

Open 2 Autism: A listening into Action Project

Introduction

Autism is a lifelong developmental disability, sometimes referred to as an Autistic Spectrum Condition (ASC). Its causes are not fully understood, although there is some evidence that genetic factors are involved. Approximately 1% of the population has an Autistic Spectrum Condition (NAO 2009).

All people with autism share difficulties with social interaction, social imagination and social communication (commonly referred to as the “triad of impairments”). In addition many individuals with an ASC display an aversion to change, a need for routine and rules and many experience hyper or hypo-sensitivities in one or more of the seven senses which can result in high levels of anxiety sometimes resulting in associated challenging behaviours. The term “spectrum” is used because autism affects individuals in different ways. Some can live relatively independent lives with little or no additional help, where others require a lifetime of specialist care and support. Approximately 50% of those with an ASC also have a concurrent learning disability (i.e. I.Q below 70) the rest have high functioning autism (including Aspergers syndrome) often with average or above average I.Q. People with high functioning autism have more verbal language but they are still affected by the impairments common to all people with autism. Other conditions associated with autism include attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia and gastric conditions such as leaky gut syndrome, celiac disease, gluten intolerance and medical conditions such as epilepsy (NAO 2009, DH 2010).

Although Health and Social Care services in England have traditionally been configured to cater for people with a learning disability, a physical illness, physical disability or a mental health problem, those with high functioning autism often struggle to access existing health and social care services unless they have a diagnosable mental illness (which autism is not), hence they fall through a gap between learning disability and mental health services and as a consequence their health outcomes are poorer than those without an ASC (NAO 2009, DH 2010).

The National Audit Office Report (2009)

In 2008/9, on instruction from the House of Commons, The National Audit Office examined the range of services for adults with autism and their carers in England, including health and social care, education, benefits and employment. The NAO report: “Supporting people with autism through adulthood” was released in 2009 and concluded that:

“Better outcomes for people across the whole autism spectrum could be achieved by greater awareness of autism in strategic planning and better knowledge amongst those responsible for assessing and meeting the needs of people with autism” (NAO 2009 page 7)

The report called for action in three main areas:

1. Improved awareness of the number of people with autism
2. Better understanding of what autism is and of the range of potential needs of people with autism by those providing services for people with autism
3. Better targeted specialised provision for adults with high-functioning autism/Aspergers syndrome (to include both diagnostic and post-diagnostic support).

The Autism Act (2009) and the Autism Strategy (2010)

In 2009 the Autism Act was given Royal Assent and became the first disability specific law to come into effect in England and Wales. The Act was created in response to increasing evidence that a significant proportion of adults with autism across the whole autistic spectrum, are excluded both socially and economically and that health outcomes for people with autism are worse than for the population at large (DH 2010). The Act itself led to the release of the Autism Strategy 2010 “Fulfilling and Rewarding Lives” which identified the government’s vision that:

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents” (DH 2010).

The strategy was designed to set overall direction including the publication of statutory guidance for health and social care and progress on delivery of the strategy was to be led nationally by a new autism programme board, co-chaired by the Minister for Care Services and the Director-General of Social Care at the Department of Health. Implementation of the Autism Strategy will be formally reviewed this year (2013).

The Autism Strategy (2010) focuses on five core areas of activity:

1. Increasing awareness and understanding of autism among frontline professionals
2. Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment
3. Improving access to the services and support which adults with autism need to live independently within the community
4. Helping adults with autism into work
5. Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities

The autism strategy highlights that the first and most fundamental step must be to increase awareness and understanding of autism across all public services:

“If staff do not know about autism and how it affects behaviour and responses, then they can have no idea of how to adjust the way they deliver services” (DH 2010 page 25).

To address this, the strategy recommends that autism awareness training should be included within general equality and diversity training programmes across all public services and that this training should focus less on the theory of autism and more on giving staff an insight into how autism can affect people, the end goal being that all NHS practitioners will be able to identify potential signs of autism, so they can refer for clinical diagnosis if necessary, but more importantly so they can understand how to adapt their behaviour and particularly their communication, when a patient either has been diagnosed with autism or displays the signs of an ASC.

NICE Clinical Guidance 128 and 142

In September 2011 NICE clinical guidance 128: “Autism diagnosis in children and young adults” was published, followed in 2012 by NICE clinical guidance 142: “Autism: recognition, referral, diagnosis and management of adults on the autism spectrum”. Both guidelines detail the care which should be provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with and make decisions concerning the care of people with autism.

The Open 2 Autism project: East Cheshire NHS Trust

East Cheshire NHS Trust has a specialist dental surgical list which is often attended by a high number of patients with autism. As a manager I have witnessed the difficulties members of the operating theatre team often have in adapting their routines practices and making reasonable adjustments to support people with an ASC and their carers when they attend the hospital for this surgical list. In addition my husband, Michael Rimmington, has worked with and supported people with an ASC for more than 10 years and recently graduated from University with an MA in Autistic Spectrum Conditions. As a consequence we have spent many hours discussing and comparing the issues and challenges faced by people with an ASC, their carers and hospital staff because the effects of Autism are so often poorly understood. In response to these discussions and observations I arranged for basic autism awareness training to take place for some of my team members in October 2012 and it was their positive response to that training and the changes in both their approach and confidence in making reasonable adjustments for people with autism which encouraged me to propose the development of a surgical pathway for people with Autism as one of the Trust's "Listening into Action" projects.

The Listening into Action project aims to engage and support staff in innovative ideas which make a difference for patients when they access the Trusts services and in January 2013 the "Open 2 Autism" project was chosen as one of the first 10 projects selected to be supported by the Trust Board at East Cheshire NHS Trust.

The Projects mission statement was simply to support people with an Autism Spectrum Condition both as a health care provider and as an employer.

The Open 2 Autism patients, carers and parents Survey

In order to focus and prioritise the project a simple 10 question survey for people with ASC and/or their parents and carers was developed and promoted through local Autism Support Networks (appendix 1). The survey asked about people's experience of any health care services or facilities that they had accessed as someone with ASC or their carer and was not restricted to East Cheshire NHS Trust services.

