



# Autism Plan for Adults in East Sussex

2013-2015

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This plan was signed-off by the Autism Partnership Board on 9 July 2013. To find out about the consultation process that contributed to the development of this plan, visit: [www.eastsussex.gov.uk/yourcouncil/consultation/2012/autism](http://www.eastsussex.gov.uk/yourcouncil/consultation/2012/autism)

## 1. Introduction

The National Autism Strategy has set out a vision where all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.

However, the experience of individuals with autism is often one where individuals struggle to access services and support. It is clear that adults with autism face particular challenges with using mainstream public services and that a strategic approach to commissioning services for individuals with autism is required.

During the summer of 2012, East Sussex County Council (ESCC) Adult Social Care (ASC) Department consulted on the development of four priority areas to support the implementation of the Autism Act in East Sussex. The outcomes of that consultation have shaped the four key outcome areas of this Autism Plan for Adults in East Sussex.

These are:

**Outcome one:** Increased understanding of local need

**Outcome two:** Helping people understand more about autism

**Outcome three:** Developing support for individuals with autism and their carers, particularly through transition

**Outcome four:** Checking the plan is working

The Autism Plan describes the commitment that ESCC is making to support adults with autism and their carers. The plan aims to deliver a person-centred approach which is responsive to need and potential amongst individuals with autism.

We are confident that we can make a real difference through continuing to listen to and work together with local people to make the most of the resource available. Because we value your input, we aim to establish a model of involvement that captures the widest possible range of voices when implementing the plan. We hope the plan will ultimately improve the lives of individuals with autism and their carers.

## 1.1 What is Autism?

Autism is a lifelong developmental disability and while some individuals with autism can live relatively independently, others will have high dependency needs requiring a lifetime of specialist care.

As a spectrum condition, individuals with autism share certain difficulties, but the condition can affect them differently. In this plan we recognise that there are a number of different terms used to describe autism, for example, autistic spectrum disorders or conditions, Asperger syndrome or neuro-diversity. The term autism will be used throughout this plan.

Autism affects how a person communicates with and relates to other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty which all individuals with autism share are known as the 'triad of impairments'. These are:

- Social communication – Individuals with autism have difficulty using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice, as well as jokes and sarcasm. Some individuals with autism might not speak or have fairly limited speech. They may understand what people say to them but prefer to use alternative forms of communication, such as sign language.
- Social interaction – Individuals with autism have difficulty recognising and understanding people's feelings and managing their own feelings. They may, for example, stand too close to another person, prefer to be alone, behave inappropriately and may not seek comfort from another person. This can make it hard for them to make friends.
- Social imagination – Individuals with autism have difficulty understanding and predicting other people's intentions and behaviour and imagining situations that are outside their own routine. This can mean they carry out a narrow, repetitive range of activities. A lack of social imagination should not be confused with lack of imagination. Many individuals with autism are very creative.

Additionally, individuals with autism may experience sensory sensitivity in one or more of the five senses. A person's senses are either intensified (hypersensitive) or lack sensitivity (hyposensitive).

Asperger syndrome is a form of autism which includes the main difficulties already outlined above. Individuals with Asperger syndrome tend to have fewer problems with speaking and are often of average intelligence or above average intelligence but may have specific learning difficulties such as dyslexia and dyspraxia.

## 1.2 Why do we need a plan?

Although there are a number of services in East Sussex that support individuals with autism, there has been a lack of strategic planning and commissioning to make the most of this support. This has resulted in inconsistent experiences for many people in the county.

This plan will aim to address these inconsistencies and gaps through the development of a more strategic commissioning approach, which identifies best value and delivery of positive outcomes that meet the identified needs of local people and communities.

Strategic commissioning is often referred to in terms of a cycle of interdependent activities. Strategic commissioning cycles include common elements such as:

- Analysis – understanding the needs, available resources and potential capacity within local communities, provider organisations and other resources to support those needs
- Planning – Identify the gaps between what is needed and what is available, establishing priorities and plans to address those gaps
- Doing – ensuring that services and interventions are delivered as planned in ways that effectively and efficiently deliver the priority outcomes
- Reviewing – managing relationships, monitoring and reviewing performance and seeking further improvement and innovation.

The Autism Plan for Adults in East Sussex takes this strategic approach to improving outcomes for people. A key part of this approach is the involvement of local individuals with autism and their carers. Opportunities for local people to get involved will be built into the implementation of the plan and supported through the Autism Partnership Board.

