

East Lothian Autism Strategy

Draft for consultation

November 2014

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About the East Lothian Autism Strategy

The Scottish Strategy for Autism

The Scottish Government launched the *Scottish Strategy for Autism* in 2011. It states that strategic action needs to be taken nationally and locally. It looks at the impact of autism on the whole life experience of people and their families. It says that people need to be supported by a wide range of services such as social care, education, housing, employment and other community-based services and that a holistic, joined-up approach is necessary. They asked every community planning area in Scotland to come up with a local strategy.

The East Lothian Autism Strategy

The *East Lothian Autism Strategy* is the result of consultation with families, carers and professionals from health, the third sector and the local authority. Our strategy sets out the commitment of the East Lothian Partnership to supporting people with autism, their families and carers and shows how we are going to do this.

Aims

We want to make sure that people with Autistic Spectrum Disorder (ASD) are given the care and support they need in a way that promotes their independence and emotional well-being and respects their dignity, for example, by ensuring that they:

- are supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens
- have care and support that meets their needs and is based on their needs and wishes
- are supported to feel safe and secure without being over-protected
- have the opportunity to achieve all they can
- have access to information, assessment and services
- engage community partners (particularly health and social care) and communities to work together to redress inequalities and challenge discrimination.

Objectives

We will do this by delivering the National Autism Indicators, set out in the *Scottish Strategy for Autism* (see Appendix 4 on page 28).

We will:

1. develop a local autism strategy with people across the autism spectrum, carers and professionals, making sure their needs inform and are included in local policies and plans
2. ensure staff training raises awareness and understanding of autistic spectrum disorders (ASD)

3. ensure easy access to useful and practical information about ASD and community services
4. develop an ASD Training Plan to improve the knowledge and skills of those who work with people who have ASD
5. improve the way we collect data about how many people with ASD are receiving services and making sure that this informs the planning of services
6. develop a multi-agency care pathway for assessment, pre and post diagnosis, and intervention to improve the support for people with ASD and remove barriers
7. encourage more feedback from, and involvement of, stakeholders to improve services to inform service developments
8. co-ordinate services so that agencies work together effectively to meet the needs of people with ASD within Partnership resources
9. ensure that there are clear multi-agency procedures and plans to support people through major transitions at each important life-stage
10. evaluate and monitor how we are doing.

Working in partnership – who are the East Lothian partners and how will they deliver the strategy?

The main partners involved in delivering these aims and objectives in East Lothian are:

- People with ASD, their families and carers
- East Lothian Council
- NHS Lothian
- East Lothian Health and Social Care Partnership
- Third sector partners
- The East Lothian community.

The East Lothian Autism Strategy is built upon effective multi-agency and partnership approaches alongside service-users and their communities.

The commitments within the strategy will be resourced within the Partnership through innovative and flexible service design and delivery making best use of Partnership resources.

All partners are committed to working with people and communities to promote the wellbeing of people with ASD.

This strategy takes account of the value that carers, families and communities contribute to the lives of people with autism.

What does the East Lothian Autism Strategy link with?

- The Scottish Autism Strategy 2011
- Getting it Right for Every Child (GIRFEC)
- The Equality Act 2010
- The Additional Support for Learning (Scotland) Acts 2004 and 2009
- Social Care (Self-directed Support) (Scotland) Act 2013
- The Children and Young People's (Scotland) Act 2014
- Public Bodies (Joint Working) (Scotland) Act 2014
- East Lothian Single Outcome Agreement 2013 – 2023
- East Lothian Council Plan 2012 - 2017
- Integrated Children's Services Plan 2013 – 2017
- Children's Strategic Partnership - Children's Services Improvement Plans
- Learning Disability Strategy – Adult Well Being
- The keys to life – Improving Quality of Life for People with Learning Disabilities
- Caring Together: The Carers Strategy for Scotland 2010.

Now read on . . .

In the next sections, we are going to look at what the strategy will do for children with ASD, adults with ASD and their carers. In particular, we will be thinking about:

- what's working well
- what's not working so well
- how we will address these issues.

Children

The Disability Team within Children's Wellbeing work with children with a diagnosis of a learning disability and autism.

What's working well?