The following summarises the survey results after four weeks from launch and includes the responses received from 52 carers and/or parents and 4 people with a diagnosis of ASC. (The survey results in their entirety appear in Appendix 2).

Summary of the Open 2 Autism Survey results

Most individuals responding to the survey had a diagnosis of autism (71%) or Aspergers syndrome (32%), although some responders ticked both of these options.

59% were attending for an outpatient's appointments and 29% were attending A&E.

75% of the responders said that they had received no written information to help them plan their visit prior to an elective attendance.

Of those who did receive written information 29% rated it "average", 25% "poor" and 12% rated the written information they received as "very poor".

95% of carers and 100% of people with an ASC said that they were not contacted by anyone prior to their visit and of those who were contacted, approximately two thirds (66%) rated the information that they did receive as "poor" or "very poor".

When asked to rate staff's ability to communicate with a person with ASC almost three quarters (72%) of carers rated the quality of communication as "average", "poor" or "very poor". Of those responders who had an ASC 25% rated communication as "average", 25% rated it as "poor" and 50% rated it as "very poor".

When asked whether they or their carers felt listened to and consulted with regards to decisions about their care, only 40% of carers answered "yes" and 75% of those with an ASC felt that they were not listened to or involved in decisions about their care.

When asked to rate staff's knowledge of ASCs 52% of carers and 75% of patients with an ASC answered "poor" or "very poor" and although there were some responses which rated knowledge and care as "excellent" these were both associated with visits to an NHS Trust with a specialist autism unit.

When asked to rate their overall hospital experience 76% of carers and 100% of patients with ASC rated their experience as "average", "poor" or "very poor".

The survey also asked for further information on some questions. No one with an ASC chose to comment further when responding to the survey and this may be due to the ambiguous nature of the request for comments which simply read "say more here:".

Many carers did take the opportunity to comment on some of their answers and these comments are included in full in appendix 2.

A selection of the comments posted by carers and parents appear here:

"There was no opportunity to explain that we had an autistic child and would therefore need a "quieter" time to attend, help in preparing our child, opportunities to explain to the staff nor any opportunity to say what would work best. Instead we had a highly distressed child, distressed and traumatised staff and we were a shivering wreck from our ordeal".

"Diagnosis queried and dismissed because my son sings and appears to make eye contact"

"They often ignore my daughter with autism, and talk about her as if she was not there. Very condescending towards both of us"

"We met several staff. Most were good but one nurse in particular was very poor, asking insulting questions about my son in front of him"

"She had an excellent understanding of autism"

"Because xxx presents as normal on first impressions, they don't see the anxieties and little give away signs that say I am so, so stressed...and don't give time for xxx to process what is being asked. Complete ignorance of autistic spectrum disorders".

"Supported with regard to the problem we went to have seen, but dismissive of difficulties caused by Aspergers"

"It was a traumatic experience - my son really needed two people constantly with him as he was very physical in his distress. I struggled to manage him and it has left me terrified of future hospital visits"

"Unable to examine child in appt as too anxious after waiting room was full of noisy toddlers. Needed quiet area to wait"

"We are often kept waiting for hours even though it is very difficult for us to stay in one place. Often we are seen by junior doctors rather than registrars or consultants, which is marked contrast to when I take my "normal" son to A&E where he has always much better treatment because he can talk"

"Unfortunately the negative encounters are the ones that stay with you"

"We will never be able to visit that hospital ever again as my son will be in severe distress at the sight of it again. He has suffered night terrors and nightmares ever since".

Open 2 Autism Project: Progress so far

On 14th February 2013 an email outlining the proposed project with an invitation to join the steering group was sent out to 26 members of staff. This group consisted of a variety of staff including doctors, nurses, play specialists, allied health professionals including therapy staff, support services (including administration, security and voluntary services) education and corporate staff and local GPs. On 21st February a further 14 members of staff were contacted in order to involve a wider circle of speciality nurses and doctors and support service staff in the project.

Of those initial 40 members of staff contacted 15 responded offering to become active supporters of the project and the first steering group meeting took place on 28th February 2013. The steering group agreed that the initial focus of the project should be:

1. To actively raise awareness of autism across the Trust
2. To develop an Autism Link Network of staff who understand the challenges of autism and can make reasonable adjustments in order to support someone with an ASC when accessing services in their own clinical area.
3. To develop a system to identify people with an ASC diagnosis (and those with autistic traits who require reasonable adjustments) on referral and/or admission to Trust services

Methods used to actively raise awareness of autism within the Trust

The communications and engagement team have actively promoted the Open 2 Autism project via a number of methods including announcements about the project via the staff infonet and in the Trust newsletter “staff matters”. A one hour lecture on Autism has also been arranged to take place on 6th June 2013 as part of “health matters” – a series of monthly lectures aimed at staff and members of the public.

Six local community support groups were also contacted in order to gain information about their experiences and to engage local people with ASC and their carers in supporting and shaping the project. These community groups were also instrumental in promoting the Open 2 Autism survey (summarised previously) which was used to further inform the project.

The National Autistic Society (NAS) was contacted by the project lead and the NAS director of accreditation visited the Trust to discuss the development of the project and to offer support and advice. The NAS director of accreditation also offered to support the project’s local campaign as part of the access accreditation process and through press office announcements at the direction of the project lead.

In March 2013 the head of training and development at East Cheshire NHS Trust agreed to include basic autism awareness training on all clinical mandatory training for Trust staff and this training is due to take place on a bi-monthly basis from April 2013-April 2014.

On 14th March 2013 the Open 2 Autism project webpage was launched on the Trust’s public website at: <http://www.eastcheshire.nhs.uk/Our-Services/open2autism.htm>

This website outlines the mission statement and purpose of the project and contains contact details for the first Autism Link Practitioner members as well as basic information about the project and is set to become a key component in raising public awareness of the project.

Methods used to develop an Autism Link Network

A request for support for the development of an Autism Link Network was circulated to colleagues via the steering group membership and 36 nursing and allied health professional staff contacted the project lead expressing the desire to join the Autism Link Network. A training workshop was organised to take place on 11th March 2013 with the intention of delivering a higher level of autism training. Feedback from this initial workshop would also be used to inform the development of any future training workshops.

