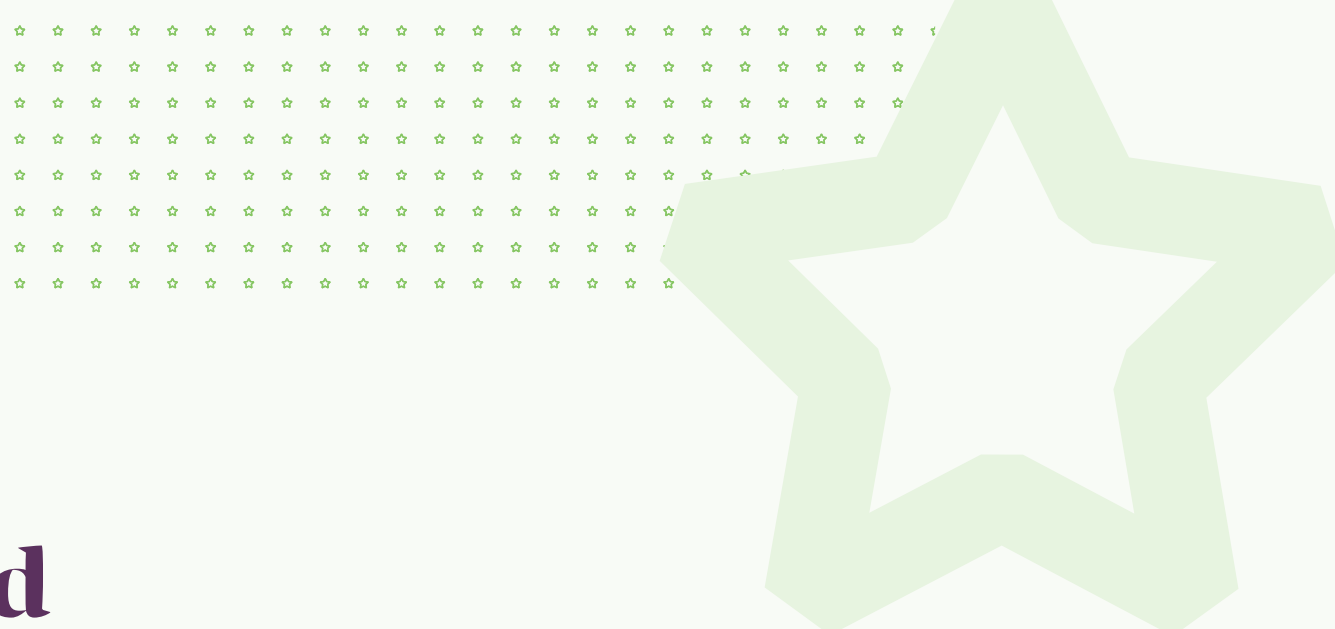


Lancashire and South Cumbria

All-Age System Strategy for Autism



July 2022



Foreword

This all-age Autism Strategy has been developed in partnership with autistic people, their families and practitioners.

Voices have been heard from across Lancashire and South Cumbria through face to face conversations, group discussions and, one to one conversations. Online questionnaires and surveys have been utilised in order to find out what people felt was needed to make Lancashire and South Cumbria more autism friendly and to improve lives for autistic people.

The first steps to improve our lives as autistic people were made with the Autism Act 2009 and the 2010 Adult Autism strategy 'Fulfilling and Rewarding lives' (and the update 'Think Autism'). However, many in the autistic community, including those in Lancashire and South Cumbria, feel that even a decade later we are still struggling in a number of areas.

In particular, our diagnostic pathways, including pre and post diagnostic support for people and their families, do not provide timely diagnoses or sufficient and appropriate support. Autistic people face difficulties accessing services and also find that the services they do access aren't always appropriate or tailored for autistic people. There isn't always the appropriate support for autistic children in education, and autistic people continue to face challenges in the areas of education, employment, housing and relationships.

As an autistic person, an ambassador for other autistic people and the co-chair of the Lancashire Autism Partnership Board, I have been fighting for clarity, fair and timely diagnostic pathways and support for autistic people for over a decade.

I have had personal struggles and listened to, and fought for, far too many others stuck within a broken system.

As an autism advocate, I need to not only to represent myself, but also be the voice of other autistic adults, their families, those who care for autistic people and those who work in roles related to autism who may currently feel frustrated by the barriers which continue to make it difficult for all of us to navigate our lives. Inadequacies mean that autistic people in our communities are struggling to reach their potential.

I need to keep positive in order 'to keep on keeping on' and so I pin my hopes and aspirations on this new all age strategy and I hope that it will address inadequacies and that there will be improvements in personal aspects of autistic people's lives.

Every autistic person, from child to adult, should be able to live in communities which pride themselves on having a better understanding of autism and therefore be able to value us and aid us to a 'gloriously ordinary life'.

Kizzy Falstead

Autism Advocate and Co-Chair of the Lancashire Autism Partnership Board

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Introduction

This Autism Strategy provides an ambitious framework to make Lancashire and South Cumbria great place to live for autistic people.

In reality this means we need to be more understanding and aware of autism and celebrate autistic people. It means making sure there is good quality support and care available to autistic people at the time they need it.

We want to ensure Lancashire and South Cumbria is a place where autistic people have **fulfilling lives**: during early years, throughout education, in employment, and during their everyday lives.

This All-Age Autism Strategy has been initiated by Lancashire and South Cumbria Health and Care Partnership (the Integrated Care System, or 'ICS'), a partnership of health and care services that **works together** to ensure the **1.8 million people** in our communities can live longer, healthier and happier lives.

This strategy does not replace any of the existing work programmes and strategies currently in place for autism across the region. But it does attempt to provide a bold, unified call to action for all organisations in Lancashire and South Cumbria to work together to have an impact on autistic people's lives.

In 2020 the ICS published a strategy describing how working with communities to improve the mental health, resilience and wellbeing of people in Lancashire and South Cumbria was a key priority.

It became clear that there was a need for a **distinct, all-age system-wide strategy for autism** which would enable the system as a whole to set out priorities to achieve positive outcomes for autistic people. This strategy therefore focuses on adults, children and young autistic people in transition.

This strategy has been a system-wide effort. Autistic people have given their time, experience and views to help create the ambitions and priorities, and people have come together from a wide range of organisations and backgrounds to give their views.

As a result, this strategy encompasses health and care, quality of life, jobs and education and happiness and fulfilment for autistic people.

This strategy is aimed to help autistic people and their families within Lancashire and South Cumbria and also those with other conditions such as a mental health problem or physical health problems.

We recognise that this strategy does not, and cannot, contain every area that either needs improvement or is important to an individual autistic person. But we hope that this is the start of a **5-year journey** to continue to improve the lives of autistic people and those who care about them across Lancashire and South Cumbria.

It became clear that there was a need for a distinct, all-age system-wide strategy for autism which would enable the system as a whole to set out priorities to achieve positive outcomes for autistic people.



Terminology and Glossary

We understand that the language around autism is important and ever-changing. Words and language are powerful tools and within the autism community there are differing views on the terminology used to talk about autism and autistic people.

We have used the terms **'autistic', 'autistic people'** or **'autistic individual'**, as we recognise that autism is an inherent part of an individual's identity.

'Autism' is used in this report as a term encompassing all Autistic Spectrum Conditions.

ADHD

Attention Deficit Hyperactivity Disorder

Attention deficit hyperactivity disorder (ADHD) is a neurodivergent condition that affects the way people interact with the world around them. Some autistic people may also have ADHD.

ASC

Autism Spectrum Condition

Having an Autistic Spectrum Condition (ASC), or simply 'autism', means that a person has a different way of understanding other people and the world around them.

DHSC

Department of Health and Social Care

The Department of Health and Social Care (DHSC) is the UK government department responsible for government policy on health and adult social care matters in England

GP

General Practitioner

A doctor based in the community who treats patients with minor or chronic illnesses and refers those with serious conditions to a hospital.

