

East Lothian Partnership



East Lothian Autism Strategy 2015 Summary

Welcome to the East Lothian Autism Strategy summary

This is a shorter version of the full East Lothian Autism Strategy. It covers all the main points of the Autism Strategy. If you would like more information about anything here, you will find it in the full-length East Lothian Autism Strategy. You can find this at www.eastlothian.gov.uk/autismstrategy

About the strategy

We consulted with families, carers and professionals from health, the third sector and East Lothian Council when we produced this strategy. East Lothian Partnership is committed to supporting people with Autistic Spectrum Disorder (ASD), their families and carers. This strategy sets out how we are going to do this.

East Lothian Partnership

East Lothian Partnership is our community planning partnership. It brings together organisations public services, the third sector, business and the community that are based, or working in East Lothian. They work together to make a real difference and improve the lives and opportunities of people in East Lothian.

What does the strategy want to achieve?

We want to make sure that people with ASD:

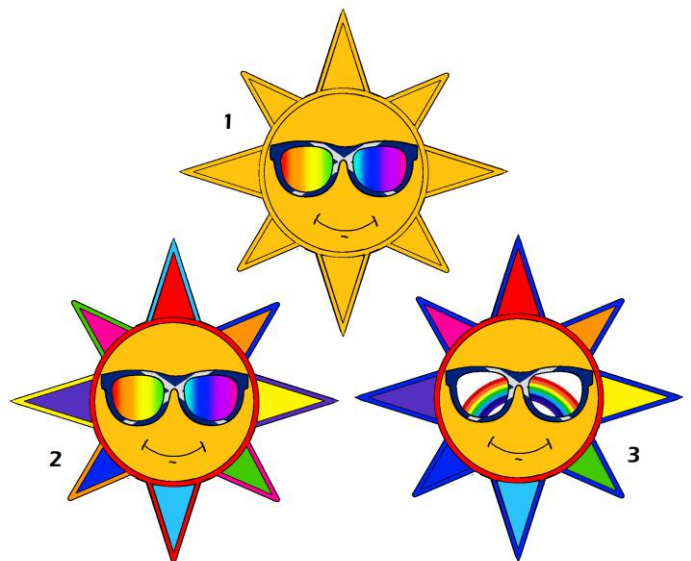
- can make choices about what happens in their lives
- can choose how they want other people to be involved in their lives
- have a say in the services they get
- get the services that are right for them
- get help to live safely **and** be as independent as they want to be.

We want them to know that East Lothian Partnership and East Lothian communities are working together to make things fairer for people with ASD. We want to help more people to understand about ASD and break down barriers for people with ASD.

How will we do this?

We are going to:

- make sure that the needs of people with ASD across the spectrum and their carers help to shape our local ASD strategy, policies and plans and that they are involved in making them



'People with autism shine differently!'

- make sure that staff training raises awareness and understanding of autistic spectrum disorder (ASD)
- develop an ASD training plan to help this to happen
- ensure that people can get useful and practical information about ASD and services easily
- improve the way we collect statistical information about how many people with ASD are receiving services and use that information to help us plan services in future
- develop a multi-agency pathway for pre- and post-diagnosis assessment and improve support by acting earlier and also remove barriers for people with ASD
- get more feedback from **stakeholders** and encourage them to be more involved in planning how services develop
- make sure that services work together effectively to meet the needs of people with ASD within Partnership resources
- make sure that there are clear multi-agency plans and procedures in place to support people with ASD through major changes in their lives (for example, moving from adolescence to adulthood)
- monitor and evaluate how we are doing and show that we are making progress.

Stakeholders

Stakeholders are people who have a direct involvement in an issue. In the case of the Autism Strategy, this would include people with autism, their families and carers, support workers, health professionals, teachers, leisure providers and lots of other people.

Children

What's working well?

- The East Lothian Diagnostic service had a positive inspection report from the ASD Achieve Alliance in 2012.
- Schools and Educational Psychology staff are working closely together to identify and support people with ASD.
- **Staged Assessment and Intervention** meetings are happening within six weeks of diagnosis.
- We are looking at providing on-going ASD training for schools and nurseries.
- Work is progressing on post-diagnostic provision.
- CAMHS is providing a 10-week education programme to parents of newly diagnosed young people.
- Information about assessment and services is improving.
- BBIBS has been supplying support in primary school to children with higher-functioning ASD who could not get help from the NHS Community Learning Disability Team