The workshop was delivered to a diverse group of 13 staff members from a variety of backgrounds including specialist nurses, Matrons (for both surgery and medicine), radiographers, physiotherapists and operating department practitioners.

The workshop was delivered by a trainer with an MA in Autistic Spectrum Conditions and over 12 years practical experience working with people with autism and consisted of a 3 hour training session using an eclectic mix of lecture, discussion and practical participation.

Feedback from the workshop was collected in order to establish a focus for future training and support for Autism Link Practitioners. This feedback appears in full in appendix 3, but is summarised below.

Autism Link Network: Training workshop feedback

Feedback demonstrated a clear increase in the confidence of staff in supporting people with autism in clinical practice, with 100% of staff scoring confidence at “somewhat” or “very” following the workshop compared to 33% of staff feeling somewhat or very confident prior to the workshop.

When asked about implementing reasonable adjustments 91% of staff said that they would feel “somewhat” or “very” confident following the workshop.

When asked if they would be interested in being the Link Practitioner for their clinical area only one candidate said no – but commented that they would be happy to with more training.

When asked if they felt they would benefit from further training 91% of candidates said that they would.

When asked if they would recommend this training workshop to their colleagues, 100% of candidates said that they would.

The candidates were also asked what further training they felt would be useful and the following responses were received:

1. Communication strategies: 66%
2. Supporting challenging behaviours: 66%
3. Mental Capacity and issues of consent: 50%
4. Sensory Processing: 41%
5. Pain response: 33%
6. Basic Autism Awareness: 8%
7. Diagnosis: 0%
8. Cognitive theories of autism: 8%
9. General Peer support and discussion groups: 8%

The feedback form also asked for comments, of which a selection appear below (a full list of comments appear in appendix 3).

“Excellent study session. Very informative, pitched at a good learning level. Definitely recommend for colleagues – everyone should do the session”

“Excellent, relevant and informative. Will help in my clinical practice. Hungry for more to help me improve patient care”

“A lot of information in a short period of time”

“Brilliant. An eye opener. 10 out of 10”

It is clear from the feedback gathered from this workshop and feedback from the patient and carer’s survey that training and development of Autism Link Practitioners is key to the success

of this project and it is proposed that a series of workshop be organised to deliver basic autism awareness, with additional elements to include communication strategies, supporting challenging behaviours, and sensory processing in order to develop link practitioners who can assess the needs of individuals with Autism and implement reasonable adjustments accordingly. Mental capacity and issues of consent should also be an integral part of the training and development of Autism Link Practitioners.

Further funding is required in order to support the implementation of a series of one day workshops and will be dependent on demand in key clinical areas; particularly in A&E, Outpatients departments and inpatient areas as well as key therapeutic areas such as radiology, endoscopy and physiotherapy. Strategies for supporting Autism Link Practitioner training across the Trust's community services should also be considered.

Methods used to develop a system to identify people with an ASC

Unless they choose to self disclose an ASC diagnosis or autistic traits, at present patients requiring support and/or reasonable adjustments are not identified prior to accessing services. Contact details of Autism Link Practitioners via the Open 2 Autism website should help patients and their carers in the process of self disclosure; however further work needs to take place with local GPs, commissioners and other services in order to develop a robust and useful system to identify those who require assessment and reasonable adjustments to be made.

Consideration should be made to the use of electronic alert systems such as the Patient Administration System (PAS) and choose and book services, often accessed by GPs, patients and carers. Raising awareness amongst ambulance services should also be a consideration. With the release of NICE guidance 128 and 142 the number of people with a diagnosis of ASC in the local community is likely to increase significantly over time and so it is important that systems are developed and implemented which will help people with an ASC to effectively access health services. A robust system of identification will also allow the Trust to identify such patients in order to monitor and improve health outcomes for them in the long term.

Conclusion

The project has made significant progress so far, including the inclusion of autism awareness training as part of clinical mandatory training and in launching the Open 2 Autism website and Autism Link Practitioner Network.

There have also been a significant number of staff members who have contacted the project lead requesting inclusion on the Autism Link program, and this number is likely to increase as autism awareness training is delivered through clinical mandatory training. The development

of a robust Link Practitioner network will be a key component in the success of this project and funding must be identified to support a responsive training programme for Autism Links. General campaigning now needs to be implemented in order to raise awareness about autism and the Open 2 Autism project not only across the Trust's employees but also into the local and national population. Engagement of local GPs will also be instrumental in facilitating the development and implementation of a process for identifying and monitoring people with autism as they access health services.

References:

The National Audit Office (2009). Supporting people with autism through adulthood. [Available as PDF at: <http://www.eastcheshire.nhs.uk/Our-Services/open2autism.htm>]

Department of Health. (2010). Fulfilling and Rewarding Lives: The Autism Strategy. [Available as PDF at <http://www.eastcheshire.nhs.uk/Our-Services/open2autism.htm>]

NICE guidance 128 (2011). Autism Diagnosis in children and young people. [Available as PDF at <http://www.eastcheshire.nhs.uk/Our-Services/open2autism.htm>]

NICE guidance 142 (2012). Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. [Available as PDF at <http://www.eastcheshire.nhs.uk/Our-Services/open2autism.htm>]

Appendix 1: Local Networks who have supported the project so far.

The following local support groups and training and consultancy firms have kindly supported the project, shared information and links to our Open 2 Autism survey.

- The National Autistic Society: Local branches (<http://www.autism.org.uk/>)
- Space4Autism (<http://www.space4autism.com/>)
- Cheshire Asperger Parents Support Group (ChAPS) (<http://www.asparents.org.uk/>)
- Autism Networks (<http://www.autismnetworks.org.uk/>)
- Ambitious About Autism (<http://www.ambitiousaboutautism.org.uk/page/index.cfm>)
- ASD Friendly (<http://www.asdfriendly.org/>)
- ProACT (<http://www.cheshire-autism.co.uk/>)

Appendix 2: Open 2 Autism Survey

Introduction

East Cheshire NHS Trust's Open 2 Autism project aims to support people with an Autism Spectrum Condition both as a health care provider and as an employer.

