

---

## Building foundations for change: Developing Autism and Asperger's services in Southend

---

### Report Summary

This report is the second from Healthwatch Southend to focus on Autism Spectrum Conditions (specifically Asperger Syndrome). The first report was published in 2014 in the wake of a Healthwatch Southend public event where local services for people with Autism and Asperger's were discussed.

The aim of this follow-up is to update on the development of services in Southend for people with Autism and Asperger's.

This report:

- Briefly summarises the current policy and legislation around Autism. Local authorities must take this legislation into account when developing their strategies for accommodating and meeting the needs of people with Autism Spectrum Conditions.
- Looks at the work that has been carried out by Southend Borough Council in developing a local Autism Strategy.
- Cites the relationship between Southend Borough Council and the charity Supporting Asperger Families in Essex (SAFE) as an example of a local authority working in partnership with a third sector organisation towards a common goal: In this case increased awareness of Autism Spectrum Conditions, better Autism-specific services, and more inclusive public services.
- Highlights the need for good quality bespoke care for people with Autism Spectrum Conditions. In this report we have chosen to focus on the South Essex Partnership University NHS Foundation Trust (SEPT) Asperger's Service as an example of a well-regarded programme of care and support that is already operating in Southend.

- Investigates the efforts of public services to adapt to the recent Autism legislation, using the local Jobcentre as an example.

What follows is a breakdown of the main points in this report with accompanying page references should you wish to read about a particular area in greater depth.

---

## Legislation

- The current legislation on Autism is embodied in **The Autism Act 2009**. The National Autism Strategy is outlined in a pair of policy documents: **Fulfilling and rewarding lives: the strategy for adults with Autism in England** and **Think Autism**. There are also some recent guidelines produced by the National Institute for Health and Care Excellence (NICE). These are aimed at addressing regional variations in the diagnosis and treatment of Autism Spectrum Conditions.
- Because Autism Spectrum Conditions are so common (there are an estimated 500,000 people on the Autism Spectrum in England) the strategy aims to address Autism in the widest ranging manner possible.
- The National Strategy can be seen as an attempt to level the playing field and address longstanding social inequalities experienced by people with Autism Spectrum Conditions. It promotes better care and support, human rights, awareness and inclusivity.
- Among the measures put forward in The National Strategy is the development of a range of services and support tailored specifically to the needs of people on the Autism Spectrum. Everyday public services must also take steps to accommodate people with these conditions. The strategy aims to promote greater independence among people who have Autism Spectrum Conditions using tools such as personal care budgets. This allows people to purchase care and support that are appropriate to their needs.

**Read more about this legislation and policy on pages 17-23**

## The Healthwatch Southend Asperger's Event

- On the 18<sup>th</sup> February, 2014, Healthwatch Southend held a public event that focused on services for people with Asperger Syndrome. Autism was also discussed at the event.
- There were speakers at the event from Supporting Asperger Families in Essex (SAFE) and the National Autistic Society. A talk was given by local writer, Julian Lemel, who has Asperger Syndrome. Also present were representatives from Southend Borough Council, Southend Hospital and the South Essex Partnership University NHS Foundation Trust (SEPT).
- The event was attended by members of the public who either had personal experience of Autism or Asperger's, or who were family members of people with Autism Spectrum Conditions.

They expressed confusion and frustration at the current dearth of services available for people with Autism Spectrum Conditions and the lack of information and support. Concerns were raised regarding:

- A lengthy and sometimes arbitrary path to diagnosis.
- An absence of information and support before and after diagnosis. Some also felt that they had been dealt with insensitively.
- It was suggested that people with Autism Spectrum Conditions might benefit from existing services that are currently available for people who have Learning Disabilities. At present they are unable to access these services because they do not meet the criteria for inclusion.
- The Jobcentre was mentioned on numerous occasions and was not regarded as a supportive place.
- A lack of awareness of the difficulties being faced by people who have Autism Spectrum Conditions. One person commented that the social exclusion of people with Autism and Asperger's is rooted in a system that does not recognise their needs or take steps to accommodate them, or include them in decision making processes.

**Read more about the Asperger's Event on pages 24-28**

# Developments since the Healthwatch Southend Asperger's Event

## Immediate impact

- Following the Healthwatch Southend Asperger's Event, Supporting Asperger Families in Southend (SAFE) were invited by Southend Borough Council to have a representative on the Learning Disability Partnership Board. This was intended as an interim position while an Autism Partnership Board was established.

**Read more on page 28**

## Training

- Southend Borough Council and SAFE both identified staff training as integral in opening up public services to people with Autism Spectrum Conditions.
- SAFE said that training must include those who work in mental health or medical professions, council staff and those who work for public services such as the Jobcentre. They pinpointed staff who carry out community assessments as being a priority for training. These assessments may result in a person being given a personal budget that they can use to buy care and support services.
- The Council has started training staff to work with people who have Autism Spectrum Conditions. They said that staff members who carry out social care assessments will be included in this training.
- The council stated that in focusing on improving services for people with Autism Spectrum Conditions they would seek to work in partnership with other organisations, including those in the voluntary sector.

**Read more on training on pages of this report 29-30**

## The possibility of services for people with learning disabilities being made available for people with Autism Spectrum Conditions

- SAFE has stated that people with Asperger's would benefit from existing services that are currently available to people with Learning Disabilities. Most people with Asperger's do not qualify for these services.
- The GP health checks for people with Learning Disabilities were identified by SAFE as a service that people with Asperger's might benefit from. Healthwatch Southend has carried out work around these health checks as a separate issue. We do not believe this suggestion to be feasible at present, as it would entail redesigning the service at a national level, and would involve the renegotiation of contracts with the GPs and healthcare providers who deliver the service. Healthwatch Southend has pledged to raise the issue of Autism and Asperger's patients being made eligible for the health checks if the service is redesigned in the future.
- The Council acknowledged that some people who have Autism may also have a Learning Disability. They said that in such cases they try to take a person-centred approach to care that takes into account the needs of individual. However they said that, for the purposes of planning and achieving service objectives, they regarded Autism and Learning Disabilities as different issues which they are dealing with in different ways. They said that the foundation of an Autism Partnership Board will help to address Autism awareness and develop services that better meet the needs of people with Autism Spectrum Conditions and affect wide-ranging change. Their commitment to improving services for people with Autism is intended to be in line with the national strategy.

**Read more about this issue on pages 31-33**

### The Autism Partnership Board

- Throughout 2014 and 2015, Southend Borough Council has been developing an Autism Spectrum Conditions Strategy in line with the National Strategy. It is hoped this will act as foundation for a coherent and wide-ranging approach to broadening awareness of Autism, for

developing services for people with Autism Spectrum Conditions and for making public services more accessible.

- An Autism Partnership Board has been established. This will play a key role in the development of the local Autism Strategy and in the development of services.
- The first meeting of the Southend Autism Partnership Board took place on December 9<sup>th</sup>, 2014. At this meeting the terms of reference were discussed along with the make up of the board.
- In addition to representation from the council and SAFE, the board will also include parties from healthcare and mental healthcare services and from the third sector. Southend Clinical Commissioning Group will also have a part on the board. The views of local people with Autism Spectrum Conditions are expected to play a significant role in the Autism Partnership Board, giving them a voice in the development of services. The meeting of the board on December 9<sup>th</sup> was attended by people with Autism who gave their views.

**Read more about the Autism Partnership Board on pages 33-37**

## Funding for local projects

- In August Southend Borough Council and SAFE worked together on a bid for government funds that had been made available to support innovation in Autism services and increase awareness of the condition. Unfortunately the bid was unsuccessful on this occasion.
- In Autumn, 2014, SAFE working in partnership with another local charity - Trust Links - was successful in securing government funding for a project. The funding will be put towards a converted shipping container classroom. This bid was administered by the local authority on the basis that it would lead to improved outcomes for peoples with Autism.

**Read more about the bids for funding on pages 37-39**

## Developments at Southend Hospital

- Southend Hospital responded to some comments made by SAFE at the Healthwatch Southend Asperger's Event and made changes that will improve the experience of people with Autism when they visit the hospital. SAFE praised the can-do attitude demonstrated by the staff who helped to bring about the changes.

**Read more about Southend Hospital on pages 39-40**

---

## The SEPT Asperger's Service

- The SEPT Asperger's Service (sometimes referred to as the Basildon Asperger's Service) has an excellent reputation. SAFE described it as “the first service we have encountered that really understands Asperger's.”
- The service covers adults aged between 18 and 30. The primary focus of the service is assessment and diagnosis. They also offer some support and intervention. They do offer signposting to other services for people who fall outside of the age range and try to offer limited support if their needs can't be met elsewhere. The waiting list for assessments is over a year. The service is working with local CCGs to reduce waiting times.
- The service currently operates on a small scale and employs a small number of part-time staff.
- They host a monthly invitation-only reading group. They also run/facilitate a running/athletics group and a sports confidence group which are open to the public.
- A representative from the service described to Healthwatch Southend in detail the ways in which they would develop if given the opportunity.

**Read more about the SEPT Asperger's Service on pages 40-45**

## The Jobcentre

- The Jobcentre was mentioned on a number of occasions at the Healthwatch Southend Asperger's Event. It was not regarded as a supportive environment for people with Autism. Some parents said that their children were not claiming benefits as the process was too stressful.
- The Jobcentre at Southend told us that they do adhere to the equality act when working with people with Autism. This includes making reasonable adjustments for people affected by these conditions.
- Specialist Disability Employment Advisors at the Jobcentre in Southend have received Autism Spectrum awareness training and have built up working relationships with organisations who work with people on the Autism Spectrum.
- The Jobcentre told us that there were no specific programmes aimed at improving employment prospects for people with Autism Spectrum conditions. However there is a programme for people with disabilities called Work Choice that could help.
- The Jobcentre told us they were currently engaged in a review of services for disabled people in the Essex Jobcentre Plus District. Part of this review would involve developing stronger relationships between local authorities and the third sector.
- The SEPT Asperger's Service reported some working links with Southend Jobcentre. Their Occupational Therapist was recently involved a Condition Management Programme.
- Southend Council have said it is likely that representatives from the Jobcentre will be invited to attend future meetings of the Autism Partnership Board.
- The responses we received from the Jobcentre date to October 2014.

