

Aberdeen City Strategy for Autism



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Contents

Section		Page
1	Summary and Recommendations	3
2	Introduction	4 - 5
3	What is autism and who is affected?	6 - 7
4	Vision, Values and Goals	8 - 10
5	The Aberdeen City Context – Where Are We Now?	11 - 21
6	Background Guidance and Legislation	22 – 24
	Glossary of Terms, Acronyms and Abbreviations	25
	References	26 - 27

1. Summary and Recommendations

Aberdeen City's Autism Strategy and Action Plan have been drawn up with the involvement of people representing all statutory and appropriate voluntary bodies, individuals on the spectrum and families. It acknowledges the challenges faced by people with autism across the lifespan and ability range and how these might be best addressed by the services in Aberdeen City. It also acknowledges the challenges faced by services required to move on from past practice to a more joined up approach.

There is anxiety about change for professionals but the Scottish Strategy provides an impetus and clear framework for the quality improvement in service delivery requested by service users.

Aberdeen City's Action Plan aims to describe how services can meet the recommendations for good autism provision described by the Scottish Autism Strategy (2011) in its "Guide to Interventions and Support for People on the Autism Spectrum" (2014) which states that there should be:

1. A local autism strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with autism (ASD) and carers are reflected and incorporated with local policies and plans.
2. Access to training and development to inform staff and improve the understanding amongst professionals about ASD.
3. A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communications.
4. An ASD training plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff.
5. A process of data collection which improves the reporting of how many people with ASD are receiving services and informs the planning of these services.
6. A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.
7. A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.
8. Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.
9. Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.
10. A self-evaluation framework to ensure best practice implementation and monitoring.

2. Introduction

“Look beyond the autism and you will see someone very special”

- 2.1 This document describes Aberdeen City’s Strategy for Autism. Autism is a national priority which requires strategic action both nationally and locally. The aim of Aberdeen City’s Strategy is to develop integrated services to enable individuals with autism to lead lives that are as independent, purposeful and fulfilling as possible.
- 2.2 In 2011, The Scottish Government, in conjunction with COSLA, launched a Scottish Strategy for Autism which provides local authorities with a framework for the development and delivery of high quality services for individuals affected by autism. The Scottish Strategy sets out ten key performance indicators, the first of which is to develop local policies and plans.
- 2.3 Aberdeen City’s Strategy for Autism sets out its Action Plan over the next ten years, building on existing good practice and developing services in line with the ten indicators of best practice outlined in the Scottish Strategy for Autism.
- 2.4 People involved recognise the challenge in developing a Strategy given the variation of presentation and complexity of autism with resulting impact on the individuals themselves, their families and services working alongside them. In order to provide the necessary spectrum of support, from low level interventions to highly individualised care packages, services are tasked to provide collaborative assessment of need.
- 2.5 Children and adults on the autism spectrum each have a unique set of conditions which do not necessarily fall within the categories of learning disability or mental health. Access to services and supports in Aberdeen City can be complicated by the eligibility criteria of particular services. As a result, the ideal of a seamless transition from one stage of an individual’s life to another may be difficult to achieve. This is particularly relevant to people with Asperger Syndrome who may not fulfill criteria for either service but have clear support needs, particularly at the time of key transitions.

In response to guidance such as the Scottish Government’s report *The Keys to Life (2013)* services are moving towards functional assessments which consider an individual’s “capacity” to manage as independently as possible with identified support in place.

The Scottish Government’s Mapping Exercise conducted in 2012 (ME) and consultation with young people and their families highlighted that, having enjoyed supports and interventions at school, some young people feel unsupported when they leave. This is particularly true for young people with Asperger Syndrome (AS) and High Functioning Autism (HFA) who would welcome support for the transition into employment. They feel adults such as Job Centre staff and employers lack knowledge about ASD.

- 2.6 Autism costs the UK more than £34 billion a year according to new research from the London School of Economics (LSE). The cost of providing care for each person with complex needs involving ASD and affected by a learning disability through his or her

lifespan, is reported to be £1.5 million in the UK. Professor Martin Knapp, LSE, concludes:

“There is an immediate need for better coordination across public agencies and levels of government.....too often responses to the needs of individuals and families are piecemeal and less helpful than they could be.....In a time of austerity, the question is not 'Can we afford to invest in autism research?' but 'Can we afford not to?’”



Picture by Brendan (9yrs)

3. What is autism and who is affected?

"We would like people to have a better awareness of our condition. We just want to be listened to, be understood and treated with respect"

*Euan Hood
Triple A's Aberdeen*

"Most people have issues that they need support for at some point in their lives. We don't expect special treatment and we need to get better at helping ourselves. When they come and look at me, I want them to see me as a person, not as the group that I'm associated with, because of the trait that I'm associated with."

