

Draft



**CAMBRIDGESHIRE AND PETERBOROUGH  
ALL AGE AUTISM STRATEGY  
2021 – 2026**



# ACKNOWLEDGEMENTS

This countywide All Age Strategy for people with autism was co-produced with parents, carers and people with lived experience of autism as well as all local partners. We wish to thank all of the people who contributed in creating this strategy and its ongoing implementation and action plan.



**AUTISM CENTRE  
OF EXCELLENCE**



Creating a safer  
**Cambridgeshire**



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## FOREWORD

### Wendi Ogle-Welbourn and Carol Anderson

As the Executive Director of People & Communities for Peterborough City Council (PCC) & Cambridgeshire County Council (CCC), and the Chief Nurse from Cambridge and Peterborough Clinical Commissioning Group (C&P CCG) it gives us great pleasure to introduce this strategy for children, young people and adults with autism.

The strategy was developed by PCC, CCC and the C&P CCG in partnership with local organisations, service user groups and parent carer forums, drawing on the knowledge and understanding of those with lived experience of autism. The development of this All Age Autism Strategy pulls together all of our autism workstreams across Children and Adults.

It also sets out our work to date; outlining the plans, ambitions and commitment to work together across Health, Social Care and Education to support people of all ages with autism including their families and carers.



Our aim is for both Cambridgeshire and Peterborough to be autism friendly; where people with autism can live full, healthy and meaningful lives, within a society that accepts and understands them. This includes focusing on needs led services being person centred; providing care informed by an understanding of what matters to a person with autism and their family.

Our strategy takes a whole life approach; with the right support, children, young people & adults with autism can live happy, healthy and independent lives within their own community; it is therefore vital to develop an All Age Strategy, focusing on what works for both children, young people and adults.

We have set out challenging but clear and achievable goals. We are aware that we are at the start of a long journey; it can only be made a success by working in partnership together.

We would like to thank all the people involved with the development of the strategy.



# EXECUTIVE SUMMARY

This five-year (2021-2026) All Age Autism Strategy supports our aim for Cambridgeshire and Peterborough to be an autism friendly place where children and adults with autism can live full, healthy and rewarding lives, within a society that accepts and understands them.

It has been co-produced in partnership with people with autism and their families across Cambridgeshire and Peterborough; we have sought to capture their lived experiences and what is most important to them.

The development of the strategy was supported by the Autism Centre for Excellence (ACE), parent carer forums Family Voice Peterborough & Pinpoint Cambridgeshire, parents, carers, Healthwatch and other interested and autism specific groups and organisations including Cambridgeshire and Peterborough's branch of the National Autistic Society (NAS) along with professionals across Health, Education and Social Care.

The foundation of this strategy was the Autism Needs Assessment collated by Public Health which provided a comprehensive overview of the prevalence of autism across Cambridgeshire and Peterborough. Both national and local data sources were used to provide up to date information specifically in relation to autism; illustrating that the number of people with an autism diagnosis across Cambridgeshire and Peterborough is predicted to rise. This is key to understanding how Peterborough City Council (PCC), Cambridgeshire County Council (CCC) and the Cambridgeshire and Peterborough Clinical Commissioning Group (C&P CCG) will support all children, young people and adults with autism.

The Autism Needs Assessment also included a review of good practice across the UK. This, alongside information specific to Cambridgeshire and Peterborough, enabled Public Health to identify a series of priorities. These priorities have been key to the development of this All Age Autism Strategy.

Our priorities include:

- Having clear pathways for children and adults based on a needs led approach with good support throughout the process, combined with good pre and post diagnosis support.
- Training and raising awareness for all areas that helps services and professionals understand the needs of people with autism within our local communities and services and recognises that autism affects different people in different ways.
- Services that take a lifelong approach and supports people with autism in school, colleges and universities, to be able to live independently and have meaningful employment opportunities.
- For Health, Education and Social Care to work together to commission integrated services that make the best of the resources available.
- For services to understand what reasonable adjustments are and how they can improve settings so people with autism can have positive experiences when they go into Health, Education and Social Care settings such as primary care, hospitals, school etc.

The Needs Analysis has illustrated the priorities that we need to address in order to best support children, young people and adults with autism and their families.

Maintaining an understanding of the needs of children, young people and adults with autism across Cambridgeshire and Peterborough is vital in commissioning and delivering sustainable provision that meets need in the most effective way possible.

As this strategy will show, we have taken a life-course approach. It is vital that we work together as a system, with all partners, to provide a range of support that people with autism may need at different times in their life. This may include Health services, Education, colleges, local businesses, housing, independent or supported living and support within the justice system.

## SPECIAL EDUCATIONAL NEEDS & DISABILITIES (SEND) STRATEGY (2019 - 2024)

PCC and CCC published the [SEND Strategy - SEND is Everybody's Business](#)<sup>1</sup> - in 2019. The SEND Strategy sets out the vision, principles and priorities to identify and meet the needs of Cambridgeshire and Peterborough's children and young people with special educational needs and/or disabilities (SEND) from birth to the age of 25. The priorities and recommendations of the All Age Autism Strategy are therefore interwoven with the wider strategic objectives for SEND Services. The three priority areas identified for SEND are:



The co-production and development of the All Age Autism Strategy is key in delivering these priority areas, and therefore relates to key actions within Cambridgeshire and Peterborough SEND Action Plans that followed the publication of the SEND Strategy. There are also key linkages to the priorities of Cambridgeshire and Peterborough's Learning Disability Partnership.

The implementation of the All Age Autism Strategy will be driven by the All Age Autism Strategy Board; this board will oversee the development of the action plan and implementation of the strategy with all partners. The All Age Autism Strategy Board, and the working groups connected, include those with autism, parents and carers alongside other professionals and organisations that have been key to the development of this strategy.

<sup>1</sup> <https://www.cambridgeshire.gov.uk/asset-library/i/imported-assets/SEND%20Strategy%20-%20Final%20Nov%202019.pdf>



# 2

## BACKGROUND

2009

The first national guidance and legislation specifically aimed at provision for autism was '[The Autism Act](#)<sup>2</sup>' (2009); this put a duty on Central Government to produce, and regularly review, a National Autism Strategy to meet the needs of adults with autism in England. This included a duty to produce statutory guidance for local authorities and clinical commissioning groups to implement strategies locally.

2010

The [Autism Strategy \(2010\) - Fulfilling and Rewarding Lives](#)<sup>3</sup>, set out what local authorities and health services should provide for those with an autism diagnosis. It focused on:

- The need for training and awareness of the needs of people with autism for all staff working within the Public Sector; including Health and Social care, specifically providing specialist training for those in roles with a direct impact on access to services.
- Set up local diagnostic pathways based on The National Institute for Health & Care Excellence (NICE) guidance and increase diagnostic capacity.
- Person centred assessment and personalised care and support for those diagnosed with autism.
- Supporting children and young people with autism in transition to adult services.
- Enabling people with autism to have support to live independently within their communities.
- Involving people with autism in the development of local services.

2014

The more recent [Adults Autism Strategy \(2014\) "Think Autism"](#)<sup>4</sup> was a revised version of the 2010 strategy and strengthened the noted priorities by re-enforcing the duty for:

- Local authorities to improve services for people with autism locally by implementing the national strategy and setting up Autism Partnership Boards.
- Having autism awareness projects with the local community.
- Developing services that promote innovation, early identification and prevention.
- Raising awareness across public services through training.
- Improving data collection and assessing local needs.

2015

The Department of Health's (DoH) 2015 "[Statutory guidance for Local Authorities and NHS organisations](#)"<sup>5</sup> placed a statutory obligation on local authorities and other organisations, such as clinical commissioning groups, to support implementation of the Adult Autism Strategy.

2017

In 2017, Central Government outlined its intention to extend the National Autism Strategy to include children and young people; whilst we await the publication of the National All Age Strategy, Peterborough City Council (PCC) & Cambridgeshire County Council (CCC) have sought to ensure that the implementation of this Autism Strategy is all age. This strategy therefore brings together previous strategies for autism across Peterborough and Cambridgeshire into one integrated County Wide All Age Autism Strategy.

<sup>2</sup> [https://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga\\_20090015\\_en.pdf](https://www.legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf)

<sup>3</sup> [https://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](https://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

<sup>4</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299866/Autism\\_Strategy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)

<sup>5</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/422338/autism-guidance.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)

# 3

## OUR VISION

Our vision is for both Cambridgeshire and Peterborough to be recognised as autism friendly places to live, where people with autism of all ages have access to equal opportunities. Autism friendly services throughout Cambridgeshire and Peterborough are those that person centred and take into consideration each person’s strengths, talents and interests; thereby ensuring that all individuals have access to the same support throughout their lifetime.

