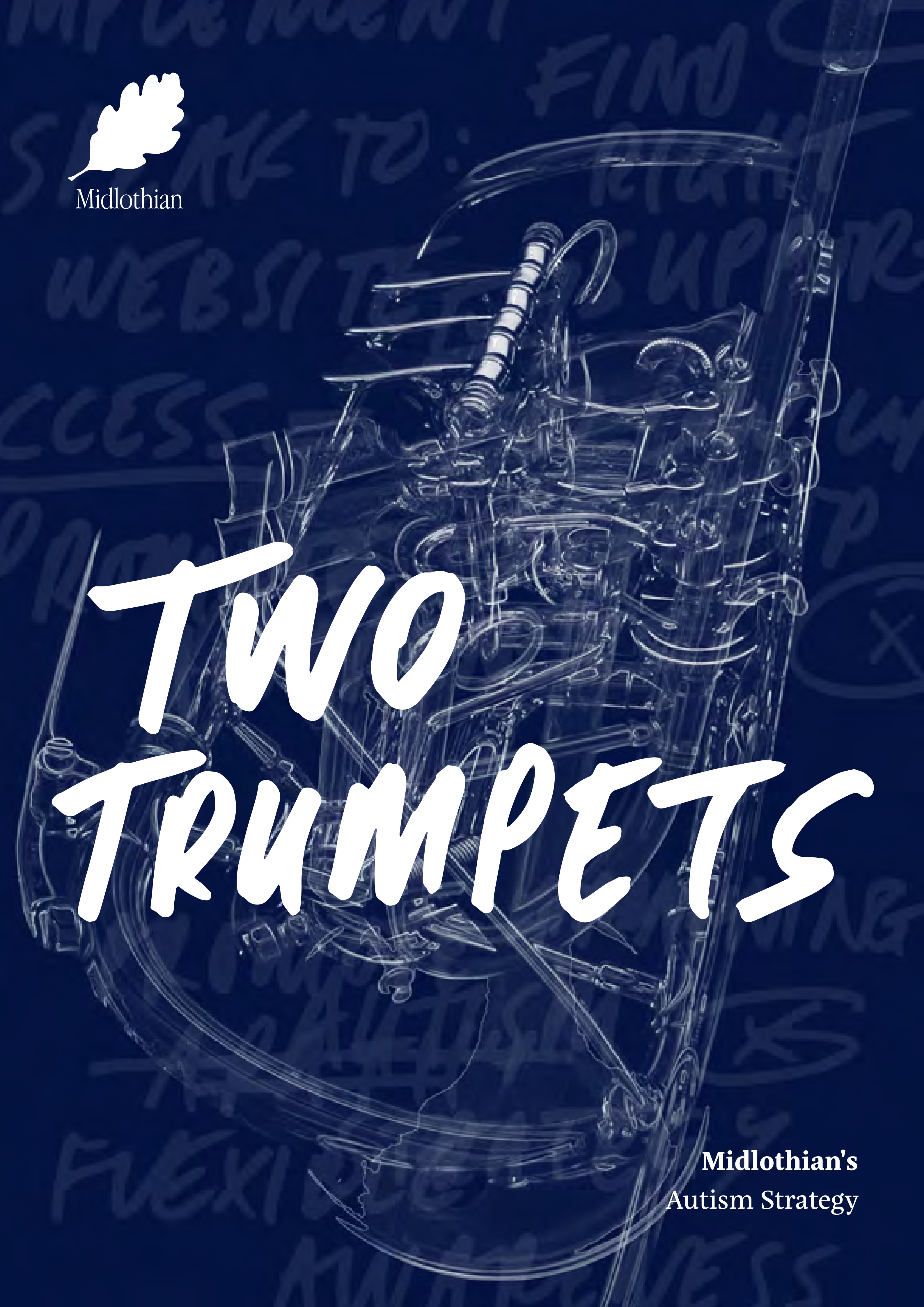
Midlothian



Two Trumpets

Midlothian's
Autism Strategy

Midlothian Council Health and Social Care
Fairfield House
8 Lothian Road
Dalkeith
Midlothian EH22 3AA

1 Introduction

In March 2014 we took the first steps in presenting our ideas and vision in supporting and developing services for and with people who have Autism. We recognise the importance of improving things for people with autism and making sure that the right people and the right services are there to support them at the points in their life when they most need it.

We made sure that as the strategy developed we set it in a direction that directly involved people with autism and their families. It is important that as the strategy develops their experiences continue to shape future work.

A strategy is only as good as the actions that it supports. Living with autism can be a struggle as lack of understanding and a myriad of services to navigate can make life hard. We believe that the actions to resolve some of these issues are not always that complicated; we realise that they do involve listening carefully and being imaginative in finding the right solutions at the right time and they always involve people.

To further inform the strategy we worked with Artlink Edinburgh and journalist and novelist Catherine Simpson to gather views from people with autism, their families and those working in the fields of education, social care and health. Catherine's interest in autism and how to access the right support is a deeply personal one; her 21–year–old daughter, Nina, was diagnosed with Asperger's Syndrome when she was ten and was raised in Midlothian and attended local nurseries and schools. Catherine worked alongside Artlink to report on conversations and meetings that took place over a 10–month period.

The article sets the tone for the strategy and our continued commitment to work with people to find the right solutions when things are not working.

2 Two Trumpets

by Catherine Simpson

‘Who decides what “quality of life” means?’
This, for me, is one of the most striking questions to emerge from the many conversations we have had over the past year with autistic people, their parents and carers and people working in the field. Following on from this question is the idea that we should attempt to look through the eyes of autistic people and, if possible, ask them what is meaningful for them. These ideas seem obvious and simple, but they are radical at the same time.

