





'Think Autism' in County Durham Autism Strategy for Children, Young People and Adults 2018/19 – 2020/21



Purpose

This is our local strategy for children, young people and adults on the autism spectrum in County Durham, with the aim of providing focus and clarity on the priorities for improving services and opportunities for these people. In line with national initiatives we have called our strategy: 'Think Autism in County Durham'

The document considers what life is currently like for people on the autism spectrum in County Durham, based on feedback from people and analysis of their needs. It sets out where we want to be in three years and what actions we will undertake to achieve this. For the public it provides a summary of the importance of services and support for people on the autism spectrum and what they can expect from local services.

This strategy has been prepared jointly by all public services and voluntary and community services including the Council and local health services, who work together to improve outcomes for people on the autism spectrum.

For those responsible for delivering services, any future work programmes should contribute to achieving the aims set out in this strategy. It can therefore be used as an aid in deciding what to do and of equal importance, what not to do. Members, officers and partners will find this document of practical use in evaluating whether to participate in new national initiatives and funding bids and help select the work programmes that we need to do. The strategy is therefore a living document that is designed to be used regularly.

Introduction

Autism is a spectrum condition that affects the way a person communicates and relates to others and makes sense of the world around them. Research shows that there is no single way of describing autism or autism spectrum disorder (ASD) that is universally accepted. Some people prefer the term people on the autism spectrum or people with autism. The term used in in this document is 'people on the autism spectrum' as it acknowledges that each person on the autism spectrum is unique.

People on the autism spectrum may experience hypersensitivity or lack of sensitivity to sound, touch, taste, smell, lights or colours. The person may experience differences with social communication, social interaction and thinking. Approximately 1% of the population have autism and it effects individuals differently. Data from Public Health confirms that within the population of County Durham there is an approximate 1.1% prevalence rate of residents on the autism spectrum.

Life with autism can be confusing and frightening and some people feel isolated. Autism is **not** a learning disability, nor a mental health problem, and many people on the autism spectrum can function well in many aspects of their life. However, mental health problems can be more common among people on the autism spectrum and one in three adults with a learning disability are also thought to have autism.

The adult strategy arose from the Autism Act 2009, which required the Government to produce a strategy for adults and young people from age 14 on the autism spectrum and guidance for local councils and health bodies to help implement the strategy. The Adult Autism Strategy – entitled Fulfilling and rewarding lives was published in March 2010. An updated strategy -

Think Autism – was published in April 2014. Its aim is to make sure that adults on the autism spectrum get the help they need.

The needs of children on the autism spectrum are met through more general legislative frameworks including the Children and Families Act (2014). There is no statutory requirement for a separate Autism Strategy for children and young people; however the need to complete a Strategic Review of Autism featured as part of SEND Action Plan for County Durham.

Consequently, a life span integrated Autism and Social Communication Strategy for County Durham has been developed.

This Autism Strategy first arose out of the adults' autism strategy which included a section on transitions, recognising the need to plan well for young people making the transition to adulthood/adult services. This strategy has now been revised to incorporate planning for both children and adults on the autism spectrum, albeit recognising that there may be separate workstreams and planning mechanisms for children and adults. This strategy pulls together all of the priorities and actions across the full age range, attempting to take a life-course approach to autism and helping to improve the lives of people on the autism spectrum whatever their age.