## Feedback on the Jobcentre from people with Asperger's

- SAFE provided Healthwatch with some accounts from its members regarding their experiences of the Jobcentre or the experiences of family members with Asperger's.

- In general the Jobcentre was not viewed positively with some distressed and disillusioned by their experience of the service. Some people had initially received support from a member of staff, only to lose it when that member of staff retired or moved on. One person said that they had been well supported, had been treated with empathy and had generally been given good advice.

Read more about the Jobcentre on pages 45-51

---

## Conclusions

- Most of the progress that has been made in evolving services for people with Autism Spectrum Conditions in 2014 was focused on developing an Autism Strategy and the founding of Autism Partnership Board. This process has been informed by the National Autism Strategy.
- Healthwatch Southend was informed that some initiatives are already underway. These are based around the training of council staff and increasing the rate of employment for people with Autism Spectrum Conditions. However these are still in the early stages.
- It is important that good quality services already operating in Southend (such as the SEPT Asperger's Service) are recognised and allowed to grow and develop subject to funding being available.
- Southend Borough Council is likely to find itself increasingly working in partnership with the third sector and drawing on the broad range of experience and expertise held by these organisations. It is important that these organisations receive appropriate support so they are able to effectively fulfil their new roles and responsibilities.
- The Autism Partnership Board will act as a forum where representatives from public services can be invited to attend and discuss the ways they could increase accessibility and user-friendliness for people with Autism Spectrum Conditions. It is hoped that this will bring about far-reaching change in Southend.

- Services for people with Autism and Asperger's in Southend will continue to evolve over 2015. Healthwatch Southend will monitor the progress of these developments.

**Read the conclusion to this report on pages 51-55**

---

# Building foundations for change: Developing Autism and Asperger's services in Southend

---

## Full Report

### Contents

|                                                                                                                                                                   |    |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Introduction .....                                                                                                                                                | 12 |
| How we gathered the information for this report .....                                                                                                             | 14 |
| The scope of this report.....                                                                                                                                     | 17 |
| Background.....                                                                                                                                                   | 17 |
| A brief summary of the Autism Act 2009, the National Autism Strategy and the current NICE guidelines on Autism.....                                               | 17 |
| A summary of the public discussion at the Healthwatch Southend Asperger Event                                                                                     | 24 |
| Developments since the Asperger's Event.....                                                                                                                      | 28 |
| Progress on the Learning Disabilities Partnership Board.....                                                                                                      | 28 |
| The importance of staff training in opening up public services for people with Autism Spectrum Conditions .....                                                   | 29 |
| The possibility of opening up Learning Disability services to accommodate people with Asperger Syndrome .....                                                     | 31 |
| Feedback from the council on the distinction between services for people with Learning Disabilities and services for people with Autism Spectrum Conditions ..... | 32 |
| The formation of an Autism Partnership Board .....                                                                                                                | 33 |
| Securing funding for local projects.....                                                                                                                          | 37 |
| Successful bids for funding.....                                                                                                                                  | 38 |

|                                                                                  |    |
|----------------------------------------------------------------------------------|----|
| Developments at Southend Hospital.....                                           | 39 |
| The SEPT Asperger’s Service: a model for quality care in Southend.....           | 40 |
| The Jobcentre.....                                                               | 45 |
| The response from Southend Jobcentre .....                                       | 47 |
| Feedback on the Jobcentre from local people with Asperger’s and their families . | 48 |
| The Autism Partnership Board and the Jobcentre .....                             | 50 |
| The SEPT Asperger’s Service and the Jobcentre in Southend.....                   | 50 |
| Conclusion .....                                                                 | 51 |
| Thank you .....                                                                  | 56 |
| About Healthwatch Southend .....                                                 | 56 |

**Links to relevant websites and documents mentioned in this report can be found in the footnotes. These links were checked prior to publication. Healthwatch Southend does not accept responsibility for the content of these websites.**

---

## Introduction

---

Since January 2014, Healthwatch Southend has hosted regular public meetings where we focus our attention on a single health or social care issue. In selecting topics for these events we gravitate towards those areas where members of the public have raised concerns about services, or where we know that there are problems.

These events are usually structured around short presentations given by a panel of three or four speakers. We invite people who are involved either in the commissioning or the provision of a given service, along with representatives from relevant charities or support groups. Where appropriate we try to include a service user as one of the speakers. Occasionally representatives from NHS England also attend and give presentations.

Towards the end of each event there is an open session where members of the public are invited to ask questions, share their experiences, raise concerns and make suggestions.

The meetings provide an opportunity for residents of Southend to hear from the people who plan, commission and provide health and social care services in the local area, and to address them directly.

The professionals in attendance get to hear the first-hand experiences of those members of the public who use these services. This can provide them with an insight into how well a given service is performing and where improvements could be made.

Healthwatch Southend organises these meetings in the hope that what is discussed will contribute towards the development of health and social care in the local area and ensure that the services that are available are tailored to meet the needs of residents.

On the 18th February, 2014, Healthwatch Southend held an event that examined the range and the quality of services that were available locally for people with Asperger Syndrome. During an occasionally fraught question and answer session, people with Autism Spectrum Conditions and their families shared their experiences and frustrations. As the criticisms piled up, it became obvious that there were significant gaps in the provision of care and that existing services were over-stretched and unable to keep pace with the current demand. It was clear that some of the people who addressed the panel were deeply affected by the stresses and strains of their situation, and by what they felt was an absence of support. There was, at times, an air of desperation in the room.

The concerns raised by members of the public were not confined to a single issue but ranged from dismay at the long wait for a diagnosis, confusion over where to go for information and support, consternation at the lack of services for people with Autism Spectrum Conditions, and annoyance at the difficulties and obstacles faced by people with these conditions when interacting with everyday public services.

Despite the many problems that were aired during the discussion and the dissatisfaction expressed by some members of the public, there was cause for a degree of optimism:

The Asperger's Event was well attended by a broad range of local health and social care professionals and by representatives from Southend Borough Council. During and after the event, Healthwatch Southend observed a number of these individuals, some of whom had not previously met before, engaged in animated conversation. We came away from the meeting with a sense that the people who were responsible for Autism and Asperger's services in Southend were motivated and committed to making changes and improvements.

Healthwatch Southend resolved to monitor the actions that were being taken locally to address the issues that had been raised at the event. We did this with the understanding that we would return to Autism and Asperger's at a later date and report on any progress that had been made.

---

## How we gathered the information for this report

---

In September, 2014, Healthwatch Southend contacted Southend Borough Council with a list of questions. These focused on the local Autism strategy and on the issues that had been raised at the Asperger's Event.

We received a detailed response to our initial inquiries from Glyn Jones, Learning Disabilities Strategy & Commissioning Manager, at the council. Glyn Jones subsequently became our point of contact at Southend Council on this particular issue.

Healthwatch Southend has also been engaged in an ongoing conversation with the charity Supporting Asperger Families in Essex (SAFE)<sup>1</sup>. Jane Neale, Chair of SAFE South Committee, was one of the speakers at the Healthwatch Southend Asperger Event. Following the event, SAFE was invited to represent people with Autism and Asperger's on the Southend Learning Disability Partnership Board. This offer was made with the expectation that SAFE would eventually play a role on an Autism Partnership Board that was to be established by the council. At the time of writing the Autism Partnership Board has been founded and includes a representative from SAFE.

The dual perspectives provided by Southend Council and SAFE are used here to chart the development of the local Autism strategy. It is hoped that this strategy will have a wide-ranging positive effect on the care and support provided for people with Autism Spectrum Conditions in Southend.

One of the issues raised at the Asperger's Event concerned the difficulties that people with Autism Spectrum Conditions were experiencing at the Jobcentre.

---

<sup>1</sup> Supporting Asperger Families in Essex) is a group made up mostly of volunteers who are either adults with Asperger's or who care for a family member with Asperger's... (continues) ...They campaign for better services, provide assistance to those who are seeking a diagnosis, and offer help and support post-diagnosis: [Link](#)

Initially Healthwatch Southend was uncertain as to whether issues surrounding employment would be covered by the work that was being carried out by the Council as part of the Autism strategy.<sup>2</sup>

Because we felt that the concerns that had been raised about the Jobcentre needed to be addressed we submitted a freedom of information request to the Jobcentre in Southend, on Tylers Avenue. The request consisted of five questions relating to points that were raised during the discussion at the Asperger Event.

We passed on the response we received from the Jobcentre to SAFE.

SAFE subsequently consulted their membership in Southend and then sent Healthwatch Southend some written accounts from local people with Autism Spectrum Conditions relaying their experiences of using the Jobcentre.

The Jobcentre is presented in this report as an example of how an everyday public service currently accommodates people with Autism Spectrum Conditions; how it works both internally and in collaboration with other organisations to improve the service it provides for people with these conditions, and whether these attempts have been successful. In the conclusion of this report we consider the ways in which input from the Autism Partnership Board might help to improve the service.

We contacted Sarah Haines - a Specialist Nurse for Learning Disability at Southend Hospital - to confirm details of the steps that had been taken to make the hospital a more accommodating place for people with Autism Spectrum Conditions. We had learned of these developments third-hand and wanted to establish that what we had read and been told was accurate.

We forwarded a list of questions to a representative from the South Essex Partnership University NHS Foundation Trust (SEPT) Asperger's Service (sometimes referred to as the Basildon Asperger's Service), which works with adults in Southend and is well-regarded by service users and by SAFE. The questions we asked focused on the type of care and support that the service provides, the challenges it faces, and how those who run it would like to see it develop. The SEPT Asperger's Service is presented in this report as an example of a good quality, well-managed programme of care and support that is already available to some residents in Southend.

