

Midlothian Autism Spectrum Disorder Strategy

March 2014

Midlothian Autism Spectrum Disorder Strategy- Draft

Introduction

More and more children, young people, and adults in Midlothian are being diagnosed with Autism, a condition that can have a serious impact on their lives and the lives of the people who are close to them. This impact can affect people's health, their wellbeing, social life, and their ability to find and keep a job. This Strategy is about how we plan to improve things for people with autism, by making sure that the right people and the right services are there to support them at the points in their life when they most need it. It is about understanding the potential of people with Autism and supporting them to achieve that potential by raising expectations and getting the support right.

Autism is complicated and throws up different challenges for each person. This means we need to plan services that are flexible and person centred. The important thing is that people are diagnosed early and that they get good advice and support very quickly. There are already some very good services in Midlothian but improvements can be made, particularly in how different services can work together in a way that works well for each individual.

Autism can be difficult to describe. It means many different things for different people but usually people with Autism will have problems with:

- Communication and understanding people.
- Understanding social behaviour and why people do what they do. This can mean that people with Autism have difficulties in social situations.
- Thinking and behaving in a flexible way. This means that people with Autism may prefer routine things and find change difficult.
- People can be very sensitive to the world around them. This includes noises, lights, and buildings for example.
- The autism spectrum includes people diagnosed with Asperger's syndrome who usually combine features of autism with high levels of intellectual ability

We estimate that there are 748 people in Midlothian with some form of autism. Midlothian Community Care Services know about 62 people with autism and Midlothian Children's Services know of 226 young people. It costs £1.5 million to look after somebody with Autism and a Learning Disability for their lifetime. A small number of people cost a lot more. It costs £900,000 for somebody with Autism and no Learning Disability. Many adults with Asperger's syndrome do not seek social care or health service support, but have a higher likelihood of remaining unemployed, and of mental health issues

There are some main areas that we need to sort out in Midlothian so that people with autism can get the right type of support when they need it.

- Help mainstream services to understand and meet the needs of people with autism
- Develop more Person centred support
- Help people and their families at times of change
- Get better at understanding and communicating with people with autism
- Develop better support for carers
- Be clear about a pathway of care for people with autism. This includes finding out where to go for help, getting a diagnosis, signposting and advice, support that people need straight away, and longer term support.
- Enabling people with autism to be as financially independent and as socially included in their community as possible

Services for People with Autism in Midlothian

Midlothian is committed to the principle of including young people with Autism into our mainstream services with the right kind of support to help them. We use the 'Getting it Right for Every Midlothian Child' approach to make sure that each young person is supported in a person centred way that is right for them, and that this support starts at the first signs of any difficulty. It also ensures that organisations work together to provide help that is right for each individual that will make a real difference. The approach supports young people to grow up as successful and confident individuals and to reach to their full potential. Wellbeing indicators are used to make sure that Children and Young People are safe, healthy, achieving, nurtured, active, respected and included.

There are three stages to this way of working:

- Staff from Health and Education Services work together to support children and young people within universal systems.
- Specialist support from an agency may be required to meet the young person's needs.
- Different agencies may work together to provide specialist support for a young person with Autism.

A range of services are available to Children and Young People with Autism in Midlothian to provide advice, guidance and assistance from an early age and these are guided by the principles of Getting it Right for Every Child. Many of these services are Community Services attached to mainstream provision and work with young people and their families to provide the right kind of support to enable them to participate as effective young citizens.

Early Years

- The **Early MAPSS** (Midlothian Assessment and Staged Planning System) Programme works with children with Autism and their families from birth to

the age of 3 years to identify and agree their needs, and to coordinate support at an early stage. Children are also helped to prepare for moving into nursery school.

- The **Multidisciplinary Clinic** (MDT) is based in a new, child friendly, clinic at the Midlothian Community Hospital. The clinic provides a one stop health assessment for Children and links directly to Early MAPSS
- The **Bright Sparks Playgroup** is a playgroup for pre-school children with a disability and their sisters and brothers. A play leader and support teachers organise activities and parents provide peer support for each other.
- **Hawthorn Children's Centre** offers day support for Children under 5 years old.

