

# Coventry & Warwickshire

## Joint Strategy for Autistic people

### 2020-2025



**THIS IS A DRAFT DOCUMENT WHICH IS BEING SHARED FOR REVIEW**

**Coventry & Warwickshire  
Joint Draft Strategy for Autistic people  
2020-2025**

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## **Foreward**

TO be completed

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## Executive Summary

Autism touches the lives of many people living in Coventry and Warwickshire and can affect many aspects of life, from school to healthcare to employment, housing and social lives. As such, this Strategy takes an all age and whole life approach and encompasses children, young people, adults, older adults and their parents and carers with the following vision:

**Autistic people and their families are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents**

This is a joint five-year strategy which is owned by the following organisations:

- Warwickshire County Council
- Coventry City Council
- NHS Coventry and Rugby Clinical Commissioning Group
- NHS Warwickshire North Clinical Commissioning Group
- NHS South Warwickshire Clinical Commissioning Group

By making this a joint strategy between key statutory organisations, all partners will be equally responsible and accountable in improving lives of Coventry and Warwickshire citizens living with autism, and their parents and carers. An All Age Coventry and Warwickshire Autism Partnership Board will oversee the delivery of this strategy, comprising representatives from the social care, health and education sector, community and voluntary sector and primarily, autistic people, their parents and carers as experts in experience.

Being autistic does not mean you have an illness or a disease. It means your brain works in a different way from other people. Autism is not a medical condition with treatments or a “cure”, but autistic people often need support to varying levels across four main areas: social communication, social interaction, social imagination and sensory processing. There are positive aspects to autism including attention to detail; an ability to focus deeply and avoid distractions; keen observation skills; an ability to absorb and retain facts, linked to high levels of expertise in particular topic areas; unique thought processes and creativity leading to innovative solutions; tenacity and resilience; and integrity and honesty.

It is recognised that not all autistic people require support, and that many lead independent and fulfilled lives without any help from specialist statutory or community

services. This strategy will therefore build on existing skills and capabilities of autistic people and will advocate for a strength based and person centred approach.

There is currently no specific budget for coordinated autism services and support. The strategy must therefore be delivered in a way that ensures existing resources are used in the most cost-effective way, including promoting prevention and early intervention and making all existing services and pathways of support more accessible and effective for autistic people.

This strategy is informed by a range of co-production and mapping activity undertaken to build a shared understanding of the experience of autistic people of all ages and their families and carers in accessing support appropriate to their needs and getting a formal diagnosis of autism. A robust co-production approach will be used throughout all stages of Strategy delivery to ensure that we build on strengths, experience and voice of individuals with direct experience of using health and social care services in supporting them in relation to autism related needs. Parent and carers will be equally supported and will be recognised as experts in experience.

A Joint Strategic Needs Analysis for Autism and ADHD, completed in 2019, highlighted the challenges in understanding the true prevalence of autism in the population as there is no national register and data is not routinely captured about where autistic people access services. The JSNA highlights the inequalities in health, education and social outcomes of autistic people compared to non-autistic groups for almost all conditions studied including mortality, self-harm, suicide, obesity, smoking, bullying, social isolation, education, criminal justice, employment and homelessness. 80% of autistic adults and 70% of autistic children and young people will experience a mental health condition including anxiety or depression and there is more to be done to reduce the numbers of autistic people admitted to mental health hospitals. This joint Strategy is aimed at reducing inequalities experienced by autistic people by delivering a range of activities which improve their overall health and wellbeing outcomes.

This strategy incorporates the statutory duties outlined in the Autism Act, Care Act, Children and Families Act and the NHS Long Term Plan and builds on the previous Warwickshire All Age Autism Strategy (2014 -2017) 'Fulfilling & Rewarding Lives' and the joint commissioning plan developed by Warwickshire County Council and Coventry City Council in 2017.

Significant progress has been made in Warwickshire and Coventry since the previous strategy to develop diagnostic pathways for adults and children; pilot new support services for autistic people pre and post diagnosis and those in mental health crisis; improve support for young people in education with communication and sensory needs; and deliver autism training for parents, carers and the wider workforce. However, conversations with autistic people and their families revealed stories of autistic people struggling to cope with the stresses of daily life and of the effort it takes for individuals, their family members and professionals to understand how pathways

work and how to access the support they need and are entitled to. Particular issues highlighted through co-production include:

- There is an increasing demand for specialist autism services and in particular long waiting times for diagnostic assessments, which is further impacted by national workforce shortages in specialist autism roles.
- People with social, communication and sensory needs who are waiting for a diagnostic assessment are not getting the support they feel they need from services. Similarly, while a diagnosis is an important step in understanding the challenges they experience, a diagnosis alone is not sufficient to meet peoples' needs while there remain gaps in specialist support and in the capability of mainstream services to appropriately support autistic people. This is particularly a priority within mental health services and education.
- Support is not coordinated across services and people working in services often do not feel confident in their capability to effectively support and treat autistic people.
- Moving between different stages of life, such as school, college and work, is especially hard if you find change difficult, as many autistic people do<sup>1</sup>. Support for autistic people therefore needs to be prioritised around periods of transition.

Based on the evidence base gained through the coproduction and research activity, as well as statutory responsibilities for partner organisations, five priority areas have been identified.

**Priority 1: Support autistic people and people with social, communication and emotional health needs to help themselves pre and post diagnosis**

Improve early identification of characteristics linked to autism through wide ranging education and training and reduce the need for a diagnosis to access appropriate support. Provide information and advice to people with social, communication, sensory and emotional health needs in order to promote self-management, family resilience, independence and wellbeing.

Enable and empower people to develop their own solutions and networks of support in their communities through developing a better understanding of the third sector services people are using; enhancing peer support networks and facilitating information sharing.

**Priority 2: Reduce inequalities for autistic people and make Coventry and Warwickshire autism friendly places to live**

Improve the health and wellbeing of autistic people through developing autism friendly towns and cities in Coventry and Warwickshire, including taking action to ensure autistic people experience equality of access and inclusive services and support. We all want to live in communities that support each other, without

<sup>1</sup> <https://www.autism.org.uk/about/transition.aspx>

prejudice, to get the most out of our lives. Respecting human rights, citizenship and offering inclusive approach to all citizens must extend to everyone, including in access to education and employment, and autistic people as well as their parents and carers should be no exception.

Commission and deliver mainstream and specialist services in a way which does not restrict access nor exclude people on the basis of an autism diagnosis. It is the responsibility of all services to ensure accessibility and appropriate support for autistic people within their service, acknowledging that this may require training and development for the workforce.

