

Experts by Experience

Learning Disability Specialist Community and Autism Liaison Service

In October 2017 we started the process of employing people with a learning disability who had accessed our services to be Experts by Experience. These are the people who can tell us what we are doing well and what we can improve on, they can help us to train staff and challenge people's perceptions of learning disabilities by sharing their stories and speaking honestly about what it's like to be on the receiving end of us.

An overview of the process

Meet and greet events were held around the county and were thrilled with the interest we received. By January 2018 we had almost 30 potential candidates and hosted an event and workshop day to look at people's interests, skills and abilities, those that were still interested were given application packs. With support from our Recruitment team we were able to develop accessible information for our candidates and to implement reasonable adjustments to ensure a smooth process. After interviews we chose 6 candidates from across the county. They became our colleagues in May 2018 and are on bank hours contracts so can choose when they want to work.

Involvement in our services

During the last 3 years our experts by experience have been involved in all aspects of our service and the wider Trust;

David B – For me, being involved in helping to train doctors and clinic staff has been really important. I share my experiences of having annual health checks and I'm very honest about what went well and what could be better. I've had great feedback and really hope I have made people think about the service they give

David S – I have been promoting the Accessible Information Standard. I am very passionate about people getting their information in a way they understand. I am involved in training and have made my own PowerPoint about my experiences with communication

Stefanie P – I made a video with my mum about my hospital experiences, it has been shown at training sessions with hospital staff. My experiences have been good and bad, and I have been very keen to make sure staff know how to support people with a learning disability

Amy H – I have taken part in lots of interviews for our service and the Trust. We collect feedback from people who have used our service and would like to ask questions and then I speak on their behalf. I think it's very important that people are heard

Aimee G – I really enjoy making information for service users and patients. We made a boredom booklet last year with tips and ideas on how people can cope during lockdown

Natalie W – I have been involved in presenting at lots of events. I made an "I am" PowerPoint showing who I am as a person and encouraging people to look beyond a label or any issues I might have. The Trust were determined that this would not be just another initiative that looked good on paper, we wanted to have true honest involvement from people with a learning disability. We haven't always got it right and we are still learning. The Experts by Experience have taught us so much about what it means to really listen. They remind us that involvement takes time, energy, tenacity and humility.

How governors can help

Governors have a statutory duty to hold Non-Executive Directors (NEDs) to account for the performance of the board. With this in mind they may wish to ask some questions such as:

- How is the board ensuring that we are reaching out to those who use our services and asking them how they want to be involved?
- How do we know if we are co-producing services with patients/service users, and what benefits are people gaining from this?
- How are NEDs assured that we are providing clear and easy to understand information, recognising that everyone has different needs?

Governors also have a statutory duty to represent the interests of members and the public. Within their networks governors may be able to collect useful feedback from people who use Trust services that can help shape future developments.