Please help us by sharing your experiences (good and bad) of any hospital or healthcare facility you have visited.

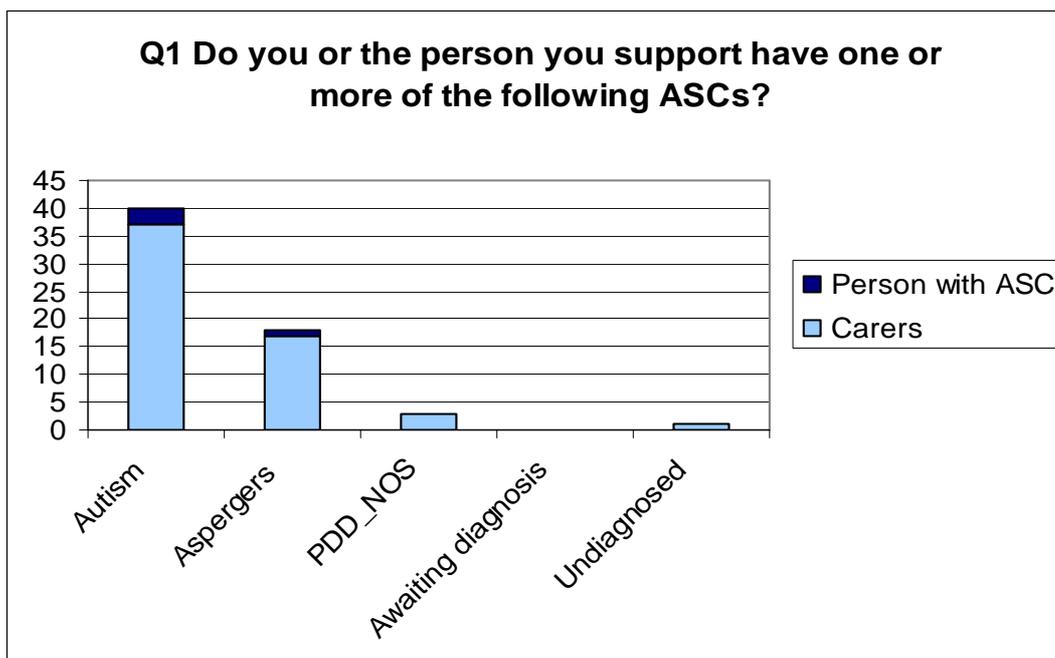
The survey is anonymous and we won't ask you to name any hospitals or healthcare facilities and please rest assured that any opinion you express in the survey will not influence the treatment you or your relative, client or friend receives in the future.

The Open 2 Autism Carers survey can be found here:

<http://www.surveymonkey.com/s/KTPHGDC>

The Open 2 Autism survey for people with an ASC can be found here:

<http://www.surveymonkey.com/s/VYN8GYS>



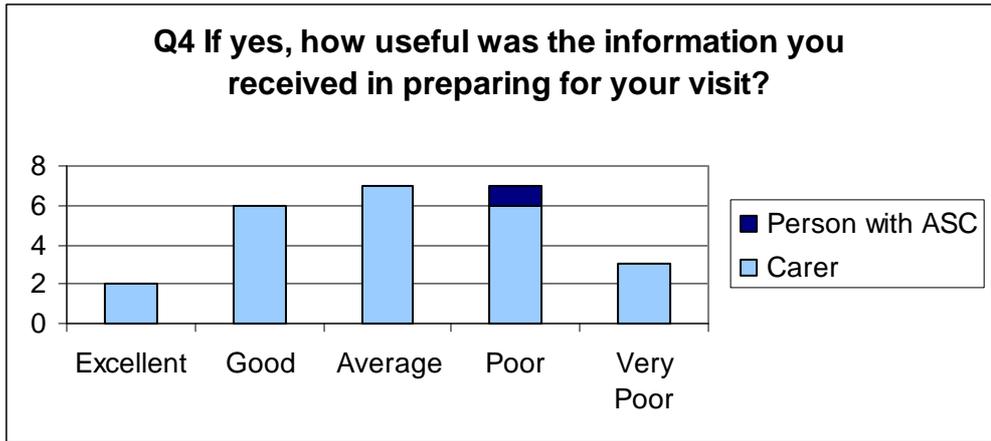
Most individuals responding to the survey had a diagnosis of Autism (71%) or Aspergers syndrome (32%),



The vast majority were attending for an outpatient's appointment (59%) followed by A&E admissions (29%)



75% said they had received no written information prior to their admission



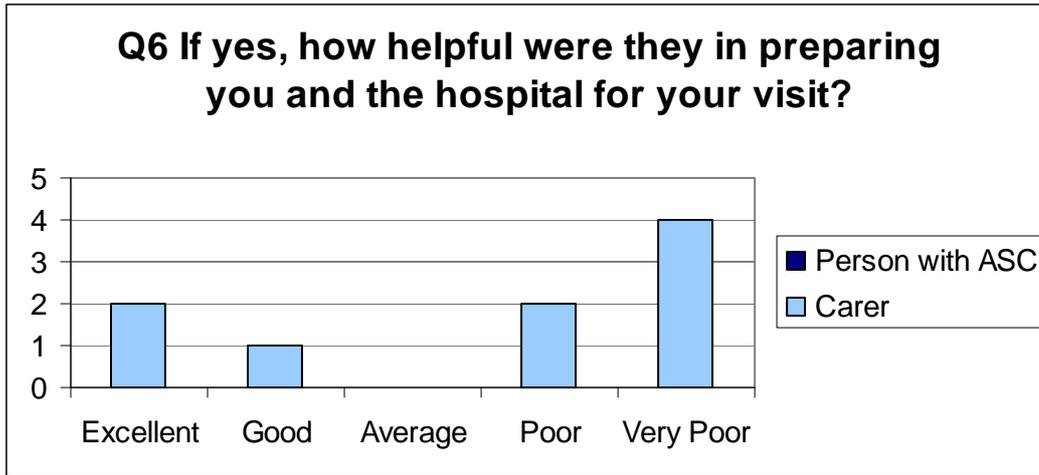
Of those who did receive written information 29% rated it average, 25% poor and 12% rated the written information they received as “very poor”.