**Priority 3: Develop a range of organisations locally with the skills to support autistic people**

Ensure that a wide range of organisations that can provide skilled support and services are available and accessible in local areas to meet the health, care and education needs of autistic people. Enhance the skills of our existing workforce to achieve more personalised support from services through an increased understanding of autism across the workforce, from awareness raising through to specialist autism expertise.

**Priority 4: Develop the all age autism specialist support offer**

Commission and deliver a coordinated and personalised offer of support for autistic people across all levels of need, promoting early intervention and enabling people to navigate this offer as their needs change. This includes redesigning the autism diagnostic pathway and focussing on all age pathways to better support transition from children's to adult's services.

**Priority 5: Co-produce, work together and learn about autism**

Co-produce solutions and services with autistic people and their families and collect and share the information that will enable us to learn and improve our offer to autistic people.

Evaluate the impact of Covid-19 on the lives of people with autism and commission services in the way that responds effectively to people's needs during and following the COVID-19 pandemic.

A number of objectives have been developed against each of the priority areas (see page 29). These Coventry and Warwickshire wide objectives will be underpinned with place-based delivery plans that will ensure this strategy is delivered within the local context of services and support and that it has an active life cycle.

# Introduction and Background

## 1. Introduction to the strategy

1.1 This is a joint Autism Strategy for adults, children and young people across Coventry and Warwickshire and is owned by the following organisations and partnership boards:

- Warwickshire County Council
- Coventry City Council
- NHS Coventry and Rugby Clinical Commissioning Group
- NHS Warwickshire North Clinical Commissioning Group
- NHS South Warwickshire Clinical Commissioning Group
- The Warwickshire Autism Partnership Board

1.2 All partners to this strategy are committed to commissioning high quality autism services and support and will work with partner organisations to improve the lives and opportunities for autistic children, young people and adults. This 5-year local strategy has been coproduced with support from a wide range of people, including autistic people and their families and people working in services and organisations that support autistic people.

1.3 The 2020-2025 Strategy builds on the achievements of the previous Warwickshire All Age Autism Strategy (2014 -2017) 'Fulfilling & Rewarding Lives' and the joint commissioning plan developed by Warwickshire County Council and Coventry City Council with the Warwickshire Autism Partnership Board in 2017.

1.4 It is recognised that not all autistic people require support, and that many lead independent and fulfilled lives without any help from specialist statutory or community services. The strategy is aimed at building a strengths-based approach and focusing on what people can do for themselves and where they want to get in life. Where they do need support, we will target it in the way that enables them achieve their goals.

1.5 There are many local schemes and services to support autistic people to achieve their goals, educate others about autism and make the community more accessible and welcoming to autistic people. The dedicated work of national charities and organisations and the many smaller local and national organisations and groups who work tirelessly to raise awareness day in and day out makes a real difference.

- 1.6 However, we know there is much more to be done. We still hear too many stories of autistic people struggling to cope with the stresses of daily life as well as navigating significant events such as moving schools, loss of friends or family and moving to a new house. We also hear about the huge amount of effort it takes (often over years) for individuals, their family members and professionals trying to understand how pathways work and how to access the support they need and are entitled to. We have heard stories about the years wasted while people wait to access support and, in the meantime, lose opportunities to achieve qualifications at school, the chance to live in a place they choose, work in a job that fulfils them and have fun with their friends and family.
- 1.7 It is recognised that autism sits on a spectrum and although autism is not a learning disability or a mental health condition, autistic people may also have these conditions. Equally, they may also have other physical conditions. This strategy focusses on principles that should be applied to everyone on the autistic spectrum. For those people with additional needs, this strategy should be read in conjunction with local strategies and action plans for:
- People with learning disabilities
  - Special Educational Needs and Disabilities (SEND) and Inclusion
  - Parenting, family and carer support
  - Coventry and Warwickshire health and care partnership system plan
  - Mental Health Transformation Plans for adults and CAMHS
- 1.8 Place based delivery plans will underpin this strategy, recognising different solutions may be required in different geographical locations across Warwickshire and Coventry. The delivery plans will describe specific commissioning activity to achieve the objectives outlined in this strategy to deliver services and support for autistic people and their carers between 2020 - 2025.

## **2. Co-production and strategy development**

- 2.1 This strategy is informed by a range of co-production and mapping activity which was completed in 2019 and 2020 which was undertaken to build our shared understanding of the experience of autistic people of all ages and their families in accessing support appropriate to their needs and getting a formal diagnosis of autism. A number of new services for autistic people have been piloted since 2018 and the learning from those pilots has contributed to the strategy.
- 2.2 Working with Grapevine, a local advocacy organisation, people with lived experience of autism, their families, as well as professionals, service providers and commissioners, we built a shared understanding of the challenges and

opportunities across the system to in supporting people with autism to stay live and remain well. Honest conversations were had around limited resources and challenges related to waiting for an assessment for a diagnosis, identifying what pre and post diagnostic support was available and whether it was meeting everyone's needs, what could be done to make things better and what could prevent needs escalating to the point where statutory services have to get involved.

### **3. What is Autism?**

3.1 Being autistic does not mean you have an illness or a disease. It means your brain works in a different way from other people. Autism is not a medical condition with treatments or a "cure", but some people need support to help them with certain things<sup>2</sup>. Autism is also referred to as Autism Spectrum Disorder (ASD), Autism Spectrum Condition (ASC) or Aspergers (used to describe people with above average intelligence). Autistic people often have other conditions, like Attention Deficit Hyperactivity Disorder (ADHD), anxiety or depression or epilepsy.

3.2 Think Autism, the National Adults Autism Strategy<sup>3</sup> defines autism as a lifelong neurodevelopmental condition that affects how a person communicates with and relates to other people. Autism also affects how a person makes sense of the world around them. Autism is often described as a 'spectrum disorder' because the condition affects individuals in many different ways and to varying degrees. Autistic people have difficulty to a greater or lesser extent with four main areas. The Autism Education Trust<sup>4</sup> highlights the importance for staff in schools and educational settings to understand and pay attention to this as most pupils with autism will have individual educational needs and a range of abilities across these areas:

- Social communication: for example, problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- Social interaction: for example, problems in recognising and understanding other people's feelings and managing their own feelings.
- Social imagination: for example, problems with predicting other people's intentions and behaviour and imagining situations outside their own routine.
- Sensory differences: Many autistic people experience some form of sensory oversensitivity (hypersensitivity) or under-sensitivity

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<sup>2</sup> <https://www.nhs.uk/conditions/autism/what-is-autism/>

<sup>3</sup> <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

<sup>4</sup> <https://www.autismeducationtrust.org.uk/what-is-autism/>

(hyposensitivity) for example to sounds, touch, tastes, smells, light or colours.