*Alastair Meek
Triple A's Aberdeen*

3.1 Autism is a lifelong developmental disorder that affects the way a person makes sense of the world, communicates and relates to the people around them. The Scottish Strategy's Menu of Interventions (2014) identified the following difficulties and challenges common to people on the spectrum:

- Understanding the implications of an autism spectrum diagnosis
- Development of effective means of communication
- Development of social communication
- Developing and maintaining relationships
- Social isolation for individuals with autism
- Social isolation for family
- Learning to learn skills
- Predicting and managing change
- Behaviour and emotional regulation protecting wellbeing
- Restricted and repetitive interests and behaviours
- Motivation issues
- Sensory issues
- Daily living skills
- Co-existing conditions (e.g. epilepsy, anxiety etc.)

It is hoped that identifying ways of addressing these issues provides a practical framework for interventions and supports where required.

Menu of Interventions (2014)

3.2 Everyone diagnosed with autism will have difficulty to a greater or lesser extent in three areas of functioning, namely: how to communicate effectively; how to think flexibly and how to deal with reciprocal social interactions. These are known as the Triad of Impairments and need to be present before a positive diagnosis can be made. Diagnostic guidelines highlight the need to consolidate knowledge and understanding of an individual's needs in order to inform planning. The National Institute for Health and Care Excellence (NICE) Clinical Guidelines for Diagnosis of Autism in Children and Young People (2011) emphasises the value of accessing contextual information from nurseries and schools to inform the diagnostic process. It also highlights the need to provide educational establishments with diagnostic information to support

planning and to provide support and advice for parents and carers. The key to planning, therefore, is the development of a process which facilitates a healthy flow of communication between and among all concerned.

The Menu of Interventions reports that while there are many hundreds of interventions currently in practice, there is very little evidence base to support any of them. The document, therefore, suggests practitioners move on from past practice and focus on the challenges posed by the nature of autism itself in order to identify interventions to address these challenges.

Prevalence studies of children in Scotland point to an incidence of 0.9% (*Green, H. et al (2005) Mental health of children and young people in Great Britain, 2004. Office of National Statistics*) or 90 in 10,000 children. This suggests that there are over 50,000 people in Scotland with autism and of these, an estimated 40% have a diagnosed learning disability. People at the higher functioning end of the autism spectrum meet the criteria for Asperger's Syndrome or High Functioning Autism. It has not been possible to audit accurate data on adults in Scotland but the Scottish Consortium for Learning Difficulties reports that in Aberdeen City there are 96 adults with an autism diagnosis, mostly with learning difficulties. Prevalence figures, however, estimate there are, in reality, approximately 2000 people in Aberdeen City with autism.

An audit carried out in 2013 (Additional Support for Learning and Young Carers report to Parliament) states that in Aberdeen City there are 2393 (recorded) children and young people in education who have additional support needs. Of those, 291 are recorded as having autism.



Picture by Demmi (11yrs)

4. Vision, Values and Goals

4.1 The Vision, Values and Goals outlined in the Scottish Strategy for Autism underpin the Aberdeen City Strategy for Autism.

4.2 Vision

“Our vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.”

*The Scottish Strategy for Autism
Scottish Government 2011*

4.3 Values

- **Dignity:** people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;
- **Privacy:** people should be 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;
- **Choice:** care and support should be personalised and based on the identified need and wishes of the individual;
- **Safety:** people should be supported to feel safe and secure without being over-protected;
- **Realising potential:** people should have the opportunity to achieve all they can;
- **Equality and diversity:** people should have equal access to information assessment and services. Health and social care agencies should work to redress inequalities and challenge discrimination.

People with ASD expect to have the support of professionals working together in their best interests to make these values a reality.

4.4 Goals

The Strategy sets out ten Good Practice Indicators:

- A local Autism Strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with ASD and carers are reflected and incorporated within local policies and plans.
- Access to training and development to inform staff and improve the understanding amongst professionals about ASD.
- A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.

- An ASD Training Plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff.
- A process for data collection which improves the reporting of how many people with ASD are receiving services and informs the planning to these services.
- A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.
- A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement.
- Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD.
- Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage.
- A self-evaluation framework to ensure best practice implementation and monitoring.

The Scottish Strategy divides the goals into three parts:

Foundations (by 2 years)

Whole-life journey (by 5 years), and

Holistic Personalised Approaches (by 10 years)

Foundations: by 2 years

1. Access to mainstream services where these are appropriate to meet individual needs
2. Access to services which understand and are able to meet the needs of people specifically related to their autism.
3. Removal of short-term barriers such as unaddressed diagnosis and delayed intervention.
4. Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis).
5. Implementation of existing commissioning guidelines by local authorities, the NHS and other relevant service providers

Whole life journey: by 5 years

1. Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism.
2. Access to appropriate transition planning across the lifespan
3. Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas.
4. Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism.