East Lothian Joint Communication Clinic (ELJCC) ASD diagnostic pathway for children and young people from 0 to 18 – this service is delivered by a Paediatrician (Community Child Health), a Speech and Language Therapist and a Consultant Child Psychiatrist (Child and Adolescent Mental Health Services (CAMHS)). The 2012 Autism Achieve Alliance (AAA) inspection of the East Lothian Diagnostic service was positive. The overall time from referral to diagnosis was shorter than many other diagnostic services in Scotland. The clinic is looking at ways of increasing their capacity, efficiency and effectiveness within existing resources, for example, by:

- developing closer co-operation and partnerships with schools and Educational Psychology staff. This could include attending staged assessment meetings in school/nursery prior to referral and would improve screening and gather as much multi-disciplinary contextual information as possible ahead of any subsequent ASD assessment
- following an ASD diagnosis, the ELJCC want to attend all school staged assessment meetings within six weeks of the ASD diagnosis
- exploring Children's Wellbeing and Education practitioners' involvement during the ASD assessment process
- exploring on-going autism training for schools, including nurseries to help them with the referral process and to support post diagnostic support.

Post diagnostic provision – ELJCC and CAMHS have initiated a short-life working group to consider post-diagnostic service provision – the group includes representation from Education, Children's Wellbeing and the Community Learning Disability Team.

Parents education programme – CAMHS are offering a ten-week parents' education programme, two hours a week

The ELJCC support for parents/carers following diagnosis includes:

- verbal feedback on the day of the clinic
- a written report about the assessment process, current issues and a plan for next steps is sent to the family and involved professionals (with their consent)
- written information and recommended reading about ASD are given at the time of diagnosis.
- the *East Lothian Parent Information Pack* providing information on supports available from Health, Education, Children's Wellbeing and other agencies as well as information on play and leisure opportunities and parental recommendations
- the offer of a follow-up appointment
- attendance by one of the team at the next staged assessment meeting (where possible) in order to feedback outcomes of the Joint Communication Clinic
- ongoing support from involved agencies
- parent programmes, for example, Hanen (run by Speech and Language Therapy department) and the CAMHS post diagnostic programme.

starting in January 2014 for up to 14 parents (of seven children newly diagnosed).

BIBSS – Following a successful application to the Autism Development Fund (ADF) in 2012, temporary funding was made available to the Barnardos Intensive Behavioural Support Service (BIBSS) to support parents of primary school aged children diagnosed with higher functioning autism who could not access support from the NHS Community Learning Disability Team, as they were without an associated learning disability diagnosis. The application to the ADF was made jointly by East and Midlothian Councils and affords provision for one worker across East and Midlothian.

Respite opportunities are provided by Aberlour Childcare Trust and Action for Children. In addition, Share the Care has a wealth of experience in supporting children and young people with autism. At present, there are no autism specific autism playschemes but this is another area being looked at in terms of service development with partner agencies.

Communications provision – most children and young people with ASD in East Lothian are educated in a mainstream setting with appropriate support. A small number of children and young people whose needs are more severe and/or complex are placed in one of our specialist Communication Provisions. These offer a more appropriate and flexible learning environment. Currently there is one primary and one secondary Communication Provision with a new secondary Communication Provision scheduled to open in Haddington in autumn 2015.

Transitions – we are working towards making sure that there is one **lead person** in each school who is responsible for co-ordinating planning transition.

My Future – During 2011, East Lothian Council Heads of Service for Children's Wellbeing, Education and Adult Wellbeing held a series of meetings to look at how to improve the experience of young people making the transition to adult life. There was a specific emphasis on young people with autistic spectrum disorders.

A multi-agency three-day My Future event took place in February 2012 and was attended by around 90 people, including parents and carers. Twenty-seven people attended on all three days. Follow-up days were held in May and September 2012 and November 2013. Three working groups took forward issues of key significance for the transitions process:

- information and communication
- my journey aged 0-25
- post-school destinations.

As a result of this work, the partnership is now considering how best to implement 0–25 years pathway in East Lothian.

What's not going so well

Playschemes – parents of autistic children consistently report that there is insufficient play-scheme capacity across East Lothian and the absence of such provision over the Easter, summer holidays and autumn break affords no carer respite. This has implications for parents finding and sustaining employment. Parents also report an absence of social activity groups/clubs for ASD children.

Lack of support groups – our mapping exercise and consultations found that parents and carers of children and adults with ASD were very keen to have more support groups where adults could share experiences and get advice.

Lack of support from health visitors/community nurses – when children enter primary school, health-visitor support ends and parents feel that they are left to cope alone. Again, a support and advice network would be very useful.

Transitions – there is a range of issues here, for example:

- there may be difficulty in ensuring that appropriate agencies are represented at transition planning meetings – especially Health or Employment Services or Further Education staff. There may be difficulties in prioritising the early allocation (or representation) of an Adult services social worker and all too often effective planning is not possible within the timescales available, which sometimes may only be a few months
- in circumstances where a young person has received a very late ASD diagnosis, difficulties with transition planning are further exacerbated
- the process of transition beyond school is particularly stressful for parents who are extremely anxious about the future. For more information, see page 14.