Moving into School

At the point of moving into nursery school the **Midlothian Assessment and Staged Planning System** ensures that a joined up approach is used to coordinate support, that people work together to make sure that a child's needs are met, and that there is a clear plan to support the child to meet their potential. This support follows the child throughout their time at school. The principle is that children are supported in ordinary schools and mainstream education with the right kind of support.

- **Building Blocks Support** is a playgroup for children with Autism run by parents, the Specialist Teaching Service, and the Speech and Language Therapy Service. The team also provide individual support for children and their families with language and communication, and reducing social isolation.
- **The Outreach Service for Autism Spectrum Disorder** provides pre-school support and advice to teachers and named workers in Primary and Secondary schools.
- **Children with Additional Support Needs and Autism** use the extra support provided by specialist Autism provisions in one nursery school, five primary schools and two secondary schools. Saltersgate School, part of the Dalkeith Campus provides education for children with more complex support needs from the age of 5 to 18 years.

Several **NHS Lothian Services** are very closely linked to the planning and support of young people with Autism in Midlothian throughout their childhood.

- The NHS Lothian **Community Children's Nursing Service** provides specialist nursing care to children up to the age of 16.
- The **Child and Adolescent Mental Health, Learning Disability and Autism Service** works with young people with more complex behaviours as well as offering consultation and training to staff.

Breaks and Respite

A range of specialist organisations provide after school support, short breaks and respite opportunities.

- Provider organisations are commissioned by Midlothian to provide opportunities and breaks for young people with Autism.
- The Midlothian Play and Activity Scheme operates during the Easter and Summer holidays to support families and provide play experiences and opportunities for young people.

Moving on from School

- Specialist workers within Children and Families locality teams support young people with a Disability and Autism, and their families both during childhood and to prepare for moving on from school.
- Social Workers from Children's Services and Community Care Teamwork closely to prepare young people for their life as an adult. Specialist **Transitions Workers** work closely with people and their families to plan for their future after school.
- An annual **Transition Fair** takes place each September to highlight the choices that may be open to young people. A Transition Forum and regular review meetings checks that planning is in place for young people with Autism who are leaving school.
- Midlothian has been successful in attracting additional investment to improve planning and services for two **Short Term Projects funded by Scottish Autism Development Fund**. The last round of bidding resulted in two new local initiatives being funded, one aimed at young people with Autism, supporting them to prepare for leaving school by having a clear plan for their future developed with their families and people who know them best, and a second in partnership with East Lothian and Barnardos supports families of young people between the ages of five and twelve who have behavioural difficulties which have an impact on home life.
- Two **new day services** for young people are currently under development in Mayfield and at Vogrie Park near Gorebridge. Both will offer support to young people with a Learning Disability and Autism.

Autism Services for Adults

- Midlothian **Community Care Assessment and Care Management** provide assessment and support to enable people to live as independently as possible in their community.
- **Number 6. The One Stop Shop for adults with Asperger Syndrome and High Functioning Autism** offers a range of information, advice and social activities to help people to live as independently and successfully as possible. The service offers social groups, befriending, and volunteering and employment support and advice.
- **IntoWork** provides supported employment services for people with Autistic Spectrum Disorders, including Asperger's Syndrome.
- **Midlothian Local Area Coordination Service** provides information, support and help for people to plan and take part in things that are going on in their local community.

- **Parents of Autistic Spectrum Disorder Adults (PASDA)** is a support organisation for parents and carers of adults (over 16s) on the autistic spectrum who live in Edinburgh and the Lothians. They can provide information to parents, relatives, friends or professionals looking for information.
- **Edinburgh and Lothian Asperger Society (ELAS)** is an independent social group for adults aged 18 and over with diagnosed or suspected Asperger Syndrome or who are on the autistic spectrum. Though based in Edinburgh, people from outside the area are welcome to attend the meetings.
- **The Regional Autism Spectrum Disorder Consultancy Service** provides diagnosis, assessment, and advice for people over the age of 18 and their families.
- **The Midlothian Community Learning Disability Team** provide specialist assessment, advice, treatment and support services for adults with a learning disability and their carers. This includes people who have a learning disability and autism spectrum disorder.
- A number of local and national voluntary organisations provide specialist **Housing and Support Services** for people with autism in Midlothian, This includes very intensive support to people with autism in their own homes and in the community.