Autism is a very complex condition, on a spectrum which encompasses all abilities from the highly articulate to others who need advocates to help express their needs. It is also life–long and, of course, as the person with autism ages their social and emotional needs change too. Many autistic people have their lives further complicated by mental health issues, learning disabilities and other challenges. When dealing with the day to day reality of autism the difficulties faced by autistic people and their families should not be underestimated; indeed at times they could hardly be over–stated.

The notion that autistic people should have agency in their own lives and that services should be more flexible and imaginative when working with autistic people and their parents and carers – and the enormous impact this makes when done successfully – was a theme that was common to all the autistic people and the families we met.

We heard from one mother about how her daughter became stressed when she kept forgetting her trumpet for high school music lessons so her teacher suggested she use two trumpets, one for home and the other for school. A second instrument was provided and her worries about missing trumpet lessons vanished overnight. For a child who has Asperger's Syndrome – which often comes hand in hand with high levels of anxiety – this solution made the difference between heading to school with a spring in her step and refusing to go at all. So simple and yet so effective.

This kind of flexible thinking and imaginative problem solving can be a life–saver for autistic people and their parents and carers, who may feel overwhelmed by the challenges of trying to fit into a non–autistic world.

* * *

Early diagnosis was viewed by many as key to accessing the right support. Children as young as two are currently being diagnosed in Midlothian which then gives them and their families a gateway to the appropriate nursery services, they can access advice, become aware of any benefit entitlement, and have a better understanding of their child from the earliest possible opportunity.

However, seeking a diagnosis is not for everyone. Some people are frightened of the consequences for their child (or themselves) of being labelled as different for life and they are fearful that the diagnosis will leave them with 'perceived limitations' that they will never be able to overcome.

One father reported that his son, who has a diagnosis of Asperger's Syndrome, 'did not want to be labelled or to associate with groups' and remained 'socially isolated, lonely and depressed'. This father believed it was not services that would affect his son's life for the better but that 'societal attitudes to hidden disabilities must change'.

Others however believe that knowledge is powerful and self–knowledge for the person with autism is very powerful indeed, and that without a diagnosis the person is in danger of just 'getting by'.

My daughter, Nina, is now an adult and keen to talk about her autism openly and make contact with other autistic people – preferably online; this being the form of communication she prefers. For her, embracing her diagnosis has been empowering. She believes that autism is not a taboo subject or an embarrassment. Autism is nothing to be ashamed of. Autism means she experiences the world differently from me – but that is neither a weakness nor a failing. She believes that if she does not accept herself it is going to be an uphill struggle to get anyone else, or society in general, to accept her and celebrate her as she is.

This difference in attitude to diagnosis highlights how complex the issues are and that the answer lies in listening to people and supporting them to make the choice that is right for them.

* * *

Of course because a diagnosis may help you understand your child, or yourself, better, it does not mean the rest of the world follows suit. Autism often being a 'hidden' condition can bring many challenges and we must continue to raise awareness of autism among service–providers and the public to counter this.

Nowadays more people have heard of autism but that does not mean they recognise or understand autism when they encounter it.

People with autism may be called 'rude' or be stared at or tutted at in public and their parents may be judged as 'bad parents' due to a lack of understanding. One mother, Liz Davidson, described how her son had an obsession with walking sticks and was sworn at and abused in Tesco for staring at a woman using two sticks.

One practitioner, Lynne Melville, suggested that if the term 'melt down' was changed to 'panic attack' it might lead to better understanding of the help some autistic children needed. She said: 'They are not being naughty, they could be experiencing sensory overload. Other people being judgemental does not help the parent or child, it only adds to an already stressful situation.'

Lack of understanding can work in the opposite way too because of the lingering 'Rainman' effect. 'What is your super–power?' Anna Holt, a young woman, with Asperger's Syndrome was asked. She lamented: 'It's either that, or they expect you to have overcome terrible suffering. Why can't we just be ordinary?'

A step further on from the idea of autism awareness is a society that truly accepts and celebrates difference. What a world that would be!

* * *

How can we make it happen?

One way is to encourage integration early. One primary school in Midlothian pairs up P6 buddies with pupils with autism in a befriending scheme and consequently friendships and understanding are created early.

Another suggestion is that autistic people themselves should be more involved in the decision–making processes and provision of services. As my daughter, Nina, said: 'Not all autistic people are the same. Neuro–typical people describe our needs but they may not be true. They need to listen to us.

We need an emphasis on the unique and to work with the individual. There needs to be an emphasis on kindness, equality and acceptance.'

There is much pressure from society to conform, and the desire to have autistic people 'fit in' is great – but is it realistic or desirable? Indeed autistic people and non–autistic people may have very different ideas of what constitutes 'quality of life' and non–autistic people should beware of imposing their ideas of what is desirable on autistic people.

Parents of children with autism are experts in parenting children with autism and this should be acknowledged – but just as importantly it should be accepted that the real experts on autism are the people who have autism themselves.

Anna Holt referred to this as an attitude of 'you will be happy if you do as we do'. She eventually rebelled against pressure to socialise in a conventional way when she realised she couldn't follow the conversations in the pub, and when she could she found them 'boring'. She has since stopped pursuing a 'stereo–typical good time', no longer goes to the 'stupid pub' and has never been as happy. She has also opted out of the nine–to–five office culture by becoming self–employed.