How we will address these issues

We have identified a list of actions that we think will help, for example:

- identifying and improving pre-diagnostic and post-diagnostic services and supports for children, young people and adults with an ASD diagnosis
- developing advocacy, befriending and mentoring services for children and young people
- providing local education services to meet the needs of local children with ASD, wherever possible
- trying to ensure that young people have a positive experience of successful transition into adult life, and into adult services where possible
- ensuring that service providers and their staff have the appropriate knowledge and skills to work effectively with service users with ASD
- ensuring that the East Lothian populations, communities and staff delivering services are autism aware and respond positively to service-users with ASD.

For more information about who is going to do this and how and when, please see the Implementation Plan further on in this document.

'I have had a bit more support this year – the school could see that I needed it and I went to social services. For me, being involved with social work is something you don't want to do – you just think you'll get your kids taken off you – but the Disability Team have been fantastic and I've had respite this summer. There are other families who don't realise and there's a big stigma about getting help from social work – people think that they'll be thought of as bad parents. I had the same worries about going to my GP for stress – for years I resisted medication because I thought that I should be able to cope without it. But I've got over my worries about taking anti-depressants and now I couldn't cope without them. To have a support worker to talk these things over with you would be fantastic.'

Parent

Adults

East Lothian Council commissions and contracts a number of different services and supports for adults with ASD. The aim of this is to ensure that people with ASD have the opportunity and support to achieve their identified outcomes.

What's working well

Information gathering and data collection has improved and this has helped with future planning of services.

Number 6 is a service for adults (aged 16 and over) with High Functioning Autism (HFA) or Asperger Syndrome (AS) who live in the Lothians and the Borders. The service is provided by Autism Initiatives UK and was officially launched in June 2005, with the opening of the Number 6 One-Stop Shop.

Eighty-two adults living in East Lothian are currently in touch with Number 6. Most are aged 16-29.

Autism Initiatives 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 and led to three workstreams aimed at improving:

- information and communication
- my journey aged 0-25
- post-school destinations.

As a result of this work the partnership is now considering how best to implement a 0-25 pathway in East Lothian. (For more information about My Future, see page 7).

Preparation for work – adults may require support and preparation with interviews from organisations such as East Lothian Works, Into Work or Number 6. Younger people with autism leaving school may benefit from Activity Agreements. There are also adults with autism in supported employment, through these organisations (and some of these individuals may also have an associated learning disability).

Housing – the most important issue here is predicting future housing need, models of housing support that may be required and the potential numbers who may require support to promote/sustain independent living.

Scottish Government data indicates that only 15% of ASD adults are employed. Many more adults on the autistic spectrum could be supported into employment and sustain employment if more employers had a better understanding of autism and made some small “reasonable adjustments” within the workplace to support employees with ASD.

What's not going so well

Local support from Autism Initiatives – it has been difficult to deliver Autism Initiatives provision locally across East Lothian due to difficulties in organising sufficient numbers of participants in the

various locations across the county. As part of our action plan, we will seek opinions and views and will continue to look at different ways to support people with high functioning autism on a more local basis.

Preparation for and support in work – routes to employment may need to be slower and more incremental for some ASD adults, starting as early as possible, with opportunities for voluntary work and supported employment in order to improve social and communication skills to begin with. At present many parents will 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 – there are a numbers of issues around transitions, for example:

- the **process of transition beyond school**
- parents having to advocate for their child – *The East Lothian Council Service Map (2013)* further highlighted the concerns expressed by parents advocating for their son or daughter .

Mental health – research indicates a high level of poor mental health associated with autism, which includes anxiety disorders and depression, with a high level of unmet mental health needs.

Criminal justice – persons with autism who come into contact with the criminal justice system are more likely to be those with high functioning autism/Aspergers Syndrome where their disability may not be immediately apparent. Such contact might either be as a victim, witness, suspect or offender and may create significant stress, anxiety and/or sensory overload resulting in unusual behaviour, which may escalate to extreme behaviour. Here are some of the issues:

- *The National Institute for Clinical Evidence NICE (2012) Guidelines* recommend that in each area a specialist community-based multidisciplinary team for adults with autism (**the specialist autism team**) should be established. The membership should include clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists and support staff. The health and social care integration and community planning agendas may further support this approach and this should be considered during the planning of local integrated services.
- **Autism Alert Card** – some people with autism may carry an Autism Alert Card, which will indicate that a person has autism and that they have social and communication

Lothian's Joint Mental Health and Wellbeing Strategy *A Sense of Belonging (2011-2016)* recognises that adults with autism often fall between mental health and learning disability services and that It says:

'There is a need to have an increased focus on those with autism and Aspergers. Services are required to explicitly and proactively respond to the needs of people with Aspergers or autism...There is a need for adult Mental Health services to be better informed about the needs of these groups.'