Based on the vision within the national autism strategy  
**‘Fulfilling and rewarding lives’**

This includes working together as partners to deliver services in a more inclusive, integrated way that puts the needs of people with autism, and their families, first, providing help, support and care informed by an understanding of what matters to each person with autism and their family. This will be supported by the implementation of Integrated Care Systems (ICSs). Integrated Care Systems (ICSs) are new partnerships between the 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.

### OUR PRINCIPLES

- ALL AGE APPROACH** Promoting an all age approach for people with autism; focused on progression across a whole life pathway, ensuring that all the traditional transition points in a person’s life are effectively managed and seamless.
- PERSON CENTRED** Ensuring that people with autism and their families/carers are at the centre of everything we do, while offering services and support for people with autism that focuses on their strengths.
- RIGHT SUPPORT  
RIGHT TIME  
RIGHT PLACE** Providing the right support at the right time and in the right place by working with key partners to enable better access to, and better experiences of Education, Health, training and work.
- EARLY INTERVENTION** Providing early access to quality, timely and relevant information, advice and intervention in line with statutory guidance and prevention agenda across children’s and adult’s services, supporting and enabling those on the journey to diagnosis.
- OUTCOMES FOCUSED** Using the resources available from public and voluntary services in the most efficient ways to improve outcomes for autistic people and their families.
- RIGHT TO RESPECT** Ensuring that children, young people and adults have a right to live free from abuse in accordance with the principles of respecting dignity, autonomy, privacy & equality.
- INTEGRATION** Commissioning services that promote integration with Health and Social Care whenever possible to develop a shared understanding of the needs of people with autism.
- CO-PRODUCTION** Involving people with autism and their families in planning and decision making at both strategic and operational levels; gaining regular feedback from individual’s experiences to help shape how services are delivered.
- SHARED RESPONSIBILITY** Accepting a shared responsibility for achieving positive, jointly agreed outcomes and effectively sharing information to inform the strategic direction of service delivery (in accordance with relevant guidance & legislation).



# 4

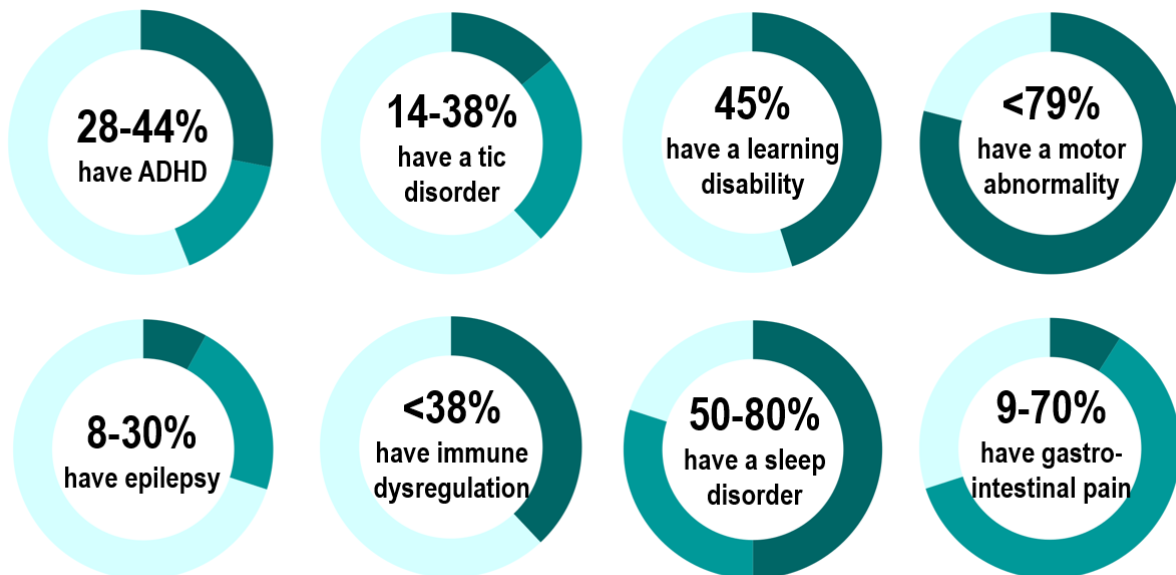
## AUTISM DEFINITION

There are several definitions used to describe autism, including Autistic Spectrum Disorder (ASD)<sup>6</sup>, Autism Spectrum Condition (ASC), and others which have been used to describe conditions on the autism spectrum such as Asperger’s Syndrome. In this strategy we use the term Autism to refer to the whole autism spectrum and the strategy recognises that autism is one of a wider range of neurodiverse conditions.

Autism is a term used to describe a group of lifelong neurodevelopmental conditions marked by how a person with autism interacts socially, how they communicate and patterns of restricted stereotyped or repetitive behaviour they may have. It is a lifelong neurological condition: people are born with it, do not grow out of it and it cannot be ‘cured’. It is a spectrum condition which means it presents differently in every person with autism.

While people with autism may share common traits, their condition will affect them in very different ways. Each person with autism will, as with all individuals, have a distinct set of strengths and weaknesses and so the ways in which people with autism learn, think and problem-solve can be wide-ranging. What some find easy others and excel at, others may find challenging and be unable to do: some individuals are able to live independent lives whilst others will require support at different times in their life or need a lifetime of specialist support. It’s important that we remember we all remain unique.

Autism is not a learning disability/difficulty or a mental illness. People with autism may also have additional needs including learning disabilities, physical health needs and/or mental health conditions; these are referred to co-occurring conditions. It is suggested that 70% of people with a diagnosis of autism have an associated physical or mental health condition. For example, the latest research<sup>7</sup> indicates that people with autism are often diagnosed with other, co-occurring, conditions including:



Therefore, an early and robust assessment of needs together with a sound understanding of the strengths and weaknesses for each person, is key to getting the right support at the right time, and this strategy recognises that.

<sup>6</sup> As used in the National Institute for Health and Care Excellence clinical guidelines for Autism <https://www.nice.org.uk/guidance/cg128/resources/autism-spectrum-disorder-in-under-19s-recognition-referral-and-diagnosis-pdf-35109456621253>

<sup>7</sup> Lai, M., Lombardo, M., & Baron-Cohen, S. (2014). Autism. The Lancet, 383(9920), 896-910. doi: 10.1016/s0140-6736(13)61539-1



## WHY AN AUTISM STRATEGY?

The national guidance “[Implementing and Rewarding Lives](#)”<sup>8</sup> and “[Think Autism](#)”<sup>9</sup> puts a statutory duty on local authorities and health services to have in place plans in relation to the provision of service for people with autism. It states that local authorities and NHS bodies need to work in collaboration with local partners to take forward the key priorities in Think Autism. Crucially, at its core, people with autism need to have access to a clear pathway to meet their needs and know that this pathway is aligned with care and support assessments, and that there is post-diagnostic support available from relevant agencies even if the person does not meet social care support criteria.

Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families.

The national guidance sets out requirements for local authorities and NHS organisations. It set out the statutory duty to work together with partners to develop a strategy for people with autism and gives a framework of what this should include, for example, in the criminal justice system, into employment. It provides clarity about what they have to do to meet the needs of adults with autism including preventative support and safeguarding.

It is therefore vital there is a local autism strategy that works for both children, young people and adults which clearly set out our goals and priorities for the next five years.

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<sup>8</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216129/dh\\_122908.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216129/dh_122908.pdf)

<sup>9</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299866/Autism\\_Strategy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)