- 3.3 It is important to recognise there are positive aspects of autism, which underlines the importance of a strengths-based approach to this strategy<sup>5</sup>. This includes attention to detail; an ability to focus deeply and avoid distractions; keen observation skills; an ability to absorb and retain facts, linked to high levels of expertise in particular topic areas; unique thought processes and creativity leading to innovative solutions; tenacity and resilience; and integrity and honesty.
- 3.4 Individuals with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. People who struggle to deal with change or an overload of information are likely to become stressed or anxious, and possibly feel physical pain. This can result in some people behaving in ways which are perceived as challenging or complex.

#### 4. Terminology

- 4.1 Throughout this strategy, we will use the word **autism** and identity-first terminology (“**autistic people**” rather than “people with autism”) when referring to autistic people - children, young people and adults. This reflects research published in the Autism journal in 2015 which looked at the preferences of UK autistic community members – autistic people, their families, friends and professionals around the language used to describe autism<sup>6</sup>. Unless otherwise stated, reference to ‘autistic people’ or ‘an autistic person’ includes children, young people and adults of all ages across the autism spectrum at all levels of intellectual ability.
- 4.2 We recognise that some people prefer other terms and all workers should wherever possible find out the term(s) preferred by the person(s) they are working with and respect this.

#### 5. Vision

- 5.1 Coventry and Warwickshire have adopted the vision within the national strategy Think Autism (2014) as follows:

**“Autistic people and their families are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.”**

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<sup>5</sup> <https://autismawarenesscentre.com/the-positives-of-autism/>

<sup>6</sup> The National Autistic Society, the Royal College of GPs and the UCL Institute of Education

## **6. Purpose**

6.1 The purpose of this strategy is to provide a clear plan for support across Coventry and Warwickshire and identify priorities and objectives which reflect local need. The strategy aims to ensure autistic people and their families and carers in Coventry and Warwickshire have access to the support and information they need to enable them to:

- Achieve their full potential in education;
- Maintain, develop and enhance meaningful connections with family, partners and spouses and others that support their health and wellbeing, including carrying out their caring responsibilities;
- Be employed in jobs, undertake volunteering roles and supported internships that maximise their strengths and feel meaningful and important to them;
- Feel safe and able to belong and contribute to their local community in a way that works for them;
- Have a comfortable home and live in a way that maximises their autonomy and independence;
- Enjoy the benefits of good health (especially mental health) and wellbeing;
- Be well informed about ways to help themselves, navigate support and access help when they need it;

## **7. Key Strategy Principles**

7.1 This joint Strategy is aimed at reducing inequalities experienced by autistic people by delivering a range of activities which improve their overall health and wellbeing outcomes. Based on the evidence base gained through the coproduction activity, JSNA, service reviews and evidence of what works in other parts of the country, a number of key principles underpin the strategy.

7.2 The process of improvement is not within the gift of any one organisation, and requires joint ownership, commitment and leadership. All partners supporting this strategy are committed to reducing the gap between the support needed and the support currently available. This strategy outlines the areas of focus to make this happen.

7.3 Delivery of the strategy will continue to be driven through co-production with autistic people and their families to ensure solutions are accessible and meet needs. In the absence of national robust evidence detailing effective interventions and support for autistic people, there is commitment to testing

approaches based on best practice and learning from experts by experience and professional experts. Partners will work together to develop our understanding about what works for autistic people and their families.

- 7.4 There is currently no specific budget for coordinated autism services and support. The strategy must therefore be delivered in a way that ensures existing resources are used in the most cost-effective way, including promoting prevention and early intervention and making all existing services and pathways of support more accessible and effective for autistic people.
- 7.5 Many people with autism can work and have shared that they want to work. It is therefore imperative to find out what people's aspirations are and agree how we can help them achieve these, building on their existing skills and experience. Enabling more people with autism to access education and meaningful paid employment will contribute to their mental and social wellbeing, increasing confidence, self-esteem and friendship networks, as well as financial wellbeing
- 7.6 Parents and carers of autistic people will be recognised as expert partners in care and supported to deliver their caring responsibilities, acknowledging the importance of preventing carer breakdown and reducing the need for further services.
- 7.7 People will be enabled to develop their own solutions and networks of support through developing a better understanding of the third sector services people are using to effectively develop their own support networks and facilitate information sharing.
- 7.8 Mainstream and specialist services will be commissioned and delivered in a way which does not restrict access nor exclude people on the basis of an autism diagnosis. It is the responsibility of all services to ensure accessibility and appropriate support for autistic people within their service, acknowledging that this may require training and development for the workforce.
- 7.9 Closer partnership working between services involved in supporting autistic people and their parents and carers, such as Health Visiting service, School Nursing, Early Help support teams, education providers, diagnostic services, mental health support and community providers will be crucial to an improved experience for people with autism.
- 7.10 The wellbeing of autistic people depends on feeling accepted and understood in all aspects of their lives and the strategy includes a commitment to develop autism friendly local communities and services. The strategy aims to enable autistic people to access housing, employment, education and benefit from being involved in cultural, sport and leisure opportunities in an equal measure.
- 7.11 Equal opportunities and access to support that responds to the needs of autistic people from Black, Asian or minority ethnic backgrounds, as well as communities

described as ‘seldom heard’ LGBTQ+ communities, recognising that some studies suggest a higher percentage of autistic people identify as lesbian, gay, bisexual transgender or queer<sup>7</sup>.

7.12 The impact of Covid-19 on people’s ability to access care and support illustrated the need to commission differently, with a re-focus of provision, including digitalisation of practices and setting up new ways of working across all sectors. Robust infection prevention measures and social distancing rules mean that face to face contact can become restricted, and this Strategy will consider alternative but accessible ways of support.

## National and Local Context

### 8. National Context

8.1 This strategy is delivered within a context of significant reform within health and social care including the implementation of the Transforming Care Programme 2015 - 2019 following the horrific experiences of those living at Winterbourne View<sup>8</sup>; Building The Right Support 2015; The Care Act 2014<sup>9</sup>; The NHS Long Term Plan<sup>10</sup>; The Children and Families Act 2014<sup>11</sup> and the SEND code of practice all of which have a golden thread of personalisation, choice and empowerment and the delivery of support that promotes prevention and wellbeing running through them. It is therefore timely to present this Warwickshire and Coventry Autism Strategy to ensure that it reflects current national and local priorities. The Strategy is further shaped by a number of published reports included in Appendix X:

8.2 In April 2014 the government published ‘[Think Autism](#)’, a strategy for meeting the needs of autistic adults in England. The strategy supports the [Autism Act 2009](#). At time of writing this local strategy for Warwickshire and Coventry, the updated national Strategy for Autism is still in development and is likely to be delayed due to the current political landscape. We are confident that this Warwickshire and Coventry Autism Strategy will compliment and reflect the imminent national developments<sup>12</sup>.