Holistic personalised approaches: by 10 years

1. Meaningful partnership between central and local government and the independent sector.
2. Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is)
3. Access to appropriate assessment of needs throughout life
4. Access to consistent levels of appropriate support across the lifespan including into older age.

4.5 Aberdeen City's Action Plan

Aberdeen City's services, in collaboration with NHS Grampian, Police Scotland and other related services, are developing an Action Plan for five age groups. Positive outcomes for individuals with ASD are set against the Scottish Strategy's timeframes of two, five and ten years. The Action Plan acknowledges the need for flexible approaches in response to the complexity of an individual's changing needs at different stages in life. The Aberdeen City Autism Strategy sets out five stages marked by important life transitions:

Birth to primary school
0 – 5 years

Primary school
5 -11 years

Secondary school
11- school leaving age

Post School
School leaving age– 25 years

Adult lifespan until retirement and beyond
25 – retirement and beyond



Picture by Jack (9yrs)

5. The Aberdeen City Context – Where are we now?

Aberdeen is a busy, prosperous city which has become the oil capital of Europe. As a result, it has, for the most part, missed the recession experienced by much of the United Kingdom. While the majority of Aberdeen's citizens enjoy a high standard of living, there are several areas of extreme deprivation, unsupported by the surrounding wealth.

The information presented in this section was collated from the following opportunities for consultation:

- The Scottish Government's Mapping Exercise (2012).
- The One Stop Shop consultations with individuals with autism, their families and service representatives (2012).
- Ongoing consultation with users of the One Stop Shop.
- Ongoing communication with members of the Triple A's.
- NAS Ellon Branch conference (2012).
- Workshops with young people and their families (2014).
- Transitions Project evaluation (2014).
- Word Café event (2014).
- Range of individual meetings and consultation with other key stakeholders.

5.1 Indicator 1: A local autism strategy

"I don't understand why services are not available to all on the spectrum?"

Mother of two sons with Asperger's

- Aberdeen City currently has universal policies in place which apply to all people in the city but no policies, frameworks or strategies specifically for people with autism.
- Aberdeen City has a Single Outcome Agreement (SOA) focussing on improved "joint working, between NHS Grampian and Aberdeen City Council, especially in relation to the delivery of services in Mental Health and Wellbeing and Learning Disability".

Action:

- A consultative group, representing all agencies and people with autism, has met, to plan the way forward.

- An independent consultant was appointed to develop the Autism Strategy and Action Plan based on information collated from all agencies, families and individuals affected by autism. Aberdeen City's Strategy and Action Plan sits in the context of the Scottish Government's Strategy and Menu of Interventions.
- An implementation group, involving a small number of people who are in a position to action recommendations will be established.

5.2 Indicator 2,3 and 4: Training, Awareness-raising and Communication

“Because he looks like any other child he's a deemed a brat when he's shouting and screaming at me”

Parent of child with ASD

“With autism people can't see what's wrong, and it can be quite hurtful....”

Parent of child with Asperger's

- The Scottish Government has supported the development of a One Stop Shop in Aberdeen. Its function is to raise awareness of autism, be supportive of the clients and their families who make contact and to signpost appropriate services, providing assistance where necessary.

The Triple A's is a group of young people and adults who themselves have Asperger Syndrome or autism. Having started as a social group, funding has allowed them to become a voluntary organisation whose aim is to raise awareness and support for people with autism. The Triple A's provide one-to-one support, social groups, support and information and together with the One Stop Shop with whom there is a close working relationship, play a key role in signposting appropriate services. There is also an Information Hub sited within the Job Centre.

As people tend to be receptive only when there is a vested interest, awareness-raising is felt to be a complex issue which would not be addressed effectively by the dissemination of information.

- The Mapping Exercise revealed that there are pockets of good practice which need to be capitalised on in order to build community capacity alongside training and awareness raising.
- There is consensus from all services that, while there are pockets of very good practice in terms of training and skills development, there are also gaps where professionals and employees alike lack the necessary knowledge to provide an informed service to children, young people and adults with autism.
- Services in Aberdeen City have accessed training from a wide range of sources:
 - National Autistic Society (provides training at a number of levels including Accreditation)
 - Grampian Autistic Society (GAS)
 - Scottish Society for Autism (now Scottish Autism)