## 1.3 The national context

In recent years, Central Government has sent out a strong message that the needs of individuals with autism should be included in service planning and provision. Commissioners have a requirement to ensure that services are in place to respond to the needs of young people and adults with autism and their carers. These requirements and recommendations are outlined below.

In 2006, the Department of Health published *Better Services for People with Autistic Spectrum Disorders* and *Valuing People* in 2009. These national strategies began to include autism in the commissioning arena.

In 2009, the National Audit Office published *Supporting People with Autism through Adulthood*, which provided a cost benefit analysis of providing preventative services for individuals with autism.

The Autism Act, passed in 2009, required Government to produce an autism strategy and autism guidance for Local Authorities and the local NHS.

*Fulfilling and Rewarding Lives*, the first ever strategy for improving the lives of adults with autism was published in 2010, followed by Statutory Guidance, which requires activity focusing on four key areas:

- training for staff
- identification and diagnosis of autism in adults
- planning of services for individuals with autism, including the transition from child services to adult services
- local leadership.

In 2010, the Government also published the first year delivery plan for *Fulfilling and Rewarding Lives*, which provided further guidance on implementing the Act.

The NHS Operating Framework requires NHS Commissioners and Trusts to take action to assess the needs of individuals with autism in their areas, and to plan and commission services as appropriate to address those needs.

In 2011, *Think Local, Act Personal* took forward radical changes to transform social care services which aimed to support people to live better lives through more choice and control over the support they use. This is often referred to as 'personalisation', where services are provided according to the needs of people who use them and provided in ways that help people to be active and contributing members of supportive communities.

In 2012, the National Institute for Clinical Excellence published guidance for autism in adults, clarifying the recommended diagnostic pathway.

## **2. The local picture**

### **2.1 Prevalence**

Nationally, it is estimated that between 1-1.5% of the population is affected by autism. The National Audit Office estimated in 2009 that there are approximately 400,000 adults living with autism in England and that autism is three to four times more common in men than in women. However, more recent studies have suggested that women are less likely to be identified with autism.

It is widely recognised that statutory organisations do not routinely collect data on the numbers of people they are providing condition-specific services to or how many people with a specific condition live in a particular area. This can make understanding the prevalence of autism a challenge.

It is estimated that up to 55% of individuals with autism also have a learning disability.

#### **East Sussex**

As part of the East Sussex Joint Strategic Needs Assessment, a Comprehensive Needs Assessment of adults with autism was published in 2012. It demonstrated the challenge of identifying the prevalence of autism in adults, estimating that there should be 4,572 individuals with autism in East Sussex, comprising 1,769 people aged 19 or younger, and 2,803 aged 20 or older.

The 2011 census also noted that the population in East Sussex increased by 7%, which may impact on the prevalence of individuals with autism in the county.

The Needs Assessment has helped to focus ASC's priorities on supporting the needs of local individuals with autism. It has provided information that will help us to meet local need in an inclusive way, whilst recognising the need for specialist support through partnership working. It is recognised, however, that that many individuals with autism will be in regular employment and will not need or want services.

## 2.2 Current services and support

Whilst there are currently a number of services operating in East Sussex which support individuals with autism and their carers, it has been noted that a strategic approach to planning and commissioning services, and particularly a diagnostic pathway to identify autism, has not been in place. This has led to inconsistencies for clients and carers across East Sussex.

In the absence of a national indicator to record any specific conditions, it is difficult to determine the number of individuals with autism who currently access ASC or NHS services.

A number of individuals with autism will have eligible needs for ASC support and will already have a Personal Budget and be accessing services. Some people may be receiving their support through a Direct Payment. Personal Budgets and Direct Payments are key elements of a more personalised approach to planning and purchasing social care support, where support can be designed and tailored to meet individual needs. For example, a person could employ a personal assistant or informal carer which could be beneficial to people who need familiarity and routine.

There are also a number of preventative services which provide information, advice, support and advocacy that can be accessed by people who do not meet ASC eligibility criteria. Many of these services take a personalised approach to supporting people through a combination of person centred planning and workforce development to ensure staff better understand the needs of individuals with autism.

Carers are also entitled to an assessment of their needs when they are providing regular and substantial care to people who meet ASC eligibility criteria. The purpose of the carers assessment is to consider the sustainability of the caring relationship, to advise carers of the information and support services available to them and to decide what additional services may be provided to the cared for person or to the carer. Again, support is provided in a personalised way to best meet the needs of carers.

