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## Making NHS hospitals more accessible to autistic people

For anyone a visit to the hospital can pose a number of challenges and cause a great deal of anxiety, some of which is exacerbated by our inability to function at our optimum level due to the state of ill health itself, hence our referral to the health provider in the first place. For an autistic person the combination of these factors along with the challenges faced on a day to day basis, can make the prospect of visiting a hospital, whether planned or in an emergency, terrifying.

The demands placed on health professionals due to high admission rates and limited face to face time, can also lead to the needs of an autistic person being missed, causing even greater anxiety.

The National Autistic Society's Autism Accreditation team was established over 23 years ago with the aim of supporting and developing autism practice in services and schools. The team works alongside providers helping them to appraise themselves against a framework for good practice in order to achieve accredited status through peer review.

The Accreditation process was used as a platform to develop and launch the new Autism Access Award which focuses on making community facilities more accessible for autistic people. One area that the team wished to focus on was health care and a partnership was sought with an NHS hospital to devise a framework and pilot it. Coincidentally, Macclesfield General Hospital had launched their own Open 2 Autism project and approached Autism Accreditation about the new NAS Autism Access Award. The pilot ran from 2013 to 2014, during which time the hospital showed great commitment and enthusiasm and gained the Autism Access Award in the summer of 2014.

The foundations for the award are based on some key principles where reasonable adjustments could be made:

- Advanced information to help prepare autistic people before their admission
- Staff and volunteer training in autism
- Consultation with autistic people

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- Environmental considerations
- Statements of Intent
- Customer service, how easy was it to alert staff about a diagnosis of autism and did they know how to deal with that information

An important lesson from the pilot was that many of the changes we required were achievable at no great cost to the hospital. The benefits could be plainly seen through very positive feedback from autistic people, families and staff in the hospital.

### **Patient/carer story**

Mrs A has a 10 year old autistic son, who came for a tonsillectomy at Macclesfield District General Hospital in August 2013.

Her son has a patient passport; these have been developed in East Cheshire NHS Trust and promoted over the past few years. Mrs A refers to her son's passport as 'my bible.'

She took her son for a pre-op assessment the day before he was due to have his operation and took the patient passport with her. She says it is good because all the information is in one place and she uses it at the dentist and other places as well as for hospital.

She added that her son likes order, structure and routine. Things highlighted on his passport include aversion to the colour green, being unable to eat food that is not white or beige, only being able to drink particular drinks and being very routine orientated.

At the pre-op assessment the day before the operation, the staff talked with her about the reasonable adjustments that would need to be made, such as food and drink (no food to be touching on the plate). They discussed his routines and what he would need help with, e.g. toilet and teeth, which he is unable to manage because of a physical condition.

The pre-op staff showed her son round the ward he would be staying on, explained the call bell, and introduced him to the staff and their uniforms and explained what they were going to do the next day. Mrs A left the passport with the hospital staff overnight.

On the day of the operation, he was the first case on the list. Where possible we liaise with theatres to ensure that autistic people, learning disabilities and other conditions for which waiting is a problem can go first on the list.

Mrs A said that the staff explained proceedings to her son in simple terms every step of the way. They told him what they were going to do and what it might feel like, such as how tight the blood pressure cuff would be. They explained that he would have (magic) cream on and a patch on his hand. He was allowed to take his favourite things to theatre with him.

Mrs A went to the anaesthetic room with her son and stayed with him until he went to sleep. The staff called her straight away when he woke in recovery to help him settle.

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Although the staff initially wanted to keep him overnight he went home that same night as he was unable to settle away from his usual environment and routines. Mrs A was very pleasantly surprised when early next morning a nurse visited to make sure that he was alright.

The hospital's unswerving commitment to improve their service for autistic people was a key to this success. The next challenge was to develop this framework to reflect the complex environment within hospitals and the effort required to validate good practice especially in larger hospitals as well as setting out how to support them. It was clear that the more intense Autism Accreditation process would suit this better and we have embarked on a second phase to develop a full blown Autism Accreditation Standard for hospitals.

The project has now entered that second phase, working in partnership with Macclesfield and other larger hospitals across the country. Good autism practice is already embedded within smaller teams but not across the whole hospital. The hope is to collate good practice examples and garner the experience of the professionals to develop a functional framework that will be rolled out on a larger scale.

The framework will take into account regulatory requirements and codes of practice such as the Care Quality Commission and the NICE Quality Standard 51 for Autism. These will reinforce the resources provided by Autism Accreditation and can be used by hospitals to meet these wider standards.

It is hoped that a basic Autism Accreditation framework will be ready for pilot before the end of 2015, and that the benefits and positive experiences arising from this work will continue to increase.

If you wish to discuss this further, or would be interested in piloting it within a local hospital setting please get in contact with Christine Flintoft-Smith at [Christine.flintoft-smith@nas.org.uk](mailto:Christine.flintoft-smith@nas.org.uk)