- Educational Psychology Service (as one of 5 core roles) to college, schools, nurseries and partnerships providers
 - NAS One-Stop-Shop
 - National conferences
 - Postgraduate certificate, diploma and Masters level from Strathclyde University. Aberdeen City Council has sponsored delegates, mainly teachers, who now inform policy and themselves, provide training and practice guidance.
 - NHS Grampian
 - Voluntary Services Aberdeen
 - TRAINS: This group which met regularly in Aberdeen City to meet training requests from parents is no longer operational
 - NAS local branches
 - Social Light Solutions
 - Teacher training: Aberdeen University provides a one half-day training in ASD awareness; a Post Graduate Certificate and Post Graduate Diploma in Autism and Learning
 - Informal awareness raising with school pupils, e.g. Mile End School
 - On-line modules
-
- Training has been available for some parents through the NAS, VSA, Educational Psychology Service, parent support groups and Barnardo's Cygnet programme.
 - Access to training, whether, parent/carer, professional or frontline staff tends to rely on the individual's interest rather than being part of a training plan to ensure relevant people are equipped to recognise and work with individuals with ASD.
 - Police in Grampian are required to take part in an annual distance learning programme on working with people with autism.
 - Education and Children's Services within Aberdeen City Council have developed an e-learning autism awareness module, which although predominantly for school based staff, is also available for other Aberdeen City Council employees.
 - The Mapping Exercise feedback suggests training, particularly for health professionals working with adults, is required in relation to Asperger's Syndrome.
 - Knowledge and understanding of autism is variable across all services. Training is required (ME) for all core and public services. In mainstream establishments where people with autism want to feel included, bullying can be an issue.

Action:

- The Implementation Group will develop a Training Plan which will:

1. Audit existing training, communication channels and awareness raising strategies.
2. Develop a plan for delivery of training as follows:

Training: for all professionals

Aberdeen City will develop a Training Plan which includes a strategy to provide basic information and training for all professionals who might come in contact, in the course of their employment, with someone who has ASD. There will be a pathway to more extensive training as required.

Training: for those who work with people with ASD

The Training Plan will ensure that all employees who work with children, young people and adults with ASD on a regular basis have access to a programme of continuous professional development, thus ensuring they have the relevant knowledge and skills to deliver an appropriate service. There should be an awareness of the need to build community capacity affording improved inclusion for people with ASD. Training will be available at three levels:

1. Basic Awareness

Service Continued Professional Development aims to meet the training needs of those likely to come in contact, in their work place, with a child, young person or adult with ASD. This includes Police, Social Work and Housing, Health, Education and the Voluntary Sector. Aberdeen City Council is considering a session in their Corporate Training Induction for all new employees.

2. Specialist

For those who have daily contact with a child, young person or adult with ASD. Specialist training should be multi-agency and involve parents where appropriate.

3. Post-graduate

For those with a specialist interest. On completion, the individual could expect to be involved in service development and delivery.

A supervision and advice process will be in place to ensure practitioners feel confident and supported.

Training: for parents and families

The Training Plan will ensure that all parents, carers and families have access to training designed specifically for them, when they need it.

5.3 Indicator 5: Data Collection

- Aberdeen City Education and Children's Services collects data on pupils with additional support needs which identifies learners with ASD. The current inclusion review will develop processes to ensure data is collated appropriately in order to inform practice generally and transitions in particular.

- Data on adults is currently collected on Scottish Consortium for Learning Disability (SCLD) and eSAY. There is as yet, no process using this information to inform practice.
- The Mapping Exercise received no information relating to data collection and how it informs policy and practice on a lifelong basis.

Action:

- The Implementation Group is tasked with developing a system for collating data which can inform planning and practice.

5.4 Indicator 6: Assessment, Diagnosis and Intervention – a multi-agency care pathway

“Autism diagnosis opens doors.....for support.....”

Parent of child with autism

- Following diagnosis for children, the current Scottish Early Years Policy (2008) outlined four principles of early intervention which have underpinned the Menu of Interventions:
 1. All children, young people and adults should have the same outcomes and the same opportunities.
 2. There should be a process for identifying those at risk of not achieving those outcomes and a means of preventing the risk materialising.
 3. Should the risk materialise, effective action is taken.
 4. Those involved work to help parents, families and communities develop their own solutions, using accessible, high quality public services as required.

The planning group which produced the Menu of Interventions identified among the “things people do to help” three categories of intervention, namely: clinical, educational and social. Within that, there tends to be intervention leading to some form of change and supports which maintain skills when developed, the two often overlapping.

- For children and young people up to the age of 13 years the diagnosis of autism is made in a hospital setting by the Department of Child and Family Psychiatry or Department of Community Child Health. Young people between the ages of 13 and 18 years are referred to the Young People’s Department. Work is ongoing to ease the transition between child and adolescent departments and onward to adult services.

The Mapping Exercise identified the need for improved support throughout the diagnostic process and beyond and the need for a clear multi-agency diagnostic/care pathway irrespective of age. Young children with complex

additional support needs are referred into a multi-agency planning process, within the Getting It Right For Every Child (GIRFEC) framework to identify and plan for the supports required both at home and in the school setting. Post diagnosis, there are key issues which impact on cohesive multi-agency service delivery. There is identified good practice established between individual practitioners, but currently there are limited links embedded in practice between the services involved in assessment and diagnosis and those providing interventions and support at local level. The embedding of GIRFEC within legislation under the Children & Young People (Scotland) Act 2014 further strengthens the requirement for a multi-agency approach.

