



# Dumfries and Galloway Autism Strategy 2014 - 2017

## **Better lives for people with Autism**

Date: 11<sup>th</sup> July 2014

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## Foreword

Strategic action is needed both nationally and locally to ensure that care and support is available for people affected by autism.

This strategy recognises that people living with autism are a group of people with specific support needs.

Autism impacts on the whole life experience of people and their families. They need to be supported by a wide range of service such as social care, health, education, housing, employment and other community based services. A holistic, joined up approach is necessary.

There are many challenges, not only for statutory health, education and social care services but for all public and local services. The vision of partnership working has been shared by local organisations in the development of this strategy.

This document presents a multi agency vision for creating better lives for people with autism in Dumfries and Galloway. It has taken into account the views of people with autism, their families and professionals. In implementing this vision, partners will ensure that:-

- more people understand autism
- it is easier for people with autism to get a diagnosis and access the support they need
- it is easier for people with autism to choose how they live and get the help they want when they need it
- people with autism have more opportunities to access life-long learning
- people with autism are better prepared and supported for vocational opportunities that include employment.

Given the changing landscape of health and social care, the way future services will be shaped is likely to be influenced by the integration of health and social care local agenda. This will become clearer over the lifetime of this document and it's supporting Action / Implementation Plans.

A range of national and local strategies links this ASD Strategy with the complex policy environment within which we live and work. Detailed information on policy and strategies can be found at Appendix 1.

## Executive Summary

The Scottish Strategy for Autism published by the Scottish Government in 2011 ([www.autismstrategyscotland.org.uk](http://www.autismstrategyscotland.org.uk)) made 26 recommendations. It envisaged a ten year strategy with 2 year goals (Foundations), 5 year goals (Whole life journey) and 10 year goals (Holistic personalised approaches) for the implementation of key priorities. Ten indicators for current best practice in the provision of effective Autism Spectrum Disorder (ASD) services were also identified. The first of these indicators required the development of local autism strategies; 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.

The overarching strategic aim for autism services in Dumfries and Galloway is to take a multi-agency approach to ensure the provision of high quality services for people living with autism, their families and carers.

Representative partners from across the whole system including Parents, Health, the Local Authority and Third and Independent Sector, met in November 2011 and formed the Dumfries and Galloway Autism Strategy Group (DGASG) which completed this draft strategy document for consultation. The original list of members of DGASG is included as Appendix 2.

In consideration of; national frameworks, local feedback from the Scottish Autism Strategy mapping exercise and in consultation with local groups, the Dumfries and Galloway Autism Strategy Group identified the following 5 priorities:

- ✓ **Raising awareness: make sure that the people who need to know, understand about autism**
- ✓ **Provide care and support for people with autism as close to home as possible**
- ✓ **Make sure that people can have an assessment for autism as soon as possible whatever their age**
- ✓ **Make sure that people's autism support needs are understood by all agencies involved at each stage of a person's life**
- ✓ **Make sure that people with autism are able to move between the services and agencies that best support their needs at that time.**

Following wide consultation on the Dumfries and Galloway Draft Autism Strategy and the identified 5 priorities, the Dumfries and Galloway Autism Strategy Group will finalise the Strategy and continue to develop an action plan.

1.	<b>What is Autism?</b>
	Autism is a lifelong developmental disorder more commonly referred to as autism spectrum disorder (ASD) but also known as autism spectrum condition (ASC). ASD affects people differently, with some individuals being able to live independently while others need very specialist support.
	Children and adults on the autism spectrum each have a unique set of conditions which will not necessarily fall within the categories of learning disabilities or mental health, although these may be present.
	<p>What everyone will have in common is difficulty in a number of areas of functioning for example:</p> <p>People experience problems with:</p> <ul style="list-style-type: none"> <li>➤ Communication. This includes spoken language, body language, facial expressions and other communication gestures</li> <li>➤ Social Interaction. This includes the ability to understand what someone else is thinking and the need for give and take in our conversations and interactions with other people</li> <li>➤ Restrictive, repetitive and stereotyped routines of behaviour. These may involve ideas held by a person with ASD (which maybe very restricting for their family, friends and colleagues but may also be psychologically distressing or inhibiting for the individual with ASD).</li> <li>➤ Sensory differences. Many people with autism have difficulty processing everyday sensory information like touch, hearing, vision and smells. This may include difficulties with all seven senses. Sensory differences can have a huge impact on everyday life and individuals can become very stressed and anxious because of the sensory difficulties they experience.</li> </ul>
	<p>The autism spectrum includes people with Childhood Autism, Aspergers Syndrome and Atypical Autism. People with ASD often have additional support needs and sometimes have accompanying conditions such as dyslexia, dyspraxia, attention deficit hyperactivity disorder (ADHD) and epilepsy. People with ASD can also have a wide range of other conditions and syndromes.</p> <p>In this strategy document we will use the umbrella term “autism” for all conditions on the spectrum.</p>

2.	<h2>Setting the Scene</h2>
	<p>In 2011 the Scottish Government published the Scottish Strategy for Autism. The creation of this national ten year strategy for autism demonstrates the efforts that have been made in the following areas:</p> <ul style="list-style-type: none"> <li>➤ to improve diagnosis and assessment</li> <li>➤ to create consistent service standards</li> <li>➤ to match resources to need</li> <li>➤ to underpin this with appropriate research and training opportunities</li> </ul>
	<p>Most recent studies suggest that 1 in 100 is currently the best estimate of the prevalence of ASD in children. This suggests that there are over 50,000 affected young people in Scotland, and up to 40% of these may also be considered to have a diagnosed learning disability. Many will have difficulties in aspects of their learning and acquiring information even though they may have high levels of general ability.</p> <p>No studies have been carried out with the adult population. Information from services across Scotland suggests that an increasing number of adults are seeking and receiving a diagnosis.</p>
	<p>Within Dumfries and Galloway (population 151,300) there are estimated to be around 1350 people with ASD.</p>
	<p>There are currently 382 children and Young People (0-18years) with a diagnosis of ASD. There are a further 147 children and young people in the process of assessment and awaiting diagnostic decision (Data for September 2012). The assessment and diagnostic processes for adults 18-65 are much less complete and no comprehensive register currently exists.</p>
	<p>It is common throughout the UK for health and social services to know only a small number of local people with autism. This is because:</p> <ul style="list-style-type: none"> <li>➤ Many people with autism (undiagnosed or diagnosed) are supported within the family unit and do not use services</li> <li>➤ Lack of awareness of autism results in people not being identified or diagnosed appropriately</li> <li>➤ There are difficulties accessing autism diagnostic assessments particularly for</li> </ul>

	those without a diagnosed learning disability or mental ill health
<b>3.</b>	<b>Core Principles</b>
	People with autism will be recognised first and foremost as individuals who are respected, accepted and valued by their communities. People with autism will be treated fairly and live meaningful and satisfying lives.
	<p>This means that people with autism are individuals and are:</p> <ul style="list-style-type: none"> <li>➤ at the centre of their care and support planning</li> <li>➤ valued and included in planning and reviewing services</li> <li>➤ supported to identify personal quality of life outcomes</li> <li>➤ informed of their rights and provided with information in a format that is appropriate to their needs so that they can make informed choices and decisions</li> <li>➤ enabled to access services</li> <li>➤ enabled to have meaningful and satisfying lives</li> <li>➤ supported in a way that understands their needs</li> <li>➤ able to move from and between services as easily as possible</li> <li>➤ assisted to maximise their independence and to live independently</li> <li>➤ encouraged to provide feedback on their experiences to inform future service planning</li> </ul>
	Agencies (including statutory, private, independent and voluntary sectors) will work in partnership to provide high quality services throughout Dumfries and Galloway.
<b>4.</b>	<b>How does autism affect families?</b>
	<p>It is evidenced that families who have a child with autism experience higher levels of anxiety and stress. Everyday living can often be fraught with worry as families try to understand, support and manage their child's responses and behaviour.</p> <p>Families can find their lives controlled and constrained for a number of reasons:</p> <ul style="list-style-type: none"> <li>• They are limited or unable to take their child out and about in case they “kick</li> </ul>

	<p>off” because everyday situations and everyday life can be overwhelming for their child.</p> <ul style="list-style-type: none"> <li>• Autism is a hidden disability and when they go out families often find their child’s behaviour being wrongly judged by others. This situation contributes to frustration, isolation and loneliness for these families.</li> <li>• Options for parents to maintain/take up work, or attend social opportunities are often restricted because of their caring responsibilities and the need for them to be constantly available (and available at unexpected times) to care for their child. This can also have a significant impact on the families’ financial situation.</li> <li>• Lack of access to services such as extra-curricular, leisure and sport activities, childcare services and short breaks and respite.</li> <li>• There is often little opportunity for parents to devote time to their relationship. Exhaustion, sustained levels of heightened emotion and disagreement on approaches can lead to the breakdown of parents’ relationships. This may also be replicated within the wider family – the impact on siblings can also be significant.</li> <li>• Signposting to appropriate advice and support networks is often not forthcoming. Subsequently parents often feel they have sole responsibility for finding out what is available and how to access it. Leaving school and entering adult services raise particular challenges.</li> <li>• Puberty is renowned as a time which brings changing relationships within families. Many parents experience particular difficulties with anger, anxiety, sexual understanding and awareness, personal safety and supporting independence in preparation for adult life. This position is made much more complex with having autism and yet families can experience inadequate focus and less involvement and support at this time.</li> <li>• Transitions are key throughout life. Fear for their child’s future as they enter adulthood is often a constant concern. With decreasing energy levels families are less able to proactively ensure progress.</li> </ul>
<p><b>5.</b></p>	<p><b>Consultation with parents/carers &amp; people with Autism</b></p> <p><b>Feedback from Parents/Carers about the impact of ASD</b></p>
	<p>A number of consultations have taken place across the region. The key headings show the following areas to be of concern for people with ASD and their families and Carers:</p> <ul style="list-style-type: none"> <li>➤ Support in Schools</li> <li>➤ Lack of standardised information and how to access it</li> <li>➤ Coping with life at home</li> <li>➤ Transitions into adulthood</li> <li>➤ Diagnosis</li> </ul>

	<ul style="list-style-type: none"> <li>➤ Service provision in a rural area</li> <li>➤ Training</li> <li>➤ Workforce development</li> <li>➤ People with ASD without a learning disability</li> <li>➤ Mainstream inclusion v Specialist provision</li> </ul> <p>A comprehensive summary of consultation conversations is at Appendix 3.</p>
6.	<p><b>Our aspirations for people with autism</b></p>
	<p>The Dumfries &amp; Galloway Strategy for Autism enables services within the region to take forward the recommendations of best practice in the national strategy.</p>
6.1	<p><b>Children and Young People</b></p>
	<p>The national strategy driver for improving the lives of children and young people in Scotland is <i>Getting It Right For Every Child</i> (GIRFEC) (2005). This document guides and directs integrated activity that will enable children and young people to become:</p> <ul style="list-style-type: none"> <li>➤ Confident individuals</li> <li>➤ Effective contributors</li> <li>➤ Successful learners</li> <li>➤ Responsible citizens</li> </ul> <p><i>Getting it right for every child</i> aims to put the child or young person at the centre.</p> <p>The recommendations contained within GIRFEC have been embedded in the Children and Young People (Scotland) Act 2014. This Act aims to further the Scottish Government’s ambition for Scotland to be the best place in the world to grow up in by putting children and young people at the heart of service planning and ensuring their rights are respected.</p>
	<p>The <b>Self-directed Support (Scotland) Act 2013</b> was implemented on 1 April 2014. The Act gives children and young people affected by autism and their families much more choice and control about how the support they need is selected, delivered and managed based on the outcomes they want for their lives. Work is underway across Dumfries and Galloway Social Work Services and other relevant agencies to prepare and train the health and social care workforce for the huge changes in culture and ways of working that this Act requires across all</p>