Priorities for Midlothian

The Views of Midlothian Families and Carers

Vocal Midlothian organised three meetings for families and carers of people with Autism Spectrum Disorder in Midlothian and these identified several main areas for improvement in local arrangements:

- Better Information particularly when people have just been diagnosed with Autism. This includes information about the condition and about services that can help.
- The need for training and awareness raising. This includes for professional staff, for families, and for the wider community in general.
- The need for good planning and support at times of change. This includes leaving school, leaving home, or planning for when parents or families can no longer provide care.
- Families feel that they need services to be coordinated and joined up so that they don't feel left on their own and having to battle for everything.

Autism Mapping

The National Autism Mapping Project produced their report for Midlothian in September 2013. They used questionnaires workshops and focus groups to get the views of:

- People with Autism in Midlothian
- Families and carers of people with Autism in Midlothian
- Providers of Autism Services
- People who worked in Health, Social Work, Education and Employment support services

The project highlighted these priorities for Midlothian:

- Better information
- Training and awareness raising
- Support for a good social life and opportunities
- Support for families
- Planning and support during important transitions
- Some new services
- Multi agency Planning and Joint Working.
- A Strategy for people with Autism Spectrum Disorder
- Better Assessment and Diagnosis
- Work opportunities

The Scottish Autism Strategy also Details Ten Indicators For Best Practice In Autism Services

- A local Autism Strategy.
- Access to training and development.
- Easy access to useful and practical information about Autism and improved communication between stakeholders.
- An Autism Training Plan.
- A process for data collection which improves the reporting of how many people with Autism are receiving services and helps to plan these services.
- A multi-agency care pathway for assessment, diagnosis and intervention.
- Feedback to inform service improvement and encourage engagement.
- A multi-agency coordinated approach to meeting the needs of people with Autism.
- Clear procedures to support people during transition at important stages of their life.
- A self-evaluation framework to ensure best practice implementation and monitoring.

The Plan for Autism Services in Midlothian

We want to use the Autism strategy as an opportunity to address the needs of people with autism throughout the whole of their life, in particular during those early years when parents need help and support to understand autism and to begin to prepare their child for a life of inclusion rather than segregation, and after they finish education, when entry into adult life and building independence may be challenging as a consequence of losing the structure that schools provide to parents and young people with Autism.

We recently did some work to try and look at how we do things from the perspective of young people with Autism and families who use our services. This looked at the way we arrange things and the processes that people have to go through to get support. This helped us to think about how we can improve the services that we offer, making sure that the people who use them really are at the heart of what we do. It also helped us to identify the kinds of blocks and barriers that frustrate families and to think about ways of overcoming these.

There will be good joint planning of Autism Services in Midlothian

We will bring together a core group including representatives from Children's and Adult Services, Resource Managers, Psychology Services in schools, Regeneration and Community Planning, and partners from NHS Lothian to further develop and implement the Strategy for Midlothian. This will include a focus on children and young people and adults with Autism who do not have a learning disability. We will link this to existing strategies for Learning Disability and Children with Autism. We will make sure that Autism services and developments in Midlothian are planned together by a Partnership Board with representatives from Midlothian Council, NHS Lothian, Service Providers, Service Users and Carers.

The £35,000 one off payment from Scottish Government will be used in two ways:

- 1) to recruit to a post in Health and Social Care to:
 - refine and further develop this draft strategy
 - identify service gaps and propose solutions
 - seek out funding to resource initiatives that respond to local need in partnership with third sector agencies who have access to funds not available to Councils or NHS.
 - explore different commissioning models

The precise specification, grading and hours for this post is in the process of being determined and will reflect the skillsets and competencies required by the postholder while maximising working time available to the postholder.

- 2) support the implementation and dissemination of the strategy

The core group will refine an effective system for collating information about young people with Autism to assist with planning for Transition and Adult Services. They will also ensure that a system is in place for people with Autism, families and carers to contribute to service improvement.

It will be easier for people to find out if they have Autism Spectrum Disorder

We will make sure that people can get a diagnosis in good time and offer access to information, advice and a personalised approach to options for support for all those diagnosed. This includes setting a clear pathway for them.