- Adults with autism feel strongly that diagnosis is essential to afford them access to appropriate services and self-help peer support. In Aberdeen city however, the eligibility criteria for referral directs people to either the Mental Health or the Community Learning Disability Team and may preclude a person with autism, but neither a mental health issue nor a learning disability. People may encounter a barrier to referral because they appear to be leading reasonably stable lives but report that the lack of early intervention in terms of diagnosis and support may, in fact lead to mental health problems and the need for expensive, more specialist services at a later date.

The Mapping Exercise highlighted a need for the NHS to consider how best to increase its capacity for the provision of easy access to diagnosis and support. There was also concern expressed about the Adult Mental Health team's capacity to respond to dual diagnosis.

Action:

- The Local Authority, in collaboration with Health and other related agencies, will establish a multi-agency care pathway, for assessment, diagnosis and intervention for children, young people and adults. Intervention planning will become more straightforward when effective links between services are established, e.g. Health/Education, child/adult, Learning Disabilities/Mental Health, core services/Criminal Justice System and services within the Criminal Justice System.

The implementation of existing commissioning guidelines provides a positive link between diagnosis and intervention. Services providing intervention, however, particularly for adults, report a lack of services which they would like to commission. The GIRFEC Framework is already established in multi-agency practice for children and young people and should articulate with an equivalent process for adults.

- There is discussion between the NHS, local authority, voluntary and third sector organisations and people with ASD as to how to build the capacity, to provide a service for people with Asperger Syndrome and High Functioning Autism. There is acknowledgement that expertise in autism is not shared by all practitioners. It is timely for services to reconsider what people, in consultation with them, actually need, possibly at minimal cost, as recommended by the Menu of Interventions.

5.5 Indicator 7 and 10: Stakeholder feedback and self-evaluation

- Stakeholder feedback is currently received and collated by the One-Stop-Shop and the Triple A's group.
- There are currently no formal systems in place for using feedback to inform policy and practice or for evaluating practice.

Action:

- Implementation group to develop a sustainable process for collating feedback from families and adults affected by autism with the aim of informing policy and practice.
- Self-evaluation to be built into single service and multi-agency processes. Evaluation should be integral to the planning process and not a separate activity.

5.6 Indicator 8: Multi-agency service delivery targeted to meet needs: Assessment of Need

“Services in Aberdeen? Not great, but getting there.....all quite fragmented”

Parent of child with autism

- It is common for people with ASD to experience a range of conditions which affect their ability to cope with life demands. As needs change in nature and severity over time, it is essential that the services which are commissioned and developed are both generic and specialist, and designed to be lifelong.
- Assessment of need over time varies from individual to individual with good transition planning key to successful outcomes for people with ASD. Good practice suggests there is a lead person at each stage who has responsibility for coordinating assessment and intervention which is ‘person-centred’. Many adults however will wish to be responsible for accessing services themselves and do not need a coordinated plan. While the needs of some are lifelong and comprehensive for others, a thin thread of access to support is sufficient for day to day life.

The young child experiences many transitions throughout his or her schooling which require careful preparation and management. The Scottish Government, in partnership with local government and the NHS, is giving high priority to redesigning services around the principles of prevention, early identification of need and early intervention. Evidence suggests better outcomes, as a result of effective early intervention for the child, can also lead to financial savings for service providers later in life. Multi-agency working is the priority outlined in *The Same As You? (2000)*, *PHIS Report (2001)* and more recently *A New Look at Health - The Early Years - Good Health for Every Child (2011)*.

- *The Children and Young People (Scotland) Act 2014* further requires that a child or young person from birth to 18 has access to a ‘Named Person’.

From birth to five years this is the Health Visitor and from 5 onwards a representative from education. There is an expectation that, for children with autism, the person making the diagnosis has a responsibility to link with the Named Person.

- Where a child requires additional support in the school setting, there is regular assessment and monitoring of need to ensure needs are met and transitions well planned for. For children whose needs involve the service of more than one agency, GIRFEC provides a process of staged intervention for meeting changing need throughout school and beyond. *The Education (Additional Support for Learning) (Scotland) Act 2004 as amended* places responsibility on education authorities to help prospective school leavers with additional support needs make the transition from school to post-school life successfully. School leaver destinations and information about progress is recorded to inform future planning.

Aberdeen City's Education and Children's Services (previously, Education, Culture & Sport Service) has, over many years, recognised the need for schools where there is access to staff knowledge and expertise in how best to support learners with Autism. Currently there is an outreach team of three teachers with experience and expertise in autism, who work with individual pupils of all ages, but also have a supportive role for schools. In addition, there are five autism specific bases (MICAS) across the city's secondary schools.