National Policy

There is a great deal of national legislative and policy impacting on services for people on the autism spectrum. Key policy areas are:

- The Care Act 2014 covers the needs of people eligible for social care needs and also
 the duties of preventative approaches such as early support; advance planning; helping
 people to maintain independence and wellbeing and avoid a crisis. The Care Act also
 requires statutory agencies to work together in partnership with individuals and families
 within assessment and care planning processes, including help with accommodation
 and employment/meaningful activity, supporting families and accessing necessary
 health and social care services.
- The Children and Families Act 2014 addresses the needs of children and young people up to the age of 25, including those with Special Educational Needs or Disabilities (SEND). Reforms include a single coordinated birth to 25 Educational, Health and Care (EHC) Plan for these children and young people whilst in education; improving cooperation and collaboration between all the services that support individual and families, particularly local authorities, education providers and health services; and the introduction of the 'Local Offer' including centralised information, advice and guidance.
- The National Autistic Society (NAS) has produced **Autism Strategy Good Practice Guides (2016)** for local authorities and NHS bodies on the following topics
 - Ensuring preventative support
 - Diagnosis and the care pathway
 - Planning and leadership
 - Training
 - Transition
 - Employment

- People with complex needs or whose behaviour may challenge
- Criminal justice
- Future in Mind: Promoting, Protecting and Improving our Children and Young People's Mental Health and Wellbeing 2015.
- Equality Act 2010
- All Party Parliamentary Group on Autism (APPGA) Transition to Adulthood 2009 recommends
 - Effective and timely planning
 - Realistic yet stretching expectations
 - Effective joint working across services
 - Understanding of autism amongst professionals
 - Accessible information for young people and their families
 - Appropriate funding
- APPGA The Right Start 2012 recommends
 - Every school has a lead teacher for autism
 - All children and young people with autism and special educational needs (SEN)
 have an action plan (including those without Statements or the proposed
 Education, Health and Care Plans)
 - There is meaningful support for all young people with autism and SEN up to 25 years, including those not in further education.
- The Autism Act 2009 and associated 'Think Autism' strategy imposes statutory duties on Local Areas for those with autism over 14 years of age. However, the principles of the strategy are relevant to all children and young people with autism or related presentation. These are
 - Having the right support at the right time during a lifetime
 - To be accepted within the local community
 - People and organisations in the community to have opportunities to raise their awareness and acceptance of autism
 - The child/young person's views and aspirations are taken into account when decisions are made
 - To be able to connect with other people, including local autism peer groups, family groups and low level support
 - That everyday services know how to make reasonable adjustments
 - To be safe in the community and free from the risk of discrimination,
 - Autism to be included in local strategic needs assessment
 - Families are able to get help and support when they need it
 - To be supported through big life changes such as transition from school
 - The criminal justice system to think about autism and to know how to work well with other services
 - For those with autism to have the same opportunities as everyone else and to be as independent as possible
- Department for Education (DfE) *Preparing for Adulthood Programme* recommends that:
 - Preparing for adulthood starts from the earliest years
 - Services that have a statutory responsibility should focus on how they can support people to progress towards Preparing for Adulthood (PfA) outcomes

- Mainstream agencies should be more inclusive and engaged
- Young people and their families should be involved in strategic planning and service design and would support commissioners in design and development of future services
- The Local Offer should provide children, young people and their families with up to date and clear information on what is available locally through the Local Offer. The Local Offer will also have a feedback and review mechanism for commissioners to capture information on where the gaps are for families
- Young people and families should be involved in the ongoing development and review of the Local Offer
- The government and other leading organisations across the health and care system are committed through *Transforming Care for People with Learning Disabilities – Next Steps (2015)* to transforming care for people with learning disabilities and/or autism who have a mental illness or whose behaviour challenges services.

Our Vision

Our vision is that in County Durham children, young people and adults on the autism spectrum will live fulfilling and rewarding lives within a society that accepts and understands them. They can 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.