We will achieve this by:

- Engaging and consulting with people accessing children's services to ascertain the barriers and blocks to effective presentation and early interventions.
- Raising awareness of the impact of an autism spectrum diagnosis within the children and families and education workforce with the aim of a reduction in the average age of diagnosis for children and young people.
- Giving people good information about what to do if they are worried that they or somebody they care for has Autism.
- Making sure that people can approach a teacher, a Head Teacher, a guidance teacher, or a Health Visitor, if the person is a child, or the family doctor if they are an adult.
- Making sure there is training for these groups so that they know how to respond and how to arrange for an assessment to be made.
- Ensuring that Diagnosis is carried out by professionals who have specialist knowledge of Autism.
- Ensuring there is a coordinated and timely approach to diagnosis strengthening partnerships between education, children's services and Lothian Health Board.

Children and Young People with Autism

We want to ensure that all children and young people with autism and those who are close to them, including their parents and carers, can benefit from expert advice and support whilst living in or near their family home.

Midlothian recently commissioned an evidential approach to review the journeys of young people with autism. The findings and themes highlighted the negative longer-term outcomes for children who are removed from their communities and highlighted the benefits of engaging with young people and their families early, developing individual support close to their community and family. This underpins our partnership vision which is to develop community-based or family-based supports for children and families wherever possible.

This work produced some very practical ideas about supporting people close to home more effectively and approaches and materials to achieve this. Specifically we are using our findings to:

- develop improved partnership working,
- develop a culture of person centred planning and person centred outcomes
- raise awareness of what good Autism services can look like
- explore more meaningful consultation and engagement with children, young people and families
- develop Care Pathways that strengthen joint working between organisations.
- improve and strengthen our existing community based services by looking at how these might be organised and delivered differently.

We will support more children with Autism within Midlothian so that family and community relationships are more easily maintained and that money is better spent. The Education provisions in Midlothian are currently under review with a view to meeting the needs of children and young people more effectively. This means any therapeutic placements that are made will be kept as short as possible with young people returning to mainstream education as quickly as possible.

Transition to Adult Services

The Transitions Team and workers within Children and Families locality teams support young people with Autism and their families from Children's Services to Adult Services and are developing particular expertise around supporting people with Autism.

There are clear procedures for supporting young people with additional needs in Midlothian via GIRFEC, the 16+ forum, a Multi Agency Assessment and Planning System, and Transition Passports.

Transition, however, remains a key area of concern for people with Autism and their families and Carers in Midlothian.

- We will build on the experience and success of the short term Autism Development Fund project based at Saltersgate School in Dalkeith. This provides a model for good planning and preparation for young people with Autism who are about to leave school.
- We will look at the role of Local Area Coordinators in working with young people to help make good plans for their future in plenty of time.
- We will ensure that transitions workers engage with young people as soon as they can in order to get time to keep people and their families at the centre of their future planning.

- We will explore how best to develop a set of Personal Outcomes for each young person and identify who will be responsible for providing the range of advice and support that they need.
- There are different routes depending on the outcomes that have been identified and agreed. For people with more complex needs local support organisations will provide support and opportunities around a clearly agreed plan.
- Midlothian Training Services Transition Coordinators will engage with young people and their families, seeking out young people who may be difficult to reach and have been disengaged from education, training or employment.
- The Midlothian Training Service will provide support, including support on a 1:1 basis, to build on young people's confidence and support their developing interests
- The Disability Social Work Team have been training in outcome focussed assessment and intervention and Carer conversations. We will review the role and structure of the team so that it is in a better position to meet future demand and to respond to the opportunities created by Self Directed Support Legislation.

Information and Support will be easy to find

- We will produce easy to understand information about autism and autism services. This will include how to access services including health, education and social care services as well as making information about Local Authority services easier to understand.

There will be clear information about:

- Connecting people to ASD Services
- Advocacy
- Counselling
- Peer support
- Social groups and activities

We will make sure that we make more use of Autism alert cards in Midlothian.

Opportunities for people with Autism Spectrum Disorder

We will develop a range of personalised services to support adults with autism to live independently, with a particular focus on supporting participation in meaningful activities including employment.

- We will build on our existing front line, preventative services.
- Employment support for people with Autism is currently provided by different organisations like IntoWork, STEM (Services for Education and Training in Midlothian) and Number 6. Support Workers from these services benefit from

Autism Awareness training but will also take part in other aspects of the Training Programme including that for Autism Champions.