7 Comments received:

1. *Not enough detail what would happen*
2. *It was an A&E visit so not relevant*
3. *Would have helped to have the sequence of events and how long each part takes, also for staff to know my son has autism so they could communicate with him appropriately*
4. *There was no opportunity to explain that we had an autistic child and would therefore need a "quieter" time to attend, help in preparing our child, opportunities to explain to the staff nor any opportunity to say what would work best. Instead we had a highly distressed child, distressed and traumatised staff and we were a shivering wreck from our ordeal.*
5. *Tick box questionnaire for my son to fill in*
6. *No info*
7. *Included email contact and direct number of nurse who did the pre med*



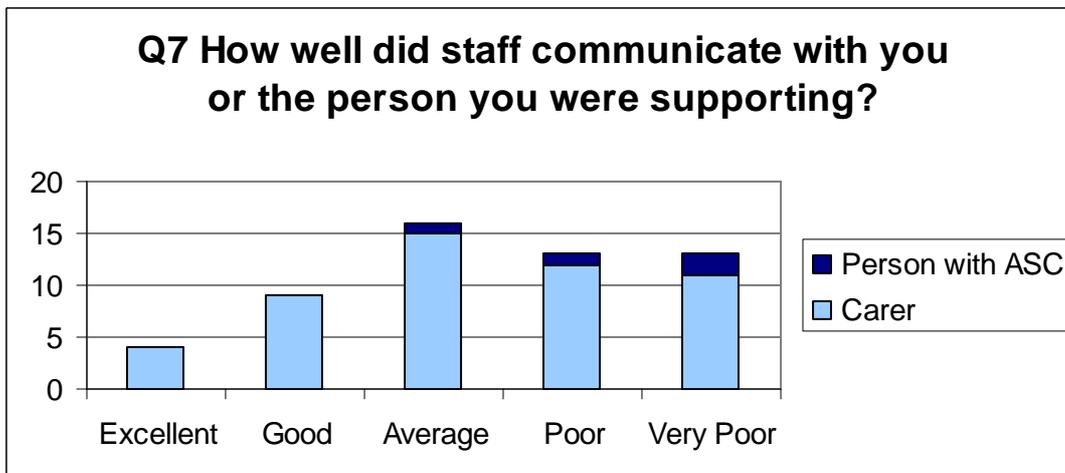
95% of carers and 100% of people with an ASC said that they were not contacted by anyone prior to their visit



Two thirds (66%) rated the information that they did receive as poor or very poor.

5 comments received:

1. Visited us at home and arranged 2 visited to the unit prior to admission
2. It was an A&E visit so not relevant
3. Promised support did not appear
4. They had sensory type toys for my little lad
5. Planned play equipment sensory toys booked by the nurse

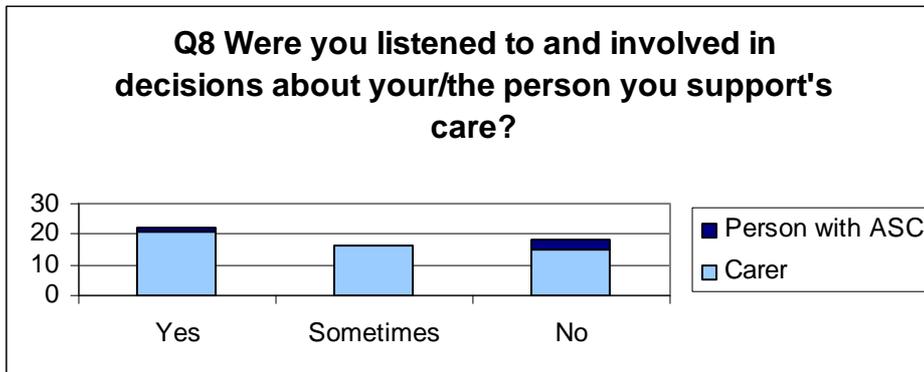


72% of carers rated the quality of communication as “average”, “poor” or “very poor” and people with an ASC rated communication as “average” (25%), “poor” (25%) or “very poor” (50%)

15 comments received:

1. It would help if people could read notes about person before visit...every time I have to say XXXX has autism. Read know a bit of background before hand
2. Diagnosis queried and dismissed because my son sings and appears to make eye contact
3. My son is non-verbal, didn't really understand what was happening and so the communication was mostly handled through me

4. *My son is three and has very limited verbal communication. Staff were kindly but no specific support with visuals etc was offered.*
5. *No understanding of autism or sensory processing disorder issues. Could not communicate with my child because he was not able to establish eye contact, so they ignored him!!!! Didn't have any PECS (Picture Exchange Communication) cards to help us, my child or them. When my child became highly distressed, hysterical, overwrought...they brought other members of staff to see my child, in a highly distressed state!!!!*
6. *They tried very hard but without success*
7. *ASC in Cheshire was not believed, attempt to manufacture evidence for Munchausen by proxy was top of the NHS agenda*
8. *The nurse was [awful] in dealing with my son and his broken leg, communication and understanding of ASD was just not there all though once on the ward she did say sorry for how she treated him bit late really distress was all ready caused*
9. *No visuals*
10. *(Daughter aged 15) consultant tends to talk to me rather than ask her questions!*
11. *It was a social worker who has dealt with us previously, she was able to communicate well with my son and myself coming up with a review date with myself after two weeks*
12. *They often ignore my daughter with autism, and talk about her as if she was not there. Very condescending towards both of us*
13. *We met several staff. Most were good but one nurse in particular was very poor, asking insulting questions about my son in front of him*
14. *She had an excellent understanding of autism*
15. *His communication skills are poor*

