



Asperger event report

Date: 18 Feb 2014 - 13:30 to 17:00

Location: Southend Association of Voluntary Services (SAVS) conference room, 29-31 Alexandra Street, Southend on Sea, Essex SS1 1BW February 2014

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Healthwatch Southend

We are an independent organisation that helps people of all ages who:

- need information about health or social care services
- want to see services improve
- need help to make a complaint or raise a concern about an NHS funded service

Everything we do is free to people who live in the Southend on Sea area.

For more information, visit www.healthwatchesouthend.co.uk

Public events

As a part of our remit to facilitate the involvement of patients, service users, carers and the general public in the design and commissioning of health and social care services, we are running a series of public events locally on specific themes. Our events are intended as opportunities for people to come together, share thoughts and ideas, hear direct from commissioners and providers of services, ask questions and have their views heard.

Our Asperger event

The idea to run an event around Asperger syndrome (AS) was born when we at Healthwatch Southend were approached by Supporting Asperger's Families in Essex (SAFE). We were invited to attend one of SAFE's support meetings where we heard direct from people with AS and family members about the difficulties they face. They told us they feel there are insufficient services available for people with AS and their carers, that their plight is too often misunderstood by professionals in health, social care and education, and that even getting a diagnosis is a long and arduous road to travel. Employment too was an issue raised for people who, whilst facing the huge challenges presented by emotional, social and communication developmental delays, are often highly intelligent and gifted individuals. Search Google for 'famous people with Asperger's' and you will see the potential people with AS can have. Yet few are in gainful employment we were told, because employers don't understand the condition and appropriate employment support is not available. And it didn't end there. The group went on to tell us about young people with AS struggling with, and having to withdraw from university, not because of lack of academic ability, but because of difficulties coping with the social aspects of university life, being taken advantage of financially by other students, being ostracised and bullied.

After two hours during which the group shared their issues with us openly and honestly, we knew we had a duty to get these seldom heard voices heard more widely.

For this event on Tuesday 18 February 2014, we invited representatives of SAFE and National Autistic Society (NAS) to come and talk about Asperger syndrome from both a health and social care perspective. We asked them to prepare presentations on 'what is Asperger syndrome', 'living with Asperger syndrome in Southend' and 'what works in other parts of the country'.

We then asked our speakers to sit as part of a panel, alongside representatives of Southend Council, NHS Southend Clinical Commissioning Group (CCG), South Essex Partnership University

NHS Foundation Trust (SEPT) and Southend Hospital, to address questions and concerns raised by our audience.

We would like to thank everyone who registered and attended the event. We were actually surprised at just how much response we received after advertising the event. The maximum number of people we could fit into the venue was 70, and we did not expect for one minute to come near to this number of attendees, but in the end we could not accommodate the number of people who wanted to come and had to operate a reserve list. If you were someone on this list and weren't able to come on the day, we apologise that we couldn't fit you in. We hope this report goes some way to giving you the information you would have liked. If you have any views or comments you would have liked the opportunity to make known, it is not too late. Send them to us by email info@healthwatchsouthend.co.uk or post to Healthwatch Southend, Prittlewell Chapel, North Road, Westcliff on Sea SS0 7AF.

We would like to thank Sarah Lennard Brown, Jane Neale and Julian Lemel from SAFE, and Tom Purser from NAS for the interesting and informative presentations they gave, and for staying throughout the event to participate so openly in the 'question time' discussions.

We would also like to thank Michelle Hill and Glyn Jones from Southend Borough Council, Alfred Bandakpara-Taylor representing NHS Southend CCG, Sharon Allison from SEPT, and Steve McEwen and Sarah Haines from Southend Hospital, who all came along and agreed to sit on our 'question time' panel to answer questions from the audience.

This report

In this report we have reproduced the slides from the presentations from our dementia event, along with brief notes of the points raised in our question time discussions. If after reading you wish to discuss any of the issues raised further with us, please contact us. Similarly, if you would like any messages passed on to any of the speakers at the event, please let us know.