# 6

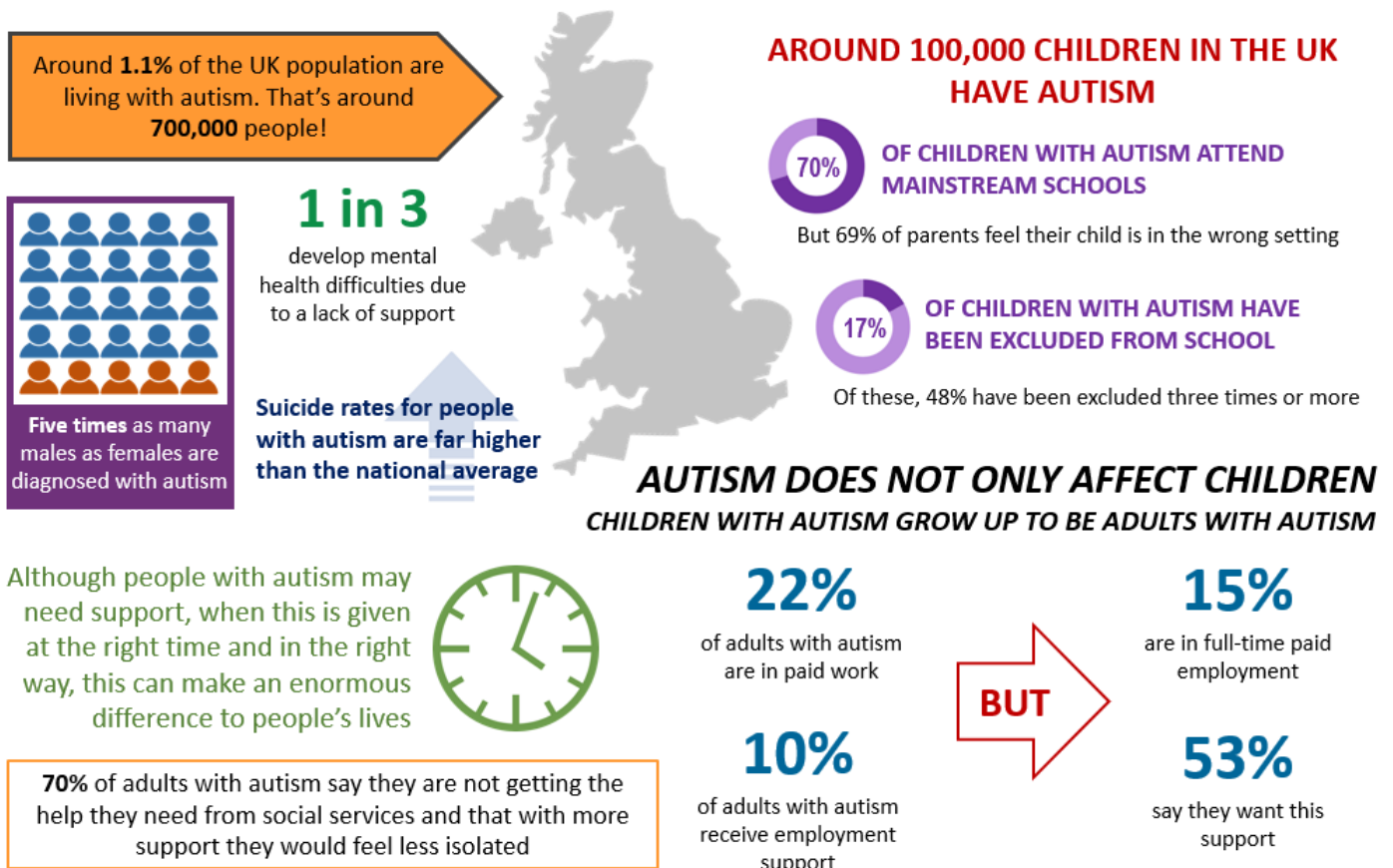
## NEEDS ASSESSMENT - NATIONAL AND LOCAL CONTEXT

To understand the characteristics and health needs of people with autism of all ages in Cambridgeshire and Peterborough, Public Health collated an Autism Needs Assessment. This used local and national sources to indicate the numbers of people with a diagnosis of Autism; forecasting how these numbers are predicted to change with time.

The Autism Needs Assessment also undertook a review to identify good practice throughout the UK; this information was used to identify priorities and make recommendations that has informed this All Age Autism Strategy.

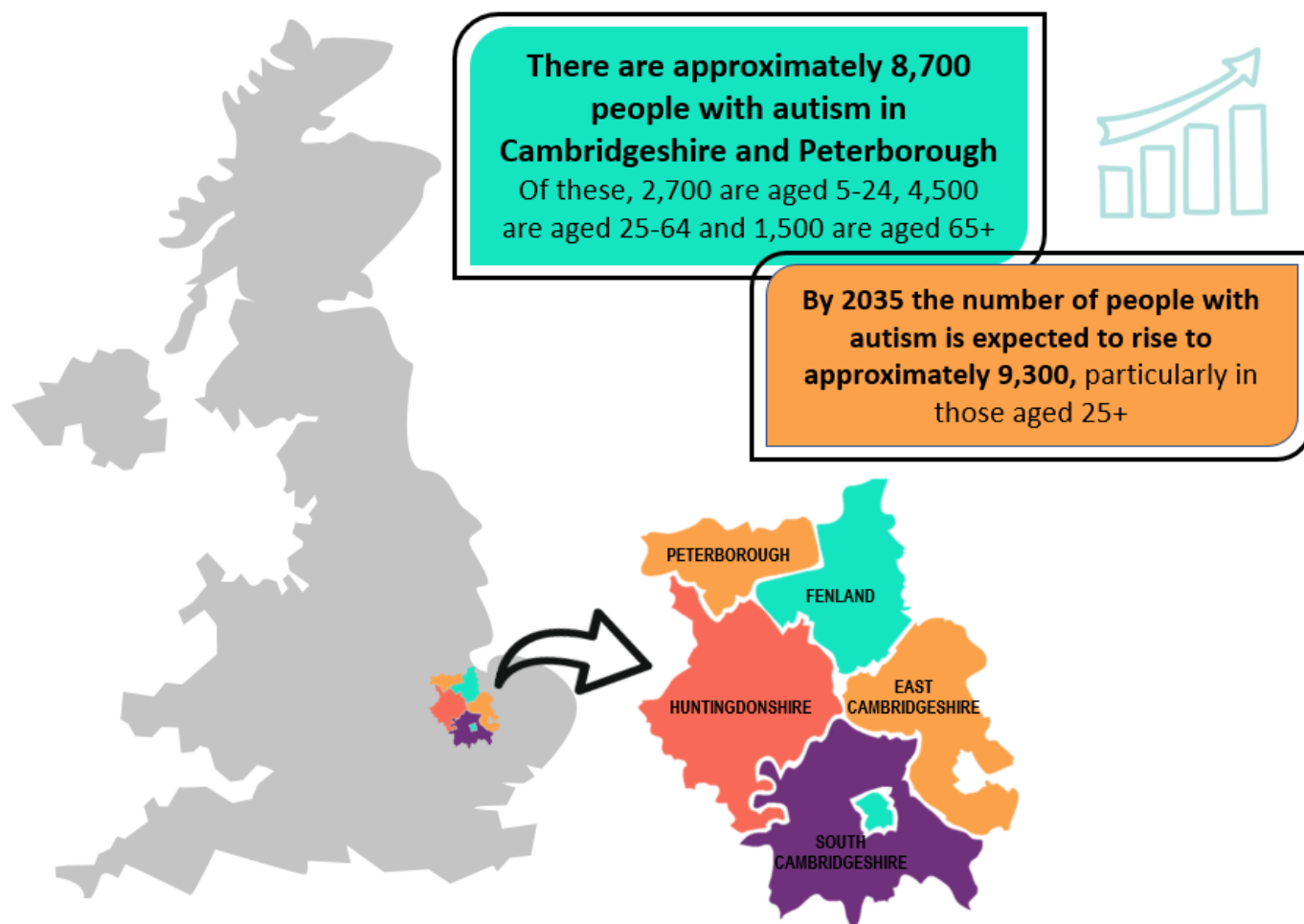
Key to the development of this All Age Autism Strategy has been mapping existing services to identify potential gaps, areas of good practice locally and areas for improvement; this has been informed by professionals, service users and their families and parent carer forums.

### NATIONAL CONTEXT



## LOCAL CONTEXT CAMBRIDGESHIRE AND PETERBOROUGH

Using national prevalence data applied to the local population numbers we estimate:



### CHILDREN AND YOUNG PEOPLE

#### Estimated Number of Children and Young People with Autism

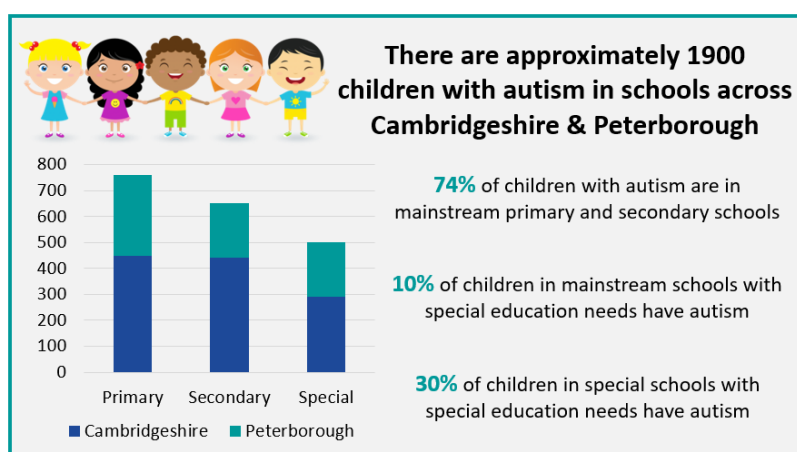
	5-10 year olds	11-17 year olds	18-24 year olds	Total
Cambridge	130	100	320	550
East Cambridgeshire	110	90	70	260
Fenland	100	90	90	280
Huntingdonshire	190	160	140	490
South Cambridgeshire	190	160	110	460
Peterborough	280	200	170	660
<b>Total</b>	<b>1000</b>	<b>800</b>	<b>900</b>	<b>2,700</b>