* * *

Across all age groups there was a desire for increased social opportunities with other autistic people; from parents wanting more autism–friendly sports clubs for kids, through young adults wanting to socialise in a more local version of Number 6, to calls for greater weekend socialising for older adults with autism.

There is a 'presumption of inclusion' as far as education goes. However there were doubts expressed by some parents, including one mother, Aileen Holmes, who said her son had been right through mainstream school but had never been truly accepted by the other youngsters.

As she put it:

‘There’s inclusion, then there’s inclusion.’

We must not assume it is necessarily better for autistic people to be surrounded by non–autistic people – surely it must depend upon the individual’s needs, which may change over time. A member of the Local Area Coordination Team, Catherine Acton, said she thought people wanted to be around their peers; people of a similar age and with similar interests and that this was more important than the ‘perception of inclusion’.

And certainly, socialising with other families with autistic children may take some of the pressure off parents, and reduce the need for explanations. Some people felt there was safety in numbers and that families needed an environment where they are not judged but had full acceptance, a situation described as ‘inclusion in an inclusive environment’.

* * *

We are currently living in austere times of course which is making life even more difficult for people with autism. One parent referred to a ‘tsunami of negativity’ caused by the welfare reforms and several people mentioned the difficulty of accessing benefits. Liz Davidson said her autistic son dealt with stressful situations like benefits assessments by answering ‘yes’ to everything.

One woman with autism was supported in her appeal against a reduction in benefits by a member of staff from Number 6 who took care of the paperwork and represented her at the tribunal. She said: ‘I don’t know how the rest of the world works without Number 6.’

Aileen Holmes described how her autistic son was left ‘feeling awful about himself’ after a PIP assessment carried out by a physio which she believed should have been carried out by someone with experience of autism – someone capable of looking through the eyes of a person with autism – or even, dare I suggest it, somebody with autism – to make a difficult situation fairer. Again, a simple yet effective solution.

* * *

Many people told us about the special members of staff who had made all the difference to them; the people who had helped them through the maze and who had been like gold dust. Are these particular practitioners born or trained? It is probably a bit of both but the starting point must be the recruitment of staff with a natural empathy and kindness.

When contact with these special staff members is consistent over years it is of huge benefit; one mother told of the 'invaluable help' given to her children by seeing the same health visitor and psychologist for 16 years.

Unfortunately, but inevitably, at times contact is lost with a special support – whether this is due to a child progressing through the education system, staff changes or reductions in funding. It is particularly important at such times for information to be passed on so that the good practices set up can be continued.

For one young boy with autism, Callum Lennie, this challenge was dealt with by his nursery teachers putting together a 'passport' for him, to help his primary teachers understand him and introduce him successfully to his new classmates. The passport explained that Callum liked to be by himself at times in his 'safe space' and that this was okay, and that one of his loves was his toy cars which he would probably bring with him on the school bus. His mum, Maria Lennie, said his transition to primary went smoothly and she thought the passport had contributed to his classmates accepting him rather than thinking he was 'weird'.

It is particularly challenging and frightening when a service is lost altogether as happens, for instance, when a child reaches adulthood and loses the support of their school. The one 'constant' in a person's life may be their parent or carer, however, in practice the parent or carer may no longer be able to access information, or feedback, about their child and may be left without even a point of contact.

It was suggested by Neil Stewart of the Community Access Team that to prevent this sudden loss of support, services could be made to 'overlap rather than having an edge between them'. One inclusive education manager, Donny McDonald, pointed out that having someone who is helpful should not be a matter of 'good luck' it should be about training and cultural change coming from the top and suggested that the autistic person may need a 'constant someone' who stayed with them throughout.

Care manager, Lynda Rowan, pointed out that young people with Asperger's Syndrome, but without learning difficulties, could 'fall through the net' when transitioning from school to college – and that consideration should be given to a 'plan B' in case it was needed.

When my daughter was at school she struggled with doing homework after school, and she also couldn't cope with PE lessons. Fortunately, in the second year of high school, both these problems – homework and PE – were solved in one fell swoop when the school agreed Nina should take part in no more PE lessons and should do homework during those periods instead.

Like the 'two trumpets' idea, the exchanging of PE for homework was a solution that came at little or no extra cost. It was an individual solution for an individual problem – the very sort of solution that can save the day for autistic people and their families everywhere.

* * *

For each individual person and set of circumstances there are individual challenges which require individual solutions. For instance we met one young man who was taught life skills at Saltersgate and now attends Garvald four days a week to take part in gardening, drama and kitchen activities, which he described as 'fantastic'. In the evenings he enjoys bowling and eating out at events organised by Midlothian Local Area Coordination and is hoping soon to attend one of their discos. This is a tailored package of services which fit together well to give him life skills, a social life, a routine and a purpose.

This young man has also enjoyed a work placement at IKEA, as have a number of other adults with autism and learning disabilities we spoke to, including one young woman whose mother described the experience as 'brilliant'. This young woman has her housing support, volunteering and social activities organised by Link Living, which provides her with a structured week of snooker, a tea dance, shopping, Garvald and some community activities which are very important to her as she takes pride in 'earning' her benefit.

One middle–aged man with autism, Ian Buerle, told us of the special relationship he had with a member of the Local Area Coordination Team who helped him move house when his father died – getting involved to the extent that the team member hired a van and helped him move furniture. This close contact with Local Area Coordination also led Ian to go on holiday for the first time in his life (in his 50s) with the Kabin, and make contact with Link Living, which now helps him organise his household bills.

Ian's case highlights the fact that autism is a lifelong condition and that throughout a person's life different types of solutions need to be found for different types of situations. We know it is not possible to 'fix' problems definitively but the important thing is to create a culture in which we are always open and alert to people's changing needs and that we listen to what people are saying and act with empathy.