ICS or 'System'

Integrated Care System

An integrated care system is a partnership organisation comprised of organisations that meet health and care needs across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities.

JSNA

Joint Strategic Needs Assessment

A Joint Strategic Needs Assessment (JSNA) looks at the current and future health and care needs of local populations to inform and guide the planning and commissioning (buying) of health, well-being, education services and social care services.

L&SC

Lancashire and South Cumbria

When we talk about Lancashire and South Cumbria in this strategy, we are referring to both the region as a whole and the partnership of health, care and community organisations working together across the region to care and support the 1.8 million people living in communities across the region.

LGBTQ++

Lesbian, Gay, Bisexual, Transgender, Queer and Others

LGBTQ++ is an acronym for lesbian, gay, bisexual, transgender, queer or questioning and others. These terms are used to describe a person's sexual orientation or gender.

NHS

National Health Service

The National Health Service (NHS) is the publicly funded national healthcare system in the United Kingdom.

NICE

National Institute of Health and Care Excellence

Provide the NHS, and those who rely on it for their care, with an increasing range of advice on effective, good value healthcare.

NHSEI

NHS Improvement and NHS England

NHS England and NHS Improvement are the leadership organisation for the NHS who are responsible for delivering improved care for patients.

All-Age

"All-age" means that this strategy covers all ages of people in Lancashire and South Cumbria - from birth, into childhood and adolescence, transition into adulthood, adulthood and older ages.

Experts by Experience

In relation to this document, Experts by Experience are people who are autistic or have recent personal experience of caring for someone who is autistic. During the engagement process used to inform this strategy we spoke with many Experts by Experience.

Lived Experience

Lived experience is a term we have used to represent personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people. In relation to this strategy, it means those with learning disability, or those closely associated with them. E.g., families and / or carers.

Neurodiversity

Neurodiversity refers to the different ways the brain can work and interpret information, but it can also be interpreted as a social movement, often with a political emphasis. It highlights that people think about things differently, have different interests and motivations, and naturally find some things easier or more challenging than others.

Autistic people can be referred to as neurodivergent. Individuals not diagnosed with a neurodivergent condition can be referred as neurotypical. A core principle of neurodiversity is that difference is celebrated and seen as a positive.

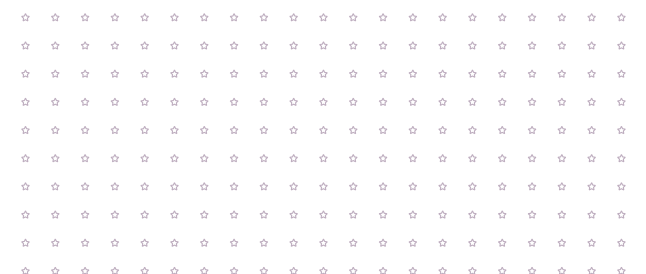
Transition

Transition can have a number of meanings. In this strategy we have used it in relation to autistic people transitioning from childhood to adulthood.

Under Reached

A term used to describe communities, or groups within the population, who are not as well served by services or initiatives as the general population.

We



The term 'we' is used throughout this strategy. It relates to the collective organisations and individuals across Lancashire and South Cumbria who have committed to developing this strategy and will ensure it is implemented.



There are five clear ambitions which make up this strategy:

Celebrating Autism

Communities in Lancashire and South Cumbria will have a better understanding of autism and will value autistic people.

Diagnosis and Support

The process of autism assessment and potential diagnosis will be supportive and timely.

Gloriously Ordinary Lives

Ensuring autistic people have access to quality housing, excellent employment opportunities, a good education and meaningful relationships.

Simple & Straightforward Services

All autism services will be simple and easy to access.

Health and Wellbeing

Organisations will work in partnership to ensure autistic people live long, healthy and happy lives.

Approach to Developing this Strategy

A proposed approach to developing this strategy was produced and shared with autistic people and a range of stakeholders and organisations across the system who provide services or care for autistic people.

It was agreed that development of this strategy would follow a three phase approach, with regular engagement, feedback and review points taking place across all three phases:



Design

A series of design workshops were held with professionals and experts by experience to tell us how this strategy should be developed.



Discovery

The core period of strategy development. Speaking to autistic people, those who work in areas related to autism and various organisations about what the priorities should be.



Delivery

Authorship of the strategy, which included a 'check and challenge' process with stakeholders and autistic people.



Core Principles and Guiding Beliefs

In co-production with system stakeholders, a set of Core Principles and Guiding Beliefs were agreed to underpin the development of the strategy:

Need For	Meaning
<u>Inclusivity</u>	Whole system and Experts by Experience engagement.
<u>Reciprocity</u>	Nothing about me without me – feedback and recognition as part of the process.
<u>Self-Advocacy</u>	Learning directly from Experts by Experience as well as their friends, carers, and supporting professionals.
<u>Use of Resources</u>	Making best use of peoples' time, recognising existing expertise and avoiding repetition.
<u>Supportive Communications</u>	Communicating only in ways that can be understood by all.



Guiding Beliefs

- 1** We believe that a strategy can only be written by all of us. 
- 2** We believe that a shared commitment will provide the energy required to deliver audacious and ambitious strategic priorities. 
- 3** We believe this strategy will never be finished, and will require regular sense checking of our thinking and evolution of our plan.
- 4** We believe that it is our job as system to facilitate the thinking and direct the resource to make change happen.

These Core Principles and Guiding Beliefs were used throughout the strategy development as a point of reference, as well as for check and challenge and quality assurance purposes.

Engagement

This strategy has been developed through discussions with autistic people, their families, practitioners involved in autism and a wide range of other relevant organisations across Lancashire and South Cumbria.

Engagement to inform the strategy predominantly took three forms:



Conversations, Interviews and Discussions

We carried out hundreds of focussed conversations to understand perspectives across Lancashire and South Cumbria.



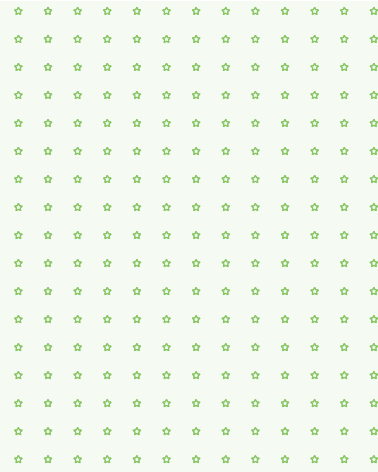
Workshops

Bringing organisations and representatives together in one space to gain insight and understanding.



Attending Existing Forums

Listening to discussions to understand what matters most to autistic people.



A wide range of organisations, groups and individuals told us what they thought needed to be included in this strategy. We'd like to thank the following organisations and groups for their honest views, willingness to engage and sharing their experiences and knowledge in order to help us write this strategy:

Triple A

Blackburn with
Darwen Borough Council

Blackpool Council

Colleagues across NHS
Primary Care Organisations

Cumbria County Council

Department for Work and Pensions

East Lancashire
Chamber of Commerce

Lancashire and South Cumbria
NHS Foundation Trust

Lancashire and South Cumbria
Health and Care Partnership

Lancashire County Council

Lancashire Mind

National Autistic Society

Pathways Associates

People First

Progress Housing Group

South Lakeland Autism
and Asperger's Support Group

UCLAN

Understanding Autism North West

West House

All eight NHS Clinical Commissioning
Groups across Lancashire and
South Cumbria

All four NHS Acute Trusts across
Lancashire and South Cumbria

We'd like to especially thank all autistic people, their families and carers across Lancashire and South Cumbria who spoke to us as part of this process.

Hello, my name is Rachel

Rachel is 31, is autistic, part of the LGBTQ++ community, and spoke at length about her experience of living in Lancashire. Her words are presented unedited to provide one example of many conversations that took place with autistic people in the development of this strategy.

I volunteer at Albion Mill in Blackburn which is a supported living centre, and I support residents with problems they have and go to residents' meetings to help and support them in appointments. There is so much that people don't know about housing and other additional support they are entitled to. I have had to learn a lot and so I help people know about things that professionals should be helping them with.