National prevalence estimates applied to mid-2019 population estimate, Office for National Statistics

## Predicted Increase in Children and Young People with Autism Based on Population Growth

		2019	2020	2025	2030	2035
CAMBRIDGESHIRE	5-10 years	720	720	680	640	620
	11-17 years	600	620	680	660	620
	18-24 years	730	720	710	800	830
	<b>TOTAL</b>	<b>2,040</b>	<b>2,060</b>	<b>2,080</b>	<b>2,100</b>	<b>2,070</b>
PETERBOROUGH	5-10 years	280	290	280	260	260
	11-17 years	200	210	260	260	240
	18-24 years	170	170	170	200	220
	<b>TOTAL</b>	<b>660</b>	<b>680</b>	<b>710</b>	<b>720</b>	<b>710</b>
<b>TOTAL</b>		<b>2,700</b>	<b>2,740</b>	<b>2,790</b>	<b>2,820</b>	<b>2,780</b>

National prevalence estimates applied to mid-2019 population estimate, Office for National Statistics



Using data from our local records we know that the percentage of pupils diagnosed with autism in primary schools is similar to the national average (1.1%) in Peterborough (1.1%) and lower than the national average in Cambridgeshire (0.9%).

Fourteen percent children and young people (5-18 years) also have a form of disability and this is slightly higher in Cambridgeshire (15%) compared to Peterborough (10%).

Thirteen<sup>10</sup> children and young people are on the Transforming Care Register (at risk of hospital admission). The majority of girls on the register have an eating disorder and are currently Tier 4 (hospital inpatients) residents and the majority of boys on the register have a challenging behaviour and live at home. All children and young people on the Transforming Care Register have autism. There are no children and young people on the Transforming Care Register with a learning disability and no autism diagnosis.

In Cambridgeshire, 30% of all community paediatric referrals are referrals for autism assessments.

In Peterborough around 50% of all community paediatric referrals are referrals for autism assessments. This is not directly comparable to Cambridgeshire as Peterborough provides

Approximately **800** children and young people are assessed for autism in Cambridgeshire each year

Most are seen within **18 weeks** of having a referral accepted

Only **30%** of assessments are females



<sup>10</sup> As at March 2021

service for all ages up to 18 as part of an integrated neurodevelopmental services with the child and adolescent mental health services.

## ADULTS

As shown in the below table, an estimated 6000 adults (25+ years) have autism across Cambridgeshire and Peterborough in 2020; this is expected to increase overtime in line with increases in population size to 6500 by 2035. Percentage of cases in the over 65s is set to increase from 25% to 32% by 2035 in line with population changes.

### Predicted Increase in Adults with Autism Based on Population Growth

		2019	2020	2025	2030	2035
CAMBRIDGESHIRE	25-34 years	852	850	818	778	805
	35-44 years	826	825	845	851	824
	45-54 years	910	900	847	832	860
	55-64 years	795	815	881	869	826
	65-74 years	664	664	668	787	824
	75+ years	520	542	674	749	835
	<b>TOTAL</b>	4567	4596	4733	4866	4974
PETERBOROUGH	25-34 years	314	313	294	277	286
	35-44 years	291	294	312	314	299
	45-54 years	260	261	263	276	293
	55-64 years	211	215	237	242	240
	65-74 years	161	163	170	193	211
	75+ years	120	124	153	174	198
	<b>TOTAL</b>	1357	1370	1429	1476	1527
<b>TOTAL</b>	<b>5924</b>	<b>5966</b>	<b>6162</b>	<b>6342</b>	<b>6501</b>	

Approximately 450 autism assessment referrals for adults are made each year, while only an estimated 130 diagnostic assessments take place each year.



The priority areas of this All Age Autism Strategy have been informed by the Autism Needs Assessment and what people with autism and their families have told us. Our priorities are:



### **PRIORITY 1: EARLY INTERVENTION**

Early identification and intervention are imperative for people with autism as research has shown that this can improve a child's overall development. Children who receive autism-appropriate education and support at key developmental stages are more likely to gain essential social skills and have better outcomes. Essentially, early detection can provide a child with autism with the potential for a better life. Parents of children with autism can learn early on how to help their child improve mentally, emotionally, and physically throughout the developmental stages.

The strain of caring for a child with autism can be an everyday challenge for families, but with early preparation and intervention, parents can prepare themselves for the road ahead, both emotionally and mentally.

When adults with autism are not diagnosed until later in life, they report a challenging childhood where many have not fitted into school, work and social settings and it's only after diagnosis do they understand why they had to face such challenges.

#### **WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US**

- *Early diagnosis is needed and early access to services when there is more than one diagnosis*
- *Parents don't know where to go to access the system*
- *Advice and help need to be easily available - I could access the local offer but advice on autism was hard to find*

- *I could not find much information on the local offer*
- *“I was under multiple doctors, Children and Adolescent Mental Health Services (CAMHS), admitted to mental health wards, attended a special school and yet I went completely under the radar.” (Young Adult)*

## WHAT WE WANT TO DO

We want a system that delivers good information and advice and clear signposting to early help when a parent carer feels they need support with:

- Services and support based on need and not reliant on a definitive diagnosis of autism or on a diagnosis pathway where early indications are recognised.
- Services that deliver a person-centered, whole system, all age approach that provides access to quality, timely and relevant information, advice and guidance in line with the statutory guidance and prevention agenda across children and adults services.
- That pre-school and education settings have appropriately trained staff that are sensitive to identifying early indications of autistic behaviors and putting in place pathways to facilitate efficient access to early support/advice.
- Ensure reasonable adjustments are made in pre-school, educational, employment and health settings.
- Work with adult services to ensure that all the traditional transition points in a person’s life are effectively managed and seamless.
- Deliver the right service at the right place at the right time to ensure timely interventions and prevents escalation of need.



**Deliver services in the right place at the right time**

## HOW WE WILL GET THERE

- All services will have appropriately trained staff that are sensitive to identifying early indications of autism.
- Our Local Offer<sup>11</sup> will have clear advice and guidance on where to get help, support and advice for parents of children with autism.
- Our diagnostic pathway for children and adults will look at good pre-assessment help, support and guidance to prevent escalation of needs.
- In line with the predicted population growth look at demand and capacity of the services to keep up the predicted need.
- Support parents and carers through the provision of parenting support and training programs.

<sup>11</sup> Peterborough Local Offer: <https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8>  
Cambridgeshire Local Offer: <https://www.cambridgeshire.gov.uk/residents/children-and-families/local-offer>

## PRIORITY 2: AWARENESS RAISING AND TRAINING

Improving training and awareness is at the heart of the national Autism Strategy. “[Think Autism](#)”<sup>12</sup> and “[Fulfilling and Rewarding Lives](#)”<sup>13</sup> states that increasing awareness and understanding of autism is fundamental towards improving services. Training and awareness raising is a key priority for all services across Cambridgeshire and Peterborough, including Education, Social Care, Health, housing, criminal justice system, local businesses and local government.

Whilst there are many good examples of effective support being provided by professionals for people with autism their experience varies from very positive to a feeling of constantly fighting the system.

Most areas agree that there is inconsistent knowledge and awareness of autism across the workforce. Communication from those across Health, Education and Social Care to people with autism which can be inconsistent and not tailored to their needs.

People can often be confused about the language used and what is meant by different terms. This confusion can extend to professionals themselves, who often use different terms for the same thing and who don't understand how other organisations work. Organisations do not always share information well with one another, meaning people must repeatedly share their stories.

### WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US

- *For all professionals in education, social care and health to understand what autism is, be able to identify potential signs of autism early and understand how needs may change with age and circumstances.*
- *Specialist training be given to staff that have key roles in assessment and identification to aid an earlier diagnosis of autism, including the assessment and diagnosis of autistic females.*
- *All staff working with people with autism to have basic knowledge and awareness of autism and training so that they can apply it to day-to-day life, roles and responsibilities.*
- *Co-production of the training and development that includes people with autism.*

### WHAT WE WANT TO DO

- For Cambridgeshire and Peterborough to become an ‘autism friendly community’ that values the contribution people with autism can make and ensures they get the same opportunities to live and work as the rest of the population.
- Work with all partners to raise awareness of the needs of people with autism and that the workforce is trained in autism appropriate to their role.
- Ensure that everyone understands ‘reasonable adjustments’ for those who also have a diagnosis of autism.
- Develop a training offer that links to other needs that may be present such as, but not limited to, mental health, learning disability and physical needs.