- Aberlour Childcare Trust, Action for Children and East Lothian Special Needs Playscheme have been providing short breaks for children with ASD and Share the Care has also been supporting families and children.
- Most children and young people with ASD can be supported in mainstream education and we have a primary education communication base and a secondary education communication base for those with severe and complex needs. Another secondary communication base is being opened in 2016 in Haddington.
- Children and young people with ASD receive support from the Children's Wellbeing Disability Team supports children with a learning disability and ASD.
- We are working towards making sure that there is one lead person in each school who is responsible for co-ordinated learning plans.
- Our multi-agency My Future project brought together people from a wide range of organisations and teams to improve the journey of young people with additional support needs from children's to adult services.
- There is now an ASD Pathway for children and young people in East Lothian to help smoother transition.

What's not going so well

- There aren't enough playschemes for children with ASD, especially over the Easter, summer and autumn holidays (when there are none). There are none specifically for children and young people with autism
- There is a lack of support groups – a support and advice network would be very useful.
- Parents feeling that there is not enough support from health visitors and community nurses
- Issues around transitions, including:
 - not all the appropriate agencies being at transition planning meetings
 - late diagnosis making transition more difficult
 - anxieties of parents about a young person's life after school
- we need to make better use of Staged Assessment and Intervention to explore the support needs of children and young people with ASD.

Staged Assessment and Intervention

Staged assessment and intervention framework
Extra support and care for children and young people
Skip to pages in this document
Sometimes children or young people and their families/carers need extra support.

This can range from support for learning and help with behavioural problems to support for children with complex physical and learning disabilities.

Our framework has three referral stages:

- Stage 1 (universal assessment and intervention)
- Stage 2 (additional assessment and intervention)
- Stage 3 (intensive assessment and intervention)



How will we do things better?

- We will identify and improve pre- and post-diagnostic services and support for children, young people and adults with an ASD diagnosis.
- We will develop advocacy, befriending and mentoring services for children and young people
- We will provide local education services to meet the needs of local children with ASD, wherever possible
- We will try to ensure that young people have a positive experience of successful transition into adult life, and into adult services where possible
- We will make sure that service providers and their staff have the appropriate knowledge and skills to work effectively with service users with ASD
- We will make sure that the East Lothian populations, communities and staff delivering services are ASD aware.

Adults

What's working well

- Autism Initiatives (AI) also receives funding to operate Number 6. Number 6 is a service....Number 6 is a service for adults (aged 16 and over) with High Functioning ASD (HFA) or Asperger's Syndrome (AS) who live in the Lothians and the Borders. Most are aged 16-29. AutismInitiatives also provides outreach support to 12 high functioning young adults in East Lothian. Some of these adults participate in social programmes at Number 6, including a Living Life to the Full group, a late diagnosis group and an employment group, while others have been offered one-to-one support.
- Transitions – the three-day multi-agency “My Future” event took place in February 2012. As a result of this work the partnership is now considering how best to implement a 0-25 pathway in East Lothian
- Preparation for work – Adults can receive support and preparation for interviews from organisations such as East Lothian Works, Into Work or Number 6. Through these services younger people with ASD leaving school may benefit from Activity Agreements. Also, adults with ASD are being supported in their employment.
- Housing is a key partner. Some of the most important issues here are:
 - predicting future housing need



- identifying models of housing support to meet predicted needs and the potential numbers of people requiring support to promote and sustain independent living.

What's not going so well

- Preparation for and support in work – many parents advocate on behalf of their son or daughter to achieve a voluntary or casual work opportunity and then may have to step in to deal with issues which may arise.
- Transitions – people affected by ASD are likely to experience a greater number of transitions.
- Mental health – research indicates a high level of poor mental health associated with ASD including anxiety disorders and depression, with a high level of unmet mental health needs.
- Criminal justice – people with ASD coming into contact with the criminal justice system are more likely to be those with high functioning ASD and their disability may not be immediately apparent.

'As [my son] becomes an adult, his erratic behaviour will become less easy for others to understand. I wonder what would happen were he to be questioned by the police for any reason. My hope is that by then police officers will have a better understanding of autism, be able to appreciate that he has a disability and be able to meet his needs, like any other member of society'.

How will we do things better?