A Police Superintendent and father of a child with autism says:

'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'.

difficulties. The card provides contact details of parents, the care agency supporting the person or relevant professional. If possible, contact should be made with parents, carers or other professionals identified on the card to inform the best way to interview the person, the presence of a familiar person and being interviewed in a familiar place (where appropriate) may help to reduce stress and anxiety. The use of an Autism Alert Card is being promoted in many areas. However, it must be acknowledged that the use of such cards is currently not widespread. The absence of an Autism Alert Card is not an indicator that a person does not have autism, as many adults with autism will have no formal diagnosis (especially older adults) and may not be in touch with any services that could encourage use of such cards. We need to ensure that relevant professionals within criminal justice settings have relevant training and will explore the use of alert cards.

How we will address these issues

Some work is already well established. We 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 and Adult Wellbeing and Housing need to be involved to help inform strategic planning and service development. Services should be developed locally if possible to avoid out of area placements.

Planning for older adults with autism also needs to be explored, given the different models that would be required. Census data for 2012 indicates 24,746 adults aged 60 or over are living in East Lothian. The 1% prevalence estimate for autism suggests that approximately 250 of those aged 60 and over are likely to be on the autistic spectrum. This represents 25% of the autistic population of East Lothian. This information has been shared with the Older People's Joint Planning Group to inform future planning.

We have also identified a list of further actions that we think will help, for example:

- providing support that delivers identified outcomes for young people and adults with an ASD diagnosis
- 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 (and into adult services, where appropriate)
- providing supported living options to young people and adults with ASD

Commitments from East Lothian Council and Health & Social Care Partnership

East Lothian Council is the largest employer across East Lothian. However, we do not know how many ASD adults we employ. Within its recruitment policy and practices, the council will try to encourage employment of ASD adults, with adjustments to the recruitment process, especially around interviews.

GPs across East Lothian will have an important role in supporting people with autism and referring to appropriate services. This will include adults who they suspect of being on the autism spectrum and for whom it may be helpful to obtain a diagnosis, in order that services and/or additional support might be offered.

- developing proposals for a model of planned respite for high functioning ASD young adults and adults, 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 autism aware and respond positively to service-users with ASD.

For more information about who is going to do this and how and when, please see the Implementation Plan further on in this document.

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Carers

Caring for a person with autism can have a greater impact on parental health and family functioning than caring for a person with other care and support needs.

What's working well?

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 autism. At present there are no autism specific autism playschemes but this is another area being looked at in terms of service development.

To provide support and respite to carers, Adult Wellbeing works with a number of third sector organisations which can support the adult with ASD achieve their identified outcomes and to ensure that carers are getting a break from their caring role. We recognise that we need to place greater emphasis on future planning to ensure we have the right services in place and to avoid people having to live out of area due to lack of local resources.

An ASD diagnostic pathway for children and young people up to age 18 has been produced by the East Lothian Joint Communication Clinic (ELJCC) 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 Joint Communication Clinic 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 Autism 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.

What's not working so well

Lack of integration between services – Parents/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 autistic behaviour to differing 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

'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.'

Parent

at great cost to their own health and the impact on the whole family can be devastating.

Lack of awareness of autism – many professionals across Health, Education and Social Work, and the community at large, have a poor understanding and awareness of the complexity of autism.

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, for example:

- The **process of transition beyond school** is particularly stressful for parents who are extremely anxious about the future. Parents/carers and young people on the autistic spectrum are faced with particularly difficult and frustrating challenges navigating complex systems within Health, Education/Further Education, Social Work, DWP benefit services, Job Centres etc. Parents often report long struggles 'fighting' for services, which understand the needs of persons with autism. The Scottish Transitions Forum note that young people and families have to cope with confusing 'language' used by differing professionals, there is also a complex and often confusing legislative and policy framework to deal with, alongside an absence of advocacy provision.
- Adult Well Being commissions **Partners in Advocacy** to provide individual and collective advocacy for adults with a learning disability and autism. We recognise that this does not include people without a learning disability and are looking at ways in which existing resources within the third sector could provide independent advocacy for people without a learning disability
- **Parents having to advocate for their son or daughter** – *The East Lothian Council Service Map (2013)* further highlighted the concerns expressed by parents advocating for their son or daughter. This was impacting on their own health, with the constant worry as to who would fulfil that role in the future, if something happened to them. Many parents of high functioning adults in East Lothian have to obtain Powers of Attorney in order to negotiate, advocate and respond to correspondence on their behalf. Without this authority, the circumstances of many ASD adults would become increasingly problematic. Typically, this could include the suspension of DWP benefits, correspondence unanswered and appointments missed. Many adults have difficulty managing finances and frequently encounter problems related to this. Those adults living alone are particularly vulnerable.