- We will build on the good practice partnerships between local employers, Borders College, and local employability organisations in providing work experience and on the job training and qualifications.
- People with Autism would like more opportunity for a better social life and to be included in their community. There is a real threat of social isolation and people are very worried about this. We have a range of strong Community Organisations in Midlothian and they can be very welcoming and inclusive to people with Autism, but a lot more can be done. We will work with Midlothian Voluntary Action (MVA) and Volunteer Centre Midlothian to develop awareness and offer advice and training for community organisations about how to be welcoming to people with Autism.
- Our Local Area Coordination Services currently work with people with Autism to people to find out information and to make choices that mean they can have control over their own situations. They also support people to part of their local community and make things happen. We will consider the role of Local Area Coordinators in the development of our Autism Strategy, particularly for people who don't use more formal support services.
- The experience of people locally is that advocacy for people with Autism is often linked to having a Community Care need that is linked to their condition. We will offer opportunities for awareness raising and training to our advocacy partners as part of the planned programme.
- We will develop and strengthen the role of children's advocacy
- We will continue to work with our existing advocacy services such as Vocal, Intowork, No6, ELAS and PASDA.

Awareness Raising and Training

We will promote greater awareness of autism to encourage social acceptance and to enable staff who are likely to interact with people with autism to operate more effectively. This includes training to recognise the characteristics of Autism, know where to refer people for diagnosis, and know where to contact for specialist advice and support.

- We will develop three levels of training, basic awareness, intermediate, and specialist, and include this in our training plan for Midlothian.
- We will develop and offer Training for Families.
- We will recruit and train Autism Champions in Community Services, Housing, and amongst Social Work Care Managers.
- We will audit our services to ensure that they are Autism friendly.
- We will include other groups in the training programme including police and criminal justice workers, staff from Job Centre Plus and Welfare Benefits Services.

Support for People with Complex Care Needs

We are well advanced in our plans to develop and build housing for people with Autism and Complex needs in Penicuik. The project will involve the building of 12 Council tenancies specifically designed for the needs of people with Autism and Complex Care needs. This will be funded by disinvesting from higher cost and out of area support packages for people with Complex Care Needs.

We will advance to a business case with NHS Lothian and our Lothian local authority partners in the development of a new tier of housing and support service for people with Autism and Complex needs. This represents a new level of joint nursing and care service between NHS Lothian Learning Disability In-Patient services and the 12 person Midlothian development.

We are adopting a Positive Behavioural Support approach for people with Autism and Complex Needs. Midlothian is a pilot site for embedding an approach to deliver safe, effective and person centred support for people in their own community. This is being implemented by supporting five Midlothian staff from the local authority and partners from a local voluntary organisation to undertake a Masters level module in developing effective, and evidenced-based strategies to address the needs of people with Complex behaviours.

Next Steps

The Midlothian Autism Spectrum Disorder Strategy Planning Group will now recruit to a post to refine and further develop the Strategy and to support its implementation and dissemination.

Appendices

Appendix 1 The Views of Midlothian Families and Carers

A group of parents and carers got together over three sessions with Vocal Midlothian to think about their experience of caring for people with Autism in Midlothian. These are the things that they agreed:

- It is difficult for people who have Autism, but not a Learning Disability, to get good services
- Parents and Carers say they have to fight to get services from Education, from Children's Social Work and from Adult Social Work. This can be stressful and exhausting
- People think that each person should be treated as an individual. There is no typical case and services need to recognise this.
- Mental Health issues can be a big problem for people with Autism but different approaches are needed for them. Conventional services are unsuitable.
- People need awareness training. Appearances can be deceptive and people with Autism can appear more able to cope than they really can.
- IQ tests are not a good way of sorting out which services are right for people with Autism.
- We need to think about the needs of the whole family, not just the person with Autism.
- Moving between services and leaving school could be better. People with Autism need time and help to get used to any changes.
- There needs to be good preparation for when parents can no longer care.
- There is a need for good information about services.
- Information after diagnosis is particularly important.
- GPs need more information and training about Autism.
- Care Manager's understanding of Autism is variable.
- Experience of Advocacy is variable.