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<sup>12</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299866/Autism\\_Strategy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)

<sup>13</sup> [https://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](https://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

## HOW WE WILL GET THERE

- Develop an Autism Training Framework detailing the knowledge and skills required at different levels within the workforce to achieve key outcomes for people with autism.
- Use the Autism Training Framework to enable individual employees, service providers and organisations to understand the knowledge and skills required, how this applies to their practice and role.
- Co-produce training to ensure that the voice of parents, carers and people with lived experience of autism are reflected in all we do.
- Co-produce impact measures and regularly review progress with partners to ensure we are meeting the outcomes we aspired to.
- Ensure autism awareness training is included within general equality and diversity training programmes for all staff working in health and care and understand how to make reasonable adjustments in their behaviour communication and services for people with autism or who display these characteristics.

## PRIORITY 3: EMPLOYMENT AND INDEPENDENCE

The Office for National Statistics (ONS) published new data in February 2021 ([Outcomes for Disabled People in the UK: 2020](#)<sup>14</sup>) that shows just 22% of adults with autism are in any kind of employment, with only 10-15% being in full time paid employment. The most concerning part of the report states that of all people with disabilities, those with autism appear to have the worst employment rate. We know that, whilst not all people with autism are able to work, most want to and/or would like to know what opportunities/pathways are available to enter employment.

People with autism often have many unique skills and talents which employers could benefit from. These may include but are not being limited to:

- Excellent attention to detail
- Strong technical skills
- Methodical and logical approaches
- Creative thinking and problem solving
- Some will be exceptionally gifted and talented

OF ALL PEOPLE WITH  
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TO HAVE THE WORST  
EMPLOYMENT RATE

The [National Autistic Society](#)<sup>15</sup> highlights that most adults with autism who want to work encounter the following barriers:

- Inaccessible recruitment methods
- Lack of effective transition from education
- Lack of reasonable adjustments at interview
- Lack of reasonable adjustments in work
- Lack of employer awareness

With the pressure of COVID-19 being put on businesses across the UK and the implications of furlough schemes ending, there are significant challenges in the whole economy to maintain stable and high levels of employment. This is leading to an increasingly competitive job market and potentially making it harder than ever for people with autism to access paid employment.

### WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US



<sup>14</sup> <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020>

<sup>15</sup> <https://www.autism.org.uk/>

Between February 2021 and March 2021, Voiceability's Speak Out Council ran a consultation called "[My Life, My Future](#)"<sup>16</sup> and gathered feedback from over 100 people aged between 13-64 with a learning disability and/or autism in Cambridgeshire and Peterborough. They were asked:

- *What they would like to change, or do in the future?*
- *What support and information they feel they would need to make those changes?*

Of the 100+ survey responses, 44 people responded advising they would like to be in paid work and/or volunteering in five years' time. Some of those know exactly what they would like to do and how to train for it however most would like more information about how to find work.

Parents and carers were encouraged to take part in the survey, they provided the following feedback for consideration:

- *They would like to know more about supporting people to find a job.*
- *They would like more information about what happens when EHCPs finish at age 25 and support to plan for their young person's future.*
- *They would like clearer information about benefits.*



## WHAT WE WANT TO DO

- Support ways to improve employers' understanding of autism across all industry sectors.
- Work with key stakeholders to co-produce a framework for Supported Employment in Cambridgeshire and Peterborough.
- Ensure people with autism have access to a diverse range of employment opportunities in Cambridgeshire and Peterborough; keeping this in line with advancing technologies and what people with autism tell us they would like to do in the future.
- Ensure preparation for adulthood is included in all pathway planning. We need to have the right curriculum, which includes a clear focus on the development of the skills needed to live as independent and fulfilling life as possible. This would include skills and opportunities around employment.
- Ensure people with autism are supported to explore work experience, placements, paid employment and/or self-employment in Cambridgeshire and Peterborough.
- Support employers to be confident to employ people with autism and provide safe places to work.
- Attract new and innovative employers to Cambridgeshire and Peterborough to encourage new employment opportunities for people with autism.

<sup>16</sup> <https://www.voiceability.org/assets/download/210407-Speak-Out-Council-My-life-my-future-FINAL.pdf>



- Establish a toolkit for professionals that encourages them to consider/explore developing employability skills, outcomes and employment pathways when supporting people with autism.

## HOW WE WILL GET THERE

- Work together with key stakeholders to increase employment opportunities for people with autism in Cambridgeshire and Peterborough.
- Work with local employers to ensure they have access to good training and awareness of the needs of people with autism and listen to employers to understand Local Labour Market Information (LMI) themes and gaps as part of our [Skills Strategy](#)<sup>17</sup>.
- Increase the number of employers in Cambridgeshire and Peterborough who have signed up to become Disability Confident (a government scheme designed to encourage employers to recruit and retain people with disabilities and health conditions).
- Establish a sustainable pathway to employment for anyone with autism in Cambridgeshire and Peterborough to access work experience, placements, and paid employment opportunities.
- Pay attention to supporting young people with autism in their preparation for adulthood towards independence and employment. We are also working with our partners to support our schools with their Career strategy and the 8 benchmarks<sup>18</sup> which include employer engagement.
- Continue to commission services to support people with autism to access employment and will encourage all our employment related services to utilise the Autism Toolkit (for more detail refer to Priority 6).
- Encourage all organisations within our health and care system to offer internships and apprenticeships to people with autism.
- Ensure people with autism who want to access employment or self-employment opportunities have the information readily available and accessible to them to support their decision making.

<sup>17</sup> <https://mk0cpcamainsitehdbtm.kinstacdn.com/wp-content/uploads/documents/Strategies/skills-strategy/Skills-Strategy.pdf>

<sup>18</sup> <https://www.gatsby.org.uk/education/focus-areas/good-career-guidance>

## PRIORITY 4: HOUSING

As previously mentioned, there were an estimated 5966 adults with autism over 25 years of age across Cambridgeshire and Peterborough in 2020; this is expected to increase over time in line with increases in population size to 6501 by 2035. Percentage of cases in the over 65s is set to increase from 25% to 32% by 2035 in line with population changes.

We know that when people are not happy with where they live, they can be more likely to display behaviours which challenge; their physical and mental wellbeing can also be affected.

### WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US

In the consultation "[My Life, My Future](#)"<sup>19</sup> the feedback from over 100 people aged between 13-64 with a learning disability and/or autism in Cambridgeshire and Peterborough was:

- *people with autism want to have their own house or live independently with a partner or friends.*
- *People also raised the lack of technology support across supported living and care packages which meant that during the Covid-19 pandemic many people felt isolated and could not access online activities.*

### WHAT WE WANT TO DO

- Have a good understanding of our available housing options for people with autism.
- Work in partnership with District Housing colleagues so that people with autism have a clear offer and process for accessing housing when needed.
- Continue to develop and utilise our framework of specialist autism providers who can provide a range of accommodation with specialist support in Cambridgeshire and Peterborough.
- Have a minimum standard of housing for people with learning disabilities and/or autism with clear agreements of responsibilities from housing providers.
- Have a clear process for how people can raise concerns and move if they feel their current accommodation is no longer meeting their needs.
- Ensure people with autism and their families are able to make realistic choices about housing based on their needs, budget and options.
- Utilise the Autism Toolkit (for more detail see Priority 6) to encourage housing providers and placement providers for children, young people and adults work to ensure that their provision is accessible for those with autism, with an emphasis on communication and integration with other service provision.
- Ensure that all of the above actions are clearly outlined in a housing strategy.

### HOW WE WILL GET THERE

- Work in partnership with people with autism to understand their housing needs.

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<sup>19</sup> Speak Out Council (2021) <https://www.voiceability.org/assets/download/210407-Speak-Out-Council-My-life-my-future-FINAL.pdf>

- Undertake data analysis to ensure we can plan ahead and consider the housing needs of people with autism in Cambridgeshire and Peterborough.
- Work in partnership with health and social care professionals during the transition process to understand future housing needs of children, young people and adults with autism.
- Share information about housing options with children, young people and adults with autism and their families as part of the approach to preparing for adulthood so that people are clear about the process for applying for social housing and also consider other options which may be available to them.
- Work with the current housing and care providers to promote awareness and understanding of the needs of people with autism through use of the Autism Toolkit.
- Continue to develop and utilise our framework of specialist autism providers who can provide a range of accommodation with specialist support in Cambridgeshire and Peterborough.

