

**East Riding of Yorkshire Strategy
for
Children, Young People and Adults with
Autism**

2012 - 2015



EAST RIDING
OF YORKSHIRE COUNCIL



integrated
children
and young
people's
services

NHS

East Riding of Yorkshire

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FOREWORD

People with autism can present a unique challenge to their families, carers, statutory and voluntary services.

The Government's vision for transforming the lives of those people with autism is:

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents' (Fulfilling and rewarding lives – Department of Health (DH) (2010).

'The East Riding vision of this strategy is that children with autism are identified early and support is provided, throughout their lives, to them and their family to ensure that they achieve their potential and become happy, valued members of their community.'

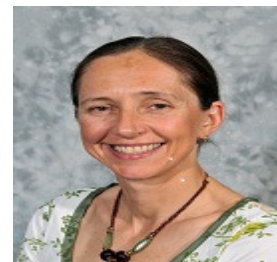
All partner agencies who have contributed to this East Riding strategy endorse both the Government's and our local vision for children and will strive to ensure that this is translated into practice.

The key objective of the strategy and recommendations is to build on current good practice and to develop more effective mechanisms for services to work together. This includes a commitment, through the creation of an action plan, for partner agencies to be responsive to new developments and commission high quality services.

In developing the strategy, consultation took place with parents, carers, schools, services in health and within the local authority which has been taken into consideration.



Nigel Pearson
Chief Executive
East Riding of Yorkshire Council



Gina Palumbo
East Riding of Yorkshire
Clinical Commissioning Group Chair

EXECUTIVE SUMMARY

The East Riding of Yorkshire Strategy for Children, Young People and Adults with Autism was developed by a multi agency group and it outlines the vision to transform services for people with autism in the East Riding. The action plan, which goes alongside the strategy, highlights recommendations, some of which will have resource implications and require scrutiny by the appropriate working groups.

Initially the strategy was developed for children and young people with autism. However, it was agreed, following consultation, that it would be good practice to develop a strategy which encompassed the 'whole' life of a person with autism.

The strategy is targeted at all those involved in the planning, commissioning and delivery of services for people with autism, their families and carers. The intention is for agencies to work more closely together in the development of collaborative services and to understand, and respond to, the needs of those with autism. This means working in partnership to ensure that protocols which include assessment, diagnosis, joint working arrangements and decision making give clarity about how services can be accessed.

Definition of Autism

For the purpose of this strategy the term "autism" will be used throughout, however it is recognised that there are a number of terms that different groups and individuals prefer to use. Similarly the term 'people' refers to children, young people and adults.

The 'Fulfilling and rewarding lives' (DH - 2010) strategy describes autism as:

'A lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them. The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments'. They are difficulties with social communication, social interaction and social imagination.'

Autism is a "spectrum disorder," meaning you can be a little autistic or very autistic. It is the most common condition in a group of developmental disorders and the term 'autism spectrum' covers a wide set of differences and disabilities in addition to autism can include the following:

- Asperger syndrome
- Childhood disintegrative disorder
- Pervasive developmental disorder

Some people with autism may also have learning difficulties and/or disabilities. They are likely to face challenges following the curriculum at school, with the social aspects that every day life presents and finding sustainable employment. Some people with autism may also exhibit a range of challenging behaviours. Although there is no cure for autism, there are educational and behavioural approaches that can help a person achieve his or her potential.

“The vision of the strategy is absolutely spot on. As a parent, all I want for my son is for him to achieve his full potential and have a happy life”-
Consultation respondent

NATIONAL KEY DRIVERS

- Our Health, Our Care, Our Say: DH (2006)
- Better Services for People with an Autistic Spectrum Disorder: DH (2006)
- Aiming High for Disabled Children: better support for families: HM Treasury and DfES (2007)
- Policy into Practice: APPGA (2007)
- Putting People First: DH (2007)
- Independent Living Strategy (2008)
- Carers Strategy – Carers at the heart of the 21st Century: DH (2008)
- Autism Bill: DH (2009)
- Valuing People Now: DH (2009)
- Supporting people with autism through adulthood: National Audit Office (2009)
- A Better Future – A consultation on a future strategy for adults with autistic spectrum conditions: DH (2009)
- Response to the consultation: Overarching report of findings from the Adult Autism Strategy: DH (2010)
- Fulfilling and Rewarding Lives: DH (2010)
- Implementing Fulfilling and Rewarding Lives: DH (2011)
- Getting in on the Act – Scrutinising services for adults with autism: Centre for Public Scrutiny (CfPS) (2011)

LOCAL KEY DRIVERS

- Workforce Placement Strategy – East Riding of Yorkshire Council (2007)
- Children and Adolescent Mental Health Strategy – (2008)
- Children and Young Peoples Strategic Plan – East Riding of Yorkshire Council(2009)
- Learning Disability Development Plan – East Riding of Yorkshire Council (2009)
- Carers Strategy – East Riding of Yorkshire Council (2010)
- Health and Wellbeing Strategy: East Riding of Yorkshire Council – NHS East Riding of Yorkshire (2012)

LOCAL CONTEXT

Nationally, the incidence of autism varies from 60 to 100 per 10,000 school age population depending on the definition used, with an 11% increase in the period 2003 to 2006. The incidence within the Yorkshire and Humberside region has risen from 39 per 10,000 to 57 per 10,000 in the same period.