---

<sup>2</sup> Healthwatch Southend was later informed that issues surrounding employment and the Jobcentre will be discussed by the Autism Partnership Board

Additional information was drawn from the

- Healthwatch Southend Asperger's Report<sup>3</sup>
- The Autism Act 2009<sup>4</sup>
- Fulfilling and rewarding lives: the strategy for adults with autism in England<sup>5</sup>
- Think Autism - Fulfilling and rewarding lives, the strategy for adults with autism in England: an update<sup>6</sup>
- NICE Quality standards QS51<sup>7</sup>

An early draft of this report was sent to the following organisations:

- Southend Clinical Commissioning Group
- Southend Council
- Supporting Asperger Families in Essex (SAFE)
- A representative from the SEPT Asperger's Service

This was done in the interests of ensuring that the content these organisations had provided for the report had been presented in a manner that was factual and accurate and did not misrepresent information.

During this review process we also sought clarification from SAFE on a bid for government funding that had been made jointly with Southend Council. It was felt that Healthwatch Southend did not have a full understanding of the bid and required further information. As part of their response SAFE provided Healthwatch Southend with information on another successful bid for government funding which they had made jointly with a local organisation called Trust Links<sup>8</sup>.

In sending out draft copies of this report for review Healthwatch Southend has taken care to state our independence and to stress that the conclusions that we draw in our reports are our own.

---

<sup>3</sup> Healthwatch Southend Asperger Event Report (the following link directs to the Asperger Event page on the Healthwatch Southend website where the report can be downloaded): [Link](#)

<sup>4</sup> The Autism Act 2009: [Link](#)

<sup>5</sup> Fulfilling and rewarding lives: the strategy for adults with autism in England: [Link](#)

<sup>6</sup> Think Autism - Fulfilling and rewarding lives, the strategy for adults with autism in England: an update: [Link](#)

<sup>7</sup> NICE Quality Standards - QS51 Autism: [Link](#)

<sup>8</sup> Trust Links is an local charity enabling people to work together to improve mental health and well-being and promote, support, inspire and cultivate wellness and sustainable living.: [Link](#)

---

## The scope of this report

---

This report updates on the progress that has been made in developing services for people with Autism Spectrum Conditions in the Southend area, and in increasing awareness of these conditions.

It follows on from a report that was written after the Healthwatch Southend Asperger Event in 2014, and forms part of an ongoing commitment by Healthwatch Southend to monitor areas where concerns have been raised by members of the public, and to ensure that these concerns are addressed and lead to improvements.

Over a year has past since the Healthwatch Southend Asperger's Event. During that time Southend Borough Council has developed its local Autism strategy and has now reached a stage where it is now beginning to act upon its plans to improve care and support for people affected by these conditions. The proposed Southend Autism Partnership Board has been established and met in December 2014 to discuss terms of reference and the composition of the board.

Bearing all that in mind, now seems like an appropriate time to draw this chapter to a close, to pass on what we have learned, and to consider what our focus should be in the future when addressing Autism and Asperger's.

---

## Background

---

### **A brief summary of the Autism Act 2009, the National Autism Strategy and the current NICE guidelines on Autism**

This section briefly summarises three documents that, taken together, embody the national strategy for the development and improvement of services for people with Autism Spectrum Conditions.

These are

- The Autism Act 2009<sup>9</sup>
- Fulfilling and rewarding lives: the strategy for adults with autism in England<sup>10</sup>
- Think Autism - Fulfilling and rewarding lives, the strategy for adults with autism in England: an update<sup>11</sup>

Supplementary to this policy, The National Institute for Health and Care Excellence (NICE) have developed a set of benchmark standards for the care and support of people with Autism Spectrum Conditions.<sup>12</sup>

Links to government websites hosting downloadable copies of these documents can be found in the footnotes. *Fulfilling and rewarding lives* and *Think Autism* are available as ‘easy read’ and ‘blue and yellow colour contrast’ versions.

The following should not be regarded as a comprehensive breakdown of the legislation and guidance on Autism and Asperger’s. Our intention here is to communicate the core principles of the government’s current strategy on this issue.

## The Autism Act 2009

Under the Autism Act 2009, the Secretary of State was required to develop a strategy for meeting the needs of adults in England with Autistic Spectrum Conditions.

This included providing statutory guidance to local authorities and the NHS covering the following areas:

- “(a) The provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- (b) The identification of adults with such conditions;
- (c) The assessment of the needs of adults with such conditions for relevant services;

---

<sup>9</sup> The Autism Act 2009: [Link](#)

<sup>10</sup> Fulfilling and rewarding lives: the strategy for adults with autism in England: [Link](#)

<sup>11</sup> Think Autism - Fulfilling and rewarding lives, the strategy for adults with autism in England: an update: [Link](#)

<sup>12</sup> NICE Quality Standards - QS51 Autism: [Link](#)

- (d) Planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;
- (e) Other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- (f) The training of staff who provide relevant services to adults with such conditions;
- (g) Local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.”<sup>13</sup>

This guidance is to be kept under review and revised where necessary.

There is a legal obligation by local authorities and the NHS to follow this guidance.<sup>14</sup>

## Fulfilling and Rewarding Lives

In March 2010, the government outlined its National Autism Strategy in a document titled **Fulfilling and rewarding lives: the strategy for adults with autism in England**.

The authors recognised that “adults with autism remain socially and economically excluded” and laid out plans to address this issue in a strategy “underpinned by the fundamental principles of equality and human rights.”

The strategy focuses on

- The right of people with Autism Spectrum Conditions to an assessment of need from social services.
- People with Autism Spectrum Conditions being given the same opportunities in education as everyone else.
- People with Autism Spectrum Conditions being given support and assistance to get a job and stay in work.
- People with Autism Spectrum Conditions having the freedom to choose where they want to live.

---

<sup>13</sup> Autism Act 2009 (2. Guidance by Secretary of State - Section 5): [Link](#)

<sup>14</sup> The National Autistic Society - Statutory Guidance: [Link](#)

- People with Autism Spectrum Conditions having the opportunity to develop relationships and social networks.
- Ensuring that people with Autism Spectrum Conditions have their health needs met properly and appropriately.
- The right of people with Autism Spectrum Conditions to be safe from hate crime and discrimination.
- Ensuring that people with Autism Spectrum Conditions live in a society where they are respected and accommodated.
- Support for people with Autism Spectrum Conditions that provides them with an opportunity to live independently as possible.<sup>15</sup>

The strategy makes a commitment towards increasing the awareness and acceptance of Autism. It states that “as a minimum, Autism awareness should be included as part of general equality and diversity training across the public sector” and that there should be an increase in related training for those working in health and social care.

It recognises that work needs to be carried out “to develop a clear, consistent pathway for diagnosis of Autism” and that, following on from a diagnosis, services need to be made available that support people with the condition.

On this issue the strategy says:

**“The NHS and Community Care Act 1990 places a duty on local authorities to assess a person who may be in need of community care services. Diagnosis of autism is a reason for such an assessment - and needs to be recognised as such.”<sup>16</sup>**

In addition to these tailored services, the strategy recognises that people with Autism Spectrum Conditions should have equal access to, and benefit from, public services and support that will allow them the opportunity to live independently in their communities. There is a duty under current equality and human rights legislation to ensure that these services have the capacity and the capability to make reasonable adjustments to accommodate people with Autism Spectrum Conditions.

---

<sup>15</sup> Fulfilling and rewarding lives: the strategy for adults with autism in England (Page 13): [Link](#)

<sup>16</sup> Fulfilling and rewarding lives: the strategy for adults with autism in England (Page 20): [Link](#)

The strategy acknowledges that steps need to be taken to “increase individuals’ involvement in assessing their own care needs, and to give them greater choice and control in planning the kind of care available.” It is thought that one way of achieving this will be through personal care budgets that allow people the freedom to purchase services that will be of most benefit to them.

Finally, there is a recognition that “adults with Autism are significantly under-represented in the labour market” and that a broader approach to employment will be required; one that focuses not only on entry into work, but also on retaining a job, developing skills, and career progression.

## Think Autism

In April, 2014, the government published a policy document titled **Think Autism - Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update**.

The purpose of this paper was to review the Autism strategy and to set priorities for the future. The authors acknowledged that, since 2010, the foundations for change have been laid and there have been some early success stories. However they counselled that there was still a long way to go in bringing about the kind of wide-ranging social change described in the national strategy.

*Think Autism* identified a number of priorities for action, all focused on promoting a greater awareness and acceptance of Autism:

These include:

- Ensuring that people with Autistic Spectrum Conditions receive a timely and professional diagnosis, that they are able to make connections with Autism peer groups and other forms of community-based support and that their families have easy access to information and assistance.
- Taking steps to ensure that people with Autism Spectrum Conditions feel safe in their communities and are able to pursue lives free from the risk of discrimination and abuse. Also, that they are regarded as complex and unique individuals, rather than being defined solely in terms of their condition.
- The inclusion of Autism as a consideration in local strategic needs assessments so that appropriate health, care and support services, that meet genuine needs, can be developed. *Think Autism* emphasises the

importance of the views and aspirations of people with Autism Spectrum Conditions being taken into account when decisions are made about these local services.