In summary, within a personalised approach to supporting individuals with autism, support can be provided in a variety of ways and through a variety of services, including:

- The ESCC Transition services
- ESCC Learning Disability Assessment and Care Management teams
- ESCC Adults Assessment and Care Management teams
- Sussex Partnership NHS Foundation Trust Community Learning Disability teams
- A wide range of local service providers, including providers of employment support services, day services, community services and accommodation based services

- ESCC & NHS Mental Health Assessment and Care Management teams
- mental health and wellbeing services
- voluntary and community sector service providers
- a range of user-led, grassroots groups
- carers respite service
- CRESS (Carers' Respite Emergency Support Service)

This is not intended to be an exhaustive list of support. It is recognised that some individuals with autism will not be accessing any of the above support and that an effective way of promoting available support, targeted at individuals with autism and their carers is needed.

## 2.3 Consultation outcomes

Reviewing the requirements and recommendations in the Autism Act, National Strategy, Statutory Guidance, National Institute for Health and Care Excellence (NICE) Guidance and Comprehensive Needs Assessment, commissioners identified activity that would support the Autism Act to be implemented in East Sussex. This activity was set out as a list of priorities which was then used to inform a consultation process.

A consultation commenced on 11 June 2012 asking whether the proposed priorities for East Sussex would help young people and adults with autism and their carers, to live more fulfilling and rewarding lives.

The four main priorities set out in the consultation were:

- Identifying individuals with autism in East Sussex
- Helping people to understand more about autism
- Better support for individuals with autism and their carers, particularly through transition, and
- Checking that the plan is working.

We wanted to work together with local people to develop a plan that would be meaningful and effective. We asked for the views of clients and individuals with autism, parents and carers, statutory partners and voluntary sector and provider organisations through a number of stakeholder meetings, for example Partnership Boards.

We held a public workshop on 3 July to help develop our plans and test draft surveys which would form part of the consultation. The 55 participants who attended this event reflected a good cross-section of parents/carers, independent and voluntary sector service providers and support staff across multiple agencies.

Following the workshop, the consultation survey was published on our website and promoted through local media and networks throughout July and August, running for 12 weeks and closing on 31 August 2012. A further workshop was held on 20 November to feedback from the consultation and outline the next steps. At this second workshop the plan to establish an Autism Partnership Board was announced and information given about how individuals with autism, their carers, and organisations can express an interest in getting involved.

Further engagement through nine stakeholder groups, the autism workshops, the results from 47 surveys and 35 telephone and email enquiries have helped to inform and develop a local plan. Ongoing involvement will be co-ordinated through the Autism Partnership Board.

### 3. Proposed local outcomes

Using the National Autism Strategy and guidance, and the findings of the consultation, four outcome areas have been identified to provide a framework for the implementation of the local plan. An overview is provided below:

#### **Outcome One: Increased understanding of local need**

Two key activities have been identified to support the delivery of this outcome.

The first is to improve our knowledge of the local population of individuals with autism, including more accurate demographic data and information about needs, provision and current levels of access. This will be achieved working together with Children's Services, the ESCC Transitions Team, other ASC teams, the NHS and local service providers.

The second is to ensure that people have timely access to assessment as well as post-diagnostic information and support. This will be achieved by working with NHS Commissioners to map the current diagnostic and clinical pathway against the NICE guidance.

#### **Outcome Two: Helping people understand more about autism**

Two key activities have been identified to support the delivery of this outcome.

The first is to provide more information about what autism is, how it affects people across the spectrum and what support is available locally and nationally. A specific project will be commissioned to ensure that information is widely available and meaningful to people who need it. This will include a new autism section of the County Council website. This will be tested with local people to ensure it meets needs.

The second is to pilot a more comprehensive training plan to develop a better understanding of autism in the wider community and improve knowledge and skills within the paid workforce. The training plan is divided into five levels: basic, higher basic, intermediate, higher intermediate and specialist.

**The Basic Level** is targeted at staff with rare or infrequent contact with individuals with autism. It will include support for staff, other organisations and the public through promotion of an e-learning package to help develop awareness of autism. This will be available to all through the ESCC website. As part of ESCC mandatory Equality and Diversity training, all staff will be required to consider an autism case study, ensuring that staff consider the needs of individuals with autism and their carers. This case study will also be promoted to stakeholders and partners.

**The Higher Basic Level** will be a one day awareness course, aimed at front line staff who have some contact with individuals with autism. The course will provide knowledge to enhance the quality of service through

increasing understanding of the condition and the triad of impairments associated with autism.

**The Intermediate Level** training will be a two day course aimed at staff providing day to day support and care to individuals with autism across ASC. This can include the independent, voluntary and community sector providers. The course will include developing understanding about how factors such as the environment and sensory perception affect individuals with autism, as well as the importance of good support planning.