* * *

This flexibility and a culture of 'bending the rules' can be very successful in serving the needs of people with autism and it is vital that staff know they have the leeway to adopt creative solutions and that autistic people and their parents and carers know they have the right to ask for them.

Hopefully, if an attitude of 'bending the rules' is encouraged, autistic people and their families can find these imaginative, flexible solutions sooner rather than later. A month, or a week, or indeed a single day, can be a long time for a person who is struggling and unhappy.

Sometimes the person who is struggling is a parent or carer and in this situation respite can be a great help. Brenda Fortune, a mother of a son with complex needs, was offered respite by Wee Breaks but was worried about leaving her son. Instead Wee Breaks provided a summer house for Brenda to use in her garden to get time alone, close at hand, while her son was with his carers. Again: so simple and yet so effective.

Some adjustments appear very small indeed and cost nothing at all but have a profound effect, for instance the 'two trumpets' musician wanted to sit beside a friend in the orchestra who played trombone. Turns out trombones don't sit next to trumpets. However in this case an exception was made and our trumpet–player was allowed to sit beside her trombone–playing friend who made her feel safe. Another simple and effective solution – like so many of the solutions we encountered.

In schools changes for the benefit of pupils with autism can have the knock–on effect of helping other pupils, for instance using clearer signposting in corridors and giving more explicit instructions in class suits not only the autistic pupils but other pupils too.

Sometimes a solution put in place for one autistic pupil goes on to benefit many more. We met one young woman with autism, Stephanie Smith, who when she was at school struggled at break times; she had trouble mixing and felt rejected by her peers. Fortunately Stephanie had a guidance teacher who understood she was not being difficult or non–compliant in not wanting to go outside for break. This guidance teacher set up a base where any child who needed it could go at lunch time. It was a safe place and for Stephanie, and for many more, it became a refuge. Stephanie has now left school but the base remains in place for those who need it.

* * *

Once these solutions are found how should they be shared? Team Leader, John Connell, said we must find a way for organisations to converse, listen, stay flexible and pass learning on. It was suggested by another practitioner that a local forum could be set up for the sharing of experience and expertise. Another suggestion from Angela Mulhern, of ASD Outreach, was the introduction of Autism Champions into the schools 'to lead on autism–friendly approaches and be an instant point of contact within their building all of the time', when ASD Outreach could not be there.

Good communication is vital for getting the support right. Parents are keen to share their expertise of their child with the services they encounter and to work hand–in–hand to find the best solutions. Having a sympathetic point of contact within a system is all–important – whether this is an ASD specialist, an understanding guidance teacher, a medical consultant or whoever – the opportunity to discuss problems face–to–face with someone who understands and is willing to listen makes all the difference. Then, when these flexible solutions are found, it is equally vital that they are shared, nursery to nursery, parent to parent.

If clear ways of working are in place it also helps prevent parents from feeling like ‘the difficult parent of a difficult child’– an easy, yet dreaded, role to slip into. People with autism are vulnerable, as are their parents and carers, because they are desperate to get the right support but frightened of wearing out the patience of those who provide it.

When a parent forms a relationship with a practitioner who understands and who is willing to listen to them, and to work with them in coming up with flexible, creative solutions, the job of parenting a child with autism becomes a less lonely one and it is, of course, even more important for the person with autism.

* * *

Over the past ten months it has been an honour to meet so many people with autism and their parents and carers, plus the people working in the field, and to have the chance to talk with them about their lives and work. I hope our research helps in the continuing search for smart solutions to the challenges facing autistic people; solutions that take imagination and maybe a certain amount of risk–taking to bring about, solutions that may not cost any more but take a more flexible approach – whether it’s as simple as giving one child two trumpets or allowing a trumpet player to sit beside a trombonist in the school orchestra. Solutions that come from listening to the people with autism and their parents and carers, solutions that take into account what the person with autism and their parents and carers need rather than what society thinks they need, as one parent put it we need to find not only ‘what is available, but what is best’.

3 The Strategy

In Midlothian we know that more and more children, young people, and adults are being diagnosed with Autism, a condition that can have a serious impact on their lives and the lives of the people who are close to them. This impact can affect people's health, their wellbeing, social life, and their ability to find and keep a job.

We estimate that there are 748 people in Midlothian with some form of autism. Midlothian Community Care Services know about 62 people with autism and Midlothian Children's Services know of 226 young people. Many adults with Asperger's Syndrome do not seek social care or health service support, but have a higher likelihood of remaining unemployed, and of mental health issues.

Through our work on the Autism Strategy we have heard about a great many experiences and it is these that inform the main themes of the strategy. They shape our priority areas of work to help us create flexible support and services which are fit for purpose.

- We want to increase **Individual Opportunity** through positive attitudes towards autism. One that accepts and celebrates difference.
- We will continue to build services that adapt to changing circumstances through providing appropriate and **Flexible Support** when this is needed.
- We recognise the importance of **Imaginative Communication** in creating appropriate individual opportunities, finding solutions, improving services and celebrating success.

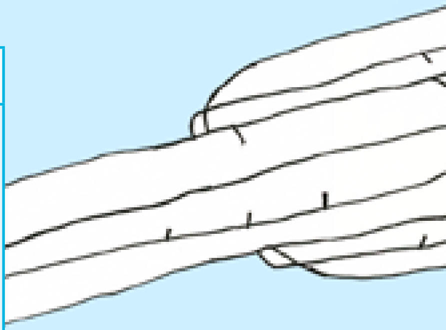
The next sections set out what we have heard and what commitments we make. We recognise it is important that we work together with people with autism, their families and those working in the field to make this happen. In the following chapter we set out more specifically how we will go about doing this.