Appendix 2 Autism Mapping

The National Autism Mapping Project produced their report for Midlothian in September 2013. They used questionnaires workshops and focus groups to get the views of:

- People with Autism in Midlothian
- Families and carers of people with Autism in Midlothian
- Providers of Autism Services
- People who worked in Health, Social Work, Education and Employment support services

This is what the Project Highlighted:

- a need for more autism specific support around socialisation and increased social opportunities in Midlothian. This is across the life span but especially relevant within education
- Parents and Carers think support should shift towards incorporating the needs of the family; a holistic approach.
- Need for greater community understanding and acceptance of autism in Midlothian, leading to improved inclusion.
- A need for more inclusion work to be developed within secondary education
- closer multi agency planning and coordination of ASD initiatives within the local authority area.” – to raise better
- A lack of strategy in Midlothian which encapsulated ‘cradle to grave’ needs and pathways.
- Despite there being a lot of good work going on, it is not always shared.
- A need for a shared focus in Midlothian and planning structure
- Planning for training for all staff
- a clearer multi agency parenting strategy
- There is a need for more autism specific services
- autism specific social opportunities and opportunities to integrate into society
- autism awareness training for staff from:

- Community Learning
- employment support
- housing
- mainstream education
- adult mental health services
- general awareness raising for the public of Midlothian
- Parents felt they wanted more information about services and about autism in general
- some parents cited a need for more information regarding education options for pre/primary/secondary/university and support strategy packs.
- teachers need more autism information
- advice and assistance for pre-school teachers and assistants
- Some parents raised the need for local autism specific social clubs/support groups and the possibility of fostering socialisation skills into education
- there is a need to develop adult services specifically for people with AS/HFA
- Parents felt they had difficulty in getting professionals to listen to their concerns in trying to get an assessment for the person they care for
- “they could listen to concerns of a parent”.
- Earlier assessments through educational and medical referrals were also raised as improvements.
- parents were keen for more information about access to services post-diagnosis: “have a list of contacts and appropriate therapies available/counselling”
- A top priority for change in Midlothian was thought to be increasing communication post diagnosis; in order to improve sharing information between agencies.
- Interventions could be improved by developing a wider support perspective, in order to include support for siblings.
- a need for a support network for siblings in Midlothian [PCQ].

- “more pre school establishments are needed for children on Autistic Spectrum in their home towns.” [PCQ].
- a local plan or strategy would improve multi-agency working in Midlothian: “A clear strategy that coordinates multi agency planning in terms of training for all staff, and a clearer multi agency parenting strategy” It is hoped that coordination of services would also improve as a result.
- Professionals identified stronger multi-agency working in children’s services and thought adult services required attention
- agencies need to be ‘on board’ with developing multi-agency partnerships and this may require a change of attitude: “A more open approach to multi-disciplinary working and an understanding that the "ordinary" is as important as the "special"
- increasing social opportunities for people with autism and reducing the risk of isolation. Parents made it clear that social opportunities would need to take the needs of the person into account, and that traditional social groups may not work for everyone: “Very few social contacts. Isolated through school and still at university. Anxiety RE meeting new people, so 'going to groups' problematic”.
- An alternative option was offered from one parent which addresses this common concern: “Befrienders would be a big help”
- A top priority for change in Midlothian, put forth by parents and Carers, includes incorporating social and emotional support/learning into the curriculum. Furthermore, parents were keen to see a ‘through-school’ for people with autism, such as Kaimes Special school, in Midlothian.
- parents also feel there needs to be more provisions available in education: “More primary schools with Autism support units in them are needed as this will let 'normal' pupils have a better understanding of autism be more tolerant of the disability”
- Professionals wish to build on the established links with IKEA and Marks & Spencer’s; this model should be extended to other employers in order to provide more employment opportunities for people with autism in Midlothian
- a need for more autism specific information and support to be made available: “Much more one-to-one care provided for those children who require it.
- MUCH more autism information, advice and assistance for pre-school teachers and assistants.” For moving into secondary education from primary

school, one parent felt more practical support would be beneficial: “more visits, 1/2 day taster visit over the course of a few months not 1 or 2 days”.

- Leaving secondary education can be particularly difficult for people with autism and their parents/Carers. Some parents felt there needs to be an increase of options for people with autism leaving secondary education including more information: “more information on what support services are available, a list of placements available in Scotland. A clear guide to who is responsible for doing what you need to have, an adult social worker , you need to get funding - who is responsible for what etc.”

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