I am on an Autism board and I speak up about my experiences and views about services and support, and be the voice for autistic people. I have supported the setting up of 'Indigo' which is a group for autistic people to help them to be independent, understand career opportunities, getting the right volunteering experience, befriending services and being socially active.

Autistic people are left out a lot. Sometimes services are not present for people who are autistic. I do lots of sewing, selling face masks and other initiatives and this money goes to Indigo. We also help with getting funding for autistic people to do social events like meals out and bowling which helps them and help their parents too.

We need information about consent and really clear black and white information.

I know lots of autistic people who don't have partners because they are scared.

Staff need to understand that just because we are over 18 it doesn't mean we know everything about relationships. We need people offering sessions and talks for autistic people. We need information about consent and really clear black and white information. I know lots of autistic people who don't have partners because they are scared.

I've never had a part time or full time job. The way I've been treated at work and school has meant that I have found this very difficult. Employers need to understand that autistic people will have different needs.

I do lots of voluntary work with the National Development Team for Inclusion - a social change organisation working to enable people at risk of exclusion. There are things that are important for autistic people to know such as people will come and go and things will change at work.

Stability and understanding change is really important to autistic people. Things need to feel comfortable and we need to understand what that change looks like.



Autistic people are left out a lot.

School teachers, those in education and organisations often don't really have much awareness and training around Autism and don't always give the right advice and help, and often the advice they do give might be different to what families and support workers might be saying.

I worked in a voluntary job, and I once got told off for not understanding an instruction that I was given. This was in front of customers, which I didn't feel was right. Adapting communication to make sure it is right for autistic people is so important.

Stability and understanding change is really important to autistic people. Things need to feel comfortable and we need to understand what that change looks like.

I often think that professionals don't really understand about Autism. It's hard making friends and most social places are too noisy and we keep getting told to go out and be more active. People would like to chat in a small group or do an activity which helps to engage them. We also need to make sure people get home safely if we meet on an evening. A lot of people don't go out at night because they are worried and scared to go out and they don't feel safe to go out and use public transport.

I am thinking of moving to Leeds because they have a supported service to get people home safely who are a part of the LGBTQ++ community. Autistic people would not engage in any services or groups because they would worry about getting home.

I tried to get help around relationships and sexual health services. I wasn't confident at school and got treated really badly when I asked questions. I don't have the right information as it's just not there for people who are autistic.

Where I have asked for help around what is safe in a relationship, I haven't had the right information and that means that I haven't been able to have relationships. Because I don't have this information, there have been misunderstandings that have happened and as a result I have been treated badly by professionals and the community.



Where I have asked for help around what is safe in a relationship, I haven't had the right information and that means that I haven't been able to have relationships.

I have been moved around a lot for a number of reasons through no fault of my own – often services don't talk to each other and this makes it really difficult. They should be communicating with each other - this includes schools, police, GPs, everyone.

There needs to be more action. I've been on the Autism Board for 6 or 7 years but there hasn't been enough change. All NHS staff should be trained on a regular basis around autism and there should be more services for autistic people, especially those in LGBTQ++ communities.

For example, people transitioning gender who are autistic need better advice and signposting, as well as services tailored to their needs.



Context

This strategy has been developed because we need to improve the lives of autistic people in Lancashire and South Cumbria, and a strategy sets the vision and strategic priorities that will enable this to happen.

Engaging with autistic people, organisations and professionals was the primary method used to create the ambitions and priorities within this strategy, but there are a number of national documents that influenced our approach:

The Autism Act 2009 sets out the clear duties and expectations on local authorities and the NHS to plan and commission appropriate services for autistic adults and their families.

The Westminster Commission on Autism published **'A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People'** in 2016, which set out the challenges faced by autistic people and provided 6 clear recommendations to improve the lives of autistic people.

The Westminster Commission on Autism also published **'Support Surrounding Diagnosis: An Inquiry into Pre- and Post-Support for the Autism Diagnosis Pathway'** in November 2021 which looked at the diagnosis pathway for the autistic community and deemed that their needs were not being met in all areas.

In July 2021 the government published **'The national strategy for autistic children, young people and adults: 2021 to 2026'**.

A number of other national reports and publications from charities, societies, healthcare organisations and community organisations were collated and used to shape our thinking and inform strategy development.

In September 2021 Dr Ian Davidson, National Autism Lead for the Royal College, completed a review on behalf of the system entitled **'Resources Required to Support People with Autism in Lancashire and South Cumbria'**. The eleven recommendations included in that review have been encompassed in this strategy.



Understanding Autism and Neurodiversity

Language and Meaning

This strategy will not attempt to describe what autism feels like for autistic people, or what autism means to autistic people. It is up to an autistic individual to define for themselves how they want to describe their lived experience, and what language feels right to articulate how they feel and define themselves as a person.

Clearly, many autistic people may not even think about autism when first asked to talk about their lives, emotions or experiences. For other autistic people it might be the very first aspect that they reference.

This strategy will also not attempt to set out any type of 'definitive' way to talk about autism. How society talks about autism, and neurodiversity as a whole, has changed over time and will continue to evolve. There is a wealth of online and offline resources and communities discussing all aspects of neurodiversity, which includes interesting and contrasting ideas around the language and representation of autistic people.

Being engaged in this can further understanding and celebration of diversity for everyone.

This strategy still needs to use language to articulate a vision and priorities around autism, and a description of autism itself is required for context. In our partnership approach with autistic people, we have made the intentional decisions around some of our language:

- We have used 'autistic spectrum condition (ASC)' as opposed to 'autistic spectrum disorder (ASD)'.
- We have not used the term 'Asperger's syndrome'. We acknowledge and respect that people have been diagnosed with Asperger's syndrome and will identify with that diagnosis. However, it is no longer used by clinicians as an official diagnosis and our understanding in this area has moved on.
- We have used the term 'autistic people / autistic person' rather than 'people with autism / person with autism', because we understand autism as an inherent part of an individual's identity.

Understanding Autism

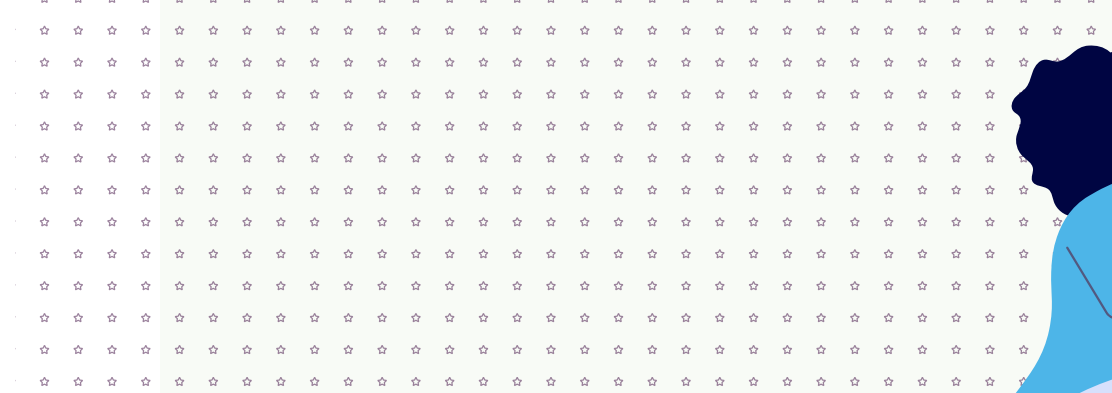
Whilst we hope that the following is helpful overview of autism, the best way to understand autism is to seek out the lived experiences and opinions of autistic people. **#actuallyautistic** is a hashtag widely used online (especially on social media) by autistic people to talk about autism, and can provide an authentic, honest, challenging and real view of all things autism.

In terms of this strategy, autism is used as a term that encompasses all autistic spectrum conditions.

1 in 100 people are believed to be on the autism spectrum and that there are around **700,000** autistic adults and children in the UK.