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<sup>7</sup> [https://sparkforautism.org/discover\\_article/autism-lgbtq-identity/](https://sparkforautism.org/discover_article/autism-lgbtq-identity/)

<sup>8</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213215/final-report.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf)

<sup>9</sup> [http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga\\_20140023\\_en.pdf](http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf)

<sup>10</sup> <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

<sup>11</sup> [http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga\\_20140006\\_en.pdf](http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf)

<sup>12</sup> extract from election status and purdah

8.3 [Statutory guidance for local authorities and NHS organisations to support implementation of the Adult Autism Strategy](#) was published in 2015 and is reflected in this local strategy. This includes:

- Training of staff who provide services to adults with autism
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- Planning in relation to the provision of services for people with autism as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults with autism
- Preventative support and safeguarding in line with the Care Act 2014
- Reasonable Adjustments and Equality
- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity
- Employment for adults with autism
- Working with the criminal justice system

8.4 The Children and Families Act (2014) requires Local Authorities and Clinical Commissioning Groups (CCGs) to make provision for joint commissioning arrangements for education, health and care provisions for children and young people with Special Education Needs (SEN) or disabilities, including young autistic people. The Act and the SEND Code of Practice (2014) requires Local Authorities to identify all the disabled children and young people in the area, including those who may have SEN, and to publish and maintain a local offer that sets out the education, health and social care provision that the local authority expects to be available for disabled children and young people and those with SEN.

8.5 NHS Long Term Plan (2019) includes a specific focus on autism and learning disabilities. There is currently no clarity on how much funding will be made available to support delivery of the plan, but it is likely that any funding will be targeted at improving the offer of support for autistic people through the wider workforce. A key deliverable of the NHS Long Term Plan (2019) and Building the Right Support (2015), is a reduction in the numbers of children and young people with a learning disability and/or autism admitted to a mental health hospital. This has been known as the Transforming Care programme.

## 9. Local Context

9.1 The development of Coventry and Warwickshire's Autism Strategy 2020- 2025 is shaped by the following local policy framework:

- [Coventry and Warwickshire Health and Wellbeing Concordat](#)
- Coventry and Warwickshire Local Response to the NHS Long Term Plan for people with Learning Disabilities and Autism (2019)

- [Warwickshire county council one Organisation plan 2020](#)
- [One Coventry: Council Plan 2016-24](#)
- [Warwickshire SEND & Inclusion Strategy 2019-2023](#)
- [Coventry SEND Strategy 2019 to 2022 Lifting the Cloud of Limitation](#)
- [Warwickshire Learning Disability Statement of Intent “Its My Life” 2015-2020](#)
- Coventry Learning Disability/Autism Services Market Development Plan for Adult Care Services 2019-2022

9.2 It is helpful to reflect on the achievements of the previous Warwickshire All Age Autism Strategy (2014 -2017) ‘Fulfilling & Rewarding Lives’ and the joint commissioning plan developed by Warwickshire County Council and Coventry City Council with the Warwickshire Autism Partnership Board in 2017. There have been significant positive changes since the previous plans were written:

- The commissioning of a specialist neurodevelopmental service to undertake diagnosis of autism, ADHD and other co-occurring neurodevelopmental services. The service now delivers pre-school, school age and adults diagnostic pathways within one service. There has been work to streamline the diagnostic pathway and improve support pre- and post-diagnosis with the introduction of online education resources, the dimensions tools and group support.
- New services have been commissioned for autistic people, both to provide early help through community outreach and at the more complex crisis end through intensive support for young autistic people with autism which has had a significant impact on the numbers of young autistic people in CAMHS Tier 4 hospital beds. We have learned a lot from the services that have been commissioned and piloted over this period.
- The SEND and Inclusion programmes have increased the support available to those with social, communication and sensory needs in schools and specialist education settings, including some young people with an autism diagnosis. There has been significant work to reduce the need for a diagnosis to access appropriate support in schools.
- There is rising awareness of autism across services, and a range of training programmes delivered to staff from health, social care, education and the third sector to support autistic people. Parent training has been delivered to parents of young autistic people and autistic adults with very positive feedback.

- 9.3 However, despite considerable work to achieve the objectives agreed in the joint commissioning plan in 2017, autistic people are still not always able to access the support they need, hence the need for this refreshed strategy.
- 9.4 In line with the principles of joint working outlined in the Health and Wellbeing Concordat, a joint Coventry and Warwickshire integrated commissioning function was established in 2018, enabling a specific focus on autism which is coordinated across health and care commissioners for Coventry and Warwickshire.
- 9.5 Autistic people are supported through a variety of services in Coventry and Warwickshire. Some of these services are not designed specifically for autistic people. The services detailed in Appendix 1 are examples of the ones that are designed specifically to meet the needs of autistic people. The list is not exhaustive but represents the key services discussed in the coproduction activity.
- 9.6 The list of services highlights the fact that the majority of autism specific support across Coventry and Warwickshire is either pre-diagnostic or very soon after diagnosis, or very specialist support to prevent admission to hospital. Many of the services listed are pilots, with reviews planned to develop business cases for ongoing services. Through this strategy the development of pathways of support for autistic people will be coordinated.

## **10. Prevalence of Autism**

- 10.1 It is difficult to measure the prevalence of Autism as there have been inconsistencies in diagnosis over time and across locations. There is no register of people with Autism recorded nationally or locally and so the true number of people with Autism in Coventry and Warwickshire is not known. Pockets of information are available only when people with Autism use certain public services that record an Autism diagnosis as part of their administrative data, like adult social care; but most do not.
- 10.2 A Joint Strategic Needs Assessment (JSNA) for Autism and Attention Deficit Hyperactivity Disorder (ADHD) was completed for Coventry and Warwickshire in 2019. As there is no accurate local data, the JSNA applied national prevalence estimates of between 0.8 and 1.1% of the population<sup>13</sup>, suggesting there are an estimated 4,770 people living with autism in Warwickshire and 3,197 in Coventry<sup>14</sup>. Due to population growth alone, the total population of people with ASD is expected to rise slowly over the next 6 years to 4,894 in Warwickshire and 3,467 in Coventry by 2025.