## PRIORITY 5: CRIMINAL JUSTICE SYSTEM

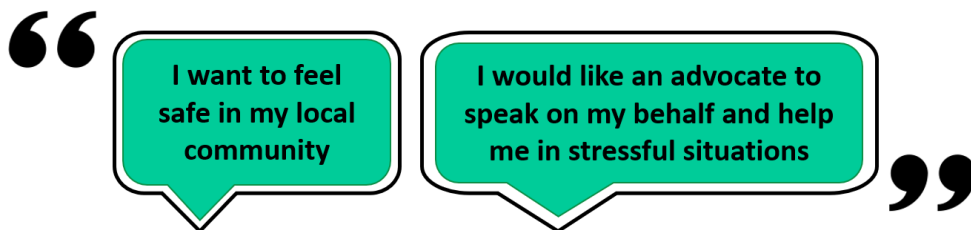
The 'criminal justice system' includes the police, courts, crown prosecution, prison service, related advocacy services and probation service.

The Office of National Statistics shows that autism and learning disability hate crime is now the most common form of disability hate crime which is officially reported.

Due to difficulties with communication some people with autism can be vulnerable to misunderstanding others' intentions and/or poor judgement. In addition, the behaviour and intentions of some people with autism may be misinterpreted by professionals who lack understanding or sensitivity.

We will work with the police and wider justice system to make sure they are aware of how to engage with people that have autism, victims and perpetrators of crime to improve the experiences of people with autism when they come into contact with the criminal justice system and the reduce the risk of offending and harm. We want to improve autism practice across every area of the criminal justice system with the aim to identifying the specific issues faced by people with autism.

### WHAT HAVE PEOPLE WITH AUTISM AND THEIR FAMILIES TOLD US



### WHAT WE WANT TO DO

- Support ways of working that improve understanding of autism across the criminal justice system.
- Ensure those in the criminal justice system have autism training appropriate to their role.
- Ensure people with autism are effectively supported if they come into contact with the criminal justice system.
- Ensure communities are friendlier and safer for people with autism that enable them to keep themselves safe and feel safe in their communities.
- Understand from youth offending teams what support is required for people with autism.

### HOW WE WILL GET THERE

- Work together with the criminal justice service to improve awareness, make reasonable adjustments and train staff to recognise people with autism and how to support their needs.
- Ensure that people with autism who are in the criminal justice system have good advocacy and support and reasonable adjustments are being met if appropriate.
- Provide people with autism with the help, advice, and guidance they need to keep themselves safe and they feel safe.
- Support a range of ways that informs professionals of specific individual needs for a person with autism if they wish to use it, such as:

- The Pegasus programme is a system adopted by the police locally to help improve public confidence and trust in the way the police interact with autistic and communication difficulties that enables timely and appropriate responses to any incidents that affect people with autism.
  - A health passport used in health settings to help professionals make reasonable adjustments for people with autism.
  - A sunflower lanyard or an awareness raising card that helps alert and inform professionals about what is important to that person, the support a person may need and how they may react in stressful situations.
  - Stay Safe Cards which tell people exactly what to do to help the person. This includes their name, the contact details of the person they need to get in touch with and what to do if you cannot get hold of them.
  - A 'safer place' is a local business or organisation that volunteers to be a designated place of safety for people seeking refuge in times of stress, threat or vulnerability. Safer places display stickers in their windows to tell people they are taking part in the scheme.
  - Understanding of autism and reasonable adjustments in Advocacy Services, Youth Offending Services, Courts, Court Liaison, Probation and the criminal justice system.
  - Develop a clear integrated forensic pathway to support people with autism at risk of offending, homelessness and substance misuse and in the criminal justice system.
  - Work in partnership with those who provide advocacy services.

## PRIORITY 6: JOINT COMMISSIONING OF SERVICES

We strongly support that services for people with autism should be inclusive, joined up and work smoothly and that commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population, and informed by people with autism and their families.

The Government Autism Strategy (2010) "[Think Autism](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)"<sup>20</sup> highlights the role local authorities and NHS bodies should have in making this happen for people with autism.

**“ Services for people with autism should be jointly planned, informed by data and feedback, commissioned, and reviewed annually ”**

In line with Central Government guidance, there are commissioning leads for autism in social care, education and health services across Children’s Commissioning, Adults Commissioning and the Peterborough Clinical Commissioning Group (C&P CCG). These lead commissioners work together to commission person-centred care that is coordinated across all relevant agencies.

C&P CCG and the Local Authority already have a commitment and a way of working that means co-production of commissioned services and strategies occurs routinely. Examples of this are our [SEND Strategy](https://www.cambridgeshire.gov.uk/asset-library/imported-assets/SEND%20Strategy%20-%20Final%20Nov%2019.pdf)<sup>21</sup> and the work we are doing through the Learning Disability Partnership.

However, we recognise we are on a journey and need to improve the experiences for people with autism locally.

### WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US

- *Avoid having different pathways across different services –children, young people and adults with autism need to be looked at holistically.*
- *Access needs to be easy to understand and be the same every time.*
- *Help families to understand and navigate provision following the diagnosis of a family member.*
- *Services need to be easy to navigate and more integrated.*
- *Remember that children, young people and adults with autism are human beings.*

### WHAT WE WANT TO DO

- Have an established Autism Toolkit that focuses on accessibility, quality, good outcomes and co-production for commissioned services for our services and meets out statutory duty for people with autism.
- Ensure Children’s and Adults Commissioners have developed mechanisms to review impact, on at least an annual basis, with local people with autism and their families.
- Continue to engage children, young people, adults and their parents and carers in feeding back regarding service provision; thereby helping to shape commissioning of services going forward and use the feedback mechanisms to review, develop and refine services to ensure they meet the aspirations of this All Age Autism Strategy.

<sup>20</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299866/Autism\\_Strategy.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)

<sup>21</sup> <https://www.cambridgeshire.gov.uk/asset-library/imported-assets/SEND%20Strategy%20-%20Final%20Nov%2019.pdf>



## HOW WE WILL GET THERE

- Continue to build upon the autism needs assessment to improve the data we collect and hold about children, young people and adults with autism to inform future joint commissioning arrangements.
- Continue to develop robust commissioning intentions for people with autism. These will be aligned with any future strategies so that, for example, an accommodation strategy will cover the needs of both adults with autism and adults with learning disabilities.
- Work together as a system (Health, Education Social Care, Children's and Adults Commissioners) with people with autism to improve awareness and recognition of autism and how to support their needs. This includes ensuring that any health or social care services we commission pay particular attention to the transition between children's and adults' services, and that there are no gaps where people are not eligible for a service because of their age.
- Commissioners across Children's Services and Adults' Services and the C&P CCG will develop an Autism Toolkit, enabling service providers to self-assess how they are accessible to children, young people and adults with autism.

## AUTISM TOOLKIT

The Autism Toolkit, as per Social Care Institute for Excellence (SCIE) [Guide for Commissioners of Autism Services](#)<sup>22</sup>, helps to ensure that:

- mainstream services are competent to support people with autism, with trained staff, and flexible processes.
- services are flexible enough to meet fluctuating support needs that can change from day to day.
- effective joint working exists between these services, and with health services.

The Autism Toolkit will link to a new Autism Training Plan, reinforcing the importance of autism awareness and ensuring that staff working across commissioned services are confident and knowledgeable about autism. This includes ensuring that staff working across Social Care, Education & Health can recognise autism and refer individuals to the diagnostic pathway and ensuring that those who require specialist training have access to it. This will help to establish autism-specific components to each provider's organisation infrastructure, irrespective of whether the service itself is autism specific, and therefore consider and monitor any changes to service delivery on service users with autism.

The intention is for the Autism Toolkit to be developed across non-commissioned services/other sectors, including:

- local businesses and employers
- voluntary sector
- blue light services and the judicial system

Alongside training, the Autism Toolkit focuses on integration of services, establishing links between services and supporting providers of services to consider/promote awareness of common co-occurring health issues within the autistic community.

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<sup>22</sup> <https://www.scie.org.uk/autism/adults/assessment-accessibility/commissioners>

A communications/marketing section has been incorporated into the Autism Toolkit to reflect the difficulties children, young people and adults with autism and their parent carers can have understanding the offer of support to them. In assessing how and where information about services is published, providers ensure that the navigation of services is easier for service users.

## PRIORITY 7: ACCESS TO HEALTHCARE

People with autism and their families in Peterborough and Cambridgeshire have reported how difficult it can be at times when they need to access healthcare settings such as going to their GP or dentist or going into hospital for a clinic appointment or medical procedure. Under the [National Health Service Act 2006](#)<sup>23</sup>, NHS bodies must have regard to the need to reduce inequalities between patients with respect to their abilities to access health services and reduce inequalities between patients.