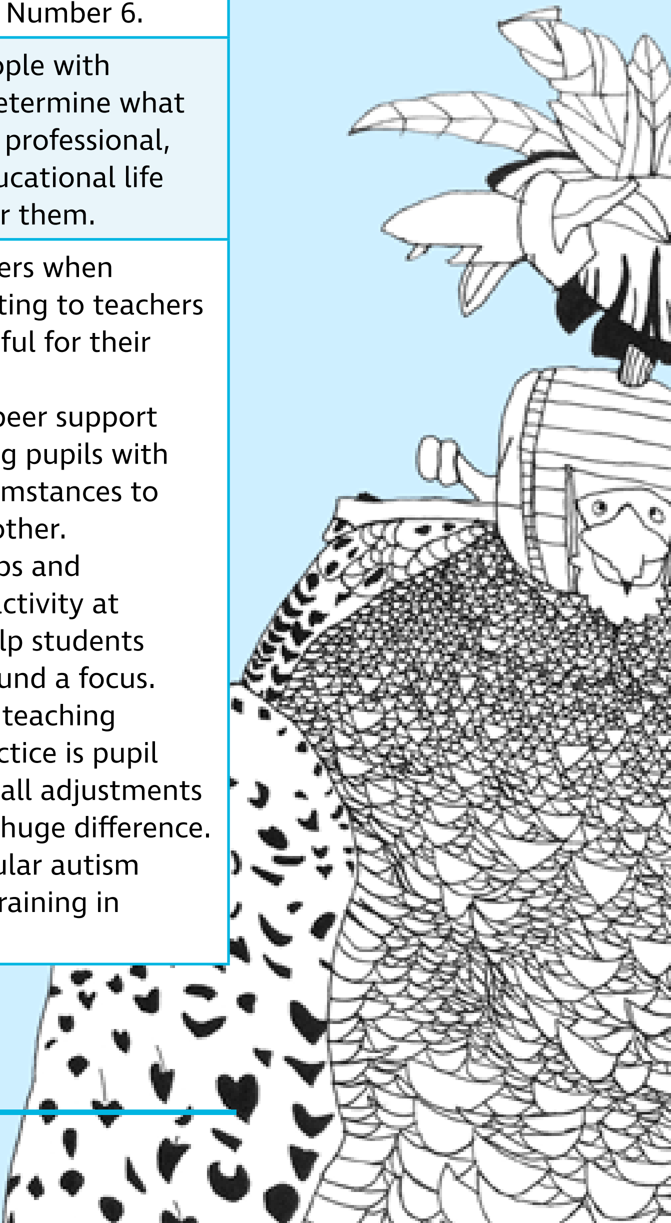
* * *

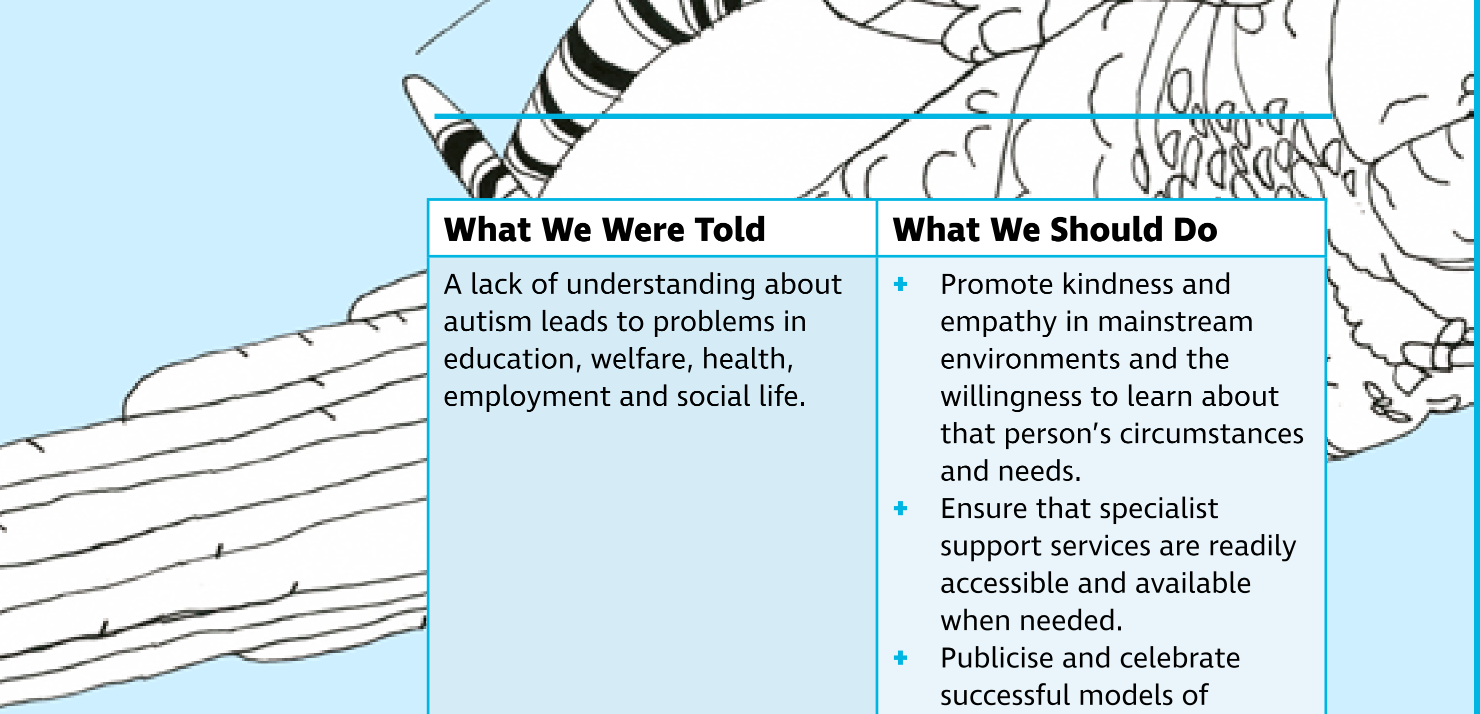
Image by Leanne Ross

3.1 Individual Opportunity

What We Were Told	What We Should Do
Many people felt there was a positive link between early diagnosis and getting the right support sooner.	+ Make sure that early Staged Support is available to all that need it. + At the point of diagnosis provide tailored information about services to support the whole family not just the child.
In late diagnosis some adults didn't feel they had enough emotional or practical support.	+ Expand the availability of a variety of supports, e.g. clinical supports such as psychology, CLDT and other support like Number 6.
Autism is not a condition but a way of thinking.	+ Support people with autism to determine what a successful professional, social or educational life looks like for them.
There is great value in peer support within schools as one way of accepting difference at an early stage.	+ Listen to peers when communicating to teachers what is helpful for their friend. + Encourage peer support – introducing pupils with similar circumstances to meet each other. + Support clubs and structured activity at playtime help students interact around a focus. + Ensure that teaching support practice is pupil centric – small adjustments can make a huge difference. + Provide regular autism awareness training in schools.