Table 1 ASD predicted prevalence 2019, by district (all age)

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<sup>13</sup> [Warwickshire and Coventry Joint Strategic Needs and Strengths Assessment 2019](#)

<sup>14</sup> [Warwickshire and Coventry Joint Strategic Needs and Strengths Assessment 2019](#)

Area	Female	Male	Total
North Warwickshire	64	473	537
Nuneaton & Bedworth	131	951	1,082
Rugby	108	804	912
Stratford-on-Avon	127	912	1,039
Warwick	140	1,061	1,200
<b>Warwickshire</b>	<b>570</b>	<b>4,200</b>	<b>4,770</b>
<b>Coventry</b>	<b>367</b>	<b>2,831</b>	<b>3,197</b>
<b>Total</b>	<b>937</b>	<b>7,031</b>	<b>7,967</b>

10.3 Local data collected by the neurodevelopmental diagnostic service suggests that national prevalence may underestimate the true number of autistic people in Coventry and Warwickshire. National prevalence estimates indicate the numbers of children in Coventry and Warwickshire with Autism should be 673 and 990 respectively, giving a total of 1663 young people across the sub-region. Since April 2017, over 7000 referrals have been made to the pre-school and school age neurodevelopmental service. On average, the service diagnoses 70% of the young people referred. This would mean that there are potentially over 4,000 young people who have been diagnosed in the last 3 years alone across Coventry and Warwickshire.

10.4 This either means that national prevalence estimates are underrepresenting the true prevalence, or we have a higher prevalence locally, or the system is over responsive to potential autism. By including a key objective through this strategy to learn more about the needs of autistic people locally and where they access services and support we will be attempting to improve our data and understanding of prevalence. It is important to note that all of the people referred to the neurodevelopmental service represent people with social, emotional, sensory and/or communication needs that require support, regardless of their diagnosis.

## 11. Inequalities experienced by autistic people

11.1 Health, education and social outcomes of autistic people are worse than non-autistic groups for almost all conditions studied, according to key outcomes from the Liverpool John Moores review<sup>15</sup> into neurodevelopmental conditions in 2017 which are summarised in Table 1.

Table 1 Summary of health, education and social outcomes of autistic people<sup>8</sup>

Outcome*	Better	Worse	Unclear
Mortality			
Self harm and violence			
Suicide			
Obesity			
Smoking			
Bullying			

<sup>15</sup> [http://allcatsrgrey.org.uk/wp/download/disabilities/Liverpool-neurodevelopmental-needs-assessment\\_final-report\\_Jan17.pdf](http://allcatsrgrey.org.uk/wp/download/disabilities/Liverpool-neurodevelopmental-needs-assessment_final-report_Jan17.pdf)

Education			
Social isolation			
Criminal justice system			
Employment			
Independent living			

11.2 In addition to the above, research has shown that 12% of a group of people experiencing homelessness showed strong signs of autism<sup>16</sup>. It is likely that autistic people are not only more at risk of becoming homeless, but also more vulnerable once they are on the streets; they may also find it more difficult to move into new accommodation.

11.3 Autistic people nationally experience long waits for autism diagnosis. The NICE Quality Standard on autism states that the wait between referral and first diagnosis appointment should be no more than 3 months. Research in 2018 from Rt Hon Norman Lamb MP and the All-Party Parliamentary Group on Autism uncovered stark regional variation and long waits for autism diagnosis nationally, with many children waiting more than two years for a diagnosis.

11.4 A quarter of the general population have problems with their mental health at some point in their life. In autistic people, this number is much higher with almost 80% of autistic adults experiencing mental health issues during their lives<sup>17</sup>.



**50%**

More than 50% of autistic adults have had depression



**79%**

Mental health issues affect 79% of autistic adults, but many do not get the help and support they need



**9 x**

Autistic adults (without an intellectual disability) are over 9 times more likely to consider suicide than the general population

<sup>16</sup> Churchard, A., Ryder, M., Greenhill, A., & Mandy, W. (2018). The prevalence of autistic traits in a homeless population. *Autism*, 1362361318768484

<sup>17</sup> [Warwickshire and Coventry Joint Strategic Needs and Strengths Assessment 2019](#)



**40%**

40% of autistic people are diagnosed with an anxiety disorder but many more will experience symptoms of anxiety that affect how they live their lives



**42%**

Anxiety disorders affect 42% of autistic children compared with just 3% of children without autism

## 12. Financial Context

12.1 The Warwickshire and Coventry health and social care economy continues to face significant financial pressures. Prioritising need and demand continue to be a challenge within a finite financial envelope. At the time of writing there is no new ring-fenced budget for autism services and support. Therefore, this 5-year strategy's primary focus is to re-shape and re-design current support offers and services within existing financial resources to adults, young people and children with autism spectrum disorder (both diagnosed and undiagnosed). As a result, the delivery of objectives will be achieved by working collaboratively as partners to ensure best value is achieved in commissioned services; by prioritising early intervention and developing an offer of care and support that prevents escalation of need.

12.2 As outlined in the Joint Strategic Needs analysis, the data available on autistic people and where they access services is not readily available. The actual amount spent locally on support for autistic people is therefore also difficult to calculate, as people are supported by a wide range of services and there are no flags in information systems to identify autistic people, for example within mental health services. National estimates have been used to calculate the cost to the Coventry and Warwickshire system of supporting autistic people. Further work is required to identify and quantify the current cost of support for autistic people and to make the case for reducing the demand for specialist and crisis services through investing in early intervention and enablement.

12.3 A 2014 study into the average cost of supporting autistic individuals over their life course estimated the cost to be £1.5 million for someone with learning disabilities and £0.92 million for someone without (at 2011 price levels). Using the population prevalence figures included in the JSNA, this suggests the total cost of supporting people with autism in Coventry and Warwickshire is approximately £9,177 Million.

	<b>Estimated cost of supporting people with autism</b>
Warwickshire	£5,495 Million

Coventry	£3,682 Million
<b>Total</b>	<b>£9,177 Million</b>

12.4 Based on what we know about where autistic people access services, we can identify potential opportunities to reduce spend on high cost services (including mental health crisis and hospital services, residential care and high needs block education funding) through investing in earlier intervention, with almost two thirds of parents considering a lack of timely support as the reason for their child having higher long term support needs.

## **Key Issues Raised Through Co-production**

### **13. Increased demand for specialist autism services**

13.1 Current demand for an Autism diagnosis, as well as for pre and post diagnostic support, is far outstripping supply; resulting in long and growing waiting lists for children and adults.

13.2 New pilot projects are in place, and planned, to better support those on the waiting lists in school and at home, but they too are oversubscribed.