On the day

70 people attended our dementia event, which began with Graham Carey, member of our advisory board, who welcomed the speakers and attendees, introduced the event and ran through the 'housekeeping'. Jonathan Keay, manager, Healthwatch Southend, then gave a brief explanation of the purpose and intended outcomes of this and future events.

Sarah Lennard Brown, renowned author and member of SAFE, opened the presentations with a fascinating talk about what Asperger syndrome is, full of information and statistics, explanations and descriptions, which debunked many a myth and gave us a really good understanding of the condition.

Sarah was followed by Jane Neale, committee member of SAFE South, who gave a moving and thought provoking presentation about living with AS in Southend, and spoke of the many challenges faced by members of the group.

Our next speaker was Julian Lemel, local writer and member of SAFE, who himself has lived experience of AS. His verbal presentation was testament to the vast untapped potential of people with AS.

Our final speaker was Tom Purser, area policy and participation officer for central England, National Autistic Society (NAS). Tom spoke about exciting and innovative projects being undertaken in other parts of England, and how these were benefitting people with AS and their families. He then went on to speak about legislation from 2010 relating to autism and how this translates to the kinds of services that should be provided.

The event ended with each of our speakers, and the representatives of our statutory bodies (named above), gathering at the front of the room and responding to questions and comments from the audience. The discussions were very lively and gave everyone plenty to think about.

Presentations

(Not all our speakers used Powerpoint presentations so, where these are not available, we have tried to represent what they said in words alone.)

- [Presentation 1: What is Asperger syndrome?](#)
Sarah Lennard Brown, Supporting Asperger Families in Essex (SAFE)
 - [Presentation 2: Living with Asperger syndrome](#)
Jane Neale, SAFE
 - [Presentation 3: Living with Asperger syndrome](#)
Julian Lemel, local writer and member of SAFE
 - [Presentation 4: Fulfilling and rewarding lives](#)
Tom Purser, area policy and participation officer for central England, National Autistic Society (NAS)
-

'Question time' discussion

Our panel of speakers, and representatives of the statutory organisations in attendance, sat as a panel at the front of the event, in the style of the BBC's Question Time. The discussion was facilitated by Graham Carey, our event chair for the day and member of our advisory board.

The following represents the notes we were able to take during the discussion. We have endeavoured to make the notes as complete and accurate as possible, but recognise the difficulty

involved in accurately recording live and animated debate. If you feel we have misrepresented any aspect of the discussion and points raised, please get in touch and let us know:

Questions and responses:

Q: "It seems that getting a diagnosis is a problem."

A: "Diagnosis is by a psychiatrist or a psychologist."

COMMENT: "When I have been in crisis with my two adult sons there was no help available. Schools, SEPT, etc wouldn't help. The only people who tried to help were the Police."

COMMENT: "Schools should help to pick up when you are young then they would get an earlier diagnosis."

COMMENT: My son had a care assistant to support him at school and the school just used them as an extra pair of hands in the classroom."

Q: "The IQ is the cut-off point for having learning disabilities and most people with Asperger's have an IQ over 70. But they also don't come under mental health either."

A: "No, but it can lead to mental health problems, at which point mental health can offer a service."

COMMENT: "We need people with Autism/Asperger's who understand the difficulties to sit on panels and be in a position to influence decisions but they are turned away."

COMMENT (Jane Neale - Supporting Aspergers Families in Essex (SAFE): "Having a diagnosis is crucial to accessing services."

COMMENT: "It can take years to get a diagnosis."

COMMENT (from Tom Purser - National Autistic Society (NAS): Regarding the Autism Bill; 'Fulfilling & Rewarding Lives' and NICE guidelines: "It is law that each authority has an Autism/Asperger's service. People are beginning to take out law suits." He referred to the 'Push for Action' campaign which people could sign up to on the NAS website.

COMMENT: "I went to Together for help and they suggested that I lobby my MP."

COMMENT: "Getting a diagnosis is a problem."