We want to help people with autism living in County Durham:

- Be an equal part of their local community
- **Get** the right support at the right time throughout their lifetime
- **Develop** their skills and independence and work to the best of their ability
- Have good mental and physical health

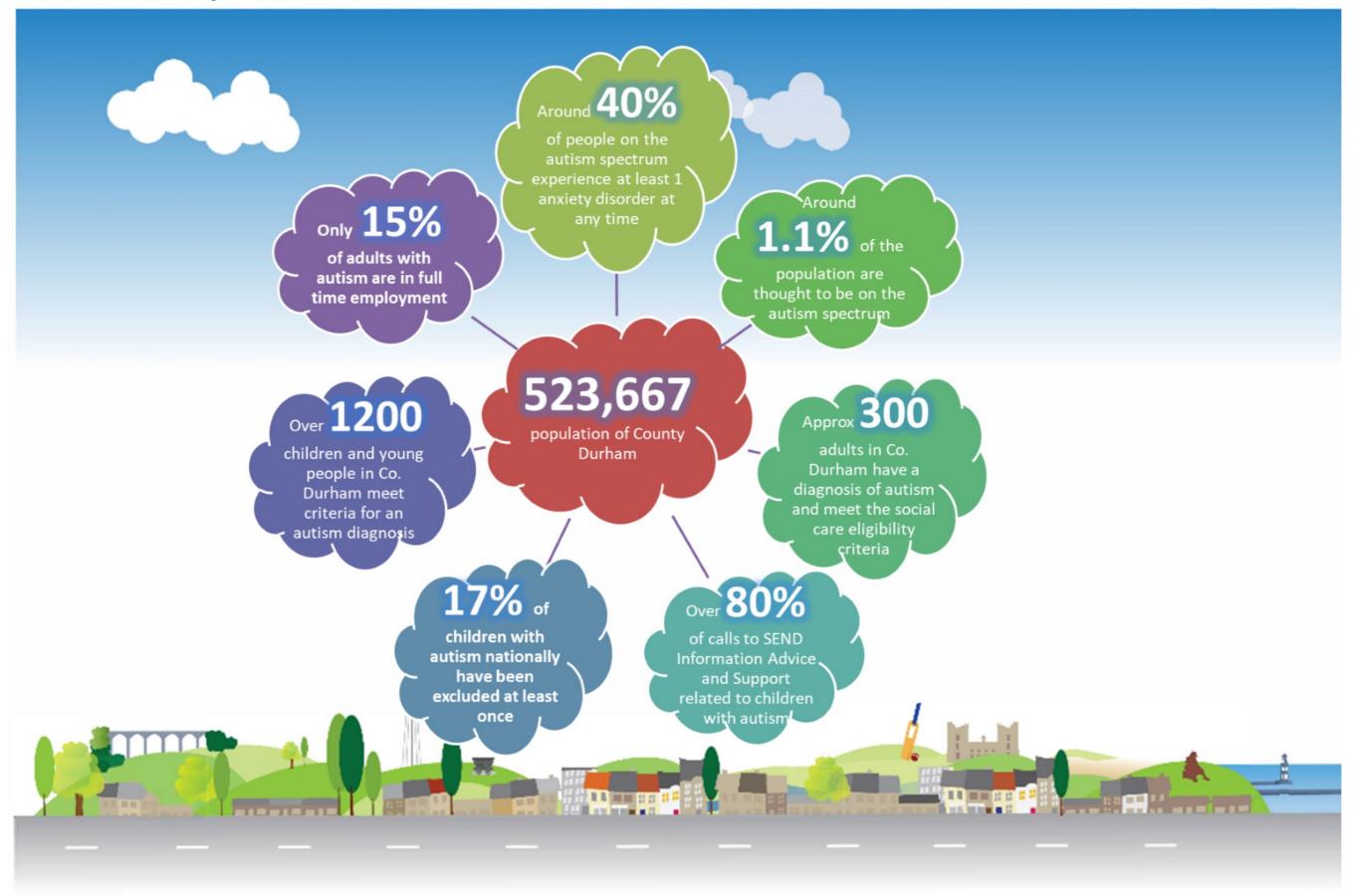
Aims

To achieve this vision, we have developed six aims based on the priority challenges of the 'Think Autism' and 'Preparation for Adulthood' agendas. These are:

- 1. The needs of people on the autism spectrum are known and understood
- 2. The workforce understands and meets the needs of people on the autism spectrum
- 3. People on the autism spectrum have good physical and mental health
- 4. People on the autism spectrum and their families receive the right amount of support at the right time
- 5. People on the autism spectrum participate equally within their community
- 6. People on the autism spectrum access aspirational employment, volunteering or learning opportunities

Where we are now

Autism in County Durham



Vision: Children, young people and adults on the autism spectrum are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can 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.