- Ensuring that staff working for public services are aware and accepting of Autism and have an understanding of how the condition affects people, particularly in stressful situations. This heightened awareness should go hand in hand with encouraging the providers of everyday services to make reasonable adjustments for people with Autism Spectrum Conditions. The criminal justice system is highlighted as a public service that should be encouraged to consider Autism and how it might work with other services when approaching this issue.
- Ensuring that people with Autism Spectrum Conditions have the same opportunities to develop skills and remain as independent as possible. This may entail providing them with support to obtain a job and also giving some thought to the role that employers can play in helping people on the Autism spectrum to remain in the workforce.<sup>17</sup>

*Think Autism* points out that there are an estimated 500,000 people on the Autistic spectrum in England and that everyday services will already be engaging with people who are affected by these conditions. Thought should be given as to how these services interact with people who have Autism and the reasonable adjustments and adaptations that can be made to accommodate them.<sup>18</sup>

## NICE quality standards

In addition to the Autism Act 2009 and the government's National Autism Strategy, there is also some recent guidance focusing on this area:

In January, 2014, The National Institute for Health and Care Excellence (NICE)<sup>19</sup> released a list of eight quality standards that were aimed at improving the care of people with Autism Spectrum Conditions<sup>20</sup>:

---

<sup>17</sup> Think Autism - Fulfilling and rewarding lives, the strategy for adults with autism in England: an update (page 7): [Link](#)

<sup>18</sup> Think Autism - Fulfilling and rewarding lives, the strategy for adults with autism in England: an update (page 45): [Link](#)

<sup>19</sup> NICE is responsible for developing guidance and quality standards in health and social care. Although they are ultimately accountable to the Department of Health they are classified as a non-department public body and operate independently of the government: [Link](#)

These are as follows:

**“Statement 1:** People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

**Statement 2:** People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

**Statement 3:** People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

**Statement 4:** People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

**Statement 5:** People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

**Statement 6:** People with autism are not prescribed medication to address the core features of autism.

**Statement 7:** People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

**Statement 8:** People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.”

These quality standards were developed by NICE to address variations in the diagnosis and treatment of Autism Spectrum Conditions in different regions of the country. Their aim is to set a benchmark for care and support provided to those affected by these conditions.

---

<sup>20</sup> NICE Quality Standards - QS51 Autism: [Link](#)

# A summary of the public discussion at the Healthwatch Southend Asperger Event

The following sections summarise the public discussion that took place at the Healthwatch Southend Asperger Event on the 18<sup>th</sup> February, 2014.<sup>21</sup>

## (i) Diagnosis

The event was attended by several members of the public who either had personal experience of Autism or Asperger's, or who were family members of people with Autism Spectrum Conditions.

Many had found diagnosis to be a lengthy, confusing and frustrating process.

Diagnosis of children was often uncoordinated and arbitrary. No two people at the event reported having gone through quite the same process. Pathways to diagnosis were not clear and many had been left with no support or guidance regarding who to contact for information.

A number of people reported that their children were given several different diagnoses over many years, prior to being diagnosed with an Autism Spectrum Condition. Concerned parents were often dealt with insensitively. One person said:

**"I raised Asperger's as a possible cause for my child's challenging behaviour and was accused by medical professionals of having Munchhausen Syndrome by Proxy."**

Another suggested that schools could play a role in identifying children who might have Autism Spectrum Conditions and that this might result in an earlier diagnosis.

Diagnosis for adults was also problematic. One person said:

**"My son is 39 and has been on the waiting list for almost a year for a diagnosis and assessment."**

---

<sup>21</sup> Healthwatch Southend Asperger Event Report (the following link directs to the Asperger Event page on the Healthwatch Southend website where the report can be downloaded): [Link](#)

A representative from the South Essex Partnership University NHS Foundation Trust (SEPT)<sup>22</sup> clarified the diagnostic process for Autism Spectrum Conditions in Southend:

**“[for children living] 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 Asperger’s service in SEPT if appropriate.”**

## **(ii) Support**

Support following diagnosis was also a problem with many reporting a lack of easily available information, or any indication of where they could go for advice.

One person said:

**“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.”**

Another commented:

**“When I have been in crisis with my two adult sons there was no help available.”**

Where support was in place it was sometimes co-opted or used inappropriately. A parent said:

**“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.”**

---

<sup>22</sup> South Essex Partnership University NHS Foundation Trust (SEPT): [Link](#)

### (iii) Access to services

The discussion highlighted significant gaps in services and a high demand for the services that are available.

It was pointed out that there are already services in existence for people with Learning Disabilities that people with Asperger's might benefit from. However they are unable to access these services because they do not qualify for inclusion under the current criteria.

Another issue raised was the hospital passport<sup>23</sup> which is designed to assist people with Learning Disabilities visiting Southend Hospital. Concerns were expressed that this did not cover people with Asperger's.

Sarah Haines - a Specialist Nurse for Learning Disability at Southend Hospital - said:

**"Under the Equality Act we can make reasonable adjustments. The hospital passport doesn't exclude anybody."**

A lack of support sometimes resulted in people with Autism Spectrum Conditions missing out on opportunities to develop skills. One person said:

**"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."**

The Jobcentre was mentioned on several occasions by panel members and people in the audience. It was not seen as a supportive place. We were told that staff there lacked an understanding of how to engage with people who have Autism Spectrum Conditions.

Two parents in the audience said that their children were not claiming benefits as the process was too stressful.

One person said:

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

---

<sup>23</sup> The Southend Hospital Patient Passport: [Link](#)

It was thought likely that people with Autism Spectrum Conditions might form part of the hidden unemployed, not appearing on government records because they do not claim state assistance.

Addressing these comments on the lack of services, Tom Purser, from the National Autistic Society (NAS)<sup>24</sup>, said:

**"Regarding the Autism Bill; 'Fulfilling & Rewarding Lives' and NICE guidelines: It is law that each authority has an Autism/Asperger's service."**

He referred to the 'Push for Action'<sup>25</sup> campaign which people could sign up to on the National Autistic Society website.

#### **(iv) Awareness and influence**

There was a feeling in the room that a lack of understanding of Autism Spectrum Conditions might be holding back progress.

One person said:

**"There needs to be greater awareness of Asperger's. People don't realise the difficulties involved in trying to manage your lives."**

Another remarked:

**"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."**

One person suggested:

**"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."**

---

<sup>24</sup> The National Autistic Society: [Link](#)

<sup>25</sup> Push for Action: [Link](#)

Glyn Jones, Learning Disabilities Strategy & Commissioning Manager at Southend Borough Council, stated that the council was currently consulting on its Autism Strategy and that input would be required at this stage.

It was pointed out that the present service for Autism and Asperger's was set up in 2009, prior to the government's National Autism Strategy, and that the service would be reviewed in the near future.

---

## Developments since the Asperger's Event

---

### Progress on the Learning Disabilities Partnership Board

One immediate impact of the Healthwatch Southend Asperger Event was the formation of a closer working relationship between Southend Borough Council and the charity sector:

A few days after the event, Healthwatch Southend was contacted by Supporting Asperger Families in Essex (SAFE)<sup>26</sup>. They told us that:

**“Following the Healthwatch event last Tuesday, after years of campaigning for a voice in Southend Borough Council, SAFE have been invited to have a representative on the Learning Disability Board with a view to setting up an Autism Partnership Board.”<sup>27</sup>**

Southend Borough Council informed Healthwatch Southend that SAFE's seat on the Learning Disability Partnership Board was intended as an interim position while the Autism Partnership Board was established.

They told us:

**“This was done in goodwill and we recognised that SAFE's contributions were useful and helped to further amplify the voice of people with Asperger's which did inform the development of the Autism Partnership Board.”**

---

<sup>26</sup> Supporting Asperger Families in Essex: [Link](#)

<sup>27</sup> The Southend Learning Disability Board: [Link](#)

Healthwatch Southend has remained in regular communication with both SAFE and the Council and has occasionally requested updates on the progress that has been made in developing Autism and Asperger's services.

In November, 2014, we asked Jane Neale (SAFE) whether having a seat on the board had been beneficial.

She reported that her time on the board had been "hard going and frustrating" and that she had been vocal in raising issues.

She also commented that while SAFE had initially been welcomed on the Learning Disability Partnership Board, it was considered by some that this forum was not an appropriate place to discuss Asperger's.

She told us that, at a council meeting in September, 2014, it was agreed that progress needed to be made in establishing an Autism Partnership Board.

Consequently a six weekly meeting was set up between SAFE and the Council to move things forward. Jane Neale (SAFE) described these meeting as "useful" and told us that they are continuing at present.

Having a seat on the board does appear to have been beneficial in terms of raising awareness of Asperger's. Jane Neale (SAFE) told us:

**"In October I was finally able to do a short presentation on Asperger's and the problems they face and the help they need. This was very well received and has led to a number of requests for me to speak to members on the board and their sections further."**

## **The importance of staff training in opening up public services for people with Autism Spectrum Conditions**

Supporting Asperger Families in Essex (SAFE) has identified better staff training as a vital component in making a broad range of services more accessible for people who have Autism Spectrum Conditions:

They mentioned mental health care as an area where Autism-focused training is essential. They also stressed the importance of an awareness and knowledge of Autism among medical staff.

They highlighted the need to educate and train all council staff on the issues affecting people who have Autism or Asperger's. Jobcentre staff were mentioned as an example of people working for a public service who required training to work with people who have Autism Spectrum Conditions.

SAFE pinpointed training of those staff who carry out community assessments as being a priority. These assessments are important as they may result in people being given a personal care budget that they can use to buy services.

A representative from SAFE said:

**“If the Council are not assessing properly they are not giving help to those in need and are unaware of the numbers requiring assistance.”**

In an email dating from October, 2014, Glyn Jones, Learning Disabilities Strategy & Commissioning Manager, at Southend Borough Council told Healthwatch Southend:

**“We are starting to initiate training which will give staff the competences to work with people with Autism Spectrum Conditions including Asperger's. This will enable services to open their offer to a wider group of people. The criteria will be flexible to respond to people's level of need. Staff members who do the social care assessments will also be a part of this training.**

**“There are also some specialist services for Southend-on-Sea residents with Asperger's. We think that the demand for services is much greater than the supply of services and so more consideration needs to go into thinking about how we develop and fund these.”**

The council stated that in focusing on improving services for people with Autism Spectrum Conditions they would seek to work in partnership with other organisations, including those in the voluntary sector.