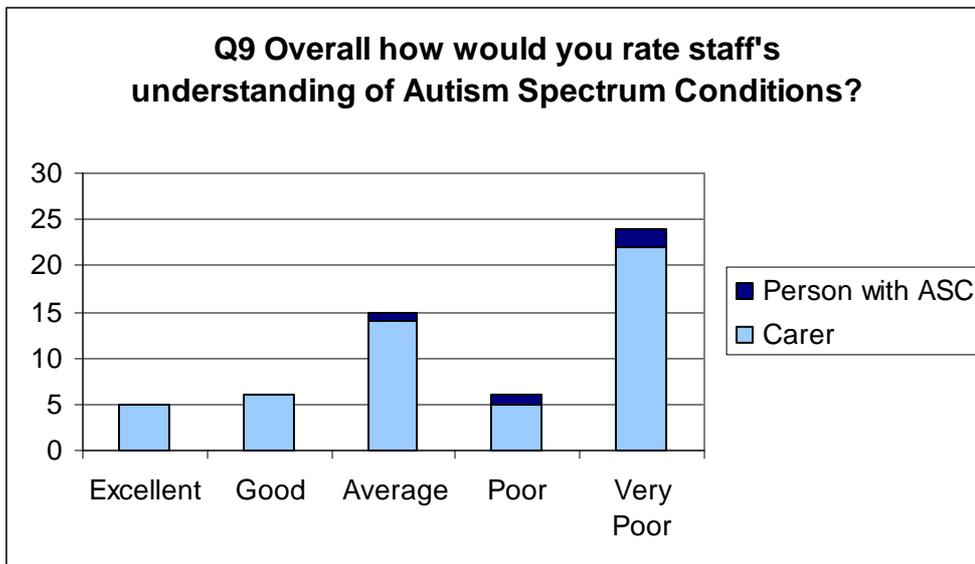


40% of carers felt that they were always listened to and consulted in decisions about care. 75% of those with an ASC felt that they were not listened to or involved in decisions about their care

12 comments received:

1. *By the time we got a doctor's attention, there was little that could be done except sedate my son - who was distressed to the point of being a danger to himself and others*
2. *Because xxx presents as normal on first impressions, they don't see the anxieties and little give away signs that say I am so, so stressed...and don't give time for xxx to process what is being asked. Complete ignorance of autistic spectrum disorders.*
3. *Supported with regard to the problem we went to have seen, but dismissive of difficulties caused by Aspergers*
4. *I was consulted with and listened throughout the visit*
5. *My son hates anything on him - he wanted the cannula out of his hand as soon as he came round after the operation. Staff could see he was distressed and agreed to take it out early.*

6. *Not at all*
7. *No decision was made without consulting us*
8. *See comments from question 7 (ASC in Cheshire was not believed, attempt to manufacture evidence for Munchausen by proxy was top of the NHS agenda)*
9. *Yes, I did feel I was listened to by someone who has a good understanding of Aspergers and is aware of how people in educational settings don't always get it right*
10. *My son has open access for his ultra rare blood disease*
11. *No. On my last visit I had gone in to ask the neurologist to investigate my daughter's seizures because despite being on an antiepileptic she was still having seizures on days when she either was supposed to have a period or ovulating. My daughter was also having huge problems not sleeping, having a sore mouth for 9 months and re-occurring bouts of gagging and sore throats and these are all listed as side effects which a doctor should be made aware of on the medication information leaflet. The neurologist was not interested and said she could raise the dose, but otherwise she would nothing else. This goes completely against NICE guidelines*
12. *We have a very supportive paediatrician who happens to be on duty during our unscheduled hospital stay. He briefed the registrars and the doctors took us seriously and listened to what we said*



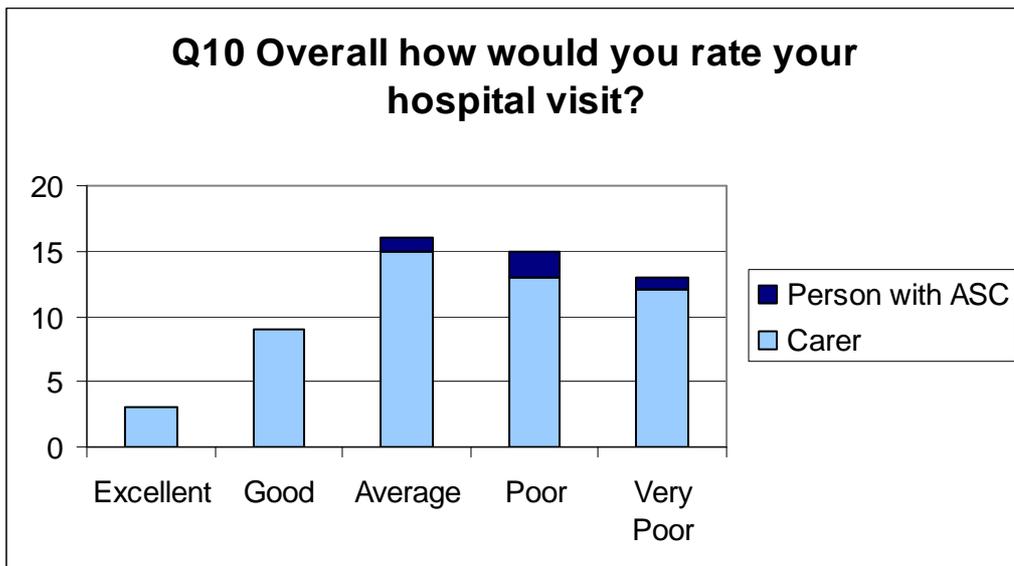
When asked to rate staff's knowledge of ASC 52% of carers and 75% of patients with an ASC answered poor or very poor

14 comments received:

1. *As above, lack of knowledge, lack of awareness. Needs to be taught and talked about*
2. *One size fits all approach. Sweeping generalisation and lack of understanding of the need to listen to me with regard to what my son struggles with*
3. *I think we were very lucky. What actually happened was this: we thought my son might have swallowed a small lithium battery and so we took him to A&E on a Saturday morning for an X-Ray. We only had to wait 5 minutes for triage, explained what had happened to the nurse and then went back to the waiting room. My Son is OK in new situations so long as he doesn't have to wait for long. After another 5 minutes the nurse came back, called us through to the treatment area, where we were met by a doctor who introduced himself as the Clinical Director of the department and asked us to follow him. He took us through to the X-Ray section and asked the radiologist to see my son immediately. He then told us that he had good friends with an autistic child and understood how difficult any kind of wait could be. We managed to get my son to keep still for the X-Ray (which was an achievement in itself - if he had been upset or in any*

kind of pain they would have needed to sedate him) and 10 minutes later we had the results. The whole visit took less than half an hour. Full marks to all the staff, but especially the doctor, who had the kind of knowledge about autism that you can't learn from a book or a training course.