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Objectives

- 1.1 There is a system to co-ordinate data across public bodies to aid planning
- 2.1 All staff working with people on the autism spectrum have the right knowledge and skills
- 3.1 Frontline staff in education, health and social care understand and respond to the signs of autism
- 4.1 The support offer available is clear and appropriate to need
- 5.1 There are reasonable adjustments enabling access to public services for people on the autism spectrum
- 6.1 Children and young people with autism access high quality inclusive education and training

- 1.2 The needs of those with and without a diagnosis are understood and planned for
- 2.2 Staff who need more specialist training access it
- 3.2 There is timely and appropriate access to diagnostic pathways for those who need it
- 4.2 All support promotes well-being and independence
- 5.2 People on the autism spectrum are able to participate fully in their local community
- 6.2 Transitions through education and into training are appropriately supported

1.3 People on the autism spectrum and their families contribute to planning

3.3 There is timely and appropriate access to mental health support if needed

3.4 There is broad

awareness of social,

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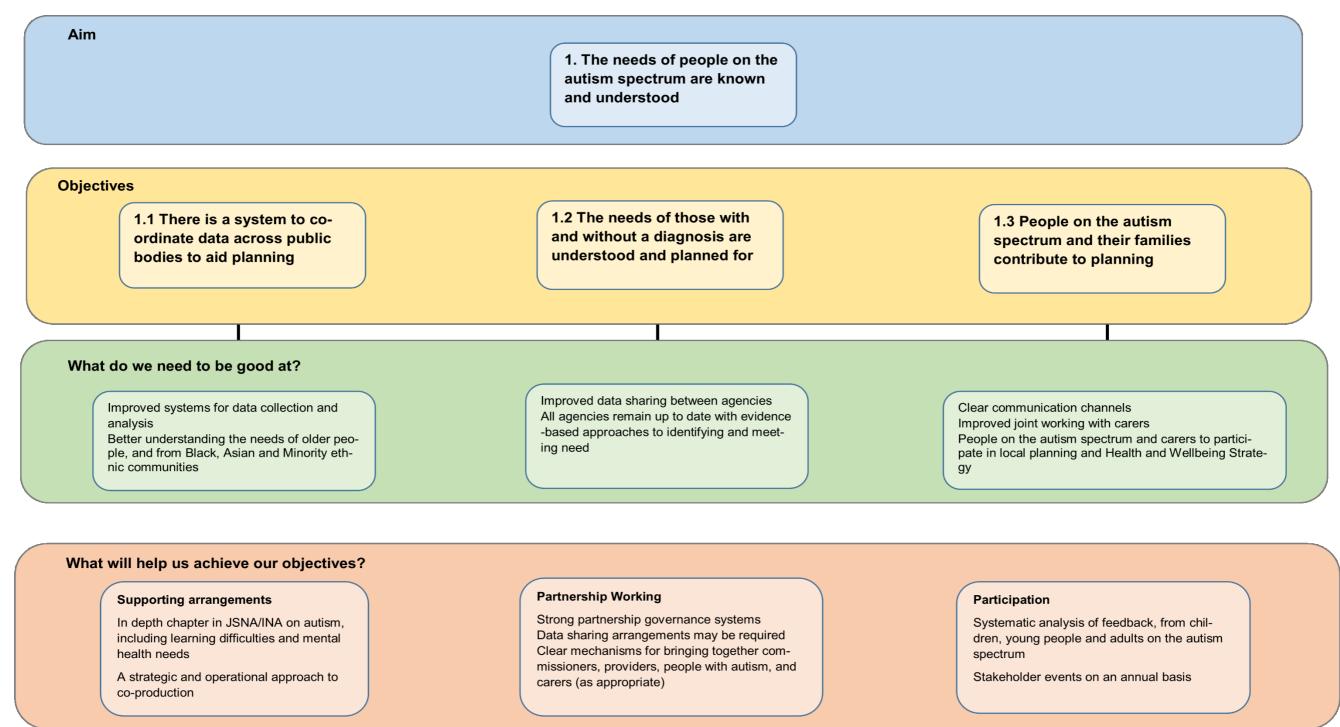
system