The recent review of provision aims to refresh the staged approach to assessment and intervention, and to broaden access to support across the city. There will be more emphasis on early intervention; the need for all schools to develop their capacity to support learners with autism and a more robust process for auditing outcomes and self-evaluation. The Mapping Exercise suggested the need for a training plan to ensure all staff, teaching and non-teaching have the knowledge and skills to address the needs of pupils with autism. This has been acknowledged and a plan is in process.

The Mapping Exercise also highlighted the need to deliver social skills training at all stages. Nurseries provide social opportunities throughout their sessions, e.g. snack-time; turn-taking; etc. There is now increasing emphasis on this at the primary stage. At secondary level all schools were also invited to take part in the "Transitions Project" funded for three years by the Scottish Government and run jointly by the National Autistic Society (NAS) and Inspire. The vision of the Transitions Project, which currently works with pupils from S2 upwards, is to support and prepare pupils with autism for progressing through and leaving school.

A small number of older pupils also attend a 'Socialeyes' programme delivered by an independent provider.

Young people report a high incidence of bullying, particularly at secondary level. Although a recognised element of adolescent culture in general and

therefore an issue for every school, it could be alleviated by awareness raising of learners with autism.

There are currently a number of pupils on part-time education or excluded from school completely. This issue is being addressed through the review of inclusion.

Young people report a positive experience of college (North East Scotland College) and the two universities. Support systems are responsive to needs and students in Aberdeen City benefit from further support available from the NAS.

There are also, however, reports of students who have not managed to make the transition to further education in spite of successful applications and others who have not completed their courses.

- The pathway for young people leaving school or further education into employment can be complex and fraught with barriers. Whilst there is a wide range of opportunities and post school supports available to all, for young people with Asperger Syndrome and High Functioning Autism there are currently no autism specific services to support them with the transition into employment. Some report feeling ill-equipped to enter the world of work and would feel more confident knowing future employers have some awareness of their condition. It is not uncommon for young people to experience anxiety and depression in such stressful circumstances, thereby accessing support from the Mental Health Team. The world of employment can be particularly difficult for those adults who have been unable to access a diagnosis resulting in situations that are too stressful for them to manage.
- Aberdeen City Council's services in partnership with NHS Grampian are implementing the Joint Strategic Commissioning Framework (2013-2023). Local authorities are also progressing implementation of the Social Care (Self Directed Support) (Scotland) Act 2013. Emphasis is on co-production, multi-agency working in partnership with individuals and their families to afford appropriate choices leading to improved outcomes in terms of leading fulfilling lives, as active citizens within their own communities.
- For adults with a diagnosed learning disability, the care pathway is provided and supported by the Adult Community Learning Disability Team in collaboration with colleagues from Health through the Community Care Assessment process.
- The Aberdeen City Local Housing Strategy (2012-2017) aims to meet all housing needs having consulted widely. Consultation included the Disability Advisory Group. For the group of people with autism, who need the support of a social worker, access to suitable housing may be relatively straightforward. Availability of supported accommodation is also improving. There are positive indications that commissioning through Self Directed Support (SDS) is not only affording individuals a more personalised choice of opportunities but services are becoming more creative in what they can offer. It is recognised that multi-agency planning with a named keyworker

is central to positive outcomes. For people with more subtle needs, e.g. sensory difficulties, there is opportunity for development. When an individual is unable to cope in a property which is unsuitable, the re-housing process is reported to be lengthy and difficult.

- It is well documented that people with autism can enter the criminal justice system unwittingly as the result of a misinformed interaction. Feedback from people with autism who experience Police contact is variable depending on the circumstances and the knowledge and skills of the Police Officers involved. There is growing awareness of the impact of autism in the prison community and the need to develop specific responses to meet individual needs. For instance, given that recent data suggests 4% (*Robinson et al (2012)*) of the prison population is on the autism spectrum, there is a strong commitment from the management team in HMP & YOI Grampian to develop an autism friendly environment and promote awareness and expertise among staff working with individuals with autism.
- The Autism Alert card, available through the One Stop Shop, is widely used and reported to be an effective means of communication.

In Aberdeen City there is a “Vulnerable Adult Scheme” supported by solicitors who are knowledgeable about autism. Documentation is available for people working within the Criminal Justice System regarding how best to communicate with a person with ASD and what to avoid.