COMMENT (from Sharon Allison - South Essex Partnership University NHS Foundation Trust (SEPT): "Assessment is a long process. For children the referral route is from the GP to the paediatrician who will be based in the child development centre in the Basildon, Billericay, Wickford, Brentwood and Thurrock areas. In Southend the referral goes from the GP to a paediatrician but sometimes these individuals are seen by the paediatricians in the hospital as well as in the Lighthouse child development centre.

"For adults the referral again goes from the GP to a local adult psychiatrist and then will come to the Aspergers service in SEPT if appropriate. For adults we cover South Essex, so Basildon, Billericay, Brentwood, Wickford, Thurrock, Southend, Canvey, Rochford etc."

COMMENT: "I live in Wickford and I went to the Lighthouse Centre. They made the diagnosis but gave me nothing. I work in a school and pick up information where I can."

A (Sharon Allison): "Where a child is concerned the route would be from GP to paediatrician at the Basildon children's centre."

Q: "Where do people get their information from? Are there leaflets available?"

A (Sharon Allison): "GPs should know the process. That is where the information should be."

COMMENT: "I raised Asperger's as a possible cause for my child's challenging behaviour and was accused by medical professionals of having Munchausen syndrome by proxy."

COMMENT: "There is a lack of information; there should be leaflets and information advising people where they can go for help. There is nothing."

A (Sharon Allison): "When an adult is diagnosed we do give them an information leaflet."

Q: "We have a lot of discussion about getting a diagnosis but once a diagnosis is made what is the treatment?"

A: Sharon Allison explained the SEPT service, based in Basildon, covers south Essex.

Q: "What can you access if you get a diagnosis?"

COMMENT: Glyn Jones (Southend Borough Council) referred to 'Fulfilling and Rewarding Lives'

"Is it all geared towards children and their futures lives. What about my son who's in his 20s, what can I do for him?"

"The whole of the health landscape is changing drastically; people here do want to make a change."

COMMENT: "My son needs social development and employment opportunities without pressure."

A (Glyn Jones (Southend Borough Council): "We will be going to consultation on the strategy and will need input at that stage. Here is a group of people whose rights and needs have not been met. In Southend we are presently involved in a pilot (one of fourteen) integrating health and social care."

COMMENT: "There needs to be greater awareness of Asperger's. People don't realise the difficulties involved in trying to manage your lives. It's a known fact that a high percentage of marriages break up when you have a child with Asperger's yet even Relate don't understand."

COMMENT: "There needs to be a basic Asperger's awareness package."

COMMENT: "Isn't that something that the NAS could do? They publish the statistics about marriage break-ups etc. They have the information."

Q: "What about those who are diagnosed later life? Where do they go?"

A (Sharon Allison): "They would be referred to us through a psychiatrist."

A (Alfred Bandakpara-Taylor - Southend Clinical Commissioning Group): "The present service was set up in 2009. We will review the service and next year decide what we are going to do."

COMMENT: "My son is 39 and has been on the waiting list for almost a year for a diagnosis and assessment. I was told this could take up to a year and I'm hoping to hear soon."

COMMENT: "The issue is the service isn't large enough."

COMMENT: "People who are older now weren't diagnosed with Asperger's when they were young. Some symptoms resemble mental health problems such as schizophrenia and people muddled through with the support of their parents, but when they lose their parents the problems come to light."

COMMENT: "The hospital 'passport' doesn't apply to people with Asperger's because they don't come under learning disabilities."

A (Sarah Haines (Specialist Nurse for Learning Disability, Southend Hospital): "The passport is available on Southend Hospital's website. I am working with staff so that they are aware of the hospital passport."

COMMENT: "But this doesn't cover people with Asperger's."

A (Sarah Haines): "Under the Equality Act we can make reasonable adjustments. The hospital passport doesn't exclude anybody."

Q: "What if my son needs to go into hospital, who will support him?"

A (Steve McEwen, Patient Experience Lead, Southend Hospital): "We can arrange for someone to be there for him or for you to be in there with him."

Q: "What if I need to go into hospital? My sons can't manage on their own. I haven't found Ashleigh Care helpful."

Q: "My son needs to be supervised. He had a placement at Growing Together but they said he needed a professional support worker, which we were told he wasn't entitled to so he had to leave. Can something be done about people with Asperger's, he can't do anything."

