The Moray Autism Strategy
2014 - 2024

Supporting those with autism - all ages,
all abilities, all agencies

Front cover by Gregor Morris

the **moray** council

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Highlands and Islands
Moray College

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Index

1.   Who is this strategy for?

Autism[1] is a general term sometimes referred to as autism spectrum disorder or autism spectrum condition. It includes conditions such as classic autism and Aspergers. Autism is a spectrum condition. Some characteristics are shared by all those on the spectrum; some are very specific to individuals.

How these characteristics affect people with autism, and their families, varies enormously.

This strategy has been written to explain what people with autism and their families have said is needed to support them in the future, no matter how young or old they are or how able they are[2] .

It will describe what services and support we plan to be available and how we aim to achieve it.

The services and support talked about are those provided by the Local Authority, the National Health Service in Moray and our partners[3] . We hope that other voluntary groups and individuals in the community will join us in making sure this strategy happens. Without the support of the whole community, we will not be able to meet the needs of those with autism.

The strategy should be read by anyone with an interest in autism, either personally or professionally.

'I am me
I will always be me
Nobody else can be me
Because you see
I am me'

Lewis Gordon

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[1] *See Appendix A for a definition of autism.*

[2] *Only when the strategy uses the words 'child' or' adult' are their separate needs being considered. Otherwise, the strategy looks at the needs of people with autism of all ages. In general, a child refers to someone still at school although it is recognised that, in Scotland, a child becomes an adult legally at 16.*

[3] *The partners include organisations such as Police Scotland, Highlands and Islands University, providers of support services etc.*

2.   Why do we need a strategy?

Autism has been agreed as a national priority by the Scottish Government.
Both locally and nationally, we know that there are some areas of very good practice where people with autism feel well supported but this varies from place to place. This is despite the fact that it was recently estimated that autism costs the United Kingdom nearly £28 billion per year[4] . This equates to £2.3 billion in Scotland.

To enable people with autism across Scotland to feel supported no matter where they live, a 10 year Scottish Strategy for Autism was agreed in 2011[5] .

The Scottish Strategy for Autism in brief

The vision of the Scottish Strategy for Autism 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.**

Values – What do we believe is important?

Values are what people think are important. Before writing a strategy, it is important that all those involved believe in the same values. The Scottish Strategy agreed the following:-

- 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 others citizens;
- Choice – care and support should be personalised and based on the identified needs 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; and
- Equality and diversity – people should have access to information assessment and services; health and social care agencies should work to redress inequalities and challenge discrimination.

Everything that happens because of the Scottish Strategy should help make sure that these values are met.

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[4] *The Economic consequences of autism in the UK. Foundation for people with learning disabilities Nov 2007.*

[5] *See www.autismstrategyscotland.org.uk for more information about the Scottish Strategy for Autism.*

The Scottish Strategy gave 10 ways in which good services for people with autism should be developed. It said that there needed to be:-

1. A local Autism Strategy.
2. Access to training and development.
3. Easy access to useful and practical information about autism.
4. An Autism Training Plan.
5. A process for data collection which improves the reporting of how many people with autism are receiving services and informs the planning of these services.
6. A multi-agency care pathway for assessment, diagnosis and intervention.
7. A way to get feedback to inform service improvement and encourage engagement.
8. A multi-agency coordinated focus on meeting the needs of people with autism.
9. Clear transitions at each important life-stage.
10. A self-evaluation framework to ensure best practice implementation and monitoring.

The strategy also made 26 recommendations which, in summary, said that:-

*   The Scottish Government would provide strategic leadership and create a strategic vision for the development of services and support for those with or affected by autism.
*   Resources would be effectively targeted with the aim of improving people's lives.
*   People with autism and their families should be involved in decision making.
*   Cross agency working would be developed.
*   Adults should be able to get a diagnosis and support following diagnosis.
*   People with autism should be supported to gain employment.

A Strategy for Moray

One of the main recommendations of the Scottish Strategy is that each local authority area has an Autism Strategy. In Moray, it has been agreed that our strategy will be shared by the Local Authority, the National Health Service in Moray and our partners, using the same under pinning values as agreed in the Scottish Autism Strategy and that it will link into the Single Outcome Agreement[6].

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[6] *The Single Outcome Agreement sets out how the Community Planning Partnership will work together to deliver agreed national and local priorities. The Autism Strategy links into Outcomes 2, 3, 5 and 7. For more information see http://www.moray.gov.uk/downloads/file85195.pdf*

What have we got now in Moray?

In Moray we have some very good services and support for people with autism[7] .

BUT

- These areas of good practice tend to exist because of an individual with a special interest or knowledge of autism[8] .

- We do not have a joined up approach. This means that someone with autism does not know what support they can get and how they can get it.

- National Statistics say we should have about 1060 people with autism in Moray. The Local Authority and National Health Service in Moray know of 320.

- Moray Council currently spends in excess of £7 million per year[9] to support people with autism yet those who took part in the consultation for this strategy said that the support they received still did not meet their needs. The main areas they said caused concern were:-

  - Difficulty in being diagnosed.
  - No support in terms of what autism is and how it will affect their lives following diagnosis.
  - Feeling that no one understands what life is like for them.
  - Do not feel part of their community.
  - Feeling that they have to fight for any support from Education, Child Care, Social Work or Adult Community Care.

'We learn, either explicitly or implicitly, that how we are is wrong, is less, that how we think and feel and move naturally is Bad and Wrong and we are Broken. When all we are is different'

www.liberateyourself.co.uk

We hope that by agreeing a strategy for autism, this will change.

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[7] *For more information and details on all of the above services please see Appendix D.*

[8] *For more information and details about what people have said about the current services in Moray see Appendix E.*

[9] *For more information and details about how much is spent in Moray supporting people with autism see Appendix C.*

3.   The Moray Strategy for Autism?

The Moray Vision

It is our vision that all people with autism are accepted for who they are and valued for what they contribute to the world.

We will know we are working towards achieving this if, by 2024:-

1.   All autism services and developments are planned by the Local Authority, National Health Service in Moray and our partners working together.
2.   There is a clear process for people to find out if they have autism.
3.   People with autism and their families understand the condition and feel supported.
4.   The wider community supports those with autism because they know about and understand the condition.
5.   Everyone with autism is supported to make the full use of the opportunities and services available to meet their needs.

Autism & My Family
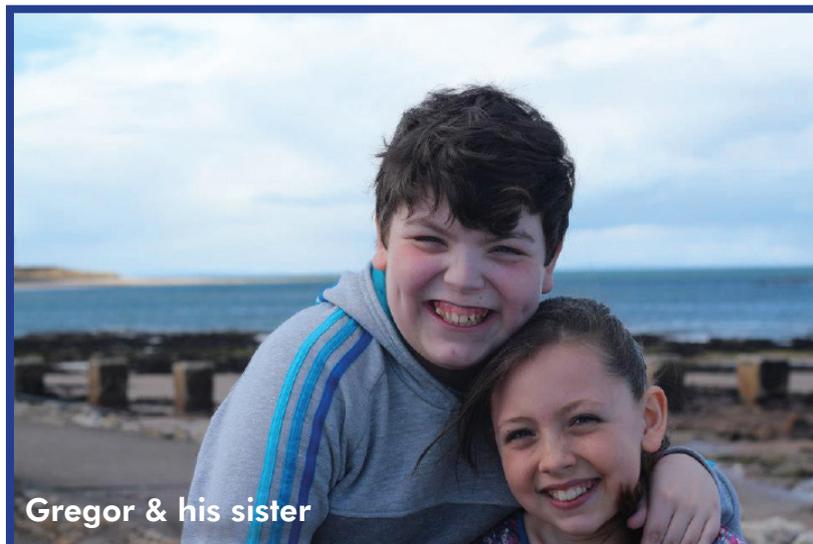
Gregor & his sister

What does that mean for Moray?

1. All autism services and developments are planned by the Local Authority, National Health Service in Moray and our partners working together. To achieve this, our aim is that:-

- Lead Officers for autism will be identified by the Local Authority and the National Health Service in Moray to provide strategic leadership to all autism services and developments in Moray.

- This work will link into the existing Moray Autism Partnership Board[10] and will make sure that people with autism and their families are part of the decision making process.

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[10] *The Moray Autism Partnership Board meets 3 times a year. People who have autism, their families and professionals meet to talk about and agree autism related topics.*

2. There is a clear process for people to find out if they have autism, if they want to. To achieve this, our aim is that:-

- People will know who to talk to if they are concerned that they, or someone they care for, may have autism:-
    - for children, this will usually be the 'Named Person'[11] .
    - for adults this will usually be the family doctor.

- The 'Named Person', the family doctor and other key professionals[12] will be aware of the signs of autism to know if a referral for a diagnosis may be helpful if agreed with the person and/ or their family.

- The 'Named Person', the family doctor and other key professionals[12] will know who to contact to arrange for a diagnosis to be made.

- The confidential diagnosis will be made by professionals with specialist knowledge of autism in a way which meets current best practice .

- The process of being diagnosed will use a co-ordinated approach to make sure that it runs smoothly eg appointments are made, reports are written, information sent out etc and will link into the co-ordinated Autism Support Services for children and adults. (see page 13)

- If the person with possible autism, or their families in the case of children, does not want to be diagnosed, they will be offered support to meet their assessed needs.

Autism is a part of me
The people would agree

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[11] The 'Named Person' is a professional who is involved with a child and is the point of contact for the child and their family. (0-10 days = midwife, 11 days – 5 years = Health Visitor, primary school = Head Teacher, secondary school= school guidance teacher). http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright/named-person

[12]For example Nursery and playgroup staff, teaching staff.

- The person with autism and their family will be able to trust all professionals to do their job.

'Hello, I am Alex, 17 years old.
I have autism
I made this butterfly.
This butterfly is like me,
From a grub to beautiful'

Alex Grant

3. People with autism and their families understand the condition and feel supported. To achieve this, our aim is that:-

- Information about autism will be available to anyone who wants to find out about the condition.

- The information will be provided in a setting which makes it easy for people with autism to go to.

- Counselling and training will be available for people with autism and their families which helps them understand what autism is and what it will mean to them including learning coping strategies, how to manage behaviours or traits which cause them difficulty, etc.

- Independent advocacy[13] and training in self advocacy[14] and citizen leadership[15] will be available to people with autism recognising that people who do not have autism can find it difficult to understand the needs of those who do.

- People with autism and their families will be enabled to link together, either in person, or by e-mail or telephone, to support each other and make friends if they wish.

- Social groups and activities for people with autism will exist for those who wish to attend.
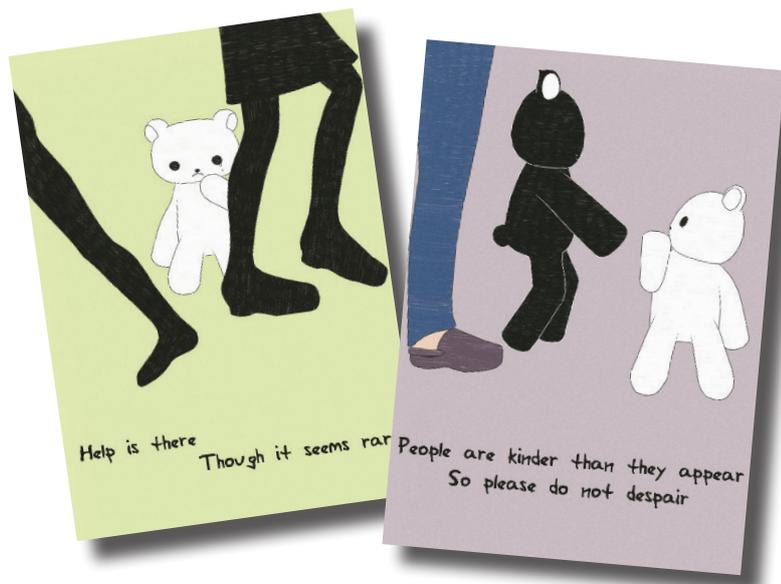
'Help is there though it seems rare
People are kinder that they appear
So please don't despair'

Rebecka Barton

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[13] *An independent advocate supports people who are vulnerable to express their own needs and make their own decisions. See www.advocacyne.org.uk or moray@children1st.org.uk for information about the advocacy services available in Moray, currently.*

[14] *Self advocacy is when people express their opinions themselves*

[15] *Citizen leadership happens when individuals have some control over their own services. It also happens when citizens take action for the benefit of other citizens.*

4. The wider community supports those with autism because they know about and understand the condition. To do this, our aim is that:-

- The Moray community will know and understand about autism through regular planned autism awareness events.

- All services provided or funded by the Local Authority and National Health Service in Moray are 'Autism Aware'.

- Local businesses and organisations are enabled to support those with autism through the 'Friendly Access' campaign[16] .

- Training is available to all organisations and community groups enabling them to support those with autism who use their services whether it is housing, the health centre, the guide company etc. This will be delivered through a Training Plan which identifies who needs what type of training and who will deliver it.

- People with autism are supported in the right way if they are in contact with the police, the courts or prison.

- Statutory services will know how many people live in their area who have support needs associated with their autism in order to plan for future services and support.

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[16] *The National Friendly Access Campaign is aimed at supporting businessess to become more accessible to people with autism. See www.friendlyaccess.org for more details*

5. Everyone with autism is supported to make the full use of the opportunities and services available to meet their needs. To achieve this, our aim is that:-

• The Local Authority and National Health Service in Moray operate a 'One Person, One Process' philosophy to reduce duplication and make life easier to understand for those with autism. For children, this would take the form of the Local Integrated Assessment Planning Process (LIAP)[17] used proportionately for all children with additional needs. For adults, this process will be agreed within the Action Plan[18] .

• There is agreement as to what is meant by the Education Inclusion Policy which is understood by all those working in and accessing the education system, giving all schools an ethos of acceptance, working in partnership with parents and pupils.

• There are co-ordinated Autism Support Services for children and adults including clear referral processes.

• There is a clear 'staged' process within education through which children and young people with autism access the support they require. This includes support to access further and higher education.

• Reliable support services, which parents and people with autism can depend on, are available in Moray to enable people with autism, who struggle to manage their lives, to stay within Moray where ever possible. This will include educational support for children and residential, fostering, respite and other support services for both children and adults.

• People with autism are able to have an amount of money agreed to meet their assessed needs in the way that they want. This is known as Self Directed Support[19] .

• Technology will be available to help meet the assessed needs of people with autism to enable them to be more independent while remaining safe eg fire and flood alarms, task organisers[20] .

'I have ambitions, goals and dreams'

Rebecka Barton

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[17] *LIAP –Local Integrated Assessment Planning Process requires professional staff involved with a child to work together to meet the needs of a child in a way in which the child and their family understand and are part of.*

[18] *An Action Plan will be written detailing who will do what and when in order that the Autism Strategy happens.*

[19] *Self Directed Support (SDS) - Self- directed support allows people, who meet the eligibility criteria, to choose how their support is provided, and gives them as much control as they want of their individual budget. For more information see www.selfdirected-supportscotland.org.uk.*

[20] *Telecare – Telecare equipment enables people, especially older and vulnerable people, to continue to live independently in their own homes. It is unobtrusive sensors, alarms and detectors which can be installed within the home to help people remain safe and secure For more information on what is available in Moray see www.moray.gov.uk/moray_standard/page_53754.html.*

- Transitions, at all key stages, must be tailored to the individual, ideally through a Person Centred Approach[21] using the Scottish Transitions Forum guidelines[22] , coordinated by an identified lead professional[23] .

- Support is available for people with autism to identify and develop their particular skills and therefore be able to contribute to their community through employment or voluntary work whenever possible.

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[21] *Person Centred Planning (PCP)- Person-centred planning has five key features:-*

the person is at the centre of the planning process, family and friends are partners in planning, the plan shows what is important to a person now and for the future and what support they need, the plan helps the person to be part of a community of their choosing and helps the community to welcome them, the plan puts into action what a person wants for their life and keeps on listening - the plan remains 'live'. For more about PCP and Autism see www.autism.org.uk.

[22] *Scottish Transitions Forum Guidelines - provides information on the principles of good transitions planning. For more information see www.scottishtransitions.org.uk.*

[23] *The Lead Professional –When two or more agencies are involved with a child, a lead Professional is appointed who is responsible making sure the different agencies work together as a team in the child's best interests. For more information see www.scotland.gov.uk/Resource/Doc/1141/0109329.pdf.*

What will happen next?

Lead Officers for autism will be identified by the Local Authority and the National Health Service in Moray.

The Lead Officer will be responsible for co-ordinating who will do what and when, in order that the strategy happens. This will be shown on an Action Plan which will be reviewed and updated as progress is made. This will be monitored through the Autism Partnership Board.

For this to be successful, all partners, people with autism and their parents and families will have to work together.

The up to date version of the Action Plan can be found on the Moray Council Website.

Autism is a lifelong developmental disorder sometimes referred to as autism spectrum disorder or autism spectrum condition. It includes conditions such a classic autism and Aspergers.

Autism affects people differently with some being able to live independently while others will need very specialist support.

What everyone has in common is difficulty in 3 areas, sometimes called the 'triad of impairment'.

1. **Social Communication**
    People with autism sometimes find it difficult to express themselves emotionally and socially. For example, they may:-

    •   have difficulty understanding gestures, facial expressions or tone of voice.
    •   have difficulty knowing when to start or end a conversation and choosing topics to talk about.
    •   use complex words and phrases but may not fully understand what they mean.
    •   be very literal in what they say and can have difficulty understanding jokes, metaphor and sarcasm.

'If my mum says, 'It's time to go to school.' I will go.....she did not tell me to put on my jacket, get my bag and bus pass.'

Jamie Brown

2. **Difficulty with Social Interaction**
    Many people with autism want to be sociable but have difficulty with initiating and sustaining social relationships, which can make them very anxious. People with the condition may:-

    •   struggle to make and maintain friendships.
    •   not understand the unwritten 'social rules' that most of us pick up without thinking. For example, they may stand too close to another person, or start an inappropriate topic of conversation.
    •   find other people unpredictable and confusing.
    •   become withdrawn and seem uninterested in other people, appearing almost aloof.
    •   behave in what may seem an inappropriate manner.

'it makes me more of a loner I'm anti-social, I can't easily cope with too many human-to-human interactions, I find it difficult to process all that verbal and non-verbal information. It's a bit like a PC, you run your PC under Windows and you select four applications to use. Then you spend ages waiting whilst the computer is trying frantically to sort out which of these tasks it is going to work on and for how long. Then, it shares out the processor time on a basis that cannot prioritise. The upshot is that I can only cope with things on a one-to-one or small group basis, and I don't know how to evaluate and prioritise things.'

Asperger.artforms@mailcity.com

3.   Difficulty with Social Imagination

People with autism can be imaginative in the conventional use of the word. For example, many are accomplished writers, artists and musicians. But people with Autism can have difficulty with social imagination. This can include:-

- imagining alternative outcomes to situations and finding it hard to predict what will happen next.
- understanding or interpreting other peoples thoughts, feelings or actions. The subtle messages that are put across by facial expression and body language are often missed.
- having a limited range of imaginative activities which can be pursued rigidly and repetitively, eg lining up toys or collecting and organising things related to his or her interest.

While these characteristics are shared, how they affect the individual can vary widely but, for all people with autism, it affects how they communicate with and relate to other people and how they make sense of the world around them.

In addition, people with autism may have sensory difficulties. This could be over or under sensitivity to some noises, colours, textures & smells.

'My experience of autism is of being very highly sensitive (on all of my senses) but not consistently. Sometimes I have no sense of smell, sometimes I find it hard to be in a room that had a person wearing perfume in it earlier.'

www.liberateyourself.co.uk

Some people with autism will use structure and routines to make the world less confusing for them.

Autism is also often associated with other conditions. It is estimated that 70% of people with autism will suffer mental health problems at some time; depression, schizophrenia, obsessive compulsive conditions being some of the most common.

Their autism may also be misdiagnosed as a mental health condition. Some people with autism may have learning difficulties such as dyslexia, dyspraxia or attention deficit hyperactivity disorder (ADHD). Some people may also have learning disabilities (estimated at 40%) while 10% of the autistic population are considered to be in the genius category compared to 1% of the general population[24] .

Although some see it as a disability, many see it as an amazing gift and recognise that without autism we would have lost much creativity in the world such as the works of Mozart, Lewis Carroll, Michelangelo, Charles Darwin, Albert Einstein.

'Alex is a lovely boy
He has no speech but the most beautiful smile
Communicates with a speaking aid
Full of mischief, always happy, a great sense of humour, great fun.
Can throw a wobbly, but easily distracted, and it doesn't last long.
He is a joy to have, I have learned so much from Alex.
I hope he has learnt from me.'

Mary Grant

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[24] Centre for Disease Control and Prevention. For more information see www.cdc.gov/ncbddd/autism/data.html.

The number of people estimated to have autism varies but the Centre for Disease Control and Prevention give estimates of 1 in every 88[25] .

Based on 2011 population estimates this means that of the 93,300 people resident in Moray[26] 1060 will have autism.

It is also estimated, at the moment for every one female with autism there will be more than 5 males[27] although it should be noted that autism is under-diagnosed in females[28] . This may change as more research is done.

These **estimates** give us the following statistics for Moray.

	Male Population Figures	Males with autism	Female Population Figures	Females with autism
0-4 years	2,700	50	2,500	10
5-9 years	2,500	47	2,400	9
10-14 years	2,900	53	2,700	10
15-19 years	3,100	56	2,800	11
20-59 years	24,100	456	24,00	91
60-80+ years	10,700	203	12,900	66
Total	46,000	865	47,300	197

*All figures are rounded up

We do not have accurate figures for those with autism in Moray for several reasons:-

• Some people with autism, especially those who have found their niche, can live independently so are never known to services.

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[25] Centre for Disease Control and Prevention. For more information see www.cdc.gov/ncbddd/autism/data.html.

[26] National Records of Scotland. Based on Census day figures 2011

[27] Fombonne, E., Quirke, S. and Hagen, A. (2011). Epidemiology of pervasive developmental disorders. In Amaral D.G., Dawson G. and Geschwind D.H. eds. (2011) Autism spectrum disorders. New York: Oxford University Press, pp. 90 – 111.

[28] Gould, J. and Ashton-Smith, J. (2011) Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. Good Autism Practice, 12 (1), pp. 34-41.

- Some who also have other conditions such as a mental health condition or learning disabilities may be known because of that or have conditions which include autistic features such as Fragile X, Angelman's syndrome and recorded as such.

- Autism, in general, has only become widely recognised over the last few years. Many people with autism did not know there was a reason for some of the things they did.

This lack of recognition has meant that life can often be difficult and may lead to a break down in family relationships, homelessness, addictions or becoming involved in criminal activities.

It is hoped that with appropriate support, all people with autism will be able to make the most of the opportunities available in life. In order to plan and target this support appropriately, we need to know how many people with autism need support.

What we know is that in 2013:-

The Local Authority and NHS (Moray) know:

- **112 school age children** who have been diagnosed with or are believed to have autism. This equates to approximately 70% of the figure suggested for Moray by the national statistics and 1 girl for every 5 boys, which matches the national statistic.

Total number of children known	Receive enhanced* support from Education and Social Work	Enhanced support from Social Work only	Enhanced support from Education only only	No enhanced support from Education or Social Work
92 boys	**11 boys**	**7 boys**	**62 boys**	**12 boys**
20 girls	**0 girls**	**3 girls**	**13 girls**	**4 girls**

* Enhanced support means that additional staff or services are being funded by the Local Authority in addition to general support eg from a class teacher.

- **200 adults** who have been diagnosed with or are believed to have autism. This equates to approximately 25% of the figure suggested for Moray by the national statistics and 1 female for every 3 males. This suggests that there are a significant number of people in the Moray adult population who have undiagnosed autism particularly in the male population.

Total number of adults known	Those with confirmed autism diagnosis, no learning disability	Those with confirmed autism and learning disability diagnosis	Those thought to have autism but no official diagnosis	Those known to be receiving a service from the local authority
153 males	**73 males**	**44 males**	**36 males**	**47 males**
47 females	**15 females**	**20 females**	**12 females**	**20 females**
200	**88**	**64**	**48**	**67**

Nationally, the aggregate cost of supporting people with autism is estimated to be £27.5 billion per year. This equates to £2.3 billion in Scotland.

Of this, 59% is accounted for by services, 36% by lost employment for the individuals with autism, their families and other carers, and the remainder by family expenses.

The lifetime cost for someone with an autism and a learning disability is estimated to be £4.7 million and £2.9 million for someone with a 'high-functioning' autism.

In Moray, the Local Authority spends in excess of £7 million per year. This is divided between education (£2 million), child care social work (£1.2 million) and adult community care (£3.9 million).

The cost of services in Moray varies enormously depending on the needs of the individual and the support provided by the family; between £1300 - £526,680 per year for a child and £2800 - £270,000 per year for an adult.

This figure does not include the cost to the NHS in terms of assessment, therapeutic and support services for example from the Rowan Centre, Speech and Language Therapy, Occupational Therapy, pediatric services, community learning disability and mental health services or more generic local support provided by the local authority such as class room teaching time, support from a social worker or care manager.

It is impossible to estimate locally the cost borne by families in terms of their role as unpaid carers, loss of income etc.

It is essential that we ensure this investment from families is supported and that the services funded by statutory bodies are used to best effect to provide people with autism the support which will meet their needs at the time they need it.

In Moray we have some very good support for people with autism. These services include:-

- Early Years Support for young children;
- An enhanced education provision for pupils;
- A specialist teacher and support worker in education;
- MIDAS – Moray Interagency Developmental Assessment and Support Service
- Specialist children health service;
- Specialist accommodation and respite for children and adults;
- Specialist service providers;
- Children's Disability Social Workers;
- Employment Development Worker;
- Diagnostic and support service for adults with learning disabilities and autism;
- Autism Alert Cards;
- Appropriate Adult Scheme;
- Autism Partnership Board;
- Autism Awareness Training;
- Autism accreditation in one school with others being supported to achieve it; and
- Local Housing Strategy 2013-18 specifically addresses Autism

In addition to these specialist services, there are many others which people with autism and their families can access. These include:-

- Carers Support;
- Advocacy for both children and adults;
- All Local Authority and National Health Services eg housing, GP's, Health Visitors, etc.

Contact information for most of these services can be found on http://morinfo/ or via your local Moray library.

James, David and Gordon Autism Awareness Trainers

When writing this strategy, a lot of people were asked what they thought about the support and services available in Moray at the moment. What they said has been summarised below.

Co-ordination

- In general, where good practice exists, it is because of an individual with a special interest or knowledge in autism.

- There is not a joined up approach which means that people with autism, or their families, do not know what support they can get or how they get it whether as a child or an adult.

- This is especially the case for people coming into the area such as military families.

- Professionals aren't always aware of what support there is for people with autism.

- Professionals don't seem to talk to each other.

- There can be duplication between services.

- There is too much paper work.

Diagnosis

- The sooner support can be offered, the better the long term relationship between the person with autism and their family is likely to be and also the relationship between the professionals and those affected by autism.

- Until recently it could take up to18 months to start the process of being a diagnosed if you were a child.

- There is no clear way to be diagnosed if you are an adult.

- Following diagnosis, there is no co-ordinated support for people with autism or their families except that available through charitable organisations such as the National Autistic Society or by individual professionals as an addition to their main role.

Understanding and Training

- Considerable time and effort is made to providing both awareness and specialist training in autism but with no co-ordination.

- Whilst the knowledge of autism is increasing, people with autism, and their families, still often feel isolated and misunderstood by both the community and the services who are supposed to support them.

- There is not always an agreed understanding of some of the policies and procedures in place within statutory services eg the Inclusion policy, Getting It Right For Every Child, eligibility to services.

- People are not sure if integration in schools works.

- How well the needs of people with autism are understood in schools varies between areas.

- You might only get one chance with someone with autism. If we get it wrong the first time, they might not engage with us again.

- People with autism can find it difficult to express what they mean or what they need.
- Professionals don't spend enough time explaining what is happening to people with autism or their families

Specialist support

- People don't trust statutory services to provide good enough support either in education, child care or in adult support services.
- Some parents feel using out of area placements are the only option
- It is difficult to secure and keep well trained staff who understand autism.
- People with autism and families/carers understand that professionals are very busy but still feel they should do a better job in terms of doing what they say, attending meetings when they should etc.
- Can schools provide for the needs of such a wide range of children?
- We know that people with autism may have alcohol or drug addictions, may have mental health conditions or may become involved with criminal activity but the professionals in these areas often do not have the knowledge to identify someone with autism and support them appropriately.

I love my mum
She is so great.
I think she makes me
Feel less hate.
When I am down she makes me better,
On the phone, chatter, chatter, chatter.
I love her
And she loves me,
Even when we are apart
We see each other with glee,
Have fun equally.

Callum Taylor

This strategy was developed in 5 stages:

1.   Over 80 individual interviews were carried out with people with autism, parents, families and professionals to allow people to give their honest views on:-

- What services we have in Moray for people with Autism.
- What services we need.
- What we are good at.
- What we need to be better at.
- What services and support should look like in 10 years time (the year 2024).

2.   Based on the information gathered, questionnaires were sent out to teenagers with autism, adults with autism, families/carers of those with autism, professionals and volunteers supporting people with autism.

The purpose of the questionnaires was to test out some of the information gathered to see if a wider group of people agreed.

40 people took part in the online questionnaires. In summary;

72% said that an official diagnosis was helpful. The main reasons given were to better understand and support, plan services or be able to access services and support.

63% did not know how to get a diagnosis.

89% thought that if someone did not want a diagnosis, they should receive support to meet their assessed needs.

76% thought that information and support following diagnosis was important. The main areas identified included training and counselling for people with autism and their families, support to access employment.

The best way to provide information was thought to be online or via a 'One Stop Shop'.

Services identified as most needed in the future were respite, employment and accommodation.

What made a good autism service was identified as

- Well trained staff;
- The right attitude towards people with autism eg positive and accepting;
- Good communication between services and home; and
- Consistency of support with strategies in place to support the person to manage their autism.

79% of people who supported those with autism said they needed more training or were not sure if they needed more training.

75% said awareness raising would be helpful with events open to the public, support for businesses to be autism aware and autism 'champions' in key statutory services being highlighted.

The full report is available at http://moray.gov.uk/moray_standard/page_88701.html

3.   Using this information, a draft vision and strategy were written by a small group which included adults with autism, parents of those with autism and providers of support to those with autism. Those in the group covered both children and adults and those with and without learning disabilities.

4.   Consultation groups took place, one for adults with autism, and 2 others which were open to all. 20 people attended and considered the suggested visions for the strategy and the main themes.

Each person voted on each area using a traffic light system – green for agreement, yellow to show concern and red for disagreement. Overall, there was 85% agreement, 12% areas of concern with 3% disagreement.

The main areas of concern were

- Single lead officer for autism.
- Who to talk to when you have concerns about autism.
- How best to raise awareness in the community.
- The use of the words 'Autism Friendly'.
- Whether we should be aware of all people with autism and, if so, how to achieve it.
- The use of Self Directed Support for people with autism.

The full report is available at http://moray.gov.uk/moray_standard/page_88701.html

5.	The draft strategy was amended based on the information gathered at the consultation events and from the Moray Council Service Map[29]. It was then sent out for full public consultation.

98% of those who responded[30] agreed with the vision of the strategy and 93% agreed with the aims of the strategy. The strategy was given final approval by The Moray Childcare Partnership and the Moray Community Planning Partnership.

Full information on the consultation process was recorded using 'VOiCE', a tool used to design and deliver effective community engagement.

The Moray Council, National Health Service in Moray and our partners thank everyone who has given up their time and shared their experiences to enable this strategy to be developed.

Lewis Brennan - Winner of 'Autism & Me'
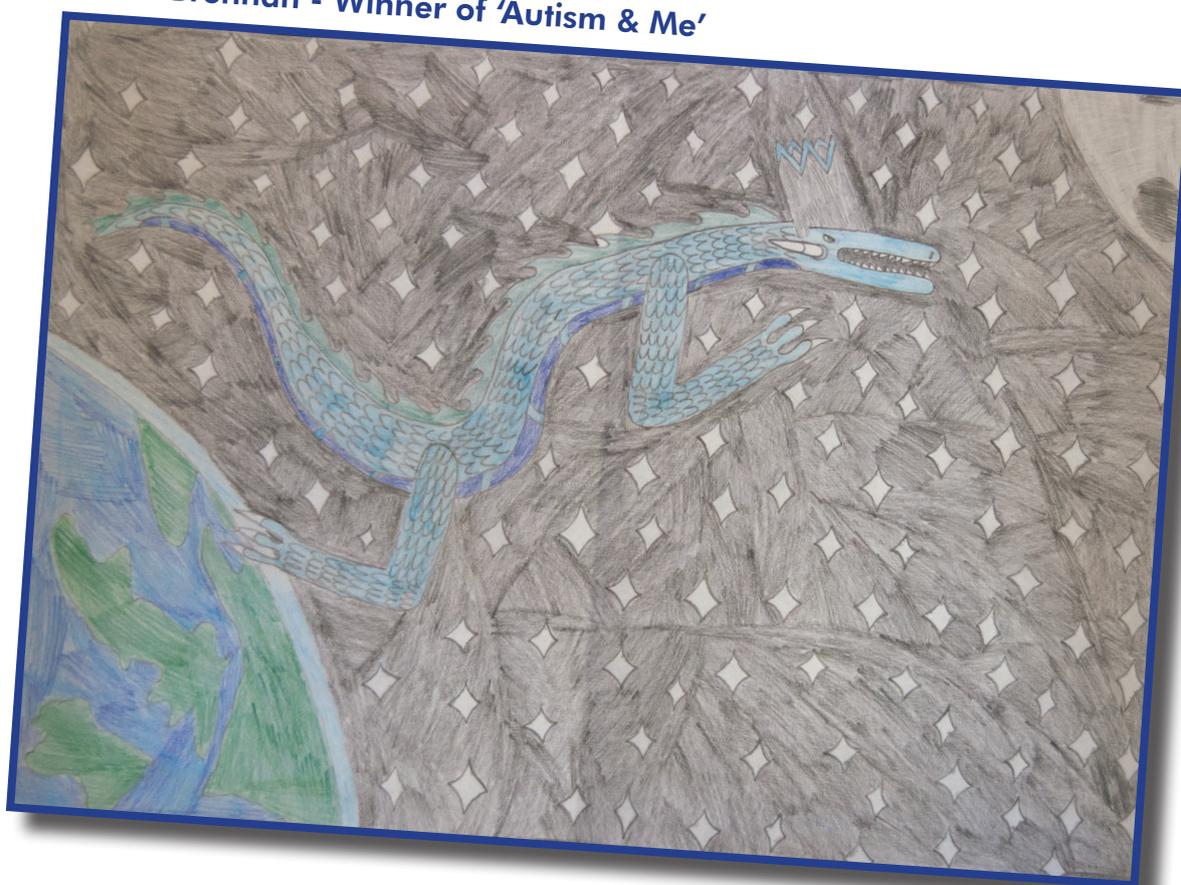
'It can be scary stuff...but our vision of the world can be incredible'

Noaki Higashida, The Reason I Jump

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[29] A mapping exercise was completed by the Scottish Government early 2013. The results have been incorporated into this Strategy but can be found at http://www.moray.gov.uk/downloads/file89297.pdf.