Some recent reports speculate that the number of actual autistic adults and children will be significantly higher than this.

A 2021 study Northern Ireland estimated prevalence of autism within the school aged population in Northern Ireland was as high as **4.5%**.



People are born autistic.







Autism is a spectrum, which means it's different for everyone.

Autism is lifelong, and isn't an illness or a medical condition with a 'cure' or 'treatments'

But as with all neurodivergent individuals who may act and feel different to neurotypical people, autistic people may require some additional support to help them with certain things.



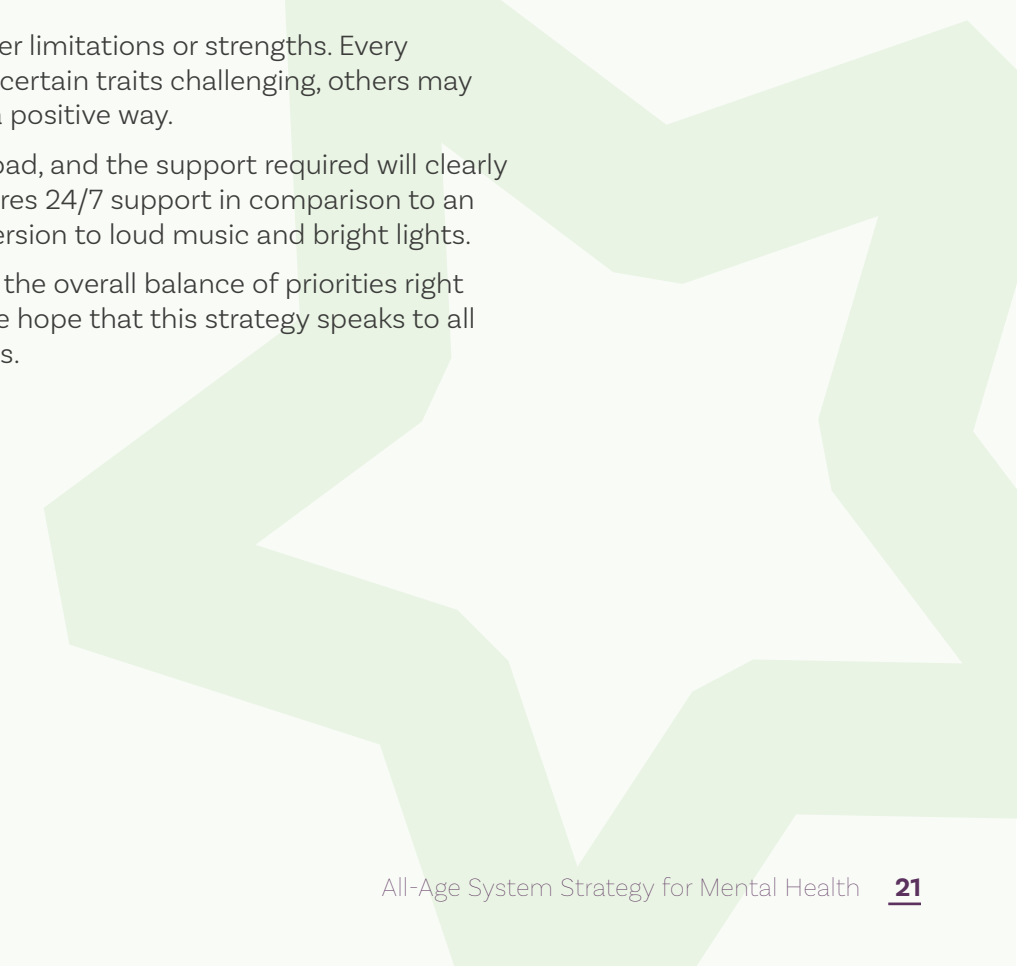
As with all people, autistic people have their own strengths and weaknesses. But autistic people may have some or all of the following:

-  Social communication and social interaction challenges.
-  Repetitive and sometimes restrictive behaviour.
-  Hyper focus on interests or hobbies.
-  Anxiety, which can range from mild to extreme.
-  Crisis moments, often referred to as 'meltdowns' or 'shutdowns'.
-  Sensitivity (over and under) to sensory inputs – light, sound, touch, taste etc.

These traits are not presented as either limitations or strengths. Every individual is different: some may find certain traits challenging, others may experience those very same traits in a positive way.

The spectrum of autistic people is broad, and the support required will clearly differ for an autistic person who requires 24/7 support in comparison to an autistic person who has a sensory aversion to loud music and bright lights.

We may not have got the language or the overall balance of priorities right for every single autistic person, but we hope that this strategy speaks to all autistic people, albeit in different ways.



The Challenge Faced by Autistic People

More than 2 out of 3

autistic adults in England feel that they do not get the required support they deem themselves to need.



Awareness of autism in the wider population is good but understanding of the complexity of autism and the needs of autistic people is not so good.

Whilst **99%** of the population have heard of autism, only

24% of autistic adults feel that understanding of autism has improved since the Autism Act of 2009.

Only **8%** of autistic adults feel that health and care services for autistic people have improved since the Autism Act of 2009.



There are a range of related co-occurring conditions associated with autism including

ADHD and Epilepsy



A recent ONS survey suggested that only around **1 in 5 people** with an autism diagnosis are in some form of employment.

Autism is not a learning disability. A recent study found that the proportion of autistic people with a learning disability is probably between

15 and 30%

In 2021 The National Autistic Society published a good practice guide for professionals delivering talking therapies for autistic adults and children. In a survey of autistic adults it was found that:

94%

Reported having anxiety.

83%

Reported having depression.

76%

Had reached out for mental health support over the past **5 years**.

8x

As many autistic people report feeling often or always lonely compared to the general population.

Misconceptions around autism include outdated myths including autistic people **lacking empathy**, that autism is a **childhood condition** (it's a lifelong condition), autism is something that can and should be **'cured'** and that autism is predominantly a **male condition**.

A recent study showed that Black and Chinese children were **26%** and **38%** more likely to be autistic.

Although autism is not a mental health condition, research indicates that

70%

of autistic people do develop mental health issues. The most common mental health diagnoses that autistic people face are anxiety and depression, which have higher incidences for anyone with a long-term illness or disability.



Nationally only **15%** of people referred for an autism diagnosis had their first care contact within 13-weeks of referral (the recommended minimum timescale).



Only **14%** of autistic people felt that there was enough mental health support in their area.

A 2016 population study in Sweden concluded that **suicide** is a leading cause of premature death in people with autism spectrum condition.

#ActuallyAutistic

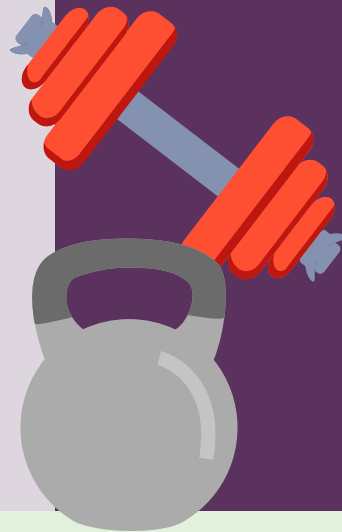
is a hashtag used online by the autistic community and is one of the best ways to find out more about autism from autistic people.



Hello, my name is Kevin

I'm a Chief Inspector with 26 years police service, all of this time in uniform. I've done a variety of roles, but I'm currently responsible for Response Policing for the City of Preston. I am a former mental health nurse with a degree in Mental Health Practice. I also have a post-graduate diploma in Evidence-based Policing and am working towards a teaching qualification.

I live with my fiancée and son. I also have three other children, the eldest having just graduated from Durham University with the younger two spending weekends with us. We're a typical family who enjoy the pleasures of life including camping, walking and sometimes going to the gym.



I'm also currently Vice-Chair of the constabularies Neurodiversity Network. This was set up a few years ago by a colleague, originally as the Autism Network. We've rebranded it to reflect the broader aspects of Neurodiversity (ND) which are now also included in the work we do.