The National School Census in January 2010 gave the following numbers of children with autism for the East Riding of Yorkshire;

		LA Nursery	Primary	Secondary	Special	Total
Foundatio n	Years NI, N2& R	2	7	0	2	11
KS1	Years 1& 2	0	20	0	6	26
KS2	Years 3, 4, 5& 6	0	65	0	16	81
KS3	Years 7, 8& 9	0	0	63	20	83
KS4	Years 10& 11	0	0	44	12	56
KS5	Year 12&13	0	0	9	0	9
Total		2	92	116	56	266
	Out County schools			2 (unit)	27	29
TOTAL		2	92	118	83	295

These figures are likely to be an underestimate as schools are only required to return data on children who have a statement of special educational need or do not have a statement, but have recognised difficulties at the level of School Action/Action plus, which relate to autism.

Also, this data does not include children in independent early years settings or children with additional disorders (e.g. co-morbid ADHD and autism) or secondary age pupils for whom there is no access to an appropriately constituted panel to give a diagnosis. There are also 71 children on the waiting list for the Social Communication Disorder Panel (December 2011).

In April 2011 there were 29 children with autism educated out of the East Riding as follows:

- 17 - special schools or units maintained by neighbouring authorities,
- 3 - neighbouring authorities' mainstream schools
- 9 - independent schools.

Based on the figures above the total number of children with autism in the East Riding is 295 and with a school age population of approximately 48,000, this gives an incidence of approximately 61 per 10,000.

It is estimated that 50% of children with Asperger's Syndrome reach adulthood without ever being assessed, diagnosed or treated. Indeed, we are faced with two populations, distinct in their experience of services: those who are diagnosed as children and are now coming to transition and facing life as an adult with limited service provision, and those who managed to negotiate childhood, and sometimes did very well academically, but present as adults with difficulties arising from Asperger's Syndrome.

There have been few epidemiological studies with no prevalence studies carried on adults. A best estimate of Asperger's Syndrome in UK is about 36 per 10,000, or 18 or so in a GP practice with a list size of 5000. In the East Riding an estimated number of people with Asperger's Syndrome is over 1000, with approximately 14 people per year presenting Asperger's Syndrome and requiring

diagnosis. The number of adults with a potential Asperger's Syndrome diagnosis who are undiagnosed as yet is likely to be high.

I.0 Increasing awareness and understanding of autism

Outcome People with autism shall experience equality of access to mainstream services e.g. education, housing, health, employment etc and opportunities free from bullying and harassment in day-to-day living irrespective of gender, faith, race and sexual orientation.

What people have told us:

Training is really important
Professionals with a good understanding of autism; Health Visiting teams, GPs and Midwives all have a critical role to play in early identification.
An environment that accepts people on the Autism Spectrum
Raise awareness amongst professionals and general public

What do we need to do?	How will we do this?
Improve autism awareness training for all frontline public service staff, in line with the needs of their job.	<ul style="list-style-type: none"> • Training will include involvement from people with autism, their families and carers either in person or by contributing to training materials. • Autism awareness is included within training programmes across education, health and social care e.g. Induction training.
Raise awareness on the needs of those with autism.	<ul style="list-style-type: none"> • Training made available to a range of organisations e.g. retailers, transport services, criminal justice system, potential employers, Job Centre Plus.
Appoint an autism lead to develop and promote good practice to ensure a consistent approach from children to adult services.	<ul style="list-style-type: none"> • Joint working between agencies.
Identify accommodation which meets the needs of those with autism.	<ul style="list-style-type: none"> • Develop a range of housing and flexible support options.

What will success look like?

- Staff will have a greater understanding of the potential behaviours of people with autism and the confidence and skills to be able to respond appropriately.
- Appropriate and reasonable adjustments made to services will accommodate people with autism.
- More people, with autism, living independently with flexible support which meets their needs.

“My son doesn’t cope well with change – he needs people who are well trained and understand him to support him and they are few and far between”. -

Consultation Respondent

2.0 Developing a clear, consistent pathway for diagnosis of autism

Outcome: High quality support and information to be provided, in partnership with people with autism and their families before, during and following diagnosis.