4. *Staff seemed to understand that my son's problems were due to autism. We were in a separate room, but if we'd been on a shared ward, I would have felt mortified at the noise and commotion he caused.*
5. *Upon explaining my child was autistic (non-verbal and in a wheelchair) we were sneered at. So I assume they only believe all the bad press and lack of understanding.*
6. *Specialised unit at Alder Hey so very knowledgeable*
7. *See comments in Q7 (ASC in Cheshire was not believed, attempt to manufacture evidence for Munchausen by proxy was top of the NHS agenda)*
8. *For a children's hospital [you] thought they would be understanding, but after a 45 minute meltdown where my child actually had her hands around my throat they stood and watched! And when I finally calmed her down they turned round and said "that was some tantrum and she never even swore". My child was terrified and she doesn't swear!*
9. *Did not know*
10. *I think it varies from professional to professional*
11. *He looks normal has the strength of a bear and blood tests need 3 men to hold him down, they expected me to do it*
12. *Staff learn a little about autism and regard it purely as a behavioural disability. They are not interested in looking at the many physiological problems people with autism have such as gut problems and heavy metal toxicity*
13. *It is hit and miss. Some staff are excellent, some very poor*
14. *When I tried to explain what new alternative strategies I was using to help with constipation, lack of sleep, fits - which were actually working it was all dismissed and he looked at me like I'm in "lala" land hence I never discuss such again with NHS professionals - only ASD moms*



When asked to rate their overall hospital experience 76% of carers and 100% of patients with ASC rated their experience as average, poor or very poor.

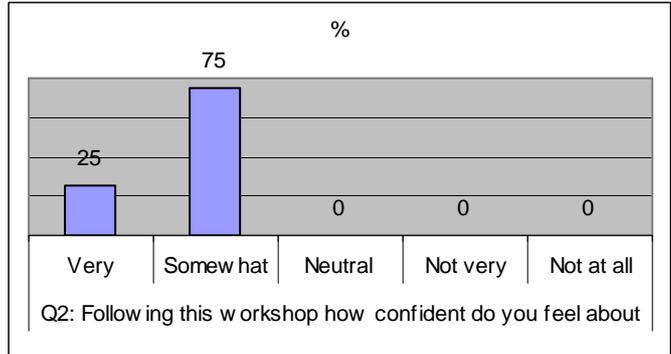
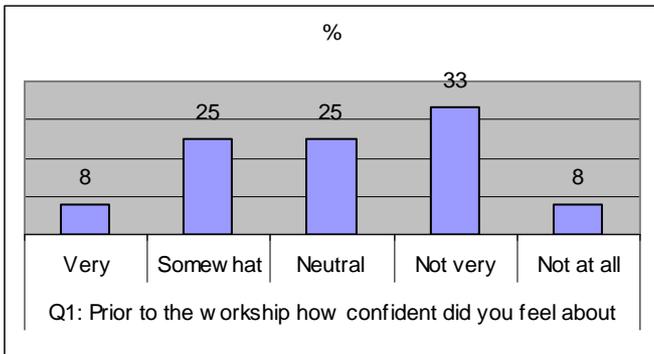
11 comments received:

1. *Sick of same questions being asked that are usually negative answers. xxx birth was talked about 13 years ago, lets move it on can't change what's done.*
2. *It was a traumatic experience - my son really needed two people constantly with him as he was very physical in his distress. I struggled to manage him and it has left me terrified of future hospital visits*
3. *See Q7 (ASC in Cheshire was not believed, attempt to manufacture evidence for Munchausen by proxy was top of the NHS agenda)*
4. *I met my son and his teacher at hospital. It was quite calm area without any crowds or busyness. It was lucky one of the staff was a grandmother and the toys she brought were donated recently*
5. *Unable to examine child in appt as too anxious after waiting room was full of noisy toddlers. Needed quiet area to wait*
6. *I have never heard of or been advised of East Cheshire NHS Trust's "open 2 autism" project. My son has been under a consultant at CAMHS for 10 years and has had his ASC & Aspergers diagnosis 3 years and his ADHD & Dyspraxia diagnosis for 8 years. It is very concerning that I haven't been informed of this project or even heard of it from others! Shocking!*
7. *Only because the receptionist failed to book us in and we were waiting over 3 and a half hours. I understand this has been reported and is being investigated as an official complaint*
8. *We are often kept waiting for hours even though it is very difficult for us to stay in one place. Often we are seen by junior doctors rather than registrars or consultants, which is marked contrast to when I take my "normal" son to A&E where he is always much better treatment because he can talk*
9. *Unfortunately the negative encounters are the ones that stay with you*
10. *Chelsea and Westminster should be used as a model of excellent care*
11. *We will never be able to visit that hospital ever again as my son will be in severe distress at the sight of it again. He has suffered night terrors and nightmares ever since.*

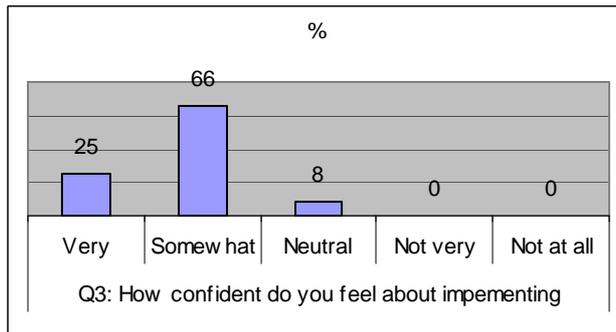
Appendix 3: Autism Link Practitioner Workshop: Feedback

Questions 1 & 2 asked about the confidence level prior to and following the workshop with respect to supporting someone with autism in clinical practice.