**Higher Intermediate Level** will be for those managing and supervising staff who provide regular support to individuals with autism. Aimed at team managers and leaders, this is a Qualification Credit Framework level 5 qualification with an emphasis on leading practice and ensuring the implementation of supportive environments, teams, and plans.

**The Specialist Level** will offer an accredited training programme and will be piloted with specialist staff who are critical to identifying the needs of individuals with autism and supporting them. Staff will be identified following a training needs analysis. Aimed predominantly at health staff, it is thought that this will improve on the identification of individuals with autism and the support they subsequently receive. It will be targeted at staff who have already demonstrated a high level of competency in working with individuals with autism.

The training will be participative and delivered in a supportive and positive environment, making best use of local experts across health, social care and the independent sector. It will also include the expertise of individuals with autism and their carers.

We encourage staff from other support agencies, eg. the NHS, independent sector, Lewes Prison, Sussex Probation Service and Sussex Police to purchase training places for the Higher Basic and Intermediate levels alongside ASC staff. We also encourage these agencies to commission the training to be delivered in-house. This will be in year 2 once the training framework has been implemented and reviewed.

All courses will be compliant with the Autism Act and the Skills for Care recommended autism self assessment checklist. Additionally, they will all reflect the required contents of the Qualification Credit Framework and so individual units can contribute towards an award or diploma in autism.

### **Champions Resource**

Access to the Intermediate, Higher Intermediate and Specialist Training will require a commitment to taking on a champion/expert practitioner role within participants' teams. Participants will be supported to act as a consultant resource for their colleagues through the training.

### **Champions Network**

A network of autism champions will be considered to support and enable the effectiveness of the champion resource.

### **Extending the Network**

It is envisaged that the network will be accessible to health, social care, and independent sector staff and staff in other support agencies who work with individuals with autism, for example prison, probation, police and further education.

### **Outcome Three: Developing support for individuals with autism and their carers, particularly through transition**

Four key activities have been identified to support the delivery of this outcome.

The first three activities will aim to provide support for individuals with autism, particularly focusing on young people coming through the transition to adulthood.

(i). An **Online Learning and Support Programme** will be commissioned to offer structured peer support, social skills training, bullying prevention, signposting, self advocacy, money management and travel training. The programme is intended to enable individuals with autism to access mainstream resources, leading to employment or supported employment.

(ii). A **Leisure and Learning Programme** for the county will be commissioned to offer:

- structured peer support, social skills training, bullying prevention, self advocacy, money management and travel training
- additional support/training and activities as identified by participants
- mentoring and one-to-one support

The programme is intended to enable individuals with autism to access mainstream resources, leading to employment or supported employment.

(iii). **Support with employment** capacity will be commissioned, targeted specifically at young people coming through transition and adults with autism. This service will take a whole pathway approach to employment, including job 'readiness' which could include volunteering, CV, job search, interview and maintenance support.

The fourth area of activity will aim to support for carers of individuals with autism.

(iv). A **Carers Support Programme** for the county to run alongside the Online and Leisure and Learning Programmes. The programme will establish carer-led groups which will connect carers with each other to share information and advice, peer support, planning for the future.

The programme will also include scope to identify and provide additional support/training as identified by carers.

The outcomes of this activity will be to ensure that:

- local individuals with autism are supported to develop and maintain their independence and confidence;
- feel they have more choice and control about their support;
- feel more integrated and connected with the wider community and less socially isolated;
- are aware of how to access advice and information and can self advocate;
- local carers of individuals with autism feel better supported to carry on in their caring role.

#### **Outcome Four: Checking the plan is working**

An Autism Partnership Board will be established to oversee the implementation of the plan. The Autism Partnership Board will link into the Learning Disabilities and Mental Health Partnership Boards and will provide a direct report into the Physical Disabilities, Sensory Impairment and Long Term Conditions and Carers Partnership Boards.

The Autism Partnership Board will include representatives from the following stakeholder groups:

- Individuals with autism
- Carers of individuals with autism
- Adult Learning Disability Commissioning
- Adult Mental Health Commissioning
- Adult Social Care Training
- Adult Social Care Assessment and Care Management
- Specialist and general service providers
- Voluntary and community sector organisations

An action plan will be developed that outlines our approach to implementing the autism plan in East Sussex. The Autism Partnership Board will be responsible for governing implementation of the plan and will ensure its effectiveness and that it remains responsive to local need and national guidance and requirements.