A (Tom Purser): "Only those whose needs are assessed as essential/critical receive social care. Nottingham presently support about 200. What you need is a personal care budget so you can purchase your own support. Having an IQ over 70 doesn't come into it."

COMMENT: "Not everyone can fight, the advocacy service should help. I tried Together advocacy service, but they didn't help."

COMMENT: "Advocacy for people with Asperger's syndrome only became part of Together's contract recently."

COMMENT (Tom Purser): "There will be a legal right to an advocate when you are going through an assessment when the Care Bill becomes law later this year. You have a legal right to a community care assessment currently."

Further discussion in summary

In the past diagnosis of children has been uncoordinated and arbitrary. No two people in the audience reported having gone through quite the same process. Many reported having been left with no support or guide as to who to contact. Pathways to diagnosis were not clear to members of the public.

A number of people reported that their children were given several different diagnoses over many years, prior to arriving at AS.

The job centre was mentioned five times, both by panel members and people in the audience. It is not seen as a supportive place. Staff appear to have no training in understanding AS.

Two parents in the audience said their children were not claiming benefit as the process was too stressful and they didn't want to put them through that. It is likely that people with AS form a part of the hidden unemployed, not appearing on government records because they do not claim state assistance.

Julian Lemel submitted the following contributions to the discussions after the event that he would have liked to have contributed at the time:

1. One of the panel said it's not possible for an Asperger's person to have social skills. I don't agree with that. They can be learnt, and it takes much longer & is slower than with other people, but it is possible. The thing is people in general pick up these skills from a young age without much effort, leaving behind the Asperger's person, who requires a lot of time, effort and energy expended upon them to achieve the same. There are techniques that help encourage the person to think in the ways necessary for interaction, which include proper social skills training, and, as mentioned, drama with the proper guidance or instruction. It will not be instinctive however - but a process of learning to think in a different way to what one is accustomed to. And when the instructors think you've learnt it, they may not be right. It can only be the beginning & needs a lot of reinforcing.

At any rate, this area of whether someone with Asperger's can learn social skills is not straightforward. On the one hand, one could argue, it's like trying to run software on a machine that wasn't designed to run that software, and so is a bit like an emulator, like one computer trying to run something written for another. The basic hardware is different, and so to run or interpret, translate, and re-interpret the same instructions is much slower.

Equally, however, one could also argue the brain has plasticity, an ability to change, certainly if self-directed. This is called neuro-plasticity in current medical literature, a topical term. It may also be that the plasticity of the brain has to be self-directed, and people with Asperger's tend not have a very good self-awareness, and so self-change is much more difficult in their case, requiring a lot of work and effort. Yet it is still possible.

Which side of the argument is true, therefore, may vary, depending upon the will or wish of the person. For some, they may never learn social skills, for others they may do. It may not be a black and white thing. Further, another factor is this:

For those helped at an early age, for example at school, it may be that they can learn these skills without the effort adults might need to put in, albeit slower than their non-Asperger's classmates. (i.e. more effort than children in general, but less effort than with an older

Asperger's brain, which has largely developed without practice, experience or inclusion of these skills.)

2. Someone in the audience asked where they can get support. With official support being so hard, the best form of support is amongst ourselves. SAFE is a very good group as people can exchange experiences, tips & news, and speak to people who are "on their side", rather than against them. It is possible to be comfortable, relaxed & open, knowing that everyone shares a similar experience to yours or your families. (Though of course it can be initially difficult to sit in a large group you don't know, especially for people with Asperger's, yet everyone is friendly, warm and welcoming, and so such things can be overcome.)

Additionally, for adults with Asperger's, there is much to be gained in meeting up. Some people that come down to Essex to run occasional seminars for SAFE point out that the adults with Asperger's are themselves the expertise and knowledgebase; It's a bit like seeing things from the inside-out, instead of the outside-in; - people without the condition, only see the symptoms rather than the inner workings.