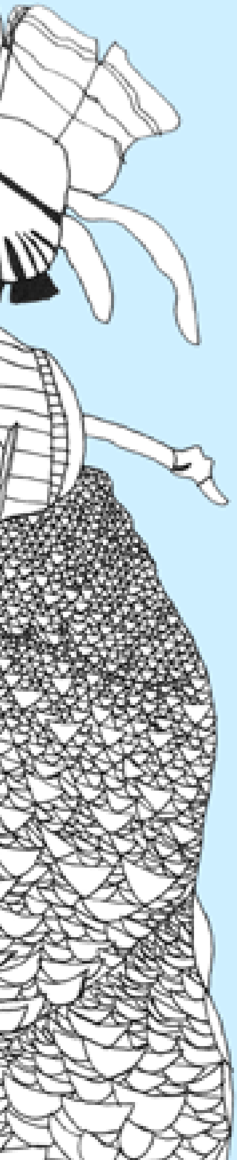
What We Were Told	What We Should Do
A lack of understanding about autism leads to problems in education, welfare, health, employment and social life.	+ Promote kindness and empathy in mainstream environments and the willingness to learn about that person's circumstances and needs. + Ensure that specialist support services are readily accessible and available when needed. + Publicise and celebrate successful models of practice (e.g. Staged Support). + Support different models of employment (i.e. flexible working, self–employment). + Provide appropriate support for advocacy, peer support, and family/carers. + Provide appropriate autism awareness information and training.

Our commitments:

1. **It will be easier for people to find out if they have Autism Spectrum Disorder.**
   We will make sure that people can get a diagnosis in good time and offer access to information, advice and a personalised approach to options for support for all those diagnosed. This includes setting a clear pathway for them.

2. **Increased opportunities for people with Autism Spectrum Disorder**
   We will develop a range of personalised services to support adults with autism to live independently, with a particular focus on supporting participation in meaningful activities including employment.

