Macclesfield District General Hospital, part of East Cheshire NHS Trust, was the first UK hospital to achieve the National Autistic Society’s Autism Access Award. The project – Open 2 Autism – has involved comprehensive cultural change to make our acute hospital services more accessible to autistic people, a challenge as health services are often very structured.

This has required flexibility across services, and to help staff do this a wide ranging project was established that includes a range of training and link practitioners. Staff are encouraged to look at the way services are delivered in a different way, promoting the concept of reasonable adjustments and flexibility.

How it began

East Cheshire NHS Trust was part of the national ‘Listening into Action’ programme where individuals and teams could put forward ideas on service improvements. Selected projects realised change by involving staff from a wide variety of areas and working together to achieve common goals. A theatre team leader at Macclesfield Hospital championed the idea of improving the patient experience for autistic people and their carers, and this became one of the first projects undertaken at the trust.

Aims

- To raise awareness among staff
- To improve patient and carer experience
- To ensure appointments, operations and procedures could take place more easily
- To improve information for patients and carers
- To make the hospital more accessible.
How it worked

The project had an executive sponsor and steering group comprising of nursing and medical staff and people in key areas of the trust such as patient experience, pre-op assessment, theatres and anaesthetics.

A key part of the success of the project was being granted funding by our trust board to establish mandatory training. Using examples from real life, the training revealed the unintentional impact of behaviours causing a great deal of stress to autistic people.

Funding was also provided to develop a group of link practitioners who had had more intensive training, and who could offer advice and support to other staff.

Negotiating the changes to become more flexible was perhaps what caused the most challenge. Acute general hospitals are - due to the nature of the work undertaken - highly structured and operate by routine. We were asking people to do the opposite of this and make changes and adjustments to normal routine to enable patients to feel more comfortable in accessing the system.

A key area where change has taken place is in theatres - staff will send through the patient passport or email reasonable adjustments required to the theatre team. In this way they are prepared for the patient. If a patient is admitted to a ward first, the anaesthetist will visit the patient and then come to theatres to discuss the approach with the team. Alternatively a patient may be admitted straight to theatre, without the need to be admitted to the ward or wait in a busy pre-admission area, both of which could be stressful for autistic people.

Some examples to illustrate:

- A teenager came to pre-op assessment with their mum, and during the conversation their autism diagnosis was disclosed. The staff immediately discussed reasonable adjustments, arranging for mum to stay with the patient when admitted and alerting ward and theatre staff.
- A parent brought their young son for an operation. Staff kept the patient passport overnight so they were fully aware of his needs, showed him round the areas he would visit and encouraged familiarisation with things such as the blood pressure cuff. Individual details of likes and dislikes were recorded such as the need for different foods on a plate not to be touching.
- A young patient coming for a dental appointment was able to come for a series of practice visits and took an oxygen mask home to practise.
- A patient coming for their own appointment with their autistic child. Staff arranged for a play specialist to be with the child when the mum saw the consultant, so that she could concentrate and get the best out of her appointment.
Outcomes

Overall the outcome is a more positive patient and carer experience, as staff more readily recognise when someone is experiencing difficulties, and can adopt a different approach to help them.

Some specific outcomes have been:

- over 800 staff trained
- e-learning module now available
- link practitioners developed via training workshops
- Open 2 Autism page on trust website
- reasonable adjustments include patients coming straight to theatre and being discharged from there, first appointments and practice visits
- named people to contact
- email helpline
- patient information leaflet
- quiet route into hospital
- option of flagging and alert system
- standard operating procedures to ensure consistency of approach
- promotion of Open 2 Autism via posters and website
- online survey
- sustainability by integrating the project into an existing strategic group, creating an autism and learning disabilities group.

Future areas of potential development

This is a project without an end – the health services face constant challenge in current times. The team leading this initiative are constantly learning from patient feedback – we don’t always get it right, but where we receive a comment, we try to look for ways to resolve the situation and make improvements. We are also looking to expand the project to our community services.

Further reading

Open2Autism

The National Autistic Society’s Autism Access Award

The National Autistic Society – Health workers