'When your child is at school age, you no longer have support from Health Visitors etc. At this point, parents are left alone to deal with situations that occur out of school hours. It would be good if there was another support network in place to fill this gap and offer advice and assistance.'

Parent

How we will address these issues

We have also identified a list of actions that we think will help, for example:

- providing support that delivers identified outcomes for children, young people and adults with an ASD diagnosis

- 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 (and into adult services, where appropriate)
- providing supported living options to young people and adults with ASD
- developing proposals for a model of planned respite for high functioning ASD young adults and adults, 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 increase 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 autism aware and respond positively to service-users with ASD.

For more information about who is going to do this and how and when, please see the Implementation Plan further on in this document.

Data collection and mapping

An essential part of the East Lothian Autism strategy is producing robust data that identifies the number of East Lothian residents with Autistic Spectrum Disorder (ASD). In our action plan, we have committed to:

- establishing a partnership ASD Services Strategic Group (ASDSG) and appoint a Chair Person
- establishing a partnership ASD Services data-sharing protocol and agree systems and timeous arrangements to share information about people diagnosed with ASD
- identifying and mapping all the demographic information and needs of children, young people and adults with ASD living in East Lothian In September 2013, there was a national autism mapping project which looked at services available in East Lothian and gaps. The findings of this exercise have informed our local Implementation Plan. You can find out more about this in Appendix 3 on page 25.

Monitoring and evaluation

There will be strategic leadership to monitor and implement our local plan. Therefore we plan to form an ASD Strategic Group (ASDSG). This group will be responsible for ensuring that the strategy action plan is successfully implemented and that links are established within existing structures and resources to ensure effective flow of information and activity.

The Scottish Strategy for Autism notes that an indicator for best practice is a self-evaluation framework to ensure best practice implementation and monitoring. The steering group will develop a self evaluation framework.

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EAST Lothian Partnership (Draft) Autism Strategy Implementation Plan 2014 - 2024

Action Reference	Workstream	National Indicator	Action	Lead	Timescale
1. DIAGNOSTIC PATHWAY					
1.1	Production of robust data identifying the number of East Lothian residents with Autistic Spectrum Disorder (ASD)	1	Establish a partnership ASD Services Strategic Group and appoint a Chair Person	Resilient People Partnership (RPP)	30-Apr-15
1.2		6	Produce a flowchart diagram depicting the pre and post diagnostic pathways for East Lothian's children, young people and adults with (or in diagnosis stage) ASD.	ASD Strategic Group (ASDSG)	30-Apr-15
1.3		5	Establish a partnership ASD Services data-sharing protocol and agree systems and timeous arrangements to share information about children and young people	ASDSG	31-Dec-15
1.4	Identify and improve pre and post diagnostic services and supports for children, young people and adults with an ASD diagnosis	5	Identify and map all East Lothian ASD service users and their diagnosis; define Children/Young People with ASD and define Adults with ASD.	ASDSG	31-Dec-15
1.5		3,5,7	Engage service users and professionals to map local pre and post diagnostic services and supports available within East Lothian.	ASDSG	31-Dec-15
1.6		6,8	Partner agencies attend and contribute to pre and post diagnostic planning and review processes to ensure effective multi-agency service delivery to children and young people and their families.	NHS Lothian Joint Communications Clinic	30-Jun-15
1.7			In line with NICE guidelines proposals for a specialist community based multi disciplinary team for adults with autism will be developed from within partnership resources.	NHS Lothian Autism Steering Group	30-Oct-15
1.8		7,8,9,	Children, young people and adults will have access to a Named Person/Lead Professional to support them through pre and post diagnostic pathways.	ASDSG	31-Jul-16