What people have told us:

	<i>Only those that are confident and shout get something done. What about those that can't?</i>
	<i>Someone to answer questions when diagnosis is given</i>
	<i>Route to diagnosis unclear</i>
	<i>Improvements in diagnostic service need to be improved – must be available quickly and easily and include children aged over 11 years of age. Improved assessment for secondary school age children.</i>
	<i>Clearer routes to a diagnosis for children, young people and adults</i>
	<i>Need to establish a strong multi disciplinary team who work together and retain workers who have an interest in ASD.</i>

What do we need to do?	How will we do this?
Have clear routes for referral, assessment and diagnosis for children, young people and adults.	<ul style="list-style-type: none"> • Through the identification of an autism lead and specialist team of multi disciplinary workers. • By the establishment of a clear care pathway to include diagnosis, assessment and appropriate support. • Implementation of joint working protocols.
Maximise the potential of people with autism enabling them to lead independent lives.	<ul style="list-style-type: none"> • Early intervention and diagnosis. • Planned provision for early years settings and schools. • Ensure there is a range of services and provision to meet needs.
Ensure appropriate information and signposting is in place.	<ul style="list-style-type: none"> • Establish a pathway which supports people with autism, their families and carers.

What will success look like?

- Professionals, children, young people, adults, their families and carers have a clear understanding of how to access services.
- People with autism, their families and carers are supported and signposted following diagnosis which helps them make informed choices.
- People with autism have a better understanding why they behave, react and respond to situations and are supported to develop coping mechanisms.
- Individuals with autism reach their potential and lead an independent life.
- Better communication between organisations.

3.0 Improving access to services and support for people with autism and their families and carers.

Outcome People with autism receive appropriate assessment and support, which takes a holistic view, values the person, their abilities and seeks to expand on strengths while overcoming weaknesses, helping them to fulfil their potential and be able to make a positive contribution at home, school, work and the community.

What people have told us:

	<i>Access to sitters and short break services</i>
	<i>Coordinated services</i>
	<i>Clear goals for the child and coordinated programmes for the child's development in communication, social interaction, play, leisure and life skills.</i>
	<i>Lots about education but what about the other parts of life such as social, every day events going to park, swimming.</i>
	<i>Practical help for parents when needed.</i>
	<i>Access to advocacy services</i>
	<i>Behaviour difficulties need help now not in a year's time.</i>
	<i>Why mental health disabilities are still such a big taboo? If my son was in a wheelchair we would have people going out of their way to help.</i>

What do we need to do?	How will we do this?
Support families, friends and carers of those people with autism.	<ul style="list-style-type: none"> • By making best use of their expert knowledge of the person.
Develop short breaks to support families and carers.	<ul style="list-style-type: none"> • Develop a range of respite and short break opportunities. • Look at ways in which to offer practical support when needed. • Encourage and support people with autism to participate in the community.
Ensure that people with autism can access the services they need.	<ul style="list-style-type: none"> • By making adjustments to existing services within resources to enhance accessibility e.g. social and leisure activities. • Explore how to support voluntary and third sector groups in the planning and delivery of services locally. • Access to advocacy and personal budgets. • Explore funding opportunities and align current funding streams.

What will success look like?

- More choice and control over the care and support accessed for people with autism and their families and carers.
- Innovation in terms of funding streams and service delivery.
- Improved independence and participation for people with autism, their families and carers
- People with autism are able to make a positive contribution.
- Participation in regular activities which will reduce social isolation for people with autism.

“When things go wrong for us, they go very badly wrong so it’s important we have the right support even when it looks like things are ok.”-

Consultation respondent

“Sometimes the barriers for families to achieve inclusion for their disabled children can be overwhelming. Mainstream services do need to take more responsibility to make their services accessible but at the same time they need support and training to achieve this. Many families are apprehensive because their children either need additional supervision or have real difficulties with making and maintaining social friendships with their peers. Some children can exhibit aggressive behaviour or be very passive or vulnerable to bullying. Families need to feel reassured that mainstream services are adequately equipped to successfully meet the needs of their children. Parents of disabled children often have to stay with their child in order for them to participate in leisure activities. This can be difficult if not impossible if they have other young children or there is more than one child with a disability within the family”-

Consultation respondent

4.0 Helping people with autism into education and work

Outcome People with autism can access universal, targeted or specialist services as appropriate, to help them meet their educational and employment potential as their needs change over time.