### **14. Reducing waiting times for autism diagnosis**

14.1 Merely redesigning the existing neurodevelopmental service, or investing in the current as is pathway to try and clear the backlog will not be a sufficiently transformational approach to deliver the required change. National workforce shortages mean that even where additional funding has been identified we have not been able to purchase sufficient additional capacity to meet the growing demand. The focus of redesign therefore needs to be on building capability and capacity across wider services to diagnose and support people with autism.

14.2 People who have autism and their families report that while a diagnosis is an important step in understanding the challenges experienced by their young person, a diagnosis alone is not sufficient to meet their needs while there remain gaps in specialist support and in the capability of mainstream services to appropriately support people with autism. This is particularly a priority within mental health services and schools. Any investment or redesign must prioritise support to meet the needs of people with autism, or characteristics that relate to autism.

14.3 System modelling undertaken in other parts of the country suggests waiting lists are most likely to be impacted through reducing demand for a diagnosis by improving access to support and services for people with needs related to autism without requiring a formal diagnosis. The most effective way to promote independence, reduce mental ill-health and maintain resilience is to give autistic

people personalised, responsive information, advice and support to navigate the most significant challenges they have. These challenges include managing anxiety, coping with transitions, navigating services and support, improving relationships with others, understanding themselves and solving problems.

People understood, it gave us a vocabulary to access support... and we stopped being offered parenting courses.

A diagnosis of autism is important but tells you very little about an individual or their family needs.

## **15. Gaps in early help and preventative services**

- 15.1 Families report gaps in adequate early help support for children and young people with autism, mental health needs and/or social communication needs. For example, there are limited resources in schools to enable identification and support for learners with social communication needs and social, emotional and mental health needs.
- 15.2 People with Autism and their families consistently stated that if there was more accessible support available early on, their needs would not have escalated to require specialist services. Parents understand that there are limited resources, but they want the system to balance investment of these resources along the whole pathway so that they don't have to wait until they are in crisis to get help.
- 15.3 There are protective factors which support autistic people and their mental health. These are similar to the support needed by all people in our community: family, friends, meaningful occupation and self-awareness. Autistic people and families want support to sleep and eat well, to access and sustain education and paid employment, to have secure housing, to have a social life and make friends, to have romantic relationships and maintain a family. Having interests and hobbies which give a person a sense of purpose and occupy them is key. Access to autism information relevant to their age is important.

## **16. Gaps in specialist services**

- 16.1 Following a diagnosis, there is limited specialist support for autistic people. Where pilots of specialist services have been successful, autistic people valued having an autism profile, shared across services, detailing their particular strengths and difficulties. Currently autistic people often access support from people with generalised non-specialist autism knowledge, or by people without any autism awareness or knowledge.
- 16.2 Gaps have been identified in access to interventions such as occupational therapy, speech and language therapy or family therapy prior to crisis point and

there is no access to ongoing mental health therapy or to psycho-education in relation to Autism needs. Autism friendly pathways in eating disorder services and services for people with gender identity issues are required.

16.3 Autistic people and families talked about wanting to access specialist support to help them understand the impact of their autism as they went through transitions, faced significant life events and as their needs changed. There are no opportunities to revisit the autism diagnosis as an older teen or adult, and update knowledge and self-awareness.

16.4 People working to support autistic people in services similarly identified a gap in specialist expertise that they could access to adjust care and support plans when people's needs change.

## **17. Support is not coordinated across services and services are difficult to access for autistic people**

17.1 Autistic people and their families want support to be based on their needs where health, education and social care work together to make things better for them. The complexity and lack of coordination of pathways and support across the system mean families (and professionals) are unable to navigate them to access the support they need.

17.2 Autistic people have experienced difficulties accessing services, using them and getting their needs met by them. They were not offered suitable adjustments to the services they used, making it more difficult to use the services and to benefit from them, and they moved through services at a faster pace than suited their ability and needs. Mental health services have not been designed with people with autism in mind and they may be excluded from support or provided with short-term help for problems which may be on-going and long term.

17.3 There is a lack of autism-specific and autism-friendly support. This reduced opportunities for social connection and a place to seek advice about what support is available. The systems across health, social care and education/training/employment are disconnected and their functions and access routes may not be well understood by the individual and their family and by the practitioners within other agencies. There is a need for training in relation to supporting people across all agencies.

## **18. Transitions**

18.1 Aligned strategies for young people and those with special educational needs and disabilities (SEND) highlight the importance of effective transition and preparation for adulthood. Moving between different stages of life, such as school, college and work, is especially hard if you find change difficult, as many

autistic people do<sup>18</sup>. Support for autistic people therefore needs to be prioritised around periods of transition.

## **19. Workforce gaps**

- 19.1 Parents reported that services could be better at making adjustments to support their autistic children to engage and access support, and professionals reported that they wanted to feel more confident and understand how they could be better at working with this group.
- 19.2 National workforce shortages exist for specialist autism expertise, which impacts on the ability of neurodevelopmental services to maintain capacity in services.

## **20. Support for those in contact with criminal justice system**

- 20.1 Multi-agency public protection arrangements (MAPPA) are in place to ensure the successful management of violent and sexual offenders. Locally, a growing number of people with characteristics related to autism are referred to MAPPA.
- 20.2 The Channel panel provides support to those who may be vulnerable to being drawn into terrorism. The overall aim of the programme is to facilitate multi-agency early intervention and divert people away from the risk they may face. Channel uses existing collaboration between partners to support individuals and protect them from being drawn into terrorism. Again, a growing trend has been identified of young autistic people who are referred to Channel panel for support.
- 20.3 There is an identified gap in specialist assessment and support for these individuals to inform multi-agency partners about the best way to support the individual and avoid re-offending. While this is a small number of people, the risks are high for the individuals concerned and in relation to public protection.

## **21. Mental Health Crisis and Admissions to Mental Health Hospitals**

- 21.1 Autistic young people 14-25 years old are being admitted to mental health hospital or diagnosed with autism in hospital. Deep dive reviews were undertaken to identify risk factors that contribute to hospital admissions for autistic people.
- 21.2 In the under 18 population, more people with autism and no learning disability are admitted to hospital. The following additional risk factors were also identified:
- Being out of school;
  - Older teenage girls who weren't identified as having behavioural problems;

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<sup>18</sup> <https://www.autism.org.uk/about/transition.aspx>

- Late (teenage) diagnosis of autism;
- A history of trauma (including bullying in school);
- Complex family dynamics including parental mental illness;
- Carer burnout;

21.3 For young autistic adults the following risk factors were identified:

- Adults with mental health diagnosis displaying risky behaviour;
- Autistic adults without a learning disability who do not meet Care Act eligibility and “fall between” services until they present to hospital or police services in mental health crisis;
- Inappropriate living environments, for example sharing with others who are not compatible;
- Significant and rapid changes and escalation in support needs that community living providers can't/won't support.