Action:

- For children and young people, the Inclusion Review aims to develop processes to ensure that all school settings increase their capacity to meet the needs of pupils with autism. More school environments should become autism friendly; all staff, teaching and non-teaching should be trained to at least a basic awareness level and those staff working directly with pupils with autism should be trained further to meet individual needs. Some may seek post-graduate training to inform service development and practice. A staged procedure for assessment and intervention has been further strengthened with the enshrining of GIRFEC within legislation.
- The Implementation Group, with the input of relevant services, should devise a process to ensure there is multi-agency assessment and planning for all individuals with autism, irrespective of age and ability. Special consideration should be given to adults with Asperger Syndrome and High Functioning autism who currently struggle to access services.
- The Communities, Housing & Infrastructure Service consider their capacity to be more flexible in terms of meeting the specific needs of people with autism. The introduction of support to develop independent living skills would be cost effective.

5.7 Indicator 9: Transitions

“How he grows up I don’t know? I just hope that he manages to have a life that’s not too bad”

Parent of child with autism

- Transition planning is considered important within the school setting with transitions large and small occurring for children and young people on a daily basis. In Aberdeen City all nursery children experience a planned induction to primary one with some schools providing individualised autism specific support. The review of inclusive practice recognises the importance of early intervention for young children with autism. Plans are underway to implement a primary/secondary school transition process for learners with autism starting in P6. The aim is to ensure individual needs and concerns are met and secondary staff are well prepared in terms of information, skills and training. There are currently five secondary schools with specialist MICAS bases. The majority of pupils considered to need a high level of specialist support access base placements. The Inclusion review is considering how best to develop capacity within mainstream settings.

All schools in Aberdeen City have had access to “Transitions”, a project funded by the Scottish Government. Transitions aim to support young people with autism through the transition from childhood to adulthood. The project leaders work in partnership with schools, through group work and social activities to prepare pupils in S2 and above as they progress through and from secondary education. A recent evaluation of the Transitions project enlisted responses from parents, school staff and the young people themselves. One parent said “I am extremely glad that my son was given the opportunity to participate in this invaluable project. He has flourished and it is a joy to watch him engaging socially with others.” Responses from pupils included:

- “I feel more confident to meet people”
- “I feel more confident talking to people”
- “I feel better equipped with how to deal and communicate with people”
- “I can now talk to people without embarrassing myself”

The Transitions Project aims, this coming session, to focus more on post-school transition. While there are supports available for post-school transitions, they are not accessed consistently.

- The Aberdeen City Youth Employment Activity Plan (2012/2013) is in place.
- Aberdeen Guarantees is a new partnership commitment to providing learning, training and work opportunities to all 14-25 year olds. The new brand represents the collective efforts of the public, private and third sector in assisting and enabling young people to progress towards employment.

Aberdeen Guarantees will profile a range of approaches in school & post school which are already in place to support young people into positive destinations, promote good news stories and advertise new training and work opportunities for young people in Aberdeen.

- The Mapping Exercise highlighted the need for support for and through major transitions with improved co-ordination of services – ideally life-long person-centred planning.
- Major problems are reported in later life with retirement and/or the loss of a partner resulting also in the loss of familiar routines and structures.

Action:

- Education and Children’s Services is reviewing its approach to supporting children and young people with additional support needs, including planning for transitions, which will incorporate the needs of those with autism.
- Consideration should be given to the sustainability of the Transitions Project, whose funding ceases June 2015.
- The Implementation Group should consider key transitions in the context of lifelong person-centred planning.



Picture by Declan (5yrs)

6. Background Guidance and Legislation

Numerous key documents have been released at national and local level which inform and shape policy and practice for people with autism:

- 6.1 *The Same as You? (2000)* reviews services for people with learning disabilities and ASD in Scotland. It sets out a ten year programme of change which will allow children and adults with ASD to lead lives which afford them more choices.
- 6.2 *The Development of a National Training Framework for Autistic Spectrum Disorder (2004)* is a comprehensive study of training for professionals conducted by MacKay and Dunlop. It was commissioned by NAS Scotland and funded by the Scottish Executive. The study reports that while people working intensively with individuals with ASD are most likely to have received appropriate training there are a significant number of people working in the field of ASD with little or no training. As specific communities such as schools and the wider community in general, strive to become ever more inclusive, the need for training and ASD awareness become increasingly important. The report recommends the development of a National Training Framework for Autistic Spectrum Disorders in Scotland to ensure that core training is given at pre-service and in-service levels for key professionals working in the ASD field.

Changing Lives was produced in 2006 by the 21st Century Social Work Review Group. The report identifies greater public expectation about the development of personalised services and the need to support individuals, their families and local communities to provide care. These messages are highly relevant to the learning disabilities agenda and are a key element in supporting people with learning disabilities to live as independently as possible within their own communities.