2. EMOTIONAL WELLBEING AND MENTAL HEALTH

2.1	Provide appropriate services, supports, information and advice to ensure service users with an ASD diagnosis maintain emotional wellbeing and positive mental health.	6, 7	Provide regular mental health assessment, support and advice within the pre and post diagnostic pathway.	ASSG	30-Jun-15
2.2		3	Review and refresh the content and availability of partner agency public information (e.g. Websites, leaflets) detailing ASD services, supports, advice and information.	ASDSG	31-Dec-15
2.3		7, 9	Develop and promote community activity and social inclusion for young people and young adults with ASD.	Head of Communities and Partnerships, ELC	30-Jun-16
2.4	Young people have a positive experience of successful transition into adult life, and into adult services where applicable.	3	Collate, map and publicise information detailing existing support services available to service users with ASD.	ASDSG	30-Sep-15
2.5		7, 8, 9	Identify gaps in support services available to service-users with ASD and agree partnership priorities for joint resourcing and commissioning of services.	ASDSG	30-Apr-16
2.6	Provide parents, carers and families with accurate timely information about ASD services and supports.	3	Collate, map and publicise information detailing existing support services available to parents, carers and families living with ASD e.g. FLIP / Family Led Information Point, PASDA/Parents of ASD Adults, Carers of East Lothian etc.	ASSG	30-Apr-16
2.7		6, 9	Offer mental health and wellbeing assessments to parents and carers signposting eligibility for personal support.	ASSG	31-Dec-15
2.8		3	Promote existing and develop new networks for young people who are siblings to children and young people with ASD e.g. Young Carers of East Lothian.	ASDSG	31-Dec-15

3. EDUCATION and TRANSITION TO ADULT LIFE

3.1	Provide local education services to meet the needs of children and young people with ASD, wherever possible.	7, 8, 9	Review East Lothian's Education Service specialist educational provision required for children and young people with ASD within East Lothian Education Service.	Head of Education, ELC	30-Apr-14
3.2		7, 8, 9	Present proposals and secure resources for development of a new Secondary School communication provision for East Lothian's secondary pupils with ASD.	Head of Education, ELC	30-Apr-14
3.3		7, 8, 9	Undertake renovation of identified site (i.e. Former Haddington Infant School) to provide an operable Secondary School Communication Unit by August 2015.	Head of Education, ELC	31-Aug-15
3.4	Young people have a positive experience of successful transition into adult life, and into adult services where applicable.	6, 9	Ensure timely and effective transitions planning for every young person leaving school.	Head of Education, ELC East Lothian Works	31-Aug-15
3.5		6, 8, 9	Develop proposals to provide a multi-agency Birth to Age 25 Years Service, addressing transitions at Nursery to Primary, Primary to Secondary, Secondary to Adult Life.	RPP	30-Jun-16

4. SUPPORTED LIVING AND ACCOMMODATION

4.1	Provide supported living options for young people and adults with ASD.	1, 7, 8, 9	Review strategic planning for Housing to ensure provision of adequate and appropriate supported living needs for residents with ASD.	ASDSG	30-Jun-16
4.2		6, 9	Review existing Service Level Agreements with third sector partners, including feedback from service users and their families, to inform specification and delivery of local support and outreach services for young people and adults with ASD living within the community.	ASDSG	31-Dec-15
4.3	Develop new opportunities for adults with autism to develop social and life skills promoting independence. This would be a stepping stone model.	8, 9	Work in partnership with service providers to different ways to promote the development of independence and social skills, linking with community based initiatives for people who do not require services from statutory agencies.	Head of Adult Wellbeing, ELC PASDA	30-Jun-16