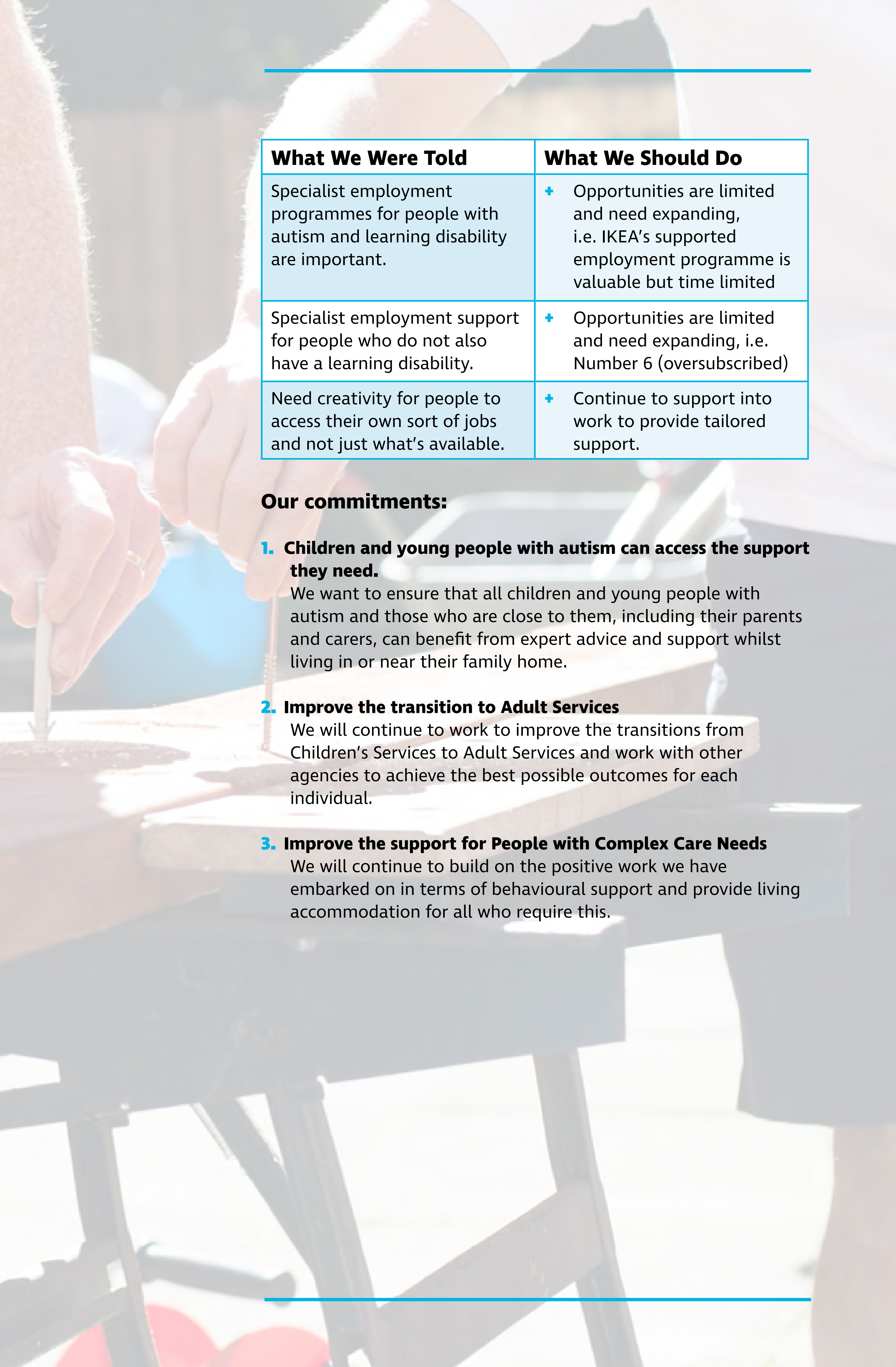
3. **The Views of Midlothian Families and Carers will inform future development**
   We will ensure that in our action planning and further consultations we have the full involvement of Midlothian families and carers, with a specific focus on improving local arrangements.



Images by Nicholas Trayner

3.2 Flexible Support

What We Were Told	What We Should Do
A listening culture is essential.	+ Support families and practitioners to combine strengths and work together to find effective solutions.
It's about how someone works with your family. We should not underestimate for example the emotional impact of how the diagnosis is given.	+ Ensure that working practices are supportive and personable.
Parents' knowledge is important and could be part of finding the solution.	+ Ensure that parents are involved in defining and finding solutions.
We all have a role in supporting wider society to accept and celebrate difference.	+ Support the Autism Alert Card. + Promote positive portrayal in local and national media. + Advocate individually and collectively for positive change.
Person centred adjustments to anxieties of environment, timetable or routines really help.	+ Support strategies that help practitioners with addressing the practicalities for each person.
The curriculum requires student to attend and pass assessments.	+ Support and seek out tailored solutions to specific barriers.
Further education and employment that responds to the circumstances and learning styles of the student.	+ Ensure that learning and employment opportunities are well supported and adapt to individual circumstances.
Support for parents in behavioural support and understanding post diagnosis.	+ Support services which provide this specialist input, i.e. CAMHS, ASD Service, Barnardos BIBS, Parent Peer support.



What We Were Told	What We Should Do
Specialist employment programmes for people with autism and learning disability are important.	+ Opportunities are limited and need expanding, i.e. IKEA's supported employment programme is valuable but time limited
Specialist employment support for people who do not also have a learning disability.	+ Opportunities are limited and need expanding, i.e. Number 6 (oversubscribed)
Need creativity for people to access their own sort of jobs and not just what's available.	+ Continue to support into work to provide tailored support.

Our commitments:

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

2. **Improve the transition to Adult Services**
   We will continue to work to improve the transitions from Children's Services to Adult Services and work with other agencies to achieve the best possible outcomes for each individual.

3. **Improve the support for People with Complex Care Needs**
   We will continue to build on the positive work we have embarked on in terms of behavioural support and provide living accommodation for all who require this.

3.3 Imaginative Communication

What We Were Told	What We Should Do
People find it hard to know what's out there.	+ Establish a comprehensive way in which practitioners, people and parents can find out and share what support is available in Midlothian.
People and families with lower level needs of support can often lose out if they don't know what's out there.	+ Make sure that people who don't necessarily use autism specific support can easily access information about what's out there.
There is a lack of consistency of contact with professionals this can become time consuming and 'like a maze' finding the right supports.	+ Understand better what the pressures are and how we can provide better consistency of support.

Our commitments:

1. **Information and Support will be easy to find.**
   We will produce easy to understand information about autism and autism services. This will include how to access services including health, education and social care services as well as making information about Local Authority, NHS and Third Sector services easier to understand. We will make sure that we make more use of Autism Alert Cards in Midlothian.

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

3. **There will be good joint planning of Autism Services in Midlothian**
   We will bring together a core group including representatives from Children's and Adult Services, Resource Managers, Psychology Services in schools, Lifelong Learning & Employability and Community Planning, and partners from NHS Lothian and Third Sector to further develop and implement the Strategy for Midlothian.

4 Ideas for Action

In addition to our commitments we want to make sure that the Strategy makes a practical difference. Our common goal is to make sure that the ideas and energy put in by all who contributed to the strategy translate into clear and imaginative actions.

On many occasions we have been told about really simple imaginative actions which make a big difference.