- 6.5 *The Sign Guidelines* published in 2007, provide clinical guidelines for the assessment, diagnosis and clinical interventions for children and young people with autism. Although the guidance applies to children and young people the importance placed on early diagnosis appropriate interventions and structured supports, is also relevant to adults. The guidance also considers how multidisciplinary working can best meet the needs of individuals with ASD.
- 6.6 The Scottish Government directs Local Authorities to consider a range of relevant policies and frameworks at national and local level. *The National Performance Framework (2007)* sets out national targets which aim to ensure that public services are efficient and of a high quality, are continually improving and are responsive to local need. *Single Outcome Agreements (2007)* negotiated annually between local authorities and government describe how local priorities can be achieved. Further development of this approach will now take place in the context of the concordat and will include outcome measures for people with learning disabilities.
- 6.7 *Commissioning Services for People on the Autistic Spectrum (2008)*. This guidance from the Scottish Government encourages services to include people with ASD in the development of outcome based approaches for adults. It acknowledges the challenges faced in providing appropriate services for some people on the autism spectrum, referring specifically to Asperger's Syndrome and high functioning autism. It recommends that community care services for people with ASD should be embedded within joint partnership service planning, commissioning and delivery, including the

implementation of Single Shared Assessment (SSA). This ensures that at any one time, a lead professional coordinates assessments, makes sure appropriate services are put in place and acts as a point of contact. There are, however, many examples where adults are the lead person in planning for their own lives and require no more than care co-ordination. This dovetails with the GIRFEC process for children and young people and provides the link at transition between children's and adult services.

- 6.8 *Getting it Right for Every Child (GIRFEC) and The Education (Additional Support for Learning) (Scotland) Act 2004 as amended* direct Local Authorities and partners to develop effective integrated processes for the identification, intervention and monitoring of additional support needs. Aberdeen City has a GIRFEC Management Group which promotes and supports the development of the Integrated Assessment Framework and associated multi-agency working. Community planning for Children's Services is devolved to the GIRFEC Management Group.

Atkinson, William, Stott and Kinder (2002) identified that effective multi-agency working provides improved services and support for parents, which in turn reduces the need for more specialist services.

- 6.9 *The Children and Young People (Scotland) Act 2014* legislates for a framework which will underpin and complement the process provided by the Additional Support for Learning legislation and GIRFEC. Key requirements include that all children and young people, from birth to leaving school, have access to a Named Person and that a single planning process, leading to a single child's plan, should be in place to support those children and young people where there is a concern about well-being. This will include children and young people who need the involvement of a range of services. The Act places a duty on public bodies to coordinate the planning design and delivery of services for children and young people with a focus on improving wellbeing outcomes, and to report collectively on how they are improving outcomes.

- 6.10 *The Keys to Life - Improving Quality of Life for People with Learning Disabilities. Scottish Government (2013)* focuses on ensuring all health professionals can better meet the needs of people with learning disabilities and enable them to be part of the community. The Scottish Government defines learning disability as a lifelong condition which means people may need support to:

- understand new information
- learn new skills
- cope independently

- 6.11 *The Social Care (Self-Directed Support) (Scotland) Act 2013* was implemented for children and adults in April 2014 and affects a person's involvement and responsibility in planning their own provision. The Act directs Local Authorities when planning provision to listen to what people want. Aberdeen City Council will assess, in collaboration with them, a person's care needs and, if eligible, agree an outcome based support plan. If appropriate, the individual is awarded a budget and provided with information and choices to inform decisions. One of the outcomes should be improved community involvement. When support needs are met appropriately, people are able to lead more independent lives as active citizens within their community.

6.12 *The Public Bodies (Joint Working) (Scotland) Act 2014* offers greater opportunities for health and social care practitioners to work more closely together. Services should work towards the integration of Health Boards and Local Authorities services for the improvement of person-centred care for adults with learning difficulties.

6.13 The current National Autistic Society publication *Count Us In (2013)* makes the following recommendations:

- Partnership working between Scottish Government, Local Authorities, support organisations and people with autism.
- The Scottish Government should appoint an autism employment ambassador to champion opportunities for people with autism in the workplace and local councils should map the need for employment support in their areas and include employment support in their local plans.
- People with ASD should be empowered to advocate for themselves or have access to advocacy services.
- Local authorities should invest in specific services that help address social exclusion and ensure community care assessors are appropriately trained to develop person-centred plans for people with Autism.

Glossary of Terms, Acronyms and Abbreviations

AS	Asperger's Syndrome
ASD	Autism Spectrum Disorders
CJS	Criminal Justice System
COSLA	Convention of Scottish Local Authorities
CPD	Continuous Professional Development
GAS	Grampian Autistic Society
GIRFEC	Getting it Right for Every Child
HFA	High Functioning Autism
LSE	London School of Economics
ME	Scottish Government's Mapping Exercise
NAS	National Autistic Society
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
P1	Primary 1
PG	Post Graduate
S1	Secondary 1
SCLD/eSAY	Scottish Consortium for Learning Disability
SDS	Self-Directed Support
SPS	Scottish Prison Service
SOA	Single Outcome Agreement
SSA	Single Shared Assessment
VSA	Voluntary Services Aberdeen

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