My interest started for a couple of reasons - one being that my son is Autistic, and I was myself diagnosed with Autism a few years ago. This came as a shock at the age of 48, but after a period of support from my psychologist I've been able to learn a lot about myself, how the condition affects me and those around me, and to learn strategies to cope with some of the challenges it can bring.

My ND journey has been tricky over the last few years, but it's helped me to understand myself better and consequently helped me to foster improved personal and professional relationships.

I am creative, have a strong sense of justice, am good at analytical thinking and very organised and logical in my working practices.

I now know that I have some sensory issues with touch, smell, sound, taste and bright light. I also know that in some scenarios I can struggle with executive functioning - information recall and processing. I sometimes experience anxiety, usually linked to unfamiliar environments and I also struggle to be able to read other people's emotions, especially when there may be few visual cues. These are just some of the challenges I have.

But being Autistic also helps me in many ways. I am creative, have a strong sense of justice, am good at analytical thinking and very organised and logical in my working practices. I've learned ways to overcome some of the challenges by slowing things down, thinking before I respond and by taking steps to prepare myself for unfamiliar scenarios or environments I may encounter.

I'm passionate about providing neurodiversity awareness training to police staff. I also provide support and advocacy to staff members who may be experiencing difficulties. I find this work very fulfilling, and it gives me a sense that I can make a difference to those affected, their families, colleagues, the workforce as a whole and the wider community.

I'm a keen advocate of changing processes to make them inclusive rather than a reliance on adjustments to remove disadvantage. The Equality Act gives certain obligations to employers, including ensuring policies and practices don't disadvantage people because of their difference. Sometimes reasonable adjustments can be offered to help overcome some challenges. These are best designed by consultation with the individual. Simple adjustments can often make all the difference.



I believe that with increased understanding of neurodiversity by employers and employees it is possible to create an environment where people with conditions including autism can feel valued and able to contribute positively to an organisation while being able to be themselves, despite some of the challenges this may bring.

I have found that being open about being autistic and sharing some of my own experiences and challenges help to create a psychologically safe environment where staff feel empowered to open up about their own experiences as an individual or parent of someone who is neurodiverse. This will help to generate the conversations that lead to greater understanding and action to support those in need.

I believe that with increased understanding of neurodiversity by employers and employees it is possible to create an environment where people with conditions including autism can feel valued.





Making Lancashire and South Cumbria a great place to live for autistic people



Our Vision

To make Lancashire and South Cumbria a great place to live for autistic people. We will be an autistic-aware society where autistic people feel celebrated and highly valued. We will ensure autistic people have access to timely and supportive health and care services.

Most importantly, autistic people across Lancashire and South Cumbria should feel safe and live longer, happier, healthier and more fulfilling lives.

Our Strategy

This strategy provides the framework for Lancashire and South Cumbria to be a great place to live for autistic people.

The following five ambitions represent a mixture of new priorities, existing programmes of work and national priorities.

The priorities range from quite specific national healthcare requirements for autistic people through to some very general priorities we heard from autistic people that would improve their lives.

The aims of this strategy are ambitious and will therefore be challenging to achieve. To be successful in achieving our objectives organisations will need to work together in a way not seen before and we will need to deliver services in different ways.

Successful implementation of this strategy will depend on autistic people working at the heart of any changes, co-designing initiatives and driving changes.



1

Communities in Lancashire and South Cumbria will have a better understanding of autism and will value autistic people.

2

The process of autism assessment and potential diagnosis will be supportive and timely.

3

Ensuring autistic people have access to quality housing, excellent employment opportunities, a good education and meaningful relationships.

4

All autism services in Lancashire and South Cumbria will be simple and easy to access.

5

Organisations will work in partnership to ensure autistic people live long, healthy and happy lives.

Hello, my name is Jonathan



Jonathan is 24, is autistic, and lives in Lancashire.

Below are unedited quotes from Jonathan about his life. The ambitions and priorities over the next few pages are designed to respond to people like Jonathan, so they feel heard and that significant improvements are made to their lives.

For some autistic people I feel like it's very hard – some people are very vulnerable and can get exploited – we need to be careful about who we are around and the environment we expose ourselves to.

I live with my Mum and our pets. It has been really tough after education for me and has been difficult to find work, especially when navigating Universal Credit.

I started off volunteering in charity shops, at a small museum in a shopping centre and at my local church that I attend. Some of the jobs were temporary and only lasted for a short while. This job I am currently at is permanent, but it's been a struggle to get here.

I went through the Job Centre to look for jobs, but I felt like they looked down at me and I didn't feel I was given help and support.

They were so very pressurising about finding any job and didn't give you a chance to get to know you and understand you better. I got this job through people and networking. It was the same with most of my other jobs, it was through friends and not through any services and agencies that are meant to help.

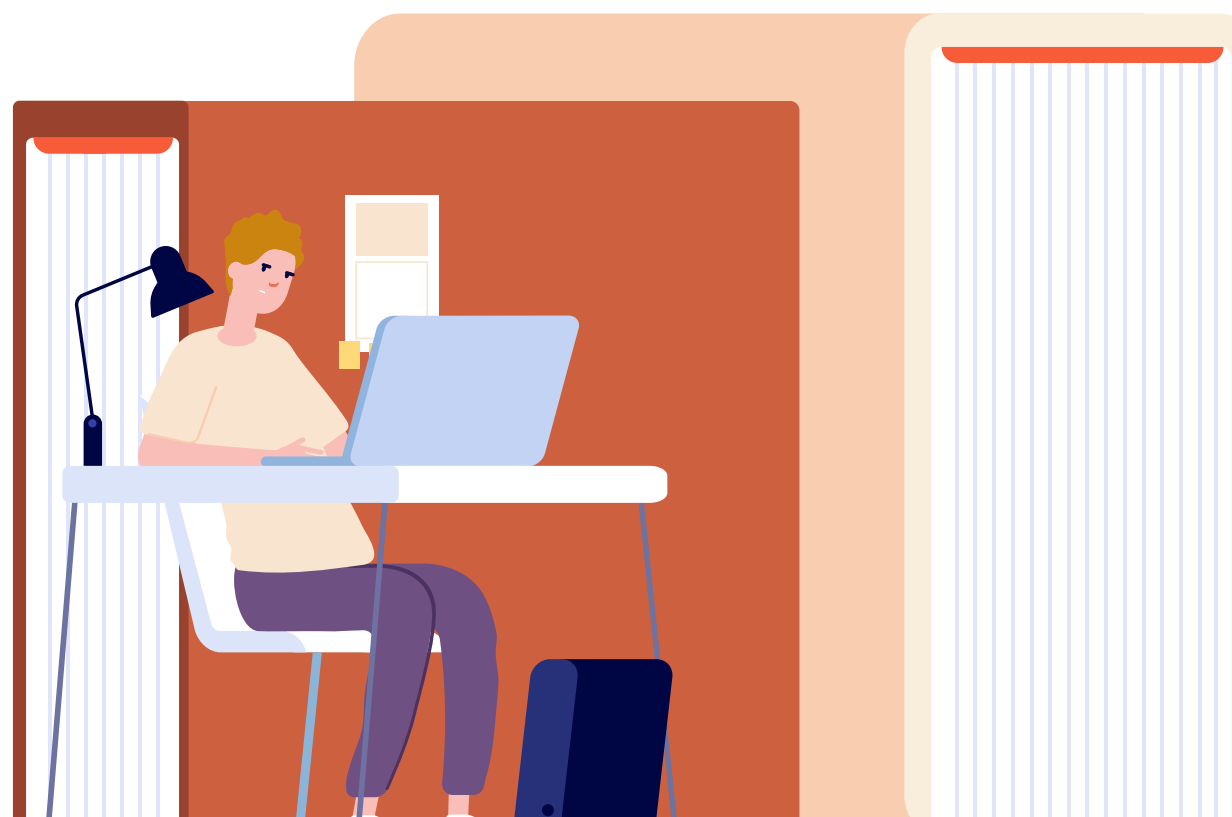


Professionals and people need to understand what autism is to create awareness. Organisations that help people who find work need to be more supportive and aware of the talents and skills of autistic people.