5. TRAINING AND AWARENESS RAISING FOR AUTISM

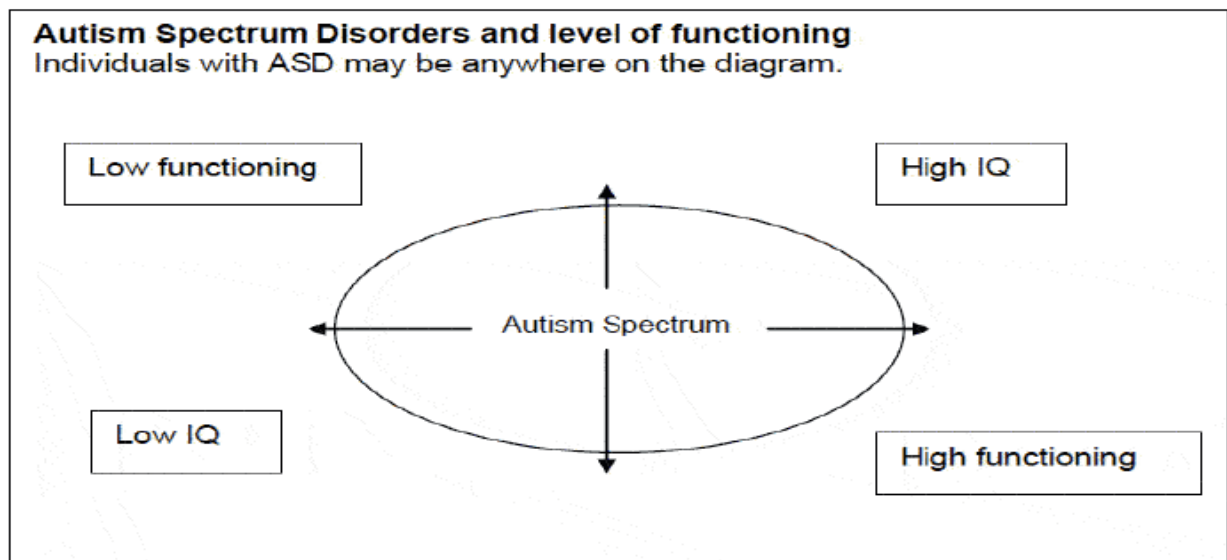
5.1	All staff and service providers have the appropriate knowledge and skills to work effectively with people with autism.	4	Undertake an analysis of multi-agency professional development needs and develop a comprehensive multi-agency training plan for professionals working with people with autism, involving service users and carers as appropriate, with particular emphasis on the awareness and knowledge of those professionals engaged in the Emergency, Public Protection and Offender Management services.	ASDSG	31-Mar-16
5.2		2	Provide a range of ASD-specific training opportunities for all school-based staff, integrating learning opportunities about ASD into the planning of the Continuous Professional Development Programme for Teaching Staff.	Head of Education, ELC	31-Mar-16
5.3	The East Lothian population, communities and staff delivering services are autism aware and respond positively to service users with ASD.	2	Implement the National Education Scotland Training Framework for all NHS Lothian staff engaged in delivery of ASD health services.	NHS Lothian	31-Jul-15
5.4		3	Promote ASD service user stories across local media and partner agency communication networks.	ASDSG	31-Jul-15
5.5		3	Source, review and make available partnership ASD awareness raising promotional and information material for public and professional use, particularly those engaged in the delivery of emergency services.	ASDSG	31-Jul-15
5.6		1, 3	Develop an 'Autism Champion Scheme' in East Lothian, promoting awareness and understanding of autism issues across the statutory agencies and wider community.	ASDSG	31-Jul-15

6. EMPLOYMENT

6.1	Provide and promote co-ordinated employment services to provide increased	6, 9	All young people with ASD leaving school in June 2015 will have a transitions plan confirming a positive post-school destination prior to their school leaving date.	Head of Education, ELC East Lothian Works	31-Dec-15
6.2	local employment opportunities and access to supported	5, 7, 8, 9	Identify, map and promote existing supported employment services and opportunities in East Lothian indicating ASD specific services.	East Lothian Works	30-Jun-16
6.3	employment opportunities enabling young adults and adults with ASD to be economically active.	5, 7, 8, 9	Agree partnership service developments generating local employment opportunities for young adults and adults with ASN, and seek to secure partnership and external funding to support service provision and new employment opportunities e.g. 'Project Search'.	East Lothian Works RPP	30-Jun-16
6.4		8, 9	Explore the 'MiEnterprise Gateway' provision to support young adults and adults with ASD to establish their own business and / or to be self-employed.	East Lothian Works, Social Enterprise East Lothian	31-Mar-17
6.5		3, 9	Promote ASD supported employment services at the annual young people's 'Futures Fair'.	East Lothian Works	30-Sep-15
Refer to Appendix 1					

Appendix 1: Definition of autism

The *Scottish Strategy for Autism* defines autism as a lifelong developmental disorder. It is often referred to as autism spectrum disorder (ASD) but it is also known as autism spectrum condition (ASC). ASD affects people differently, for example, some people are able to live independently but others will need very specialist support.



What everyone will have in common is difficulty in three areas of functioning, sometimes referred to as the triad of impairments.

People experience problems with:

1. Communication - both verbal and non-verbal, for example, difficulties with use and interpretation of voice intonation, facial expressions and other communicative gestures;
2. Reciprocal social interaction – this includes the ability to understand what someone else might be thinking in a real-time situation and to understand the need for social 'give and take' in conversation and overall interaction;
3. Restrictive, repetitive and stereotypical routines of behaviour - these may involve enthusiasms held by a person with ASD (which may be very restricting for their family, friends and colleagues but may also be psychologically distressing or inhibiting for the individual with ASD).

Appendix 2: Prevalence of ASD in East Lothian

In East Lothian, it is estimated (based on the prevalence rate of 90 in 10,000) that there are 835 people across the life span with autism. We have improved the way in which we collect and use information about children and adults with a diagnosis of autism.