4.4 There is specific support for those in the criminal justice

4.3 There are suitable,

- 5.3 Young people are prepared for adulthood across education, health and social care
- 5.4 People on the autism spectrum have access to a range of accommodation
- 6.3 There is easy and positive access to employment and benefits pathways
- 6.4 There is support to help retain employment or access volunteering or learning

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Aim 2. The workforce understands and meets the needs of people on the autism spectrum **Objectives** 2.1 All staff working with peo-2.2 Staff who need more ple on the autism spectrum specialist training access it have the right knowledge and skills What do we need to be good at? (Core deliverables) Identifying staff who require specialist That staff working with those on the autism spectrum have appropriate skills, knowledge and training knowledge and training across key organisations Providing high quality training and staff Having a graduated approach to workforce development and support based on evidence based practice support and up to date research Communicating with confidence to people on the autism spectrum and their carers that needs are understood and appropriate adjustments, supports and interventions are in place All NHS, DCC and relevant partner organisations to pledge to 'Think Autism' What will help us achieve our objectives? (Enabling factors) Communication Supporting arrangements Performance management Commissioning Clear promotion of 'Think Autism in County Interagency audit of current training and gap Complete workforce development audit Needs analysis informs training offer and provision

analysis

Development of joint training/shared resources across agencies

Database of roles developed and access to specialist training monitored

Durham'

Clear communication strategy regarding the workforce knowledge, skills

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Aim

3. People on the autism spectrum have good physical and mental health

Objectives

3.1 Frontline staff in education, health and social care understand and respond to the signs of autism

- 3.2 There is timely and appropriate access to diagnostic and care pathways
- 3.3 There is timely and appropriate access to mental health support if needed
- 3.4 There is broad awareness of social, communication and sensory needs of people with autism

What do we need to be good at? (Core deliverables)

Staff in frontline services have the right training and resources to recognise presenting characteristics and how to signpost on if necessary Staff in front line services understand how to make reasonable adjustments for those with social, communication and sensory needs relating to autism

Inclusive access to initiatives such as Wellbeing for Life and Active Durham Partnership for people with autism Utilising data to inform commissioning, and access to services that identify and meet needs Ensuring all diagnostic assessments are holistic and take account of the person and their context when reaching a conclusion and meeting need Support for people on the autism spectrum and their families should relate to identified need, and not necessarily diagnosis

Implementing NIHCE recommendations for assessment

Have good access to personal budgets and direct payments for people on the autism spectrum

Access to timely information on autism and local support

Establish and maintain links with the Recovery College

Access to support to be based on need rather than IQ

Staff in mental health teams to be trained on the presenting characteristics and needs of people on the autism spectrum and how to support them

All medical staff to be aware of the needs of people on the autism spectrum and how to make reasonable adjustments
Staff undertaking needs assessments in all agencies have an awareness of preventative and enabling approaches
Implementing NIHCE recommendations for support

What will help us achieve our objectives? (Enabling factors)

Supporting Arrangements

Ensure partners work together to deliver person centred care

Commissioning

Clear commissioned services that identify and meet need
Use of social care data return to support

Performance management

Contract monitoring for providers of diagnostic pathways

Specialist staff performance management to reference needs of service users with autism