The more the Asperger adults talk and exchange experiences and views about the condition, the more the knowledge of the condition grows, due to ideas bouncing between everyone and new ideas sparking off the exchange. Thus, the knowledge grows due to "experts" all together in the same room.

Of course there are practical problems such as not having the social skills to talk easily. Often it is the case, that non-Asperger's people facilitate the dialogue. Having a structure to events helps as well, because of the Asperger need for structure. When the unfamiliar become familiar therefore - and this applies to both people and environment - spoken interchange becomes much easier between the adults with Asperger's, and more natural once they get to know each other & settled

where they are. Different individuals will still struggle with this though, to different levels. Some are more outspoken than others, and some want to talk and some don't. [It should also be pointed out that currently the Southend arm of SAFE is stronger at parental meetings and the Chelmsford arm at adult meetings. As the number of diagnoses rise and people get older, however, the need will only increase to cater for both aspects.]

3. One person asked "Why is it so hard to get anywhere?" It's because these needs do not fit the system just as the individuals concerned do not fit in. Additionally, people simply don't understand the condition.

Last but not least, there is a third reason:

Our entire system, health, medical, governmental, civil service and state, etc is run on the basis of numbers. What treatments help the greatest numbers of patients. If it ever is 99% that's seen as ideal, and the upto 1% can be overlooked as they're not seen as significant. We live in a society that believes in power, the power of people, not that might itself is right, but that might of numbers is right - in other words, the majority. (and Asperger's people are perhaps one of the smallest minorities, albeit growing, which explains a possible emerging increased influence.)

Evaluation of event

Asperger event feedback forms: statistics and comments (overview)

18 feedback forms received

1. How did you hear about this event?

E-mail from third party: 6

Healthwatch Southend e-bulletin: 6

Word of mouth: 4

Newspaper: 2

Other website: 1

(Several respondents gave more than one answer)

2. Why did you attend this event?

For information: 17

Networking: 5

To support Healthwatch: 4

Personal growth and development: 4

Speakers: 4

To express own views: 3

Other: 4

(Several respondents gave more than one answer)

3. Were you able to get what you wanted from the event?

Yes, absolutely: 9

Yes, partly: 9

4. Overall satisfaction with event

Event content:

Very satisfied: 11

Reasonably satisfied: 5

Neutral: 1

Registrations process and communications:

Very satisfied: 13

Reasonably satisfied: 4

Venue:

Very satisfied: 13

Reasonably satisfied: 4

One respondent did not give an answer.

5. Comments

What was good about this event?

- *“Great venue, great speakers, very knowledgeable - personal experiences discussion afterwards.”*
- *“People affected by Aspergers coming together to share views.”*
- *“Very informative. Brought together a good mix of people, including AS sufferers, parents and carers.”*
- *“Committed speakers - especially the ‘patient’ professional presentation. Important subject.”*
- *“Time to listen to other people’s comments and to hear from the experts.”*
- *“The presentation - an excellent chairperson! Excellent afternoon. Thank you.”*

- *“Healthwatch is to be commended for organising this event. The information was imparted by experienced people.” 2*
- *“The variety of speakers covering all aspects of the syndrome.”*
- *“Broad range of speakers.”*
- *“Hearing professionals talk.”*
- *“Sharing information. Honest dialogue about positives and negatives of services.”*
- *“Everything - information and speakers excellent.”*
- *“The chance for government agencies to become aware of the problems that people with Aspergers have.”*
- *“Excellent. Presentations were informative and helpful.”*
- *“It was very informative and good to know support is out there. Sharon Allison very kindly took my son’s details and promised to look into his situation.”*

What could be better?

- *“Sometimes difficult to hear people in the audience.”*
- *“Panel was far too big!”*
- *“More on coping with someone with Aspergers.”*
- *“Audience to be given ‘mikes’ as difficult to hear their questions and opinions.”*
- *“Audience participants should be handed a microphone and asked to speak slowly and clearly!”*
- *“Nothing, just grateful for the help.”*
- *“I found out a lot of things that I did not know.”*

Comments taken from evaluation forms

What changes to services in Southend would you like to see happen?