## The possibility of opening up Learning Disability services to accommodate people with Asperger Syndrome

A lack of services for people with Autism and Asperger's in Southend was discussed at length during the Healthwatch Southend event.

We were made aware of existing services that are currently being offered to people with Learning Disabilities. It was felt by some members of the public who were present at the event that people with Asperger's might benefit from these services, but could not access them at present because they did not meet the criteria for inclusion.

In an email to Healthwatch Southend, Jane Neale, Chair of the Supporting Asperger Families in Essex (SAFE) South Committee, said:

**“We just want to have fair access to services and for officers to consider us when they are developing a service.”**

In September 2014, we asked Jane Neale (SAFE) whether any progress had been made in opening up some of these services to people with Autism or Asperger's. She responded:

**“It has been a real eye opener being on the [Learning Disabilities Partnership] Board seeing what people with Learning Disabilities do get access to, whilst our people with Asperger's are still very much left out.”**

She said that she “found some board members reluctant to be flexible in their thinking when it came to enabling people with Asperger's to have access to services that were readily available to those with an IQ of less than 70.”

SAFE highlighted the annual GP health checks that are currently offered to people over the age of 14 with diagnosed learning disabilities, as a service that could also benefit people with Autism Spectrum Conditions. They told Healthwatch Southend:

**“People with autism may experience pain differently and also they may find it difficult to explain what is wrong with them.”**

During 2014, Healthwatch Southend carried out some work on the annual health checks for people with Learning Disabilities. At present these health checks are commissioned by NHS England. They are classified as a direct enhanced service, meaning that they do not form part of the core GP contract but can be taken on by GP practices, or by other healthcare providers, in exchange for additional funds. Healthwatch understands that, in Southend, all GP practices are currently signed up to provide the checks.

There is little likelihood of people with Autism and Asperger's being included in the health checks at present, as this would necessitate significant changes to the service and to pre-existing contracts between NHS England and those healthcare providers who deliver the checks.

If the Learning Disability health checks are re-procured in the future, Healthwatch Southend will contact NHS England and ask that the needs of people with Autism and Asperger's are taken into consideration in the redesign of the service.

## **Feedback from the council on the distinction between services for people with Learning Disabilities and services for people with Autism Spectrum Conditions**

In a bid to understand the division between the services for people with Learning Disabilities and those provided for people who have Autism Spectrum Conditions, Healthwatch Southend asked Southend Borough Council whether they discussed Asperger's and Autism alongside Learning Disability and Mental Health, or if they considered these to be separate issues. Glyn Jones, Learning Disabilities Strategy & Commissioning Manager, at the council, responded:

**“If both Autism Spectrum Conditions and Mental Health and Learning Disabilities are all present in one person then the objective will be to achieve the best outcomes for that person.**

**“We increasingly want that any representative of the council will see the whole person, so in that respect, they are not separate issues. There is much to learn both locally and nationally about the relationship of these conditions and how to work with people**

to get the best response. It is a challenge for services to respond optimally to these conditions which we hope greater training and awareness will address. Whether in the council or the wider community, we want approaches to be person centred and holistic.

“For purposes of planning and achieving service objectives we do think they are different issues which we are dealing with in different ways.

“It is with the recognition of different issues that we will be setting up an Autism Partnership Board. It will have a very different agenda to the Learning Disability Partnership Board, even though many people with a Learning Disability also have an Autism Spectrum Condition. One of the key objectives of the Autism Partnership Board will be Autism Awareness in the wider community and the building up of provision across all sectors that better meet needs where historically there has been a gap.

In the interim period, before setting up the Autism Partnership Board, representation for people with Autism and Asperger’s has been on the Learning Disability Partnership Board. It is through this route that people with Autism Spectrum Conditions and Asperger’s fed into developing a bid for funds for people with Autism.

We have also initiated regular meetings with SAFE to help make sure that engagement continues and improves.”

## The formation of an Autism Partnership Board

In 2014 Southend Council carried out a mapping exercise of the services available to people in Southend with Autism and Asperger Syndrome.

This was intended as a step towards developing a local Autism strategy.

In October, 2014, Healthwatch Southend contacted Glyn Jones, Learning Disabilities Strategy & Commissioning Manager, at the council, requesting information on the progress that had been made on the strategy. He replied:

“The Autism Spectrums Condition Strategy will be completed later in 2014 or in the early part of 2015. A draft was delivered in May 2014.

“The delivery of this draft came before the government’s ‘Think Autism’ Strategy, which changed some key aspects. These changes will be included in the Draft Strategy. Our partners, representing people who have Autism, have rightly guided us to recognise this and we think that an updated strategy in line with new approaches will have a greater impact.

“The strategy will also go to an Autism Partnership Board. We will be scheduling the first meeting for this in December 2014. This will give the Strategy the leverage and influence that it deserves.

“It will then go to formal consultation which will be 12 week period.

“Increasingly, we want to co-produce strategies so that they are more effective in meeting the needs of people.”

Healthwatch Southend asked what would happen once the strategy had been signed-off. In particular we wanted to know what action would be taken as a result of the strategy. The council responded:

“The Autism Partnership Board will play a greater role in the development of the strategy. Its involvement will give the strategy more impact.

“We are drafting a terms of reference for the Autism Partnership Board which will also seek to specify its relationship with the Health and Wellbeing Board<sup>28</sup>, again strengthening its impact.

“The most important members of the Autism Partnership Board are people with Autism Spectrum Conditions.

“The CCG (Clinical Commissioning Group<sup>29</sup>) will also have a part on that Board and there will be other partners on it to achieve a wider response to improve Autism Awareness.

“This wider approach will help to make sure that the right ‘words are turned into action’ and that people with Autism can see that this is happening and that the actions have an impact on people’s lives.

---

<sup>28</sup> Southend Health and wellbeing Board is made up of local statutory organisations and health related partners. They work in partnership to improve health and wellbeing for Southend residents: [Link](#)

<sup>29</sup> Southend Clinical Commissioning Group: [Link](#)

“Some of the actions in the draft strategy, including initiating training and seeking ways to increase employment through a recent bid for funds, are already being undertaken and in a way designed to have continuing learning and impact. This will be picked up by the Autism Partnership Board.

“We will agree with the CCG how the final strategy will go to the CCG for sign off. It will also be signed off by Cabinet.

“It is worth pointing out that we are working with the CCG in the context of the Pioneer project<sup>30</sup> which is helping to integrate health and social care and joint commissioning. This will help us to commission together to remove gaps in provision and communicate services effectively.”

In November, 2014, we asked Supporting Asperger Families in Essex (SAFE) whether any progress had been made in establishing the Autism Partnership Board. They responded:

“Following on from our involvement in the Learning Disability Board, SAFE met with officers of the Council in September to discuss the lack of implementation of the Autism Act, especially with regard to Asperger services. As a result SAFE is now having 6 weekly meetings at present to ensure some progress is made.

“Due to our pressure and as a result of support from Councillor Norman an Autism Partnership Board is to be set up in December 2014. At our last meeting on 19<sup>th</sup> November we discussed the make up of the Board and how to make it as Autism Spectrum Condition friendly as possible.

“We have a tentative list of those invited to the Autism Partnership Board and this includes adults with Asperger Syndrome and the lead officer for SAFE. Also a Clinical Commissioning representative, A GP, [representatives from] mental health, a Basildon Asperger Syndrome rep, Southend Borough Council officers, a SHIELD<sup>31</sup> rep and advocate, etc.”

Healthwatch Southend contacted Southend Council again in early December, 2014, requesting an update on the Autism Partnership Board.

---

<sup>30</sup> NHS Pioneers Programme: [Link](#)

<sup>31</sup> SHIELDS (Supporting, Helping, Informing Everyone with Learning Disabilities in Southend) is a local charity that helps people who have learning disabilities. [Link](#)

In response to our inquiry, Glyn Jones, Learning Disabilities Strategy & Commissioning Manager, Southend Borough Council, replied:

**“We had a meeting today (9<sup>th</sup> December 2014) to set up the Autism Partnership Board and discuss the Terms of Reference. The meeting was chaired by Simon Leftley (Corporate Director, Department for People), and was attended by professionals from across health and social care, children and adults services. People with Autism also attended and gave their views. It was agreed to start the Autism Partnership Board in February 2015.**

**“In the meantime preparatory work would be done, focusing on Joint Strategic Needs Analysis<sup>32</sup>. The JSNA would be driven by issues that are the concern of people with Autism. The Southend-on-Sea branch of SAFE will inform on issues in discussion with the Autism Lead. This was considered to be a good base to develop an effective commissioning strategy and programme of work for the Autism Partnership Board.”**

Healthwatch Southend also contacted SAFE and asked for their perspective on the developments. They told us that at an early meeting of the Autism Partnership Board it had been agreed that there should be a consultation meeting with those with Autistic Spectrum conditions and their parents or carers. The purpose of this meeting would be to prioritise key issues for the board to address and to provide input for the Joint Strategic Needs Assessment.

SAFE expressed a willingness to be involved in the process and to ‘help and inform’ but stressed that they did not represent the entire Autism Spectrum Community. They counselled that steps should be taken to ensure that everyone’s needs are recognised, in particular those whose requirements are not addressed by the Learning Disabilities Partnership Board.

Summarising the meeting SAFE said:

**“It seems that the views of local people with Autistic Spectrum conditions will play an important role in the Autism Partnership Board.**

---

<sup>32</sup> Joint Strategic Needs Assessments (JSNA) are a product of the Local Government and Public Involvement in Health Act 2007. They are drawn up by local authorities and are intended to promote the health and wellbeing of a local community.