- We will continue to gather data on individuals who are likely to require high cost care packages and appropriate models of housing and support. This is done by colleagues in Children's Wellbeing, Adult Wellbeing and Housing.
- Housing colleagues need to be involved to effectively inform strategic planning and service development. Services should be developed locally if possible to avoid out of area placements.
- Planning services for older adults with ASD also needs to be explored. We have identified a list of further actions to enhance services across East Lothian, for example:
 - providing support that delivers identified outcomes for young people and adults with ASD
 - developing advocacy, befriending and mentoring services for young people and adults with ASD
 - providing parents, carers and families with accurate, timely information about ASD services and supports
 - providing local education services for young people with ASD, wherever possible



- helping young people to have a positive experience of successful transition into adult life
- providing supported living options to young people and adults with ASD
- developing proposals for a model of planned respite for high functioning young adults and adults with ASD, offering opportunities to develop social and life skills promoting independence
- ensuring that service providers and their staff have the appropriate knowledge and skills to work effectively with service users with ASD
- providing and promoting co-ordinated employment services to provide increased local employment opportunities and access to supported employment opportunities enabling young adults and adults with ASD to be economically active
- ensuring that the East Lothian populations, communities and staff delivering services are ASD aware and respond positively to people with ASD.



Carers

What's going well

- The monthly carer support group held by Pasda in Musselburgh
- Respite opportunities are provided by Aberlour Childcare Trust and Action for Children in partnership through East Lothian Council's Children and Adult Wellbeing services. In addition Share the Care has a wealth of experience in supporting children and young people with ASD.
- An ASD Spectrum Disorder (ASD) diagnostic pathway for children and young people up to age 18 has been produced by the East Lothian ASD Assessment Team (ELAAT) team. This team consists of a Community Paediatrician (Community Child Health), Speech and Language Therapist and Consultant Child Psychiatrist (Child and Adolescent Mental Health Services (CAMHS)). Referrals are made to the clinic by Community Paediatricians, Speech and Language Therapists, CAMHS staff and Teachers. There is an established, transparent pathway for referrals to the East Lothian ASD Assessment Team and the pathway is integrated with the staged assessment and intervention process within Education. For adults there are clear referral routes for diagnosis via the GP to the Regional ASD Service or the Community Learning Disability Team. The pathways are well developed and at present there is further work being done to ensure that the post diagnostic support element is included.

'There is a severe lack of support groups for parents to share experiences and offer advice to each other in East Lothian. I currently attend a group run by parents themselves who have children with Autism and Aspergers. If it wasn't for this, we would have nothing.'

What's not working so well

- Lack of integration between services – Parents and carers of adults with ASD report extreme levels of stress and

frustration that services are not joined up.

- Parents and carers report having to repeat lengthy accounts of their children's or young person's behaviour related to their ASD to different professionals, as well as continuously recounting the emotional, social, physical and financial burdens and stresses they themselves endure.
- Many parents of adults in this age group report finding themselves with the burden of navigating complex service networks and continuously advocating on behalf of their son or daughter to achieve understanding and awareness of needs. This is frequently at great cost to their personal health and the impact on the whole family can be devastating.
- Caring for a person with ASD can have a greater impact on parental health and family functioning than caring for a person with other care and support needs.
- Lack of awareness of ASD – many professionals across Health, Education and Social Work, and the community at large, have a poor understanding and awareness of the complexity of ASD.
- Carer's Assessments – as part of the assessment process, we need to ensure that carers are aware that they are entitled to their own assessment and if eligible to receive a service in their own right.
- Transitions – there are a numbers of issues around transitions including worries about life after school , accessing and navigating Further Education and Higher Education, benefits
- More specialist advocacy for people with ASD is needed.



How we will make things better

- We will listen to what carers are telling us.
- We will provide support that delivers identified outcomes for children, young people and adults with ASD.
- We will develop advocacy, befriending and mentoring services for young people and adults with ASD.
- We will provide parents, carers and families with accurate, timely information about ASD services and supports.
- We will provide local education services for children and young people with ASD, wherever possible.
- We will help children and young people to have a positive experience of successful transition into adult life (and into adult services, where appropriate)
- We will provide supported living options to young people and adults with ASD
- We will develop proposals for a model of planned respite for high functioning young adults and adults with ASD, offering opportunities to develop social and life skills promoting independence
- We will ensure that service providers and their staff have the appropriate knowledge and skills to support people with ASD.

- We will provide and promote co-ordinated employment services to provide increase local employment opportunities and access to supported employment opportunities enabling young adults and adults with ASD to be economically active.
- We will ensure that the East Lothian populations, communities and staff delivering services are ASD aware and respond positively to people with ASD.

To see the full action plan (and the full East Lothian ASD Strategy 2015), go to www.eastlothian.gov.uk/ASDstrategy