## 22. Good practice

22.1 People told us positive stories of what had helped, and they made suggestions about what we need to do more.

### *It helped when.....*

The psychiatrist listening to him thinking he had autism and getting a diagnosis fast.'

Professionals listening to us and treating us parents as experts on our child and asking us "What do you think should happen?"

Someone in the workplace who understands and can help make small changes. They made me realise I am human. They enhanced my good points and built on my skills.

### *We need more....*

A compassionate online friendship and family support (sometimes from people I barely knew) was vital in maintaining my well-being.

Peer support network from the earliest stages with trained experienced parent.

Support for parents accepting diagnosis and understanding their own traits.

Mentoring to help young adults and adults through transitions.

Online peer-support - particularly when people are housebound.

Ongoing support structure outside the NHS that adults with autism can access as needed.

Support and services working to the young person's timescales; not withdrawing because they haven't connected or responded in the given time, but allowing trust to build.

Someone who saw you and knows you are trying. Somewhere to signpost to when realise something wasn't working.

Inclusive practice and leadership in schools, community, youth settings.

Autism-specific emergency phone line for Young People and families who are in an autism crisis, not a mental health crisis.

Giving parents the tools and understanding to help their child early; face-to-face groups as well as resources, to avoid crisis situation.

## Priorities and Objectives

Based on the evidence base gained through the coproduction and research activity, as well as statutory responsibilities for partner organisations, five priority areas have been identified for the Coventry and Warwickshire Strategy. A number of objectives have been developed against each of the priority areas. These objectives will be underpinned with place-based delivery plans that will ensure this strategy is delivered within the local context of services and support and that it has an active life cycle.

### **Priority 1: Support autistic people and people with social, communication and emotional health needs to help themselves pre and post diagnosis**

Improve early identification of characteristics linked to autism through wide ranging education and training and reduce the need for a diagnosis to access appropriate support. Provide information and advice to people with social, communication, sensory and emotional health needs in order to promote self-management, family resilience, independence and wellbeing.

Enable and empower people to develop their own solutions and networks of support in their communities through developing a better understanding of the third sector services people are using; enhancing peer support networks and facilitating information sharing.

### **Priority 2: Reduce inequalities for autistic people and make Coventry and Warwickshire autism friendly places to live**

Improve the health and wellbeing of autistic people through developing autism friendly towns and cities in Coventry and Warwickshire, including taking action to ensure autistic people experience equality of access and inclusive services and support. We all want to live in communities that support each other, without prejudice, to get the most out of our lives. Respecting human rights, citizenship and offering inclusive approach to all citizens must extend to everyone, including in access to education and employment, and autistic people as well as their parents and carers should be no exception.

Commission and deliver mainstream and specialist services in a way which does not restrict access nor exclude people on the basis of an autism diagnosis. It is the responsibility of all services to ensure accessibility and appropriate support for autistic people within their service, acknowledging that this may require training and development for the workforce.

### **Priority 3: Develop a range of organisations locally with the skills to support autistic people**

Ensure that a wide range of organisations that can provide skilled support and services are available and accessible in local areas to meet the health, care and education needs of autistic people. Enhance the skills of our existing workforce to achieve more personalised support from services through an increased understanding of autism across the workforce, from awareness raising through to specialist autism expertise.

**Priority 4: Develop the all age autism specialist support offer**

Commission and deliver a coordinated and personalised offer of support for autistic people across all levels of need, promoting early intervention and enabling people to navigate this offer as their needs change. This includes redesigning the autism diagnostic pathway, developing specialist services and focussing on all age pathways to better support transition from children's to adult's services.

**Priority 5: Co-produce, work together and learn about autism**

Co-produce solutions and services with autistic people and their families and collect and share the information that will enable us to learn and improve our offer to autistic people.

Evaluate the impact of Covid-19 on the lives of people with autism and commission services in the way that responds effectively to people's needs during and following the COVID-19 pandemic.

DRAFT

**Priority 1: Support autistic people and people with social, communication and emotional health needs to help themselves pre and post diagnosis**

**Improve early identification of characteristics linked to autism through wide ranging education and training and reduce the need for a diagnosis to access appropriate support. Provide information and advice to people with social, communication and emotional health needs in order to promote self-management, family resilience, independence and wellbeing.**

**Enable and empower people to develop their own solutions and networks of support in their communities through developing a better understanding of the third sector services people are using; enhancing peer support networks and facilitating information sharing.**

This objective supports people with characteristics linked to autism to be able to find and use advice and information that helps them make the most of their strengths and pro-actively manage the challenges and barriers that they face. Information and advice needs to be available to everyone, regardless of their Autism diagnosis status. There is a lot of information and some useful tools and guides available, but people need to be supported to find this in one place with a way to filter the elements that will be most useful to them. The aim is to support all the services that are used by autistic people to better identify potential autism characteristics and provide useful and accessible advice and guidance. This is about supporting people with social, emotional and communication difficulties to get the information and support they need to continue to live a good life and achieve their goals without waiting until needs escalate or a person receives their diagnosis to offer support.

By enhancing support options available to parents and carers through the provision of appropriate and timely information and advice, commissioning of need based parenting training programmes, development of place based peer support groups as well as improving links with local carers support services, it is envisaged that people can access support which is tailored to their needs and enables parents and carers look after their autistic family members more effectively.

**I statements**

- I have the information and support I need in order to remain as independent as possible.
- I know where to get consistent, accurate and up to date information about what is going on in my community and where to access support for autistic people and their families.
- I can speak to people who know about care and support for autistic people and can make things happen for me or my family member.
- I have help to make informed choices if I need and want it.
- I don't have to wait until I have a diagnosis or am in crisis to get the help I need.
- The parenting support I receive is tailored to take account of my autism or my child's autism.

- I have a place I can call home, not just a ‘bed’ or somewhere that provides me with care.

