Involving people with learning disabilities

A Learning Disabilities service in Leicester found that EBCD was ideal way to bring together users, families and staff to share experiences of care and design and implement change.

One of the things speech therapist Jane Parr likes about working with people with learning disabilities is the way they communicate. “Our clients communicate so honestly, it can be very refreshing and in some ways it makes things simpler,” she says. But health services are not always sure how to capture these frank views and involve the service users in the solutions.

This was something Jane, who is patient experience lead at Leicester’s Adult Mental Health and Learning Disabilities service, had been puzzling over. She explains “I am passionate about enabling people to get their voices heard, but there was little evidence of experience incorporating the voices of people with learning disabilities and their families.”

Jane’s service includes an inpatient team; a crisis team; and a community team, made up of psychiatrists, psychologists, occupational therapists, speech and language therapists and physiotherapists. Its wide-ranging activities include running short-term specialist interventions, supporting other health specialties to work better with people with learning disabilities, and prevention and wellbeing services.

“I expected problems communicating with our service users themselves. But in fact a bigger problem was that the project highlighted that the services we offer are not clear cut – every individual’s journey is different.”

After attending a course with The Point of Care Foundation in experience-based codesign (EBCD), Jane felt she had found the approach she had been looking for. “It was really good to have a structured approach to refer to, and to know what the next step would be, to keep the momentum going through the nine months,” she explains.

Running the approach

Before the project started, Jane spent several weeks with service users working through issues around consent, so that they could give informed consent to the process.

Jane recruited people with moderate-to-mild learning disabilities, as well as parents and carers. She found she needed to adapt the EBCD process to the participants’ needs, although she emphasises that much of this came naturally: “Eighty per cent of the task was to make sure the people felt valued, understood and safe, and that they enjoyed the process.”

She made sure that any information sent out was as accessible as possible and at events made the issues for discussion more concrete, asking questions such as ‘What was good?’ and ‘What was bad?’

“We had to constantly reassure the participants that they and the staff were equal partners in the process,” explains Jane. “Participants would sometimes give their view and then ask us ‘Is that OK?’”

Patient and staff experience

“Service users said they wanted more clarity from services. They wanted to be treated with respect and to be given enough time do to things at their own pace. All of the findings were about ensuring positive interactions and feeling safe,” says Jane.

Parents expressed a lot of anger as they felt they had not been involved or communicated with properly in the past, and there was no support in place once a person had been discharged from a specific intervention.

Staff, too, felt they were not listened to. They felt under pressure to move people with learning disabilities through the system towards discharge, but were facing resistance from families as discharge meant reverting to no support at all. They described the value of being part of a team and getting that support.

Co-design work

The co-design groups focused mainly on providing better information about services, and also better communication within wider health services. Changes have included:

- ‘talk and listen groups’ where Learning Disabilities Service staff help other healthcare staff develop a repertoire of communication skills.
- a summary profile for each individual, explaining the person’s needs and how best to communicate with them
- formally involving people with learning disabilities in staff recruitment processes
- developing a brochure to explain clearly what services are available, working with carers to understand what content and presentation was most helpful and accessible for them.

One challenge was a difficulty in engaging carers in the project, and this revealed a need to work more closely with carers. Jane is now building a network with carers looking at setting up community schemes in local areas to build positive relationships with families and to ensure co-production in developing services – not in individual projects, but as an ongoing way of working.

Another unexpected benefit was the therapeutic value simply of taking part, says Jane. “The participants loved being involved and the events were such great fun – everyone came in so full of enthusiasm. Everyone was joking and the project was full of laughter.”