4.1 What Works Well

What We Were Told	What We Should Do
In primary, secondary and further education students and families appreciate a flexible approach to learning styles, learning environment and transitions for one level of learning to the next. Key aspects of success were seen as planning around the individual and planning ahead.	Setting alarms for each lesson. Swapping PE for Homework. Being flexible about timetable. Offering activity at playtime. Signposting. Quiet spaces/ Base support. Peer support to find next class. Help to explain schedule of the day. Asperger study skills tutor. Specific equipment. Flexible attendance for tutorials. Online learning.

What We Were Told	What We Should Do
Parents valued transitions which were planned from the perspective of 'what's needed'.	Person Centred Planning is used widely to help students plan and involve other agencies in transition from school to adult services. Informal autism 'champions' exist in most services – people who help people and families get to the right support because they have an understanding of what would be helpful, and a knowledge of the network. Could autism champions be more formalised a support across sectors?
Parents value peer support relevant to their circumstances.	VOCAL have a variety of initiatives including mentorship, forums, groups and training for carers. PASDA support parents of adult children.

In the current financial climate we know we need to work together and be smart in finding the right solutions. Over the last years the Scottish Government Autism Innovation Fund has supported new ways of working in Midlothian. These bring new ideas and perspectives on how opportunities and services might develop in the future.

What these initiatives have in common is that they:

- Took time to listen and understand the individual pressures.
- Brought together different experiences to find new solutions.
- Were imaginative and very practical in working out and testing the new approach.
- Checked back to see that the new approach was working further down the line.

4.2 Core Strategy Group

What has been learned to date will inform how the suggestions, commitments and issues identified through the strategy development will be taken forward. We want to make sure that this is done with the same imaginative approach to the issues and possible solutions that we came across in developing this strategy. This work will be managed by the Core Strategy Group, how we meet bi–monthly.

The Core Strategy Group will be asked to ensure:

- The effective promotion of the strategy and the principles that underpin it.
- That the commitments outlined in section 3 are progressing.
- That the ideas, suggestions and issues identified throughout the strategy development process are built upon.
- Respond to any service pressures or gaps that are identified by people with autism, families or services.

4.3 The Bigger Picture

We recognise that that there are other issues and possibilities that are not fully addressed in this strategy. It will be the responsibility of the Core strategy Group to make sure that issues which directly affect people with autism and their families are explored within the wider responsibilities and concerns of Midlothian Council and its partners. These are:

- Getting It Right For Every Midlothian Child Action Plan
- Improving Opportunities for People in Midlothian Action Plan

- Midlothian Local Housing Strategy
- Midlothian Health Inequalities Plan
- Midlothian Adult Learning Action Plan
- Midlothian Equalities Plan
- Midlothian Mental Health Plan
- Midlothian learning Disabilities & Complex Needs Strategy

4.4 Expert Panels

To make sure action is taken on the ideas, suggestions and issues, the Core Strategy Group will create short life Expert Panels (led by a member of the Core Strategy Group) to create specific solutions which will be shared on the Strategy Blog and highlighted at the annual Strategy Review event.

In the development of the strategy a range of gaps and pressure points came up which the Strategy Group will invite the Expert Panels to help address. These are:

- Easy and better access information and improved communication
- A better range of social opportunities for people with autism
- Increased employment Opportunities for People with Autism
- The need for increased autism awareness and skills training for staff

For every issue identified the strategy group will develop a key question for the Expert Panels to explore and address.

Highlighted Issue	Suggested Response
Lack of autism friendly children's sports clubs as current provision is oversubscribed.	Increase capacity of Beeslack All Stars and Loanhead Dolphins.
Care management is over subscribed	Investigate feasibility of establishing these.
There is a lack of teenage Aspergers specific social groups.	Investigate feasibility of establishing these.
There is a lack of adult autism specific social groups	Investigate increased response from LAC, Connecting Midlothian, Number 6.
There is a lack of respite opportunities.	Investigate feasibility of expanding of overnight and emergency respite services.
It is difficult for parents to find staff to employ through Self-Directed Support.	Establish a Midlothian 'bank' of support staff interested in work
There is pressure on welfare advocacy and advice services.	Increase capacity of services.
Support providers who can work around the pressures of high turnover in the care sector.	Good support/ prof development for care staff Decent working conditions mean staff retention is higher.
A support service for adults who would like a relationship.	Explore the potential for developing this type of support.
Activities for over the summer – children and adults	Increase the capacity of existing provision or individual respite option.
Are we planning for increasing demand of older people with autism?	Explore the issue further.
Pressure on the Health Visitor Service as more people move out from the City Centre.	Increase capacity and/or collaborative working to meet demand.
Most parents felt that generic clinical therapies for anxiety, depression and eating disorders needed an autism specific perspective.	One parent worked with Royal Ed clinical psychiatry to adapt CBT/ FBT specifically for her daughter.

4.4 Sharing Ideas

Sharing experiences and ideas are important in how this strategy develops; the Core Strategy Group and Expert Panels will regularly share and publish what they are working on and what they have found out. This information will be available on a dedicated Strategy Blog.

We recognise that ultimately there is nothing more important that talking with each other and every year a member of the Core Strategy Group will take responsibility for organising the Strategy Review Event. This will be an opportunity to share experiences, look at what is really working for people and understand where the new or continued pressure points are.

The Core Strategy Group are:
- MLC Health Social Care
- MLC Complex Care Provision
- 2 Parent Representatives
- VOCAL
- PASDA
- Local Area Coordination
- Midlothian Practitioner Group
- MLC Community Planning & Performance Manager
- Artlink

Notes

Midlothian