### Priority 1 - What We Will Do

- 1.1 Spark community action to tackle isolation and loneliness, help people to self-organise and develop their own solutions. Identify existing and potential autism champions in the community and facilitate their support of others.
- 1.2 Promote the importance of early identification of needs related to autism to system partners: Schools, health visitors, nurseries, GP’s, mental health professionals, families and community centres; and provide information and advice about how to offer relevant support and adjustments for people with social, communication, sensory and emotional health needs.
- 1.3 Make useful information and tools readily available to people and families with needs related to autism, including self-management techniques relating to bullying, anxiety, sleep, social interaction, and sensory needs.
- 1.4 Improve the primary care support offer through working with new social prescribing and health and wellbeing roles in Primary Care Networks to develop autism awareness and networks of support, including identifying opportunities to support young adults transitioning from children’s services.
- 1.5 Increase the support available to people with characteristics linked to autism through the early help and enablement offer. This will maintain people in their own homes, in education and/or employment, in relationships with the people who are important to them and through transitions by connecting people with their communities and supporting them to try new social interactions and achieve their aspirations.
- 1.6 Deliver a mixed model of family and carer support for families and carers of autistic people to include conferences, peer support, autism specific parent training and parent coaches to harness the capacity of families and ensure the needs of autistic parents and parents and carers of autistic children are reflected in local parenting and carer strategies and offers.
- 1.7 Identify financial incentives for having an autism diagnosis and where possible adjust eligibility criteria to focus on need, not diagnosis.
- 1.8 Work with housing leads to raise awareness of autism, implement the Autism and Homelessness Toolkit<sup>19</sup>, review prioritisation criteria for housing to reduce reliance on the need for an autism diagnosis to access housing and ensure autistic people have access to accommodation that meets their needs.

<sup>19</sup> [https://www.homeless.org.uk/sites/default/files/site-attachments/Autism\\_Homelessness\\_Toolkit.pdf](https://www.homeless.org.uk/sites/default/files/site-attachments/Autism_Homelessness_Toolkit.pdf)

**Priority 2: Reduce inequalities for autistic people and make Coventry and Warwickshire autism friendly places to live**

**Improve the health and wellbeing of autistic people through developing autism friendly towns and cities in Coventry and Warwickshire, including taking action to ensure autistic people experience equality of access and inclusive services and support. We all want to live in communities that support each other, without prejudice, to get the most out of our lives. Respecting human rights, citizenship and offering inclusive approach to all citizens must extend to everyone, including in access to education and employment, and autistic people as well as their parents and carers should be no exception.**

We recognise that autistic people do not enjoy the same levels of physical or mental health as neurotypical people. This objective aims to ensure that autistic people in Coventry and Warwickshire live, work and go to school in autism friendly environments. We want to make sure that autistic people can access adjusted and accessible care and support. This objective is highlighting that it is the responsibility of everyone to ensure they design and deliver services that consider the needs of autistic people. Through development of Autism Friendly Communities, as well as autism related awareness raising resources and training options, it is intended that everyone will be able to access and benefit from being involved in cultural, sport and leisure opportunities in an equal measure. This objective includes working with the Criminal Justice service to reduce instances of 'hate crime', improve awareness and understanding of autism across the criminal justice system and support people with autism keep themselves safe and feel safe in their communities.

**I statements**

- I feel welcomed and included in my local community.
- I feel valued for the contribution that I can make to my school, workplace and community.
- I have the same opportunities as everyone else to train, study, work or engage in activities that match my interests, skills, abilities.
- I have access to a range of support that keeps me healthy, both mentally and physically, helps me to live the life I want and to remain a contributing member of my community.
- The people who support me understand my autism, accept me as I am and make efforts to communicate with me in ways that make it easier for me.

- The environments in which I work and access support are designed to make me feel safe and welcomed.
- I feel that my community is a safe place to live and local people look out for me and each other.

## Priority 2 - What We Will Do

2.1 Review service specifications for commissioned services and collect evidence that services and environments are being adjusted for people with autism and/or a learning disability and that personalised support is offered based on need not diagnosis.

2.2 Through the SEND and Inclusion agenda, promote and champion strong leadership and drive continuous improvement in inclusive practice for autistic children and young people across mainstream and special education settings. Particular focus needs to be given to how autistic young people with autism experience bullying and social isolation.

2.3 Ensure the mental health workforce have the required training, skills and confidence to recognise co-occurring Autism and choose and tailor interventions appropriately. Review risk assessments and develop pathways to more effectively identify and support autistic young people and adults. Consider use of screening tools for autism within mental health assessments for adults and children and ensure that IAPT services, eating disorder services, self-harm pathways and services for people with gender identity concerns include an accessible offer for autistic people.

2.4 Expand the work on reducing health inequalities for people with learning disabilities to include autistic people, including piloting annual health checks in primary care and ensuring there is an appropriate offer of support delivered following these checks within community and acute health services. *(linked to national pilot through Long Term Plan)*

2.5 Promote the benefits of employing autistic people through engaging employing organisations, people with autism and workplace mentors. Support employers and workplaces to become more autism friendly.

2.6 Strategy partners commit to learning from good practice around inclusion and lead by example by becoming autism friendly organisations and employers.

2.7 Develop and disseminate autism awareness training that focuses on practical ways to be autism friendly across community organisations, businesses, services and environments, including

- Education providers (schools, colleges and universities)
- Health service providers (primary care, acute)
- Social care support and housing providers, drugs and alcohol providers
- Police, criminal justice and probation services
- Community organisations, arts and leisure, businesses and public transport

2.8 Work with community and third sector organisations to maximise the potential for inclusive access to cultural, sports and leisure opportunities, including through the Coventry City of Culture activities in 2021.

### **Priority 3: Develop a range of organisations locally with the skills to support autistic people**

**Ensure that a wide range of organisations that can provide skilled support and services are available and accessible in local areas to meet the health, care and education needs of autistic people. Enhance the skills of our existing workforce to achieve more personalised support from services through an increased understanding of autism across the workforce, from awareness raising through to specialist autism expertise.**

This objective aims to ensure that where autistic people require support, that there is a choice of organisations and providers who can offer personalised, skilled and high quality support. Some services will be formally commissioned by statutory bodies and other support will be available through the voluntary sector and in local community networks. All of these services and support networks need to be connected to each other and the autistic community so they can meet the needs of autistic people. Where people are eligible for support through the local authority or the NHS we want to make sure there are providers available who specialise in supporting autistic people and who have an appropriately skilled workforce.

#### **I statements**

- I have a network of people who support me – carers, family, friends, community and if needed paid support staff.
- I have choice and access to a range of support that helps me to live the life I want and remain a contributing member of my community.
- I have care and support that is directed by me, responsive to my needs and helps me to live independently
- I am supported by people who help me to make links in my local community.
- I have considerate support delivered by skilled people who understand that I am autistic and how this affects me in different settings and in all aspects of my life.

<b>Priority 3 – What We Will Do</b>
3.1 Work with charities and other third sector organisations to map the support available for autistic people in local areas and strengