasn't because of mental health services, it wasn't because I've had medication, it was because I found something I was good at. I found people that understood me, I found people that supported me, I found people that treated me as a human being.

I had lots of support from third sector and voluntary organisations, so I started off going to an organisation called Newham Coalition of Disabled People, and I started volunteering there – because volunteering is so important when you are on your journey to finding employment as someone who hasn't been in employment for a long time.

I went from volunteering to a paid position, then I was able to go off and find other opportunities, so the voluntary sector has been a natural fit for me because actually there

are people who have mental health challenges, there are people who, its diverse, its embracing, its natural, its messy.

I had to say goodbye to mental health services. I obviously still see a psychiatrist, but I have one therapy a week, on Zoom, from a voluntary sector organisation. I don't need to be in mental health services because I don't need that level of support and I had to walk away because actually walking away is a really important part of your journey to recovery and management.

I've been able to manage on a day-to-day basis. I still wake up some days and I'm like: 'I just don't want to be here.' That's my mental health condition but I've got enough support to work through that on a daily basis. Those days where the world just looks so dark, that's just part of my life. The idea is that I reach out for help and I've got lots of support and people around me that can help me just find something in that day to get through. Then the next day it's a little bit better and after a week it's a lot better.

My advice to people providing mental health support would be to remember that you have lots of power and lots of opportunities to make a difference. If we go into the work we do with the mindset of ensuring that people are essential to that, it will work, it will save you so much time, but actually it will enable people to overcome the barriers that they've faced. It will mean that people recover, manage, find purpose, get back to a life, find a new life....you can't really be effective in your role without embracing co-production. So its coming together, sharing power, working as equals, recognising that people have an immense amount to contribute, that they already have the solutions, they might need support from you as someone with lots of skills and abilities to find the solution that works for them.

And that can be really difficult at times, but its so worth it. It saves so much resource, it saves so much heartache, and helps people live really good lives.