	<p>support services. An easy read statement of the SDS Act's principles and values was published in June 2014 and this can be found by clicking the link <a href="http://www.scotland.gov.uk/Publications/2014/06/8424">http://www.scotland.gov.uk/Publications/2014/06/8424</a>.</p>
<b>6.2</b>	<b>Adults</b>
	<p>As it states on the National Autistic Society's website (click link: <a href="http://www.autism.org.uk/living-with-autism/benefits-and-community-care/community-care-for-adults/community-care-self-directed-support.aspx">http://www.autism.org.uk/living-with-autism/benefits-and-community-care/community-care-for-adults/community-care-self-directed-support.aspx</a>) <i>'Self-directed support (SDS) is a system of social care that lets people take control of their own lives and support. Under the old support system, social services and other professionals assessed you and then told you what services they were going to provide. In this system, you get to say what you want out of life, and plan what support would be best for you'</i>. Through agency partnerships and co-production with individuals and communities, Dumfries and Galloway's Autism Strategy will aim to endorse the development of forms of support that meet the individual needs, personal outcomes and interests of adults affected by ASD in our region and empower them to be as fully involved in that process as possible.</p>
	<p>The <i>Regulation of Care (Scotland) Act 2001</i> set up the Care Commission (now known as the Care Inspectorate) to regulate and inspect all the services registered under the Act, taking into account the National Care Standards issued by Scottish Ministers. The six principles contained within the National Care Standards are dignity, safety, choice, privacy, diversity and potential. Dumfries &amp; Galloway Strategy for Autism aims to ensure that these principles are adhered to in all aspects of service delivery.</p> <p><i>The Keys to Life (2013)</i> published by the Scottish Government builds on the principles and values of <i>The Same as you? (2000)</i> aimed at improving the lives of, and services for, people with learning disabilities and those with ASD. It is a ten year strategy with particular emphasis on health issues.</p>
<b>6.2</b>	<b>How we will achieve this</b>
	<p>The overarching strategic aim for autism services in Dumfries and Galloway is to take a multi-agency approach to ensure the provision of high quality services for people living with autism, their families and carers. Partners across the whole system, Health, the Local Authority and Third and Independent Sector, will work together to provide support, information and care in a timely, safe and appropriate manner, safeguarding and protecting people while enabling them to lead a sustainable, independent life as close as possible to their own home or local community.</p>
	<p>Within the context of health and social care there is significant opportunity to drive progress through the new National Person Centred Health and Care Programme. This was launched in November 2012 and aims to deliver positive personal</p>

	outcomes through a person-centred approach offering choice and control.
	<p>Closely linked to ensuring that a person-centred approach is taken is “co-production”. This can be defined as the design and delivery of public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Co-production approaches value lived experience, and support people to take control individually and as communities to help people to stay well for longer.</p>
	<p>The multi-agency vision is to create better lives for people and their families living with autism in Dumfries and Galloway. In implementing this vision, partners will ensure that:-</p> <ul style="list-style-type: none"> <li>➤ more people understand autism</li> <li>➤ it is easier for people with autism to get a diagnosis and access the support they need</li> <li>➤ it is easier for people with autism to choose how they live and get the help they want when they need it</li> <li>➤ people with autism have more opportunities to access life-long learning</li> <li>➤ people with autism will be better prepared and supported with vocational opportunities that will include employment.</li> </ul>
	<p>Dumfries and Galloway Autism Strategy Group looked at the challenges faced by people with autism and their families and at how services and agencies could work together to support people with autism to have better lives.</p> <p>The Group identified 5 priorities to work on first. These are:</p> <ul style="list-style-type: none"> <li>✓ <b>Raising awareness: make sure that the people who need to know, understand about autism</b></li> <li>✓ <b>Provide care and support for people with autism as close to home as possible</b></li> <li>✓ <b>Make sure that people can have an assessment for autism as soon as possible whatever their age</b></li> <li>✓ <b>Make sure that people’s autism support needs are understood by all agencies involved at each stage of a person’s life</b></li> <li>✓ <b>Make sure that people with autism are able to move between the services and agencies that best support their needs at that time.</b></li> </ul>

## Appendix 1. Information on Policies and Strategies

### **The Scottish Strategy for Autism (2011)**

Autism is a national priority. Children and Adults with autism need to be supported by a wide range of services and a holistic joined up approach is necessary. The Scottish Strategy for Autism provides direction for the way ahead identifying that Strategic action is needed both nationally and locally. Strategic actions include the development of local strategies and action plans.

For further information on The Scottish Strategy for Autism (2011) click the link below.

[www.autismstrategyscotland.org.uk](http://www.autismstrategyscotland.org.uk)

The **Self-directed Support (Scotland) Act 2013** was implemented on 1 April 2014. An easy read summary of what the act covers is available on the Scottish Government Website and can be found by clicking the link

<http://www.scotland.gov.uk/Resource/0042/00423126.pdf>.

An easy read statement of the SDS Act's principles and values was published in June 2014 and

this can be found by clicking the link

<http://www.scotland.gov.uk/Publications/2014/06/8424>

The SDS values are Respect, Fairness, Independence, Freedom and Safety.

The SDS Act should give children, young people and adults affected by autism and their families much more choice and control about how the support they need is selected, delivered and managed based on the outcomes they want for their lives. Work is underway across Dumfries and Galloway Social Work Services to prepare and train the health and social care workforce for the huge changes in culture and ways of working that this Act requires across all support services.

The **Public Bodies (Joint Working) (Scotland) Act 2014** received Royal Assent on 1 April 2014. Access is by clicking the link

<http://www.legislation.gov.uk/asp/2014/9/contents/enacted>.

The Act provides for Scottish Ministers to put in place a number of Regulations and Orders to bring about the integration of Health and Social Care. Consultation on the first set of draft Regulations began on Monday 12 May 2014 and runs until Friday 1 August 2014. Integration between health and social care with strong, active partnerships with the Third and Independent Sectors should deliver better and more cost-effective support across the multi-dimensional aspects of autism.

### **The Children and Young People (Scotland) Act 2014**

The Children and Young People (Scotland) Act 2014 received its Royal Assent on 27 March. The Act covers a variety of issues relating to the wellbeing of children and young people. The Scottish Government's overarching plan envisages that issues will principally be taken forward in each of the individual policy areas, working in cooperation with relevant stakeholders to ensure that the planning for implementing the different elements of the Act is taken forward timeously and efficiently.

For further information on **The Children and Young People (Scotland) Act 2014** click the link below.

<http://www.legislation.gov.uk/asp/2014/8/contents/enacted>

**Caring Together: The Carers Strategy for Scotland 2010 - 2015**

The national strategy recognises carers as equal partners in the delivery of care in Scotland and fully acknowledges carers' expertise, knowledge and the quality of care they give. *Caring Together* sets out 10 key actions to improve support to carers over the next five years. The focus is on improved identification of carers, assessment, information and advice, health and well-being, carer support, participation and partnership.

For further information on **Caring Together: The Carers Strategy for Scotland 2010 – 2015** click the link below.