Communication

Clearly communicate support arrangements that can be accessed with and without a diagnosis Clearly communicate diagnostic pathway to all stakeholders

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Aim 4. People on the autism spectrum and their families receive the right amount of support at the right time Objectives 4.3 There are suitable, local 4.4 There is specific support 4.2 All support promotes well-4.1 The support offer available services for those with for those in the criminal jusbeing and independence is clear and appropriate to need complex needs tice system What do we need to be good at? (Core deliverables) Having a graduated offer of support to people on the au-Timely access to quality preventative Access to independent advocacy Criminal justice systems that are able tism spectrum and their carers with a focus on independservices which reduce the need for services who are autism aware to assess the needs of people with ence and inclusion inpatient and residential services autism Individuals are aware of their rights to a needs assess-Having high quality community based ment or carer's assessment if appropriate services for those with complex needs Access to support should be based on assessed need Residential and inpatient placements rather than IQ should be regularly reviewed and People on the autism spectrum and their families/carers should be as local as possible should be able to access information about autism and appropriate supports Providing access to safe and appropriate relationship and sexual health support What will help us achieve our objectives? (Enabling factors) Partnership working Communication Commissioning **Supporting Arrangements** Joint working between social care, CCG and Public Health with re-

All DCC and NHS services, and partners to nominate an autism lead

All services to promote the 'Think Autism'

Relevant staff to understand and implement the Mental Health and Mental Capacity Acts

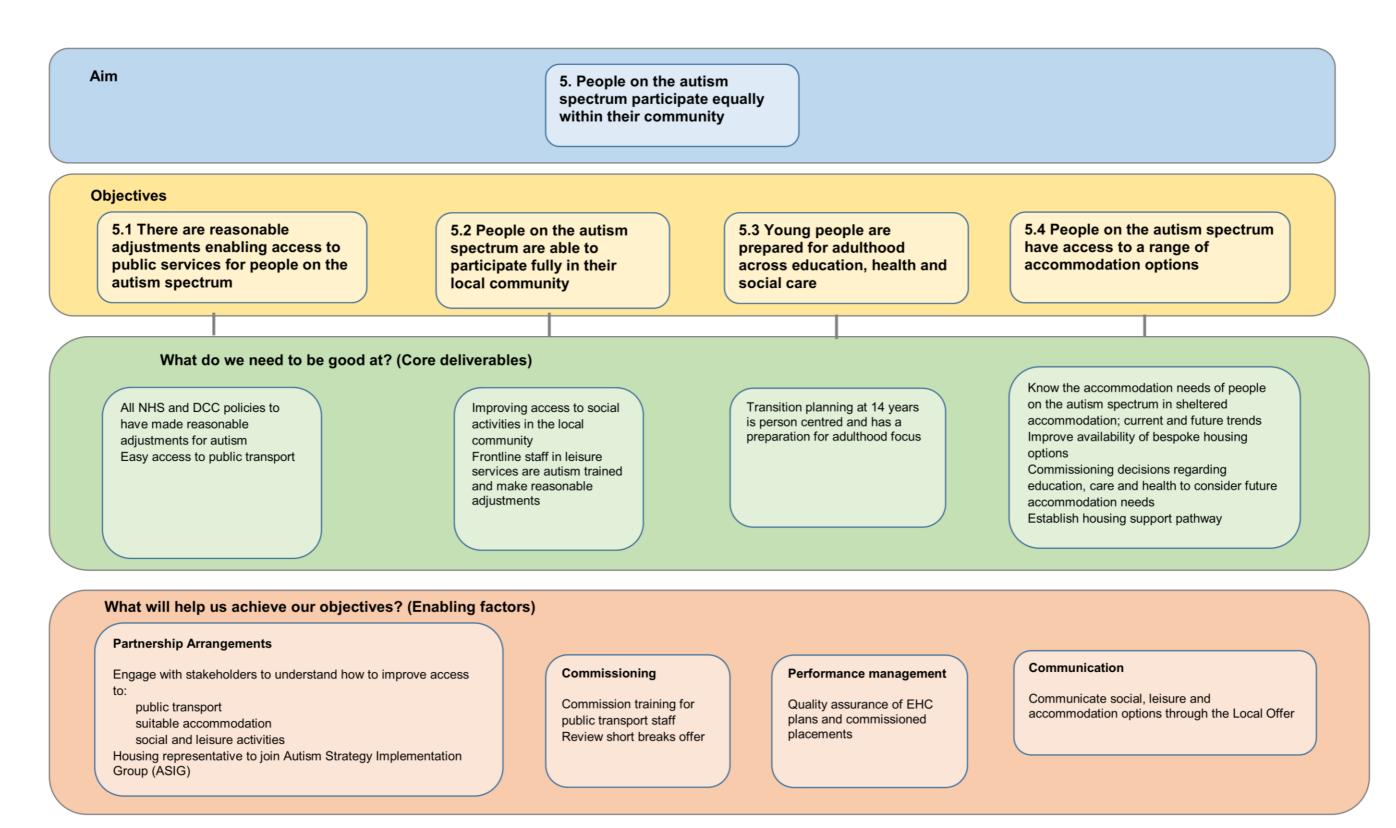
Joint commissioning between partners regarding discharge planning, crisis intervention and preventative community care and support