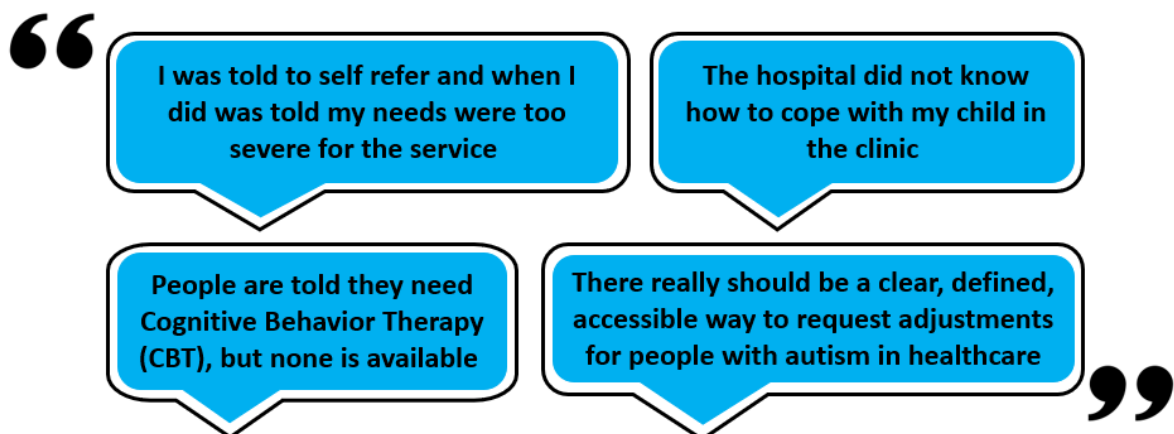
Children, young people and adults are more likely to have or develop mental health conditions, such as anxiety, obsessive compulsive disorder (OCD) and depression, than neuro typical people. Families highlight the need to have appropriate mental health services for people with autism and access to the right service at the right time, yet we know that many people with autism have poor experiences with mental health services. These include:

- *being unable to access services*
- *experiencing long waiting times*
- *finding the transition from children and young people's mental health services to adult mental health services difficult.*

The National Institute for Health & Care Excellence (NICE) [Quality Standard on Autism](#)<sup>24</sup> (2014) states that everyone who undergoes an assessment for autism should be assessed for any co-existing mental health problems. NICE also advise psychosocial and pharmacological interventions for the management of co-existing mental health problems in children, young people and adults with autism.

Early intervention services are crucial in supporting people with and their families with low level mild to moderate mental health concerns. Timely and effective early intervention lessens the chance of a person with autism and their families going into crisis.

### WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US



### WHAT WE WANT TO DO

- Mainstream health services such as GPs, dentists, optometrists, chiropractors need to make reasonable adjustments to ensure people with autism get access to the health support they need, in line with the national [NHS Long-Term Plan](#)<sup>25</sup> and NICE guidance.

<sup>23</sup> [https://www.legislation.gov.uk/ukpga/2006/41/pdfs/ukpga\\_20060041\\_en.pdf](https://www.legislation.gov.uk/ukpga/2006/41/pdfs/ukpga_20060041_en.pdf)

<sup>24</sup> <https://www.nice.org.uk/guidance/qs51>

<sup>25</sup> <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>

- We know that a holistic approach is needed for the assessment, diagnosis, treatment and management of support for people with autism. This should include clear pathways to access high quality mental health and wellbeing services with staff appropriately trained to deliver interventions that meet the needs of people with autism of all ages.
- Cambridgeshire and Peterborough's long-term plan is to have a joined up approach to address the emotional and mental health needs of children, young people and adults over the next five years and acknowledge that there are increasing numbers of people with autism who require mental health support (including those on the Transforming Care register).
- Within our commissioned mental health services across Cambridgeshire and Peterborough the C&P CCG and Local Authority will continue to ensure that people with autism receive high quality, equitable, planned and timely mental health support, while working towards an improved understanding of autism in primary and acute health settings to enable reasonable adjustments to deliver better health care.
- We want to work with healthcare settings to support appropriate training that helps services make reasonable adjustments to enable people with autism have more positive experiences in health care settings.
- Identify any opportunities to deliver yearly proactive health checks and screening for people with autism aged 14+ to enable the early identification of health needs.
- Early identification and response to support people with autism who have mental health needs within the community to prevent crisis and hospital admission.
- The Transforming Care programme focuses on prevention of admission and early discharge, and the C&P CCG is working to prevent crisis and unnecessary admissions to hospital by working together to find solutions that will enable people with autism to remain in the community or have as short a stay as possible when admitted to a hospital.
- The C&P CCG alongside Peterborough City Council (PCC) & Cambridgeshire County Council (CCC), are working to improve the ability of Mental Health services staff to recognise and respond appropriately to people with autism needs, ensuring they are better able to support their mental health and wellbeing needs.

## HOW WE WILL GET THERE

A new partnership has been set up to bring together mental and emotional health services for children and young people in Cambridgeshire and Peterborough. The partnership is made up of the two main mental health providers in Cambridgeshire and Peterborough; this includes the NHS's Cambridgeshire & Peterborough Foundation Trust (CPFT) and Cambridgeshire Community Services (CCS) NHS Trust. These providers will work alongside those within the voluntary sector; specifically, Centre 33 and Ormiston Families. Together, they will bring their expertise to help build relationships across our mental health and care system to ensure clinical services, voluntary organisations and local authority services work closer together to support children and young people and adults with their mental health and wellbeing. This partnership will be committed to investing more, and bringing services together so they are co-ordinated, equitable and easy to access for all people with autism and mental health needs.

As part of this new and improved modelling and support pathway, we will include appropriate psychological support for, and make reasonable adjustments to, mental health and wellbeing services for children and young people and adults with mental health needs.

- Ensure all providers of mental health services apply reasonable adjustments for people with autism to receive the right support including Child & Adolescent Mental Health Services (CAMHS) so that fewer people with autism access in-patient settings for long periods.
- Ensure that autism is recognised in the local Mental Health strategy and future service models which includes reasonable adjustments.
- Ensure that autism awareness and training is provided/encouraged to early intervention practitioners (Child Wellbeing Practitioners (CWP), Education Mental Health Practitioners (EMHP) and Mental Health Support Teams (MHST)).
- Ensure better information and signposting for people with autism and their family's pre-diagnosis in partnership with our Parent Carer Forums, Pinpoint and Family Voice.
- Ensure that when commissioning mental health services, these services can make reasonable adjustments and that their quality is monitored.
- Consider inclusion of special schools in each MHST cohort and enable the spread of learning of autism training provided by special school settings.
- In recognition that many children and young people with autism may also have additional needs such as emotional health and wellbeing we will develop specialist Enhanced Resource Provision (ERP) which provide additional specialist facilities on a mainstream school site for a small number of pupils jointly across health, education and social care. The pupils accessing ERP and Hubs usually have Education, Health and Care Plans (EHCP) as these specialist ERP/Hubs will tend to provide for a specific need such as Speech, Language and Communication Needs (SLCN), Hearing Loss (HL) or Visual Impairment (VI) or autism.
- Ensure better partnership working with school settings – ensuring all emotional health and wellbeing practitioners work in partnership to plan interventions.
- Ensure people with autism are supported in a smooth transition between children and young people mental health services to adult mental health services (taking into account children and young people with an EHCP and different pathway age limits).
- Ensure that advice and guidance provided on websites<sup>26</sup> is written in an accessible and reasonably adjusted way.
- Work together with acute services to look at pathways into hospitals for people with autism that ensures areas make reasonable adjustments and adopt a person centred approach with a range of information, such as health passports.

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<sup>26</sup> For example: <https://www.keep-your-head.co.uk/>

## PRIORITY 8: DIAGNOSTIC PATHWAYS

### CHILDREN

The National Institute for Health and Social Care Clinical Excellence (NICE) Guidelines for children with autism spectrum disorder<sup>27</sup> recommends that a diagnostic assessment should be undertaken by an autism team within 12 weeks of a referral. It recommends this team should include a range of specialists to inform their diagnosis and should be inclusive of education and social care where appropriate, and that everyone who undergoes an assessment for autism should also be assessed for any co-existing physical and mental health conditions.

In addition, it states that where the young person is transitioning to adulthood, it should be considered that a joint diagnosis assessment to be undertaken with adults' services for autism.

Clinical Commissioning Group (CCG) commissioners are expected to take the lead on the development of a local pathway for diagnosis working in partnership with the local authority to provide a joined-up integrated approach.