“The meeting was very positive. Three people with Asperger’s spoke briefly on the problems they faced on a daily basis. I spoke again on the needs and problems of people with Asperger Syndrome. My last slide was very hard hitting - how many of our members committed suicide last year, and how members were isolated in their homes and not accessing services or community at all. The chair asked me to keep up my last slide for the whole meeting (on the need to reduce loss of life, provide access to the community and services for those isolated at home, etc) as he was so struck by the importance of the board by our needs and it was agreed the board needed to do more than write reports - it needed to deliver services. Also there was the need for views of real people to be heard.”

In February, 2015, Southend Borough Council told Healthwatch Southend:

“We have been committed to develop an Autism Partnership Board for some time in line with Think Autism and now have the relationship with partners to deliver this effectively and in a way that will be done co-productively.

“We also want the Autism Partnership Board to build on aspects of the work being delivered by partners in Southend-on-Sea including for instance within health and the Criminal Justice System where we are a pilot area. It will also be a forum where we will want to innovate further through applying best and forward thinking practice.”

## Securing funding for local projects

In August 2014, Supporting Asperger Families in Essex (SAFE) was asked by Southend Borough Council for input on a bid for government funds which had been made available to support innovation in autism services and increase autism awareness in England.<sup>33</sup> The money comprised £1 million to support innovation projects focusing on advice and information, gaining and growing skills for independence, early intervention and crisis prevention, and employment.

---

<sup>33</sup> The National Autistic Society - Government releases innovation funds: [Link](#)

A further £200,000 had been allocated to fund the national co-ordination of the Autism awareness and champions network.

In reference to the council's request, Jane Neale, Chair of SAFE South Committee, said:

**“SAFE has had to decline taking the lead on this kind offer as it's very late to prepare a bid. Help was requested in early August (the deadline for bids was at the end of August). We are a voluntary organisation, unpaid and part time, staffed by parents /carers of those with Asperger's, or adults with Asperger's. As such we do not have the resources, grant expertise, or time to do this. A lot of council officials are on leave and the time frame is so tight. However, we are happy to liaise with the Council and give them our support and expertise of Asperger's.”**

SAFE informed Healthwatch that they had recently appointed a development worker, Andrea Walter, whose role would be to review the services offered by the charity and explore how they might expand their services in the future.

Southend Borough Council, with the support of SAFE, were able to put in a bid on time. Unfortunately, the Council was not one of those selected for funding.

## Successful bids for funding

In Autumn, 2014, SAFE, working in partnership with Trust Links<sup>34</sup>, was successful in securing government funding for a joint project. This bid was administered by the local authority on the basis that it would lead to improved outcomes for people with Autism.

The money will be put towards a converted shipping container classroom, which will be based at Growing Together in Westcliff.

Growing Together is a one acre social and therapeutic community garden. It supports adults and young people with a range of conditions including mental health problems and learning disabilities. Several

---

<sup>34</sup> **Trust Links** is an Essex-based charity enabling people to work together to improve mental health and well-being and promote, support, inspire and cultivate wellness and sustainable living.: [Link](#)

beneficiaries have Asperger's and Autism. Trust Links also provides support for school groups and children and young people.

SAFE told Healthwatch Southend:

**“The new facility will provide a facility for the SAFE group to meet regularly and for young people from SAFE to have appropriate activities on Saturday mornings.**

**“The facility will take account of hypersensitivities and have low level lighting. It will also provide a quiet environment for staff to meet individuals in a relatively secluded area of the garden away from the hustle and bustle of the main office.”**

## Developments at Southend Hospital

At the Healthwatch Southend Asperger's event in February 2014, there was some discussion around the accessibility of the patient passport at Southend Hospital to people with Asperger's.

The patient passport<sup>35</sup> enables people with learning disabilities to easily pass on information about themselves to hospital personnel. In addition to including basic personal details there are also sections covering habits, likes and dislikes, and things that cause anxiety.

Copies of the patient passport can be downloaded from the hospital website, printed out, filled-in and then handed to the nursing staff when a patient visits the hospital.

Concerns were raised that people with Asperger's who might benefit from the passport were excluded because they were not classified as having a learning disability.

Sarah Haines, a Specialist Nurse for Learning Disability at the hospital, was present at the meeting. Addressing these worries she said:

**"Under the Equality Act we can make reasonable adjustments. The hospital passport doesn't exclude anybody."**

Since the Asperger Event, Jane Neale, Chair of the Supporting Asperger Families in Essex (SAFE) South Committee, and Sarah Haines have worked

---

<sup>35</sup> The Southend Hospital Patient Passport: [Link](#)

together to improve the experience of people with Autism and Asperger's who use the hospital. In a message to Healthwatch Southend, following the event, Jane said:

**“Progress has also been made on accessing hospital services for people with Asperger's who have been excluded from the learning disability passport. These steps are a huge encouragement to us.”**

The August 2014 edition of Southend Hospital's in-house magazine - *The Look*<sup>36</sup> reported on the positive changes that had resulted from Sarah's efforts:

**“Jane [Neale (SAFE)] said: “We got talking and [I] challenged that Asperger's was not included on the hospital passport and how some found accessing services very difficult. Unlike the majority of people I meet, Sarah never once said that it wasn't her remit but was genuinely interested in helping with this problem.”**

In an email to Healthwatch Southend on the 27<sup>th</sup> September, 2014, Jane Neale (SAFE) said:

**“People with Asperger's are now included in the learning disability Adult service at the hospital and my son recently had cause to use the service and it really helped him access tests without having meltdowns, etc. Brilliant - just shows what Sarah Haines' can-do attitude achieved.”**

---

## **The SEPT Asperger's Service: a model for quality care in Southend**

---

While gathering information for this report Healthwatch Southend heard favourable accounts of the Southend South Essex Partnership University NHS Foundation Trust (SEPT) Asperger's Service. This is sometimes referred to as the Basildon Asperger's Service.

---

<sup>36</sup> The Look (August 2014): [Link](#)

Jane Neale, Chair of Supporting Asperger Families in Essex (SAFE) South Committee told Healthwatch Southend that more resources should be put into the service. She told us:

**“[The SEPT Asperger’s Service] has an excellent reputation but is a small part-time service and the wait for diagnosis and services is much too long - over 18 months.**

**“It is the first service we have encountered that really understands Asperger’s and is working to help young people cope with life better. They do 1:1 social skills courses, sensory assessments; have a book club, and sports groups. They also have a diagnostic service (diagnosis of Asperger Syndrome). Every meeting I have attended with SEPT (South Essex Partnership University NHS Foundation Trust), people (parents and people with Asperger Syndrome) are requesting access to this service.”**

Healthwatch Southend contacted Sharon Allison, Consultant Clinical Psychologist at the SEPT Asperger’s Service with a list of questions. We were interested in the approach taken by the service and the challenges it faced. We also wanted to know how it might develop if given the opportunity to do so.

We have reproduced the responses we received below:

1. Can you briefly summarize the SEPT Asperger’s Service. What kind of services do you provide and how are they structured? Are these tailored around individual needs and are any long-term goals set? How many hours a week do you spend with each person?

**“The service started in 2009. The primary focus is for assessment and diagnosis but we also offer some support and intervention for those individuals who are aged 18-30 years.**

**We take referrals from psychiatry and the First Response Teams (the first point of contact for mental health services), this is so that individuals can be assessed for other mental health concerns or worries and directed to appropriate services. We carry out formal assessments using the Diagnostic Interview for Social Communication**

Disorders - Wing and Gould<sup>37</sup> for the more formal and detailed assessments.

Once the assessment is complete we will think about what their needs might be and what support we could offer (for those people who are over 30 this tends to be mostly signposting if there are any areas they want support in, although they can access the groups we run/jointly facilitate). We do look at individual needs and tailor support around them. We try to take things step by step but there are some longer term bigger goals such as getting back into work, living independently, further training/education, being able to travel independently.

Our service consists of an Occupational Therapist (2 days/week), Assistant Psychologist (full-time), Family Therapist (1/2 day/week), Clinical Psychologist (2 days/week).

We try and be as flexible as we can in what we offer so as a team we can offer work/support around for example:-

- day-to-day functioning
- vocational and pre-vocational work
- travel training
- sensory needs
- daily living skills
- direct social skills work
- accessing the community,
- help around budgeting
- work around anxiety and low mood
- family support.

In terms of the groups we run/facilitate two (a running/athletics group and a sports for confidence one) are jointly organised with the Basildon Sporting Village. These have a social basis and are aimed to help facilitate social skills and interaction, they are open to the public so people do not need to be involved with the service or have a diagnosis to access.

Once a month we have a reading group that is by invitation only where we alternately read around a topic once a month and a specific book the next month. At the moment we have about 10 people attending this and again it's aimed at providing social

---

<sup>37</sup> Lorna Wing and Judith Gould carried out pioneering work in the area of Autism diagnosis. In 1981, Wing published a paper that first used the term Asperger Syndrome. [Link](#)

opportunities. In this group the members also take the opportunity to arrange other social outings outside the formally organised ones.

It is difficult to state exactly how much time/week we spend with individuals as it depends on their needs and what work they are engaged in at the time so it can be weekly, fortnightly, monthly, regular reviews etc.

Where possible we try and help people access mainstream services and sometimes our work is about getting individuals to the point at which they can access these."

2. At the Healthwatch Southend Asperger's Event there was some confusion as to whether Southend was covered by the SEPT Asperger's Service. I understand that it is, but can you clarify this?

"We cover all of South Essex so that includes Southend as well."

3. How do people access the service and how long is the waiting list?

"People access the service at different levels so some people come simply for assessments and then are discharged, some just access the groups some people are involved with the occupational therapist, the assistant psychologist and myself.

Others might have varying combinations and some people are just open for review so it is difficult to say exactly how many people are open to us at any one time. It probably is about 20-25 individuals who are accessing one or more of us on a weekly/two-weekly basis and then a number of others who are in the process of assessments, accessing the groups.