At college I felt very depressed, and it made me feel discouraged and made me lose my confidence. I just had to accept that I didn't have the help that I needed. I did have someone to help me at college with my timetable, but it didn't really help, and it didn't last long.

When I was young, I didn't know much about autism and what it meant. In primary school I had a Teaching Assistant to help me, but when I got to high school there wasn't much support at all. When I was at college, I didn't have much support. It was really difficult at times.

I believe every autistic person is different.



I believe that every autistic person is different. Even though we are the same in terms of being human, we have different things that effect us and one person is not the same as another. It's a learning curve. Services and people need to understand autism better and not have a universal view that everyone's the same in terms of our personalities, capabilities and backgrounds.

People need to have more patience and understanding when dealing with autistic people, as some people need more help than others. Education doesn't have to start and finish at school and university; it can be through networks and opportunities and we need help with that.

1

Communities in Lancashire and South Cumbria will have a better understanding of autism and will value autistic people.

Autistic people have told us that increasing public understanding of autism is an incredibly important priority. The myths, stereotypes and misconceptions around autism means that autistic people can feel socially isolated and misunderstood. We want people and organisations in Lancashire and South Cumbria to understand autism and to celebrate neurodiversity.

We need to:

Improve overall awareness, public understanding and positive celebration of autism and neurodiversity with a focus on highlighting the perspectives of autistic and neurodivergent people, their families and their carers.

From both a statistical and societal perspective, we need to ensure that there is an accurate picture of autism and neurodiversity across Lancashire and South Cumbria.



Therefore, we will:

- Develop specific and targeted communication and engagement materials across education, health, social care and broader community settings to raise awareness, increase understanding and ensure positive acceptance of autism within all communities.
- Work with local businesses, including the chamber of commerce and large regional employers, to increase the understanding, awareness and positive celebration of autism, with a view to increasing employment rates and improving the experience for autistic people in employment.
- Ensure the use of Joint Strategic Needs Assessments (JSNA) across the region to better understand the likely needs and demands of autistic people based on the individual and the demographics of their local communities.
- Agree common minimum core training requirements for health and social care organisations in relation to autism, using The DHSC Autism Core Capabilities framework.
- Work with schools to help them make simple and reasonable adjustments, which will often make all the difference to how a child or young person functions in school.
- Ensure there is a strong focus on engaging with 'under reached' individuals and communities (black and minority ethnic groups, LGBTQ++ groups, the travelling community, those in deprived areas etc.) in relation to autism, including awareness, understanding, positive acceptance, diagnosis and ongoing support.
- Build on the existing good practice of the recently developed Lancashire and South Cumbria autism dashboard and undertake comprehensive system-wide data analysis to gain accurate metrics in relation to autism which will be used to drive decision making and evaluate performance.

This will feel like:

A Lancashire and South Cumbria where there is a greater understanding of autism across all settings; where we feel comfortable to talk openly about autism and autistic people feel fully included and celebrated in the communities in which they live.

A Lancashire and South Cumbria where we have a detailed and thorough understanding of the health and care performance related to autism so that autistic people live happier, healthier lives.

A Lancashire and South Cumbria where there are higher than average paid employment rates for autistic people.

A Lancashire and South Cumbria where autistic people have a positive educational experience where they suffer no trauma due to being autistic.

2

The process of autism assessment and potential diagnosis will be supportive and timely.

Whilst it can be a very emotional journey, an autism diagnosis can be a tremendously powerful and positive thing for an individual and the people around them. We need to acknowledge that autism diagnosis in Lancashire and South Cumbria can currently be a challenging and difficult experience for autistic people and their families.

Autistic people across Lancashire and South Cumbria have said that they need timely and supportive diagnosis and both pre and post diagnostic support, with information given to them by professionals who understand their needs.

We need to:

Continue to design and develop our autism diagnostic services in partnership with autistic people so that they meet the needs of our local population and all national diagnostic standards.

Ensure that there is a high-quality, standardised support package for the individual and their family during the assessment pathway, including pre-diagnostic support, so that there is a clear understanding of the outcome.

Therefore, we will:

- Ensure there is a multi-disciplinary approach to autism diagnosis and that NICE guidance and the NHSEI National Autism recommendations around diagnosis are followed as standard.
- Agree a common system-wide set of autism data, standardised reporting mechanisms, and a standardised autism diagnostic report for individuals.
- Ensure that all people with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 13 months of their referral.
- Standardise, agree and be transparent on the key milestones for individuals in contact with autism diagnostic services. All individuals should be completely clear from the outset what their diagnosis journey will look like, what their key milestones will be and what support they will receive.
- Aim to hit at least 75% positive diagnostic rates wherever possible to ensure the reduction of people being kept waiting and neurotypical people being unnecessarily put through a diagnosis process.

- Set a date for removing the current backlog of autism diagnoses and have a more realistic timeframe for children and young people in education settings as a priority.
- Ensure that all autistic school-age children, and young people at university, have a comprehensive and thorough support package in place.
- Provide everyone who has been assessed as autistic, or is being assessed, with a comprehensive virtual and physical toolkit which outlines key steps, timescales, important information and the support available to them.
- Develop a discrete and dedicated Autism Assessment Team / Service which will provide autism management and support.
- Acknowledge that diagnosis may not be the right thing for everyone. Support will be available for those that need it, regardless of having a diagnosis or not. Conversely, we will recognise that autistic people may not want, or need, further support.
- Improve pre-screening to ensure the appropriate people are referred for an autism diagnosis, including training for referrers and screening processors to aid inappropriate referrals.
- Work with GPs and adults in the community to discuss whether an autism assessment may be appropriate or if a diagnosis has been overlooked and provide the relevant required support.
- Ensure that diagnostic reports provide more than a binary 'yes / no' feedback and provide the positives around autism as well as a focus for ongoing work and support.
- Develop a virtual and physically available resource package for self-support and self-appraisal related to autism.
- Ensure that autism diagnostic services are commissioned to provide specialist sensory assessment, and that there are specialists who can offer sensory specialist support for autistic people.
- Develop a support package and signposting for those who have been assessed and not been diagnosed with autism, as well as a comprehensive support package post-diagnosis for those that have been diagnosed as being autistic.
- Ensure that any individual, or parent/carer, can access an online tool which provides a 'one stop shop' around their diagnosis journey. This will

- include live waiting times, where they are in the process, support resources and signposting to online materials and communities that could benefit their experience.
- Increase our overall understanding and awareness of the sensory needs of autistic people and take relevant action in a variety of settings, including healthcare, education, employment and leisure.

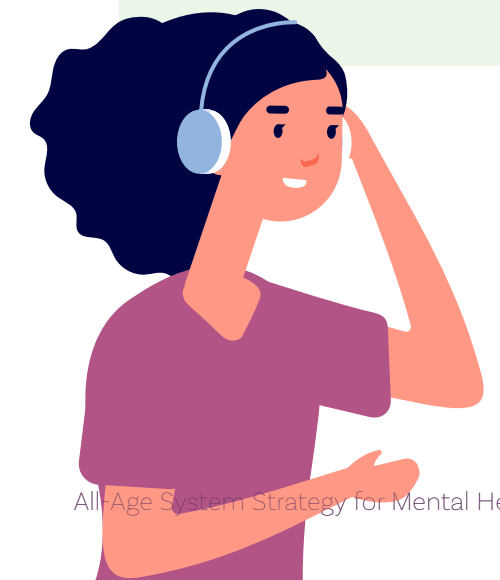
This will feel like:

A Lancashire and South Cumbria where autistic people are able to live their life in a positive way because of a diagnosis and support package that works for them.

A Lancashire and South Cumbria where we see fewer negative diagnoses and quicker care is made available to autistic people who need it.

A Lancashire and South Cumbria where autistic individuals feel happy, supported and able to cope with the challenges of an autism diagnosis.