What people have told us:

	<i>School staff to understand the Autism Spectrum and the child's needs in curriculum access and a modified environment</i>
	<i>The Bridlington Support Group has approached the Local Authority and the local secondary school about establishing unit provision for pupils on the autism spectrum.</i>
	<i>Why can't our children get the specialist help that they need rather than struggling in main stream or a special school that is not equipped for their needs. Why can't we have a specialist school?</i>
	<i>Need more specialist provision to engage older children otherwise disengaged from education.</i>
	<i>I think there should be another MLD school in the East Riding as I am aware of the large number of parents desperate for their child to go to Riverside school. We are very lucky our child goes there but he has to travel over an hour each way.</i>
	<i>No appropriate provision post 16 (only Ganton).</i>
	<i>Planning for transition to adulthood</i>

What do we need to do?	How will we do this?
Ensure young people and adults with autism benefit from wider training, higher education and employment initiatives.	<ul style="list-style-type: none"> Plan and assess the needs of individuals ensuring access to appropriate support services including 'buddying' or mentor schemes.
Develop new approaches that will better support people with autism into education and training.	<ul style="list-style-type: none"> Encourage learning organisations to develop courses and support mechanisms which are tailored to meet the needs of those with autism. Strengthen links between children and adult services. Better approach and earlier planning for transitions to adulthood for young people. Identify funding opportunities to support the transition to adulthood.
Support people with autism into employment.	<ul style="list-style-type: none"> Engage with employers to promote the potential benefits of employing a person with autism. Ensure employers are better informed and trained on the needs of people with autism. Offer continuing support to both the employer and employee to sustain the placement.

What will success look like?

- Well planned and seamless approach to adulthood for young people with autism.
- Improved self esteem and confidence of those people with autism.
- Better informed employers to overcome barriers, increase employment access and sustainability.
- People with autism will be equipped with the skills required to be as independent as possible and lead a fulfilling life.

*“As a parent of two boys with Autism I have been seeking service improvements for 17 years and here I am with a 17 yr-old looking to an empty future with no relevant provision to meet his needs & a 14 yr-old in a very difficult situation too. My daughter who has no additional needs had no problems at all accessing her future goals & attainments so why do my boys face such difficulties”- **Consultation respondent***

*“Personal budgets are great, but I need to have services I can buy that have the specialist know how to deal with my son’s autism, the money is no use otherwise”- **Consultation respondent***

*“Our son still struggles with mainstream and would benefit with specialist provision and support. Since his diagnosis in 2005 we have felt compelled to provide these ourselves via home programme of ABA. Access where appropriate socialisation to mainstream would be ideal so child could have neuro-typical role models-this unit provision would be ideal. More speech and language and sensory integration therapy which is important for holistic.”- **Consultation respondent***

5.0 Enabling local partners to develop relevant services for people with autism

Outcome Appropriate support and services are developed through the engagement and participation of people with autism, their families and carers giving them confidence in local provision to meet their needs.

What people have told us:

	<i>Plans in place to meet increases in demand</i>
	<i>Need to be able to lead a normal life not one that leaves you feeling anxious and defensive all the time.</i>
	<i>Family involvement and high quality information</i>
	<i>Families to be listened to</i>

What do we need to do?	How will we do this?
Establish the number of people with autism.	<ul style="list-style-type: none"> • Improve health and social care data collection through the local area Joint Strategic Needs Assessment. • Obtain information from education and children services to estimate prevalence to inform transitions to adulthood. • Strengthen lines of communication between statutory and voluntary sector partners.
Meaningful involvement of people with autism, families, carers and professionals, in service development.	<ul style="list-style-type: none"> • Develop multi-agency forums that bring together commissioners and the autism community to identify local priorities. • Implement a system for people with autism, families and carers which enable them to give feedback about their experience of services.

What would success look like?

- Effective multi-agency working between partners with clearly identified roles and responsibilities.
- Robust information to better inform commissioners of services.
- Strategic approach to developing and realising better outcomes for people with autism.
- Improved and effective transitions to adulthood for young people with autism.
- People with autism, families and carers feel valued and listened to.

EQUALITIES

An equalities impact assessment has been completed on this strategy to ensure that services are equally accessible to all, regardless of colour, culture or ethnic origin, nationality, religion or belief, gender, age, sexuality, geographical location or any other status.

IMPLEMENTATION

There will be two work streams one for adults and one for Children and Young People. Adults will report to the Clinical Commissioning Group (CCG), Learning Disability and Mental Health Partnership Boards as appropriate, with Children and Young People reporting to Children and Young People Emotional Well Being Strategy Group and up to Children's Trust Executive Board.

MONITORING AND REVIEW

- The Autism Strategy Group(s) will submit reports as requested to Senior Management Teams, the Health, Care and Well-being Action Group and Children's Trust Executive Board
- The Autism Strategy Action Plan(s) will be reviewed and updated, as required.