Our needs assessment supports the national picture that the diagnostic rate is much lower for females and that autism presents differently in girls and women "girls and women can present with a slightly different set of features and often work hard to mimic neurotypical children and adults" This has led to misdiagnosis and often, due to consistent behavior in various environments such as school or work, this has had a significant impact on family/carers.

### WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US

- *Early intervention and recognition could have prevented the trauma later caused*
- *Ensure that education and healthcare workers are aware of the typical signs of autism in females to ensure appropriate identification and referral*
- *"Mental health services are not picking up on autism in females"*
- *Early intervention: needs-led holistic support for children and families as well as building relationships and resilience in families and increasing capacity in assessment and post-assessment support courses*
- *Commissioning of services for children and young people requiring behavioural support and social skills/relationship*

**Children and young people's needs need to be treated holistically**

### CURRENT SERVICES

Locally parent carers and people with autism's experience of the diagnostic pathway is varied and ranges from very good to feeling they have to constantly fight the system.

We want to change this perspective by having a clear, evidenced based pathway for children and young people that meets NICE guidance.

<sup>27</sup> <https://www.nice.org.uk/guidance/cg170/resources/autism-spectrum-disorder-in-under-19s-support-and-management-pdf-35109745515205>

There are also different pathways to diagnosis across Cambridgeshire and Peterborough which sometimes leads to an inconsistent approach to early identification and pre and post diagnosis support.

### WHAT WE WANT TO DO

- Have a pathway that picks up autism early and provides the right support and diagnosis that delivers a consistent offer across the county.
- Develop a person-centered approach that includes a holistic assessment of needs including physical and mental health.
- Ensure our pathway links to all services, especially SEND and the Learning Disabilities Partnership.
- NICE guidance states those children and young people who have been referred to an autism diagnosis service will wait no longer than 18 weeks from referral to first appointment.

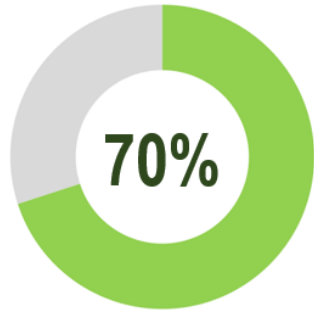
### HOW WE WILL GET THERE

- Develop a consistent integrated diagnostic pathway for people with autism across Cambridgeshire and Peterborough in line with NICE guidance, ensuring access to a multidisciplinary assessment of needs that can support the development of skills and opportunities to promote independence, as well as improved health and wellbeing outcomes.
- Advice and training to other health and social care professionals on the diagnosis assessment, care, and interventions for adults with autism (as not all may be in the care of a specialist team).
- Early identification, preventative (including post diagnostic) specialist care and interventions.
- Reduce the current waiting lists for an assessment in line with NICE guidance to 18 weeks for children and young people.
- Ensure we work closely with early help and support teams to identify needs early and provide the support needed.
- Look at joint assessments for people transitioning to adult services.
- Work closely with the Autism Centre of Excellence (ACE) to ensure we look at the latest evidence-based care.
- Work closely with parents, carers and organisations that represent them such as Family Voice, Pinpoint, Healthwatch and VoiceAbility as well as people with lived experience of autism to ensure we co-produce the diagnostic pathway and action plan and involve them in decisions regarding services for people with autism.

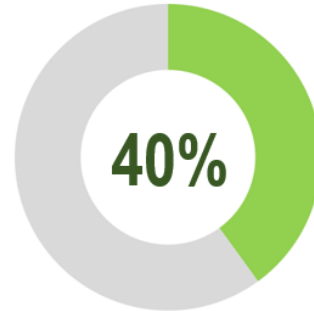
### ADULTS

There are approximately 6,708 adults with autism in Cambridgeshire and Peterborough. It is estimated that 40% of these people will be known at some point to health and social care services, and around 7% likely to require specialist or hospital services.

Our needs assessment show that the numbers are increasing and that people with autism (single and dual diagnosis) are among the most at risk in this rise in demand.



**of people with autism also have a mental health disorder**



**of people with autism have a dual mental health disorder**

### CURRENT OFFER

We have an excellent local adults Autism Diagnostic Service provided by Cambridgeshire and Peterborough Foundation Trust which is commissioned to provide specialist diagnostic assessments for adults with autism aged 18+, however it does not currently have the resources to meet the existing or projected increases in demand for assessments.

This is resulting in adults being referred for assessment for autism experiencing significant delays in getting a diagnostic assessment. In addition, the impact of COVID-19 created a large gap between demand and capacity combined with the lack of specialist intervention services lead to the adult autism diagnostic service been paused in March 2020.

There are currently also differences in service provision in health and social care across Cambridgeshire and Peterborough which has resulted in inequity of services for diagnosis and pre and post diagnosis support

### WHAT PEOPLE WITH AUTISM AND THEIR FAMILIES HAVE TOLD US

“

It is hard as a woman, people don't understand female autism or Asperger's

Trying to get a diagnosis as a woman can be terrible

I waited for over 2 years to be assessed

A lot of mental health conditions spring from being misunderstood

”

### WHAT WE WANT TO DO

- To provide a sustainable, person-centred system of Health and Social Care for people with autism across Cambridgeshire and Peterborough which delivers better access and improved experience and outcomes.
- Improve specialist diagnostic and assessment services to meet the predicted increases in demand for autism diagnoses.



- Improve our information, guidance and support service in the community to support adults with autism.
- Provide advice and training to other health and social care professionals on autism, the diagnosis and assessment processes and meeting needs for adults with autism and help early identification.
- Improve our pre and post diagnostic support offer to ensure information, advice and guidance is available in relation to mental health, housing, education, employment, and social care.

## HOW WE WILL GET THERE

We will work together as a health and care system in partnership with providers, and people with lived experience of autism to develop an integrated diagnostic pathway including an offer of both pre and post diagnostic support, information and advice and guidance.

We will invest in a range of interventions which are evidence based to develop and expand the existing CLASS service to include post diagnostic support, which will include:

- Psychoeducation and psychotherapy, either in a group or on line 1:1
- Sensory integration interventions
- Social communication interventions

We will work as a whole system to co-produce the post-diagnosis programme content and look to incorporate Local Authorities and Third Sector Voluntary Organisations expertise in terms of development and delivery.

We will work in partnership with other stakeholders and people with autism and their families to provide improved carer support, self-management interventions, peer support and ways of increasing independence.

By mapping the pathway as a whole system with the person at the centre of care, we hope to create a more integrated system to supporting people with autism, ensuring that they get the right support at the right time.

We will include appropriate psychological support for, and make reasonable adjustments to, mental health and wellbeing services for adults with mental health needs.

We will ensure we look at a whole pathway approach and link with adult services for autism to ensure transitions are carefully planned and form part of a lifelong approach that focusses on independence and opportunities to live and work locally.



## SUMMARY

This All Age Autism Strategy is the continuation of the journey to deliver good local services to people with autism and their families and meet statutory duties.

Together Cambridgeshire County Council, Peterborough City Council and Cambridgeshire and Peterborough Clinical Commissioning Group will work with local organisations and groups to co-produce and achieve the vision and outcomes together.

The county wide All Age Autism Strategic Group will lead on co-ordinating the implementation of the strategy across partners to achieve the outcomes and to provide clear, accountable leadership in collaboration with all partners with the responsibility, expertise and passion to take forward work together to improve outcomes, services and lives of people with autism and their families. This strategy is a living document that we will continue to use to review our progress and work with partners to deliver the outcomes that we want for people with autism and their families.



## REFERENCES

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“Autistic voices” Local people’s health experiences Healthwatch Cambridgeshire and Healthwatch Peterborough. Autism focus Group (May 2021)



## HOW TO TELL US YOUR VIEWS

You can share your views in a number of ways:

- Fill in the questionnaire found online on our website:  
<https://www.cambridgeshireandpeterboroughccg.nhs.uk/get-involved/consultations-engagement/all-age-autism-strategy-proposal/>
- Find more information, the full All Autism Strategy and The Autism Needs Assessment are on our website here:  
<https://www.cambridgeshireandpeterboroughccg.nhs.uk/get-involved/consultations-engagement/all-age-autism-strategy-proposal/>
- Email your views to us at: [autismstrategyconsultation@peterborough.gov.uk](mailto:autismstrategyconsultation@peterborough.gov.uk)
- Call us on 01733 863730
- This information is available in Easi Read with an Easi read questionnaire on our website here: <https://www.cambridgeshireandpeterboroughccg.nhs.uk/get-involved/consultations-engagement/all-age-autism-strategy-proposal/>
- Other languages and formats on request. To request alternative formats, please contact us at [autismstrategyconsultation@peterborough.gov.uk](mailto:autismstrategyconsultation@peterborough.gov.uk)

**The closing date for responses is Tuesday 19 October 2021.**