- "Personally, I believe awareness should begin in school. A talk like today's given to school staff would help them understand the condition better and could lead to less exclusions, thus reducing the services when the child becomes an adult."
- "Services need to be more 'joined up'. More funding and more awareness training for staff in all public sectors."
- "Aspergers needs to be seen as a learning disability."
- "Recognition of Aspergers by NHS and Southend Borough Council. Persuade CCG to expand the Basildon service to a base in Southend. The information needs to be spread further with a press release."
- "More commitment by Southend-on-Sea to support adults in the community and to help people into work."
- "Councils, SEPT and NHS taking it seriously! Especially something to help families and carers - more medical treatment, housing, assistance with living."
- "Easier route to diagnosis for adults over the age of thirty. More public awareness of Aspergers/autism. Mental health services to have a better understanding and training. SEPT and Southend CCG to review services for Aspergers. Jobcentre to provide specialist services to support people with Aspergers into paid work."
- "A quicker diagnosis - a one year wait is not good enough."
- "Aspergers specific health and social services in Southend would be the ideal, but in the absence of these, existing learning disabilities services should broaden their remit to include people with Aspergers. Examples include: Southend Borough Council's "Making It Work" employment support scheme and NHS Health Passport. A lot more focus should be given to providing early interventions and low-level support to larger numbers of Asprergers sufferers rather than provide services only when there are serious mental health problems. More support to help AS sufferers into employment."
- "More support and access to early diagnosis."

- "More support for ASD and Aspergers, currently they fall through the net."
- "Access to services for Aspergers is restricted and needs to be corrected eg. no employment scheme as is available for other groups. Programs of awareness training for all staff. Much better coordination between health services and council. Some form of help/facility based at Southend Borough Council."
- "To have more information readily available."

Pledges made at the event

- Support any campaign for better services.
- Continue to press for full implementation of national autism strategy, NICE guidelines in Southend.
- Help raise awareness.
- Try to be less intolerant of others with this and other personality disorders.
- Once I recognise that someone has got Aspergers, then my reactions will be adjusted accordingly.
- More awareness, more funding.
- To continue to promote the needs of people with Aspergers and their carers.
- Share my knowledge and encourage others to become aware of Aspergers Syndrome.
- I have given the school two copies of the book 'The Reason I Jump', to help them realise how Aspies think and act.
- Educate JobcentrePlus re. Aspergers
- Continue to support SAFE and raise issues in my job as a councillor.

Thank you

We would like to thank everyone who attended our Asperger event. Whether public or professional, your openness, involvement and willingness to think constructively made the event a real success for us. We hope that this report will help inform the ongoing development of services and initiatives to support people with Asperger syndrome in Southend.

We genuinely believe events of this kind are a great way to facilitate discussion that is targeted on specific issues. They provide opportunities for learning and information sharing but, most importantly, give people the chance to air concerns and questions, and have these answered by key people in our local services. In this way we can break down barriers of communication and learn to listen to each other without preconceptions or prejudices.

There is nothing that cannot be improved if people have the will to cooperate and share ideas. If you are a commissioner or service provider, please read the comments in this report carefully and think about how you might be able to contribute to positive change.

Many thanks for your continuing support,

Your local Healthwatch team

Message from Jane Neale, SAFE, following the event

I would like to thank you for your help and support over the past months. It has been invaluable to our group SAFE (Supporting Asperger families in Essex) here in Southend during the review of the Autism Strategy last summer and also following that in organising the Asperger event last Tuesday at SAVS and helping to raise awareness of the gap in services experienced by our group and the suffering this causes.

Following the Healthwatch event last Tuesday after years of campaigning for a voice in Southend Borough Council I have been invited to sit on the Learning Disability Board with a view to setting up an Autism Partnership Board. Progress has also been made on accessing hospital services for our Asperger's who have been excluded from the learning disability passport also. These steps are a huge encouragement to us.

I have found working with Southend Healthwatch to be very easy. Staff are friendly and accessible but very professional. We have been a very good working relationship and I look forward to working with you again in the future.

Jane Neale
SAFE South