A clear communication strategy outlining how needs are identified, basic information about the condition, and how to access support if needed.

gard to people in the criminal justice system

Identify and work with organisations that support people on the autism spectrum who are in prison, or who are the victims of crime to develop and promote training and support programmes

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Aim 6. People on the autism spectrum access aspirational employment, volunteering or learning opportunities **Objectives** 6.4 There is support to 6.1 Children and young people 6.3 There is easy and **6.2 Transitions through** help retain employment with autism access high quality education and into training are positive access to or access volunteering or inclusive education and training employment and benefits appropriately supported learning pathways What do we need to be good at? (Core deliverables) Increased use of supported Have a wide range of quality local provision from internships Improve access to employment and mainstream to specialist provision Improved business and training opportunities Develop autism aware Understand needs and gaps in Local provision employment links apprenticeships, internships and A clear employment support pathway that lead to out of area placements traineeship opportunities Clear information to young Clear links with independent All education providers to be autism aware and people and adults about assessment leading to Personal confident in making reasonable adjustments Independence Payment. sources of support Parental confidence in the local offer Increased use of employment Supporting and challenging all providers to be passport/profile inclusive What will help us achieve our objectives? (Enabling factors) **Partnership Working** Commissioning Performance management Closer links with DWP Commission a Young person's group to inform decision making relating to Work with stakeholders to explore barriers to employment and training employment to inform planning Invite local employers and Jobcentre Plus to join ASIG

Delivery Framework

There is a delivery framework underpinning the strategic aims and objectives which includes detailed action plans and programmes for improvement. These will be developed and monitored through the Autism Strategy Implementation Group (ASIG) and Children's Autism Steering Groups.