A model of involvement will be developed that enables individuals with autism and carers to feed in their views on the plan and the work of the Autism Partnership Board.

An Autism Project Group will be established to implement the plan for East Sussex. This group will include members from the following teams:

- Adult Learning Disability Commissioning
- Adult Mental Health Commissioning
- Adult Carers Commissioning
- Adult Social Care Training

### **Information sharing**

To ensure all stakeholders are kept up-to-date, information and minutes from the Autism Partnership Board will be made available on the County Council website.

The Autism Partnership Board will produce an Autism Bulletin to ensure other Partnership Boards and relevant groups are kept up-to-date with the latest developments.

#### **4. Schedule for approval and review of the plan**

The plan will be shared at the first meeting of the Autism Partnership Board in April 2013. The Board will be asked to provide comments on the plan ahead of the second meeting in July 2013, at which the plan will be agreed.

The plan covers the two year period April 2013 to April 2015, after which it will be reviewed by the Autism Project Group, and shared with the Autism Partnership Board.

#### **5. How to get copies of the plan**

The plan will be available from the County Council website:  
[eastsussex.gov.uk](http://eastsussex.gov.uk).

The plan will also be made available in Easy Read format.

To request a copy of the plan or to contact the Autism Project Group or Autism Partnership Board, please email the autism inbox:  
[adults.autism@eastsussex.gov.uk](mailto:adults.autism@eastsussex.gov.uk) or write to:

Autism Partnership Board  
B Floor, North Block  
East Sussex County Council  
County Hall  
St Anne's Crescent  
Lewes BN7 1UE

### Developing an Autism Commissioning Plan for adults in East Sussex Consultation results summary

Thank you to everyone who took part in the consultation on developing a plan to implement the Autism Act for adults in East Sussex. All your comments have been reviewed and form an important document of people's views and experience. Your views will continue to shape the development and implementation of the plan.

#### What we did

From 11 June 2012 we attended a series of meetings with the existing Partnership Boards and other stakeholder groups. We also held a public workshop on 3 July 2012 to help develop our plans and test the draft surveys. Delegates reflected a good cross-section of parents/carers, independent and voluntary sector service providers and support staff across multiple agencies.

The survey was then available on our website throughout July and August. The consultation ran for 12 weeks and closed on 31 August. People took part in the consultation in a number of ways:

- **Forums and groups:** 9 groups/meetings were attended by the consultation lead or other commissioners.
- **Public workshop:** 50 people attended (parents, carers, organisations and partners).
- **Survey:** 48 people completed the survey
- **Other feedback:** Approximately 35 organisations and individuals contacted us via email or spoke to us to share their views.

#### What you told us

The consultation responses reflected the significant challenges that people with autism and their carers experience when seeking support. The majority of responses also broadly supported proposals to implement the Autism Act for adults in East Sussex and that, subject to effective implementation, the plan had the potential to impact positively on the lives of people with autism and their carers.

The consultation found that the highest priorities for local people included:

- support into employment,
- better information about autism and available support targeted at those who need it most,
- better training for support staff and a better understanding of the prevalence and needs of people with autism.

Other priorities included:

- a clearer route to getting a diagnosis,
- a clear plan for how we will support people with autism and how this will be implemented,
- peer support,
- carers breaks and support,
- internet support for people who find face-to-face contact challenging.

The consultation also noted that:

- peer support needs to be managed and sustainable,
- for some, the proposed online support raises concerns about safety which will need to be carefully managed,
- carers support needs to be planned in a way that works for the whole family,
- effective implementation of the plan is critical to its success.

## What happens next?

The draft consultation report was considered by the Adult Social Care Departmental Management Team in September 2012. The updated version of the report, and this summary (including an Easy Read version), will now be published on our website. You can request a copy of the full report by contacting us on the details below or downloading it from the website:

[www.eastsussex.gov.uk/haveyoursay](http://www.eastsussex.gov.uk/haveyoursay)

We held a workshop on 20 November 2012 to feedback from the consultation. As a result of the consultation and feedback from key stakeholders, we will establish an Autism Partnership Board for East Sussex in 2013. The first key task of the Partnership Board will be to sign-off a work plan for autism. We will then publish an Autism Commissioning Plan and an Easy Read version. We want to continue to work with local people to implement the plan, harnessing our collective expertise to ensure the most effective use of local resources.

If you have any questions about the consultation or are interested in attending the workshops please contact us:

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Email: [autism.adults@eastsussex.gov.uk](mailto:autism.adults@eastsussex.gov.uk)

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