Children and young people

Within Children's Wellbeing, the Disability Team are involved with 43 children and young people with an autism diagnosis; they have all been assessed and are eligible for a service. The age range goes from 3-16 years and services include:

- care at home
- respite
- residential school placements

For the academic year 2013 – 2014 there were a total of 211 students with a diagnosis of ASD. The breakdown is as follows:

Type of provision	Number of students
Mainstream or East Lothian specialist provision (P1-7)	98
Mainstream or East Lothian specialist provision (S1-S6)	104
Pupils in out-with East Lothian placements (day school)	4
Pupils in out-with East Lothian placements (residential school)	5
	211

Adults

In 2013, there were 88 adults with ASD known to Adult Wellbeing and receiving services, at a cost of £2,764,316.88. The types of services range from:

- care at home/housing support
- day opportunities
- respite
- residential care placements.

We know that adults with autism may also have co-morbid mental-health needs and other conditions, which should be better recorded. We have continued to improve the way in which we collect data and to ensure that people with a diagnosis are recorded more accurately on our information system. Equally we are working with health colleagues to share information about need to inform future planning.

Appendix 3: Mapping exercise

In September 2013 there was a national autism mapping project which looked at services available in East Lothian and gaps. There is a link to the full report in Appendix A. The findings of this exercise have informed our local action plan. The key areas for improvement noted were:

- friendships and opportunities for socialisation are key, there needs to be more opportunities for people to develop friendships
- better training, understanding and awareness of autism for professionals and throughout the community is required
- the need for a service or point of contact for people and families which could sign post and provide ongoing post diagnostic support
- better information about what is available needs to be clearly communicated.

There were also a number of key areas where things are working well:

- individual professionals were noted as making a real difference to people's lives
- parents and carers are involved at the various stages of care planning
- local carers organisations provide a significant level of support to carers
- there has been an increased awareness of autism
- more information is available to parents and carers about assessment, diagnosis and resources for additional needs
- information/data gathering has improved and is now being used to inform future planning
- local services are highly regarded by parents/carers
- evidence of good partnership working across professions.

Establishment of East Lothian Autism Working Group

Following on from the mapping exercise, the partnership established an autism working group which had membership from carers, providers, health, education, community learning and development and social work. Within this working group there were five workstreams identified, these included:

- Education/Further education and Employment
- Transition – across the lifespan
- Emotional Wellbeing and Mental Health
- Independent Living – this will include support to live independently, housing & supports in the community
- Diagnostic Support and Pathway.

An independent consultant was recruited to collate the information and intelligence gathered within each of these groups. There were also focussed sessions on specific themes which helped to inform our local implementation plan.

In addition to these main workstreams, key thematic areas emerged. One of these areas was autism champions and how champions could support the implementation of the local plan. The role of the champions would be to promote knowledge, understanding and awareness of autism. This is a scheme which has been progressed by many councils. It has been reported that the scheme is more effective when the champions are spread across a wide range of Council services, NHS, Job Centres, and Police etc. Staff have volunteered to become champions with agreement of their employer organisation and require to make a commitment to regular and ongoing autism training, at least twice a year. This is an area we are committed to exploring given the high impact of the scheme.

DRAFT

Appendix 4: /Links and resources

Resource	Link/contact details
Scottish Autism Strategy	http://www.autismstrategyscotland.org.uk/
East Lothian Mapping exercise	 East Lothian Service Map.pdf
Single Outcome Agreement	http://www.eastlothian.gov.uk/downloads/file/7403/the_east_lothian_plan_single_outcome_agreement_2013-23
Integrated Children's Services Plan 2013-17	
Corporate Equalities Plan	http://www.eastlothian.gov.uk/downloads/file/6685/east_lothian_council_equality_plan_2013-2016
Self Direct Support	www.selfdirectedsupportscotland.org.uk
Keys to Life	http://www.scotland.gov.uk/Resource/0042/00424389.pdf
FLIP – Family Led Information Point	www.eastlothian.gov.uk/flip or Flip East Lothian on Facebook
PASDA - Supporting families of adults with autism	57 Albion Road Norton Park Edinburgh EH7 5QY 0131 475 2316 http://pasda.org.uk/
Autism Initiatives (Number 6)	11 Granton Square, Edinburgh EH5 1HX Tel: 0131 551 7260 www.autisminitiatives.org
Lothian Autistic Society	Lothian Autistic Society, Davidson House 57 Queen Charlotte Street Leith, Edinburgh EH6 7EY telephone 0131 661 3834 http://lothianautistic.org/
National Autistic Society	http://www.autism.org.uk/

How to contact us

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