<http://www.scotland.gov.uk/Publications/2010/07/23153304/0>

## Appendix 2. Membership of Dumfries and Galloway Autism Strategy Group December 2011

Dr Stewart Biggar, Principal Educational Psychologist

Barbara Aitken, Team Manager, Social Services

Clare Bannister-Phillips, Team Manager, Learning & Development

Dr Graham Batti, Clinical Psychiatrist,

Beth Bleasdale, Manager, ARC, Newton Stewart

Dave Bleasdale, Operations Manager, Turning Point Scotland

Dr Carolyn Boyd, Clinical Psychiatrist

Claire Clanachan, Supported Employment & Development Manager

Sheila Clingan, Strategic Planning and Commissioning Manager Children and Families; Social Work Services

Barrie Cooper, Independent Consultant/Early Bird Training

Laura Dykes, ASDIN Co-ordinator: Parent

Jim Gordon, Pupil Support Officer, Youth Justice

Sharron Harper, Depute Principle Educational Psychologist

Alyson Hogg, Lead Speech and Language Therapist

Donna Inglis, Family Protection Unit, D&G Police

Jim Lemon, Consultant Clinical Psychologist

Alexandra Little, Strategic Planning Manager, Cancer, Palliative Care and Children's Services

Penny Nowell, Joint Strategic Planning Manager, Adult Mental Health

Karen Priestley, Parents Inclusion Network

Dina Van Der Hulst, Assistant Psychologist

Libby Welsh, Quarriers

## Appendix 3. Consultation & Involvement

### Support in Schools

Some parents mentioned that they felt schools were unwilling to make the reasonable adjustments they are legally bound to make. Others said their child's school did not wish to take on board the parents' input into supporting their child, although the parents knew they were the experts and the best resource for their child.

Sometimes when schools felt unable to cope with a pupil's behaviour they would phone the parent to come and pick their child up and take them home.

It was generally felt that schools encourage 'fitting in', which is an appropriate aim but isn't always going to happen for some people with autism. Some parents said their child received some support in class but, due to insufficient funding, the support was not enough, so, for periods of time, their son or daughter had no-one to help keep them on task and concentrate. This often led to problematic situations within the school, both for the pupil, the teacher and the rest of the class.

### Lack of standardised information and how to access it

The lack of knowledge about where to seek out information and support was also cited as a concern for parents. There is no 'one-stop-shop' where parents can access information and help.

Parents felt they had the sole responsibility for finding out what is available and how to access it. Parents expressed feelings of helplessness in not knowing the best person to speak to or the various supports which are on offer. They said they were frustrated in trying to ensure the best possible support for their son or daughter.

### Life at home

The comment, 'he holds it together at school but loses it at home' was echoed by everyone. It is at home where families struggle and absolutely cry out for support which often isn't available.

In this region, support from Social Services usually requires a high tariff of need such as child protection issues, or very complex disabilities. The majority of families with a son or daughter with autism, particularly one without a learning disability, are not eligible for support. Finding the support providers that are available without a social work referral is a very random exercise, depending on where you live and/or who you know.

### Adult Services

A common concern is that for many people reaching adult services at 16 or 18 years no support is being funded, unless someone has a complex learning disability as well as autism or there is a known crisis. People with autism are vulnerable to being isolated as they can lack the necessary social and communication skills or ability to read a social situation.

### Diagnosis

Parent Inclusion Network has collected a number of stories from parents about poor post-diagnostic support, where families were given the diagnosis and afterwards felt they were 'left hanging'. Young adults, 18 and over, face a real challenge to obtain a diagnosis. At the moment, there is no diagnostic pathway for those ages over 18 years, where they do not also have a mental health illness and/or learning disability. That leaves a significant number of people unable to obtain a diagnosis.

### Transition

All transitions were mentioned as a special time when understanding of autism is paramount in ensuring the best transition, at whatever stage, and particularly into adult services. Everyone was agreed that a seamless transition was the goal.

### Rurality of Dumfries and Galloway

A number of parents commented on the impact the large, rural nature of our particular authority has on service provision, and noted that the Scottish Government needs to acknowledge that and reflect this logistical difficulty into service provision.

With often remote, very rural, small towns and villages spread throughout a very large region, services are difficult to provide in an equitable, consistent way throughout the authority and families do suffer because of this. This rurality and remoteness means there is a lack of suitable resources.