The waiting list for assessments is over a year but we are working with local CCGs to try and address this as it is not acceptable for individuals to have to wait for this period of time. For individuals who have an existing diagnosis and require intervention/direct support rather than an assessment there is a much shorter list as more members of the team can offer this support."

4. I have been told that your service covers adults aged between 18 and 30. Can you confirm this? What happens when people who have used the service no longer qualify because of their age? Are they sign-posted elsewhere?

“The service is for individuals who are over the age of 18 years. For those individuals who are aged 18-30 we offer assessment, diagnosis and intervention. For those who are above this age the service is primarily to contribute to the diagnostic assessment, but yes we do signpost them to other services which might meet their needs and on occasion we do try and offer some time limited support if we feel that their needs can’t be met elsewhere. All ages can access the groups.”

5. Roughly how many people use the service?

“Again it’s difficult to give you exact figures we currently have about 20-25 people who are seen by a member of the team on a weekly/fortnightly basis and access the groups and then others (about 5-10) who are accessing the groups only, and others (about 10-15) who are in the process of assessment.”

6. In an ideal world how would you develop the service? Is there anything you need that you don’t have at the moment?

In an ideal world we would like to be able to:-

- offer a significantly shorter waiting list and be able to offer people an appointment (whether for assessment or direct intervention) within a month of referral (or better still within a few weeks)
- more support, more direct work, more social opportunities, more work opportunities
- more training for other staff working with individuals who have these areas of difficulty
- to be able to offer a mentoring (type) service so individuals could be supported to pursue more activities in the community
- a lending library of resources including things to meet sensory needs like noise cancelling headphones - so that people could for example try before they buy
- to be able to have a system through which individuals who had experienced autism spectrum disorders could support others (if

they chose too) becoming experts in their field to then support individuals who are more newly diagnosed or more recently aware of their difficulties

- to be able to have the similar social groups in southend (we tried a sports group but despite publication, visits, phonecalls etc it was really poorly attended and not viable so was postponed)
- dedicated social work time to help people around benefits, housing, self-directed support
- a direct advocacy service across the area (we have accessed a good one in Southend but the support isn't necessarily the same in other areas)
- a website and facilities to let individuals access us via email or support online (Trust Policy doesn't currently allow email interaction with individuals)
- a bigger team

---

## The Jobcentre

---

At the Healthwatch Southend Asperger's Event, the Jobcentre was mentioned on five separate occasions by panel members and by members of the public. It was not regarded as a supportive environment for people who have Autism Spectrum Conditions. There were claims that the staff demonstrated little understanding of these conditions and appeared to lack the training that might allow them to help people who were affected by them.

The activities of the Jobcentre fall outside the influence of Healthwatch Southend. However it was felt that, given the level of frustration expressed on this particular issue at our event, we should investigate these concerns further.

We did this with the intention of making any information we uncovered available to organisations who work with people with Autism Spectrum Conditions, and to members of the public, in the hope of generating awareness and debate.

We were also interested in the kinds of difficulties that people with Autism Spectrum Conditions might be experiencing when engaging with public services.

In approaching this issue we considered the points that had been raised at the Healthwatch Southend Asperger's Event:

- The possibility that the environment at the Jobcentre, or the way that staff interact with customers, might be causing distress to people with Autism or Asperger's.
- The possibility that those who have Autism or Asperger's might actively avoid claiming benefits because of personal anxieties, or the anxiety of their families, about how they might be treated at the Jobcentre, and whether they would be able to cope with the environment and the demands that would be placed upon them.
- The possibility that people with Autism or Asperger's who attend the Jobcentre might not have the same opportunities for securing employment as those who do not have the condition: That a disproportionate number might find themselves unemployed for long periods of time, working in low income jobs, or enrolled in long-term programmes in which unpaid work experience is carried out while benefits are being claimed. There were worries that if people with Autism or Asperger's were more likely to occupy the lower end of the socio-economic scale, they might be placed at a greater risk of developing a broad range of health problems that are often experienced by those on low incomes.

To find out how warranted these concerns were we contacted a local branch of the Jobcentre Plus with a list of questions.

We subsequently passed on the response from the Jobcentre to Supporting Asperger Families in Essex (SAFE).

SAFE had previously stated to Healthwatch Southend that there is a need for appropriate volunteering, work experience opportunities and support into work.

They provided us with feedback on the Jobcentre from people who have Asperger's and their families.

## The response from Southend Jobcentre

On the 26<sup>th</sup> September, 2014, Healthwatch Southend submitted a freedom of information request to the manager of the Jobcentre Plus on Tylers Avenue.

The questions we asked, along with the responses we received from the Jobcentre, are listed below:

1. Does the Jobcentre have any policies or procedures in place for working with clients who have Asperger's or Autism? If these exist can you provide details and tell me when these policies were last reviewed. If there are no policies currently in place, are there plans to implement any in the future?

**“The DWP [Department of Work and Pensions] /Jobcentre Plus does not have any specific procedure for working with people with Autistic Spectrum Disorders (ASD). We do adhere to the Equality Act, however.”**

2. Do staff at the Jobcentre in Southend town centre (Dencora Court Tylers Avenue) receive any training focused on working with people who have Asperger's or Autism?

**“Our Specialist Disability Employment Advisers have received some training in awareness of ASDs and help and guidance on this subject can be found on our internal intranet, they will also have built up working relationships with organisations such as Autism Anglia.”**

3. Do staff at the Jobcentre in Southend town centre (Dencora Court, Tylers Avenue) make any accommodations in order to meet the needs of people with Asperger's and Autism?

**“If we become aware that one of our claimants has an ASD we will make whatever reasonable adjustments necessary to give that person a good experience while visiting the Jobcentre, for example we have private interview rooms available if the person is sensitive to noise or crowds etc. and we have in the past made arrangements for a claimant to use the staff entrance at the rear of the building as they were fearful of using the main entrance.”**

4. Are you aware of any issues surrounding the accessibility of the Jobcentre in Southend town centre (Dencora Court, Tylers Avenue) to people who have Asperger's or Autism? If you are aware of any issues would you provide general details and explain any measures that have been taken to address the situation.

**“I am not aware of any issues regarding accessibility for people with ASDs at Southend Jobcentre.”**

5. Does the Jobcentre run any programmes aimed at improving the employment prospects for people who have Autism or Asperger’s? If no programmes exist at present are there plans to develop any in the future?

**“There are no specific programs for claimants with an ASD, however there is a program for people with disabilities called Work Choice, that can help.”**

The Jobcentre stated that they were currently engaged in a review of services for disabled people in the Essex Jobcentre Plus District. Part of this review would include developing stronger relationships with “charities, providers of disability services and local authorities.”

They said that they welcomed the input of specialist service providers who they could work with to provide employability support for people with Autism Spectrum Disorders, and that a small amount of grant funding was available in some circumstances.

## **Feedback on the Jobcentre from local people with Asperger’s and their families**

Healthwatch submitted the letter we received from the Jobcentre to Supporting Asperger Families in Essex (SAFE)

SAFE circulated the letter among people with Asperger’s and their families and asked for their experiences of using the Jobcentre. They subsequently sent five of the responses they had received to Healthwatch Southend. In the interests of preserving anonymity any names mentioned have been removed.

In general the Jobcentre was not viewed positively with some distressed and disillusioned by their experience of the service:

**“They do not have any personnel staff who are trained in high performing Asperger (they think every should one should work in a factory). I have witnessed my self how they treat people. It has left \_\_\_\_ extremely upset by the way \_\_\_\_ has been treated by**

the job centre. I also know of other Asperger persons who cannot go to the job centre because of the way they have been treated.”

Another commented:

“My observations of \_\_\_’s visits to the Jobcentre are very negative. They were all booked in at one time and anyone suffering from a nervous complaint or autism felt very uncomfortable.”

One person claimed:

“I have an agreement with my Doctor. While I’m not working, he basically helps me with giving me a Sick note, so that way I do not have to deal with the stress that the job centre used to make me suffer from.”

Some of the respondents reported that while there had been assistance for people with Autism and Asperger’s in the past, this support appeared to be dependent upon a particular individual within the Jobcentre and had ebbed away when that person was no longer in position.

One respondent said:

“ \_\_\_\_\_ originally was allocated a Disability Adviser but she retired and nothing was done to replace his services until I protested.”

Another stated:

“I suffer from Asperger’s, and was helped at one point. But since then, which was probably a year ago now, they changed the process. The one advisor who helped me, got moved wherever else. And I was then just put with a normal agent. The advisors in the job centre itself are really of no help whatsoever.”

One person said that a family member who had attended the Jobcentre Plus in Southend had been treated with empathy, had generally been given good

advice, and that a sincere attempt had been made to accommodate their needs:

**“The lady that I spoke to was really understanding regarding the difficulties \_\_\_\_\_ faces in attending appointments at the job centre. Good advice was received, although the solution offered regarding me becoming his appointee was not really suitable. Following another telephone conversation a member of staff advised that, because \_\_\_\_\_ was finding it extremely difficult to attend the Jobcentre, she would refer directly to a Disabilities advisor to see what the best solution would be. That was only a couple of weeks ago and we are still waiting to hear.”**

## **The Autism Partnership Board and the Jobcentre**

Healthwatch Southend contacted Southend Borough Council and asked whether representatives from the Jobcentre would be invited to attend Autism Partnership Board meetings. We were informed that the possibility of including the Jobcentre had been discussed during a meeting held on the 9<sup>th</sup> of December. Glyn Jones, Learning Disabilities Strategy & Commissioning Manager, at Southend Borough Council said:

**“The meeting raised a number of issues that were relevant to improving the quality of life of people with Autism. Getting a job was one of those issues. The Autism Partnership Board will be inviting agencies to its meetings where those agencies can help achieve relevant objectives. This will likely include the job centre. Again, being led by the perspective of people with Autism will provide the best opportunity for this.”**

## **The SEPT Asperger’s Service and the Jobcentre in Southend**

As part of a list of questions submitted to the SEPT Asperger’s Service, Healthwatch Southend asked whether they taught any skills for coping with environments like the Jobcentre or with job interviews in general.