[30] 60 responses to the final consultation were received. this included some group responses which included multiple people.

1   The National Performance Framework, Scottish Government, 2007
     http://www.scotland.gov.uk/Publications/2007/11/13092240/9

2   The Education (Additional Support for Learning) (Scotland) Acts 2004 & 2009
     http://www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL

3   Caring Together and Getting it Right for Young Carers, The Carers Strategy
     for Scotland 2010-2015, Scottish Government, 2010
     http://www.scotland.gov.uk/Publications/2010/07/23153304/0

4   A Guide to getting it right for every child (GIRFEC)(2008)
     www.scotland.gov.uk/gettingitright

5   Public Health Institute of Scotland Autistic Spectrum Disorders Needs
     Assessment Report, 2001, updated 2006
     www.scotland.gov.uk/Publications/2006/02/28094616/0

6   SIGN publication No 98 Assessment, diagnosis and clinical interventions for children
     and young people with autism spectrum disorders
     http://www.sign.ac.uk/guidelines/fulltext/98/index.html

7   Commissioners of health and social care services for people on the autism spectrum,
     Policy and Practice Guidance, (2008)
     http://scotland.gov.uk/Publications/2008/03/27085247/0

8   Education for pupils with autism spectrum disorders, (2006), HMIE
     http://dera.ioe.ac.uk/6489/1/epasd.pdf

9   National Guidance on the Implementation of Local Area Coordination, Scottish
     Government, (2008)
     http://www.scotland.gov.uk/Publications/2008/03/27092411/0

10   Report on the Future Delivery of Public Services by the Commission (chaired
     by Dr Campbell Christie, (2011).)
     http://scotland.gov.uk/About/publicservicescommission

11   McKay, T & Dunlop, AW (2004). The Development of a National Training Framework for
     Autistic Spectrum Disorders, NAS & University of Strathclyde.

12   Learning Together: Meeting needs of children and young people with Autism
     Spectrum Disorders. Quality Indicators Learning Disabilities, NHS QIS (2004).

13   Towards an Autism strategy for Scotland, Scottish Government, 2010
     http://www.scotland.gov.uk/Publications/2010/09/07141141/0

14   The same as you? (2000), Scottish Government (2001)
     http://www.scotland.gov.uk/Publications/2006/04/13144910/1

15   Mental Health Strategy for Scotland 2011-15 – a Consultation September 2011
      http://www.scotland.gov.uk/Publications/2011/09/01163037/0

16   Single Shared Assessment of Community Care Needs Circular CCD8/2001
      http://www.sehd.scot.nhs.uk/publications/DC20011129CCD8single.pdf

17   Talking Points:
      http://www.jitscotland.org.uk/action-areas/talking-points-userand-carer-involvement/

18   Guidance on Care management in Community Care, Circular CCD8/2004
      http://www.scotland.gov.uk/Publications/2005/02/20728/53035

19   Knapp, Martin and Romeo, Renée and Beecham, Jennifer (2009) Economic
      cost of autism in the UK. Autism, 13 (3). pp. 317-336.

20   NHS National Institute for Health and Clinical Excellence (NICE) Autism
      Spectrum Disorders in children and young people 2011.
      http://www.nice.org.uk/CG128

21   National Guidance on Local Area Coordination
      http://www.scotland.gov.uk/Publications/2008/03/27092411/0

22   Health Needs Assessment Report, NHS Health Scotland, 2004
      http://www.healthscotland.com/documents/1040.aspx

23   Tackling Indifference Report, National Overview Report, 2009
      http://www.healthcareimprovementscotland.org/previous_resources/performance_review/
      tackling_indifference.aspx

24   Curriculum for Excellence, Education Scotland
      http://www.ltscotland.org.uk/understandingthecurriculum/whatiscurriculumforexcellence/
      index.asp

25   Reshaping care for older people, Scottish Government
      http://www.scotland.gov.uk/Topics/Health/care/reshaping

26   Health Quality Strategy, Scottish Government, 2010
      http://www.scotland.gov.uk/Publications/2010/05/10102307/0

27   Carers Strategy, Scottish Government, 2010
      http://www.scotland.gov.uk/Publications/2010/07/23153304/0

28   Shifting the Balance of care, Integrated Resource Framework, NHS Scotland,
      http://www.shiftingthebalance.scot.nhs.uk/initiatives/sbc-initiatives/integrated-resource-
      framework/