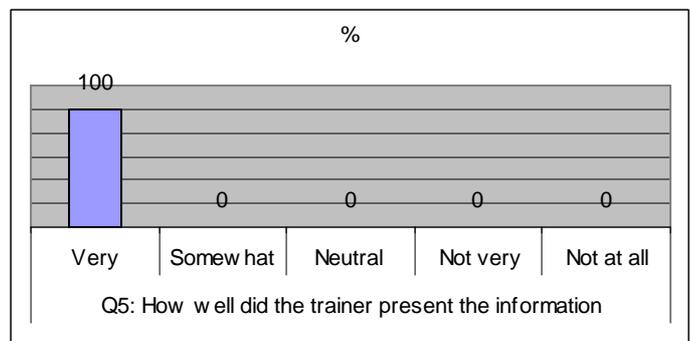
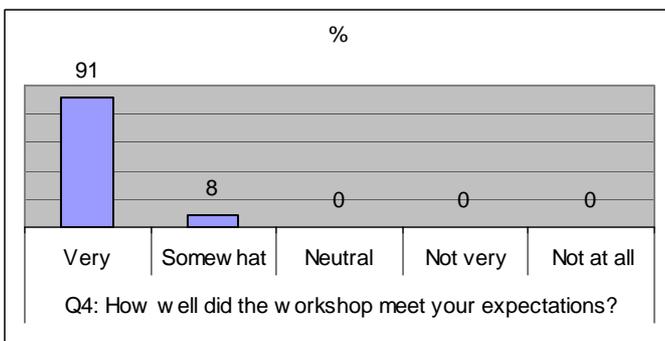
The feedback showed a clear increase in confidence with 33% of staff scoring “somewhat” or “very” confident prior to the workshop compared to 100% of staff scoring “somewhat” or “very” confident following the workshop.



Question 3 asked about confidence in implementing reasonable adjustments following the workshop with 91% of staff scoring “very” or “somewhat” confident following the workshop



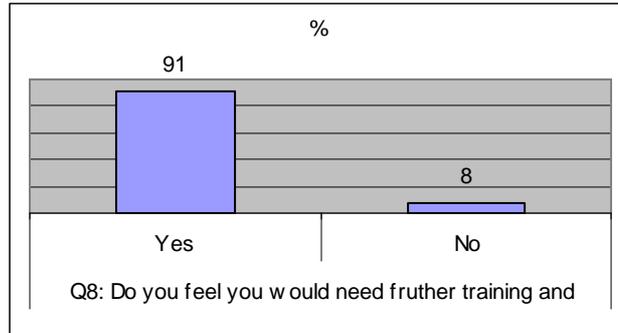
Question 4 and 5 asked about the workshop itself with 100% of staff scoring that the workshop met their expectations as “very” well or “somewhat” and 100% of staff scoring the trainer’s presentation of the information as “very” well.



Question 6 asked the candidates whether they would be interested in joining the Autism Link Network, and only one person said no – but had commented that they would be interested with more training.

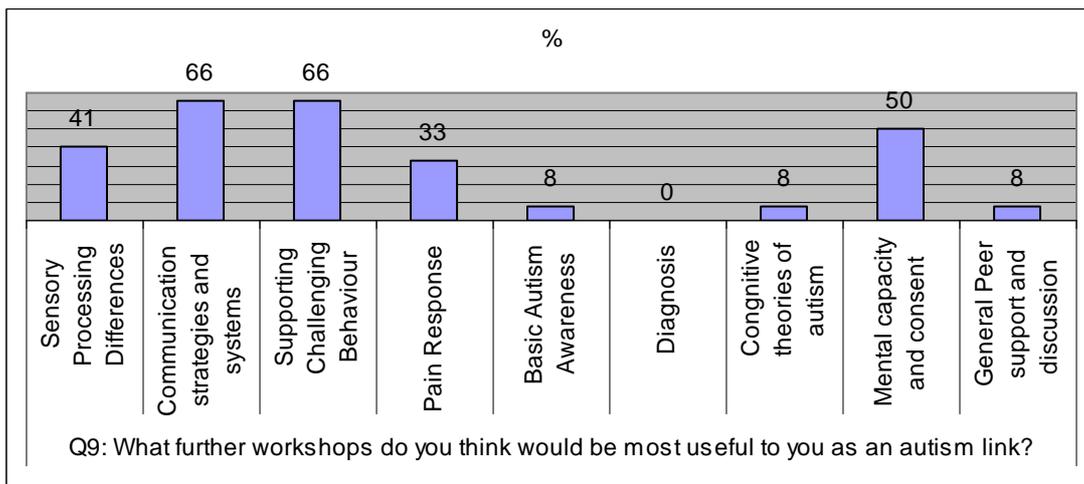
Question 7 asked about contact details

Question 8 asked whether the candidate felt they would need further training and support following this workshop and 91% of candidates felt that they would



Question 9 asked which workshops candidates felt would be most useful if further training workshops were delivered.

- 41% said Sensory processing differences
- 66% said Communication strategies and systems
- 66% said Supporting Challenging Behaviours
- 33% said Pain Response
- 8% said Basic Autism Awareness training
- 0% said Diagnosis
- 8% said Cognitive Theories of Autism
- 50% said Mental Capacity Act and issues of Consent
- 8% said General Peer support and discussion



Question 10 asked whether the candidates would recommend the training to colleagues. 100% answered that they would.

The feedback forms also asked for general comments and the following comments were noted:

“Very Good presentation, thank you”

“Excellent informative session with relevant points to all areas of work, thank you”

“Excellent study session. Very informative, pitched at a good learning level. Definitely recommend for colleagues – everyone should do the session”

“This training would have been very useful while I was working as a teaching assistant working with an autistic child”

“A lot of information in a short period of time”

“Excellent, relevant and informative. Will help in my clinical practice. Hungry for more to help me improve patient care”

“Brilliant. An eye opener. 10 out of 10”

“Really interesting and informative. Full of useful information. Presented in a really good way which led to open discussions and learning opportunities”.

“Use of quizzes and interaction was good”.

“Gave a great insight into what would be expected of us when patients with autism arrive on our lists”.

“I will be more comfortable in future when caring for patients with autism”.

“Very enjoyable and relative to my place of work, enabling me to improve patient care in the future”.