We also asked whether the service had ever been approached by the Jobcentre or by employers for advice on how to better accommodate the needs of people who have Asperger's

Sharon Allison, Consultant Clinical Psychologist at the SEPT Asperger Service, responded:

**“We have started to have some links with the job centre in Southend and our OT was involved in the Condition Management Programme. We work with the Employment Specialists within the mental health services who provide direct support around interview skills, job applications etc. We have also worked with individuals to help them get their needs understood by their employer whether that's to help them do it directly or to pursue it as a joint venture, there are also a couple of employers of individuals we are currently involved with who have expressed an interest in better meeting the needs of their employee and sought our support in doing this.”**

---

## Conclusion

---

This report is a sentence in an ongoing conversation and, as such, should not be regarded in isolation. It forms a small part of a much larger discussion based upon a recognition that people with Autism Spectrum Conditions are numerous in our society, and an acknowledgement that people who have these conditions need to be afforded the same rights and opportunities as everyone else.

### Forward planning

While progress was made in the evolving and expanding local services for people with Autism Spectrum Conditions during 2014, much of this work appears to have been confined to developing a plan of action for the future.

Southend Borough Council has made Healthwatch Southend aware of some initiatives that are already under way. These are based around the training of council staff and exploring ways of increasing the rate of employment for people with Autism Spectrum Conditions. However we understand that these programmes are still in the early stages and probably not at a point where their effectiveness can be judged.

Over the past year, Southend Council has moved slowly but purposefully towards developing a local Autism strategy - one that takes into account the statutory guidance laid down in the *Fulfilling and rewarding lives* and *Think Autism* government policy documents. The latter of these two papers was published in April 2014, a few months after the Healthwatch Southend Asperger Event, and required some adjustments to be made to the draft of the local strategy.

Having a well thought-out strategy in place will hopefully lead to a more structured and coordinated approach being taken in the future when addressing the issues surrounding Autism and Asperger's.

## Recognising quality care provided by existing Services

In this report we have cited the SEPT Asperger's Service as an example of high quality care. This service takes a very broad and practical approach to Asperger's. It is important that quality services of this kind, that are already providing support to people in the local area, are recognised and allowed to grow and develop, should funding be available. The SEPT Asperger's Service have described to Healthwatch Southend in some detail the ways in which they would develop if given the opportunity to do so.

## Working in partnership

In seeking to effectively fulfil its responsibilities towards people with Autism Spectrum Conditions, the Council is likely to find itself increasingly working in partnership with a variety of service providers and organisations, including those from the voluntary and charity sector.

Drawing on a broader range of experience and expertise and, where appropriate, working in collaboration with other agencies should, in principle, increase the success of projects designed to improve the quality of life for people with Autism and Asperger's in Southend.

Earlier in this report we have described the working relationship that has developed over the past year between Southend Council and Supporting Asperger Families in Essex (SAFE). In this collaboration the Council benefits from SAFE's direct contact with people affected by Autism and Asperger's, and from the charity's knowledge and familiarity with the key issues. SAFE benefits from being in a position where its members are able to influence policy and guide attention towards those areas where there is the greatest need for improvement.

This relationship has not always been an easy one and there have occasionally been differences of opinion. At the time of writing a good working relationship appeared to exist between both parties. By combining their efforts toward a common goal they have set the stage for a better, wide-ranging approach to developing services to accommodate Autism and Asperger's.

One of the benefits of multiple agencies working together on an issue is the potential for these parties to support each other on large or complex projects, and bring about better outcomes than might be expected from organisations working in isolation.

As has been mentioned in this report, in 2014 SAFE was invited by Southend Council to bid for government funds that had been made available to support innovation in Autism services and to increase awareness of the condition.

This bid was made during the early stages of the working relationship between SAFE and Southend Borough Council and against a very tight time frame. Although the bid was unsuccessful, SAFE has since made a successful joint bid for funding in collaboration with another local organisation. This bid was administered by the local authority and stands as an example of local organisations working together to bring about positive outcomes.

In reference to the joint SAFE/Southend Borough Council bid for funding, Jane Neale, Chair of SAFE South Committee, told Healthwatch Southend that SAFE is a voluntary organisation staffed by a mix of unpaid and part time workers. They had felt that they lacked resources and grant expertise to lead the bid.

This raises a pertinent issue - one that lies beyond the scope of this report but is still worthy of consideration: As third sector organisations take on new responsibilities in health and social care, whether there exists any kind of structured training or support, available either locally, or via some form of national scheme, to guide these organisations, and allow them to acquire the necessary skills and knowledge, so that they can proceed with confidence and be effective in their new roles.

Just prior to the publication of this report, Healthwatch Southend was made aware of the Voluntary Community Social Enterprise Review (VCSE)<sup>38</sup>.

The review is the result of recognition by the Department of Health, NHS England and Public Health England of the importance of the voluntary and community sector in improving the nation's health and wellbeing. It will consider any changes that could be made to support these organisations in achieving their goals.

---

<sup>38</sup> Voluntary Community Social Enterprise Review: [Link](#)

It is hoped that as the local Autism Strategy is implemented and those agencies involved in improving services become more practised at working in collaboration, and well-versed in sharing skills and support, they will find themselves in a better position to undertake ambitious projects and bid for funding where it has been made available.

## Working with public services

The long-term principles and goals laid down in the local Autism Strategy will be supplemented by the work of the Southend Autism Partnership Board. This will be made up of health and social care professionals and representatives from the third sector.

The Autism Partnership Board will act as a forum for debate and planning. Representatives from everyday public services can be invited to attend meetings and discuss the ways they could increase accessibility and user-friendliness for people with Autism Spectrum Conditions. In casting the net widely and involving as many services as possible, the board will be able to exert a wide-ranging influence on services in Southend.

This is appropriate given that 1% of the population in England are estimated to be directly affected by Autism to some degree.<sup>39</sup> Clearly it is not sufficient to address the condition purely in terms of tailored services; consideration should also be given to the ways in which everyday public services can be modified to better accommodate people with Autism Spectrum Conditions.

There may well be public services in Southend that want to improve accessibility for people with Autism Spectrum Conditions but are unable to do so because they do not fully appreciate the difficulties faced by people with these conditions, or because they lack a clear understanding of how to change their services in a way that will make them more accessible.

Earlier in this report Healthwatch Southend highlighted some of the difficulties that were being experienced by people with Autism Spectrum Conditions at the Jobcentre in Southend, despite the provisions that had been made there to accommodate them.

In its response to a freedom of information request from Healthwatch Southend, the manager of the Jobcentre in Southend stated that there was currently a review under way of services for disabled people in the Essex Jobcentre Plus District and that this would include developing stronger relationships with “charities, providers of disability services and local authorities.” This includes involvement from the SEPT Asperger Service.

---

<sup>39</sup> Think Autism - Fulfilling and rewarding lives, the strategy for adults with autism in England: an update (page 45 - 5.2): [Link](#)

It is likely that, in developing and improving its approach to Autism and Asperger's, the Jobcentre would benefit from drawing on the expertise represented by the Autism Partnership Board.

It is likely that the Jobcentre will be one of the public services that are invited to attend a meeting of the board in the future.

## Closing remarks

In closing this report it seems fitting to consider those people in Southend who are affected in one way or another by Autism Spectrum Conditions. Among this group are members of the public who attended the Healthwatch Southend Asperger Event in February, 2014.

A year is a long time for someone who is living with an Autism Spectrum Condition and struggles to cope, or for the family of someone with Autism who need information and support.

The issues that were raised during the discussion at the Asperger's Event have not gone away. Those who were at the meeting and expressed a need for immediate assistance may have grounds for concern at the pace of change.

That being said, the local authority now appears to have reached a point where there is a strategy in place and where there is a forum for discussion whose sole purpose is to address issues relating to Autism and Asperger's.

There now exists the potential for the careful and considered planning that characterised 2014 to crystallise into action.

There have already been some stirrings of activity focused around training is being given to council staff and increasing employment for people with Autism Spectrum Conditions, although these have not been described to us in detail. It is hoped that these and other initiatives will gather momentum over 2015.

Over the coming year Healthwatch Southend will focus its attention on the ways in which the local Autism Strategy is being applied. We will look at any attempts that have been made to improve services and increase the quality of life of people affected by Autism Spectrum Conditions. We will attempt to judge the success of these programmes by talking to people with Autism and Asperger's and their families.

## What happens next?

Copies of this report will be forwarded to representatives from Southend Council, the Southend Clinical Commissioning Group, NHS England and Healthwatch England.

It will also be available to members of the public.

It will be promoted through the Healthwatch Southend website, mailing list and social media accounts.

An up to date version of the report will be hosted on the Healthwatch Southend website. In the interests of transparency any amendments that we make to the final draft will be listed at the bottom of the report.

Healthwatch Southend will review developments in the provision of services for people with Autism Spectrum Conditions in 2016 and will report on what we find.

---

## Thank you

---

Healthwatch Southend would like to extend our thanks to everyone who contributed to this report by responding to our questions and providing information. We would also like to thank everyone who attended our Asperger Event in February, 2014.

---

## About Healthwatch Southend

---

Healthwatch Southend is 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.

## Contact details

Healthwatch Southend  
SAVS Centre  
29-31 Alexandra Street  
Southend-on-Sea  
Essex  
SS1 1BW

Tel: 01702 356 066

Email: [info@healthwatchsouthend.co.uk](mailto:info@healthwatchsouthend.co.uk)

Our office hours are 9am-5pm (Monday-Thursday) 9am-4.30pm (Friday). We are closed at the weekend.