Monitoring and Review

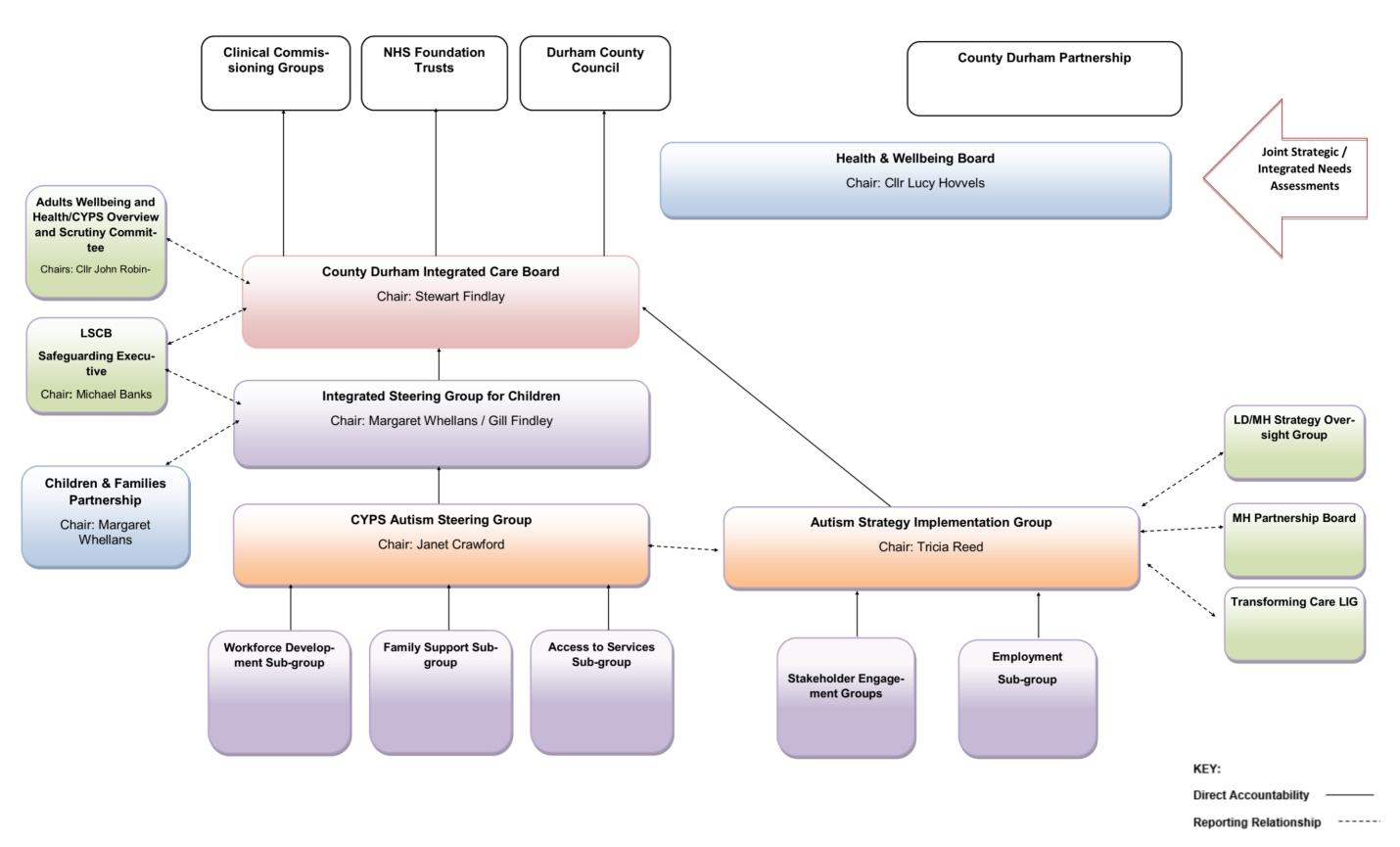
Each delivery framework will be monitored through the framework described above using a range of performance indicators and actions (each of the sub groups will have delivery plans and be responsible for the delivery of those plans).

Scrutiny of Progress

Working together to achieve the vision for children, young people and adults with autism will be through reporting to the Integrated Steering Group for Children and into the Health and Wellbeing Board (see Appendix 1)

Self-evaluation will also be undertaken in line with the statutory requirements of the 'Think Autism' framework.

Governance for All Age Autism Strategy



With thanks to the following partner organisations









Durham County Council

NHS North Durham
Clinical Commissioning Group

NHS Durham Dales, Easington and Sedgefield Clinical Commissioning Group

NHS Tees, Esk and Wear Valley Clinical Commissioning Group