### Training

The need for everyone who works with people with autism to have a thorough understanding of the spectrum of disability is paramount. This includes teachers, classroom assistants, heads of schools, social workers, support workers, third sector employees, dinner ladies, taxi drivers etc. They all agreed that the best way to support someone with autism is to understand the disorder and know how it impacts on the individual, enabling them to make whatever adaptations are necessary to meet the individual's support needs.

Education for children with autism continues to be problematic, and lacks consistency across the region. Parents find some schools to be excellent, and others encounter problems from day one. Those who experience difficulties with the school continue to press for teachers and other school staff with more understanding and knowledge of autism disorders.

The need for families to gain a good understanding of autism is equally important. They are often frustrated in their own ability to support their child due to a lack of understanding of the disorder and how this impacts on their particular child. Training for parents, carers and other family members is equally crucial.

Awareness training needs to extend to the community at large as well. Parents spoke of wanting to make sure that the staff at mainstream activities in the community understood how their son or daughter might display their autistic impairments and how to support them, but sometimes found it impossible. ASDIN is able to offer parents and carers on the Communication Disorders Assessment Team (CDAT) waiting list the 'How and Why' Parent Training

Programme course which is an excellent provision. ASDIN has also received funding to develop training for parents whose children are on the CDAT waiting list and are between the ages of 8 and 18.

#### People with ASD without a learning disability

People with ASD, without a learning disability, have often been marginalised in terms of support and this presents a real hardship for them, their families and their community, as their support needs can be just as great as those with a traditional learning disability. There is a risk of marginalisation and isolation as a consequence of lack of opportunities and support.

Dumfries and Galloway does offer the Partnership In Action drop-ins and other activities for more able young adults and this is a great service. The Adult Mental Health facility for adults without a learning disability is also an excellent support, but only for adults with a mental health illness.

People have also spoken about the lack of work opportunities due to unfriendly and unpredictable work environments and a lack of understanding by employers. Training is an area people feel they could contribute more to and share their experience of living with autism and the good and not so good supports they have had.

There is a need for a clearer strategy for developing social and life skills training to further enhance the prospects for more independent living.

It is thought that people who have autism, because of their differences in social understanding and interaction, may be more vulnerable to others but may not attract attention of adult support and protection due to their isolation and lack of involvement with support services.

People at the higher end of the spectrum may not attract self directed support funds if their level of need is not assessed as being critical and yet they are more likely to suffer from depression than other parts of the population.

#### Transition

The value of Recommendation 18 in the Scottish Strategy, which addresses transition, is supported by parents with regard to all transitions.

#### Diagnosis

Regarding diagnosis, there are several recommendations in the Scottish Strategy which cover diagnostic processes, and Recommendation 10 considers immediate support which should be clearly made available. Adults without a learning disability or a mental health illness are currently not able to access a diagnosis.

#### Accessible information

Parents felt strongly that there is a gap in the provision of easily accessible information about how they can best ensure good support for their son or daughter. A robust, clear pathway about support provision should be available, for all families which is consistent throughout the region and provides clarity about what parents can ask for and how to ask for it. Recommendation 10 covers this and clearly includes coordination of all services and interventions.

Support must also be available for families prior to diagnosis well to help people with the autistic features which have prompted the diagnostic process.

A multi-agency pathway for assessment, diagnosis and intervention, and access to useful and practical information about ASD and local action, are provisions included in the 10 indicators and strongly endorse the importance of this support need. The identification of clear diagnostic and support pathways is also a priority for DG Autism Strategy.

Mainstream inclusion vs Specialist provision

There is always discussion, when autism is on the menu, about the benefits of autism specialism and universal support. Parents seemed to feel that if the people supporting their son or daughter had a good understanding of autism and how it affects their child, they would be happy for this to be under the auspices of universal support, with allowances for exceptions at any given time or situation. Parents continue to disagree with the automatic goal of 'inclusion' for people with autism when the necessary knowledge and understanding cannot be guaranteed.