A Lancashire and South Cumbria where autistic people do not suffer mental health issues due to a negative experience around diagnosis or lack of support.



3

Ensuring autistic people have access to quality housing, excellent employment opportunities, a good education and meaningful relationships.

Therefore, we will:

- Launch a regional campaign to demonstrate the positive impact autistic people are having in business and education.
- Raise awareness in all employers (large, medium and small) that autism can be a 'hidden' condition and reasonable adjustments may be needed for autistic people.
- Work with employers to increase the number of autistic people in sustainable paid employment by making employers aware of autistic talent and the benefits of a truly neurodiverse workforce.
- Ensure that employment support is delivered through regional autism hubs, including a range of vocational and pre-vocational programmes and specialist support to break down barriers to employment to meet the needs of autistic people.
- Tailor the classroom environment and educational programmes to meet the individual strengths and needs of autistic children and students.
- Provide training and guidance material to schools to enable teachers and management teams to improve their knowledge of autism and to organise the whole school provision appropriately.
- Ensure that the clear statutory duties that all local areas should be complying with in relation to transition are being carried out.
- Acknowledge that a proportion of autistic people have a learning disability, but also understand that autistic people want to be seen as distinct from those with a learning disability.
- Deliver training for autistic people via an autism practitioner with clear information around love, sex and relationships, including online awareness, guidelines and advice.
- Increase joint working between pre-16 organisations so there is an understanding around supported decision making related to love, sex and relationships.
- Work with community organisations and groups, sports clubs and other recreational groups to ensure that their organisation is welcoming and accessible to neurodivergent people.
- Ensure that all autistic people live somewhere they have chosen and that meets their needs.
- Allocate a higher proportion of new affordable homes for autistic people and provide a long-term sustainable, consistent housing benefit regime for supported housing.
- Ensure the sensory needs of autistic people are considered when developing housing.
- Ensure all training and guidance material focuses specifically on the sensory requirements of all autistic children and learners.

We need to:

- Ensure that autistic people have access to a first-class education which is tailored to their individual needs and that more autistic people move on into meaningful and paid employment opportunities.
- Ensure that autistic people live a rich and fulfilling life, with a recognition of the importance of love, sex, friendships and relationships.
- Ensure that autistic adults have strategically planned and sustainable, quality supported housing where required.

There is often a mainstream view around autism and autistic people that doesn't reflect the ordinary lives of autistic people.

We should strive to ensure that there aren't limited representations of autistic people and that autistic people live gloriously ordinary lives.

This will feel like:

A Lancashire and South Cumbria where autistic people live happy and fulfilled lives in their communities.

A Lancashire and South Cumbria where autistic people have reduced incidents of trauma, with a goal of zero incidents.

A Lancashire and South Cumbria where we see fewer negative diagnoses and quicker care is made available to autistic people who need it.

A Lancashire and South Cumbria where autistic people have a more positive experience in education and employment.



4

All autism services in Lancashire and South Cumbria will be simple and easy to access.

Autistic people, along with their families and advocates, have clearly told us that it is complex, confusing and frustrating to access autism services related to autism across Lancashire and South Cumbria. We need to make people's lives easier and simpler.

We need to:

Provide locally delivered and integrated systems to deliver care.

Ensure that autistic people, their families and carers, and any professionals and organisations can access autism support in a clear and easy way.

Therefore, we will:

- Design, develop and implement multi-disciplinary run AUTISM HUBs across the region to provide a 'one stop shop' for autism services.
- Ensure that AUTISM HUBs become a familiar point of first contact for any query by any autistic person or their families or supporters.
- Allow employers, educational facilities and community organisations to access additional training and understand the needs of autistic people via AUTISM HUBs.
- Ensure that AUTISM HUBs provide information about local community assets and ensure a strong focus on 'community' rather than just 'service provision'.
- Develop a strong, vibrant and modern virtual presence as part of the Autism Hub implementation for those who do not want to access a physical building for whatever reason.
- Ensure AUTISM HUBs have good links with other statutory and third sector providers for elements which are important for autistic people but are not autism specific e.g., career advice, job schemes, welfare rights and benefits and support for co-occurring conditions.
- Ensure there is a 'no wrong door' policy, enabled through multidisciplinary teams who have a comprehensive understanding of autism, so that all individuals and their families can access the right care, in the right place, at the right time.

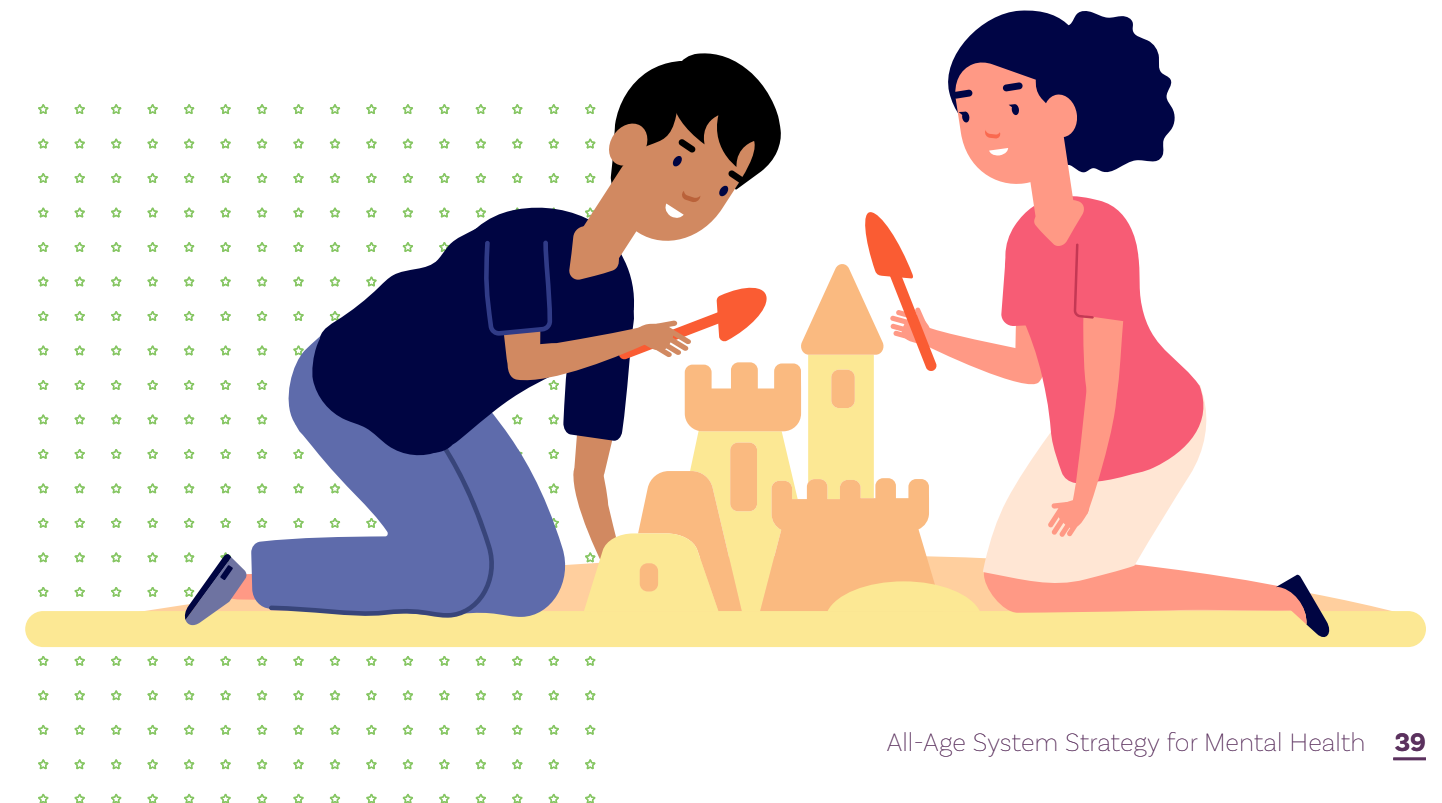
- Ensure that it should not matter to the person receiving the service which organisation employs the people they see, or which team they belong to, or where they are based, as long as they deliver the right standard of care and / or treatment needed by that person in a timely easily accessible manner.
- Ensure that autistic and neurodivergent people are offered virtual interaction as well as a face-to-face appointments, as well as the option of booking online.

This will feel like:

A Lancashire and South Cumbria where autistic people live a happier and healthier life because their interaction with services and support is simplified and straightforward.

A Lancashire and South Cumbria where organisations specifically for autistic people are visible and accessible in communities.

A Lancashire and South Cumbria with improved health outcomes and reduced health inequalities for autistic people.



5

Organisations will work in partnership to ensure autistic people live long, healthy and happy lives.

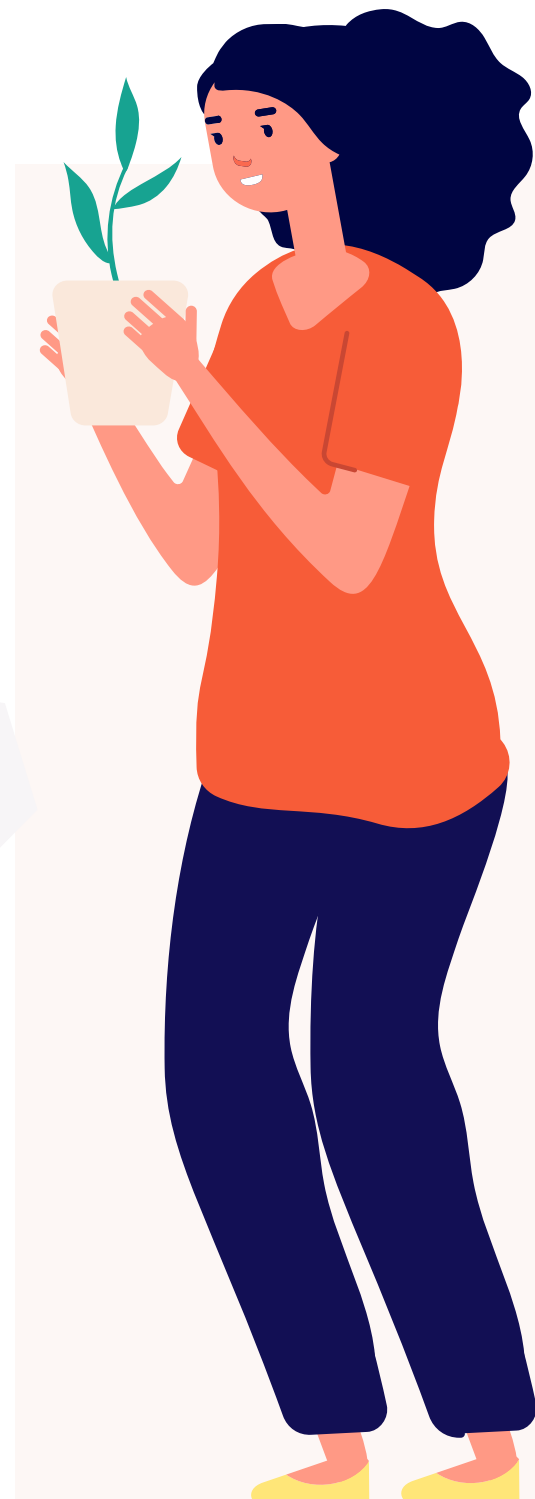
Everyone wants to live a long, healthy and happy life. The life expectancy of autistic people is significantly lower than their neurotypical peers and many medical conditions are significantly more prevalent in autistic individuals than in the neurotypical population.

There is an urgent need to focus on ensuring we address this and other health inequalities for autistic people in Lancashire and South Cumbria.

We need to:

Work collaboratively as a system to ensure autistic people receive first class healthcare.

Address health inequalities facing autistic people and improve health outcomes for autistic people.



Therefore, we will:

- Develop a lead provider model specifically for autism to cover all ages and from pre to post diagnostic work so that there is clear oversight and accountability for autism services.
- Implement an autism provider collaborative with its own clear governance structure including reporting arrangements to the board of the lead provider and necessary links and reporting to partners, other agencies and the public.
- Agree and implement a system-wide agreement on data quality, measurement and key metrics relating to diagnosis and a variety of other autism-related metrics.
- Communicate with autistic people in relation to their healthcare in a style and delivery method appropriate to them. If an individual wishes to receive information digitally rather than by post (or vice versa) we will ensure this happens.
- Ensure that no autistic person is prevented from accessing any health or social care service or treatment because they are autistic.
- Provide better support to autistic people who may be self-harming or having suicidal thoughts.
- Invest in community autism teams to in reach into inpatient facilities to support good quality treatment and support effective and timely discharge, along with providing general support to autistic people.
- Ensure that all autistic people have a note on their GP record stating that they are autistic so that services, information and their experience can be tailored appropriately.
- Ensure that all GP surgeries work to ensure that appointments are adjusted, where appropriate, for autistic people, including the consideration of longer timeslots.
- Deliver services as locally as possible, with clear rationale if and when services are provided outside the locality.
- Use data effectively to map current gaps in provision and/or knowledge. This will use JSNA and other data to help predict likely need based upon an understanding of the make-up of local communities and their health and social care needs.
- Maintain a strong commitment to reducing reliance on inpatient mental health care for both adults and children who are autistic.
- Ensure health equity for all autistic children, young people and adults regardless of race, ethnicity, socioeconomic status and geographical location so that individuals can reach their full potential.

This will feel like:

A Lancashire and South Cumbria with significantly reduced illness rates and disease prevalence within the autistic community.

A Lancashire and South Cumbria where autistic people have a life expectancy in line with the general population.

A Lancashire and South Cumbria where autistic people have more positive health and care experiences, spend less time in hospital and feel safer in relation to self-harm and suicide.





How Lancashire and South Cumbria will deliver on our Vision

Achieving our vision will be dependent upon a strong partnership approach that takes positive action across all five areas outlined in this strategy. Doing this will ensure that Lancashire and South Cumbria is a great place to live for autistic people.

Implementing the priorities and achieving the outcomes set out in this strategy will require an array of organisations and individuals to come together to develop new ways of working and transformational initiatives to improve the lives of autistic people in Lancashire and South Cumbria.

Most importantly, autistic people will be at the heart of decision-making, design and implementation.

This strategy has been endorsed by the Lancashire and South Cumbria System Transition Board, which has responsibility

for the transformation of autism services across the region. The responsibility for monitoring the achievement of the outcomes presented in this strategy will belong to this Transition Board.

The outcomes are a deliberate mix of improved outcomes for autistic people (such as happiness and healthiness or individuals) and broader population measures (such as employment rates and reduced suicides). Detailed metrics will be developed around these outcomes and will be measured.

Working groups will be set up to develop action plans in order to deliver the priorities and outcomes outlined across the five ambitions.

The membership of all working groups will be strongly represented by autistic people and their family members (no one is better placed, for example, to design the support an autistic person needs during diagnosis than autistic people who have been through that process), alongside relevant professionals. A wide range of organisations will be invited to participate in the process.

As an immediate first step, a piece of work will be carried out to review the ambitions, priorities and recommendations set out in this strategy and assign them in to one of three categories.

Existing Initiatives

Priorities which relate to an existing programme of work, or ongoing initiative.

Business as Usual (BAU Initiatives)

Priorities which may not yet be enacted, but could be categorised as 'business as usual' i.e., could potentially be picked up and implemented by an existing team/ service organisational.

Transformational Initiatives

Priorities which will require a transformational approach, potentially with additional resource (finance, workforce etc.) and a structured transformational plan to design, mobilise and implement.



Lancashire and South Cumbria

All-Age System Strategy for Autism



For more information contact:

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**Lancashire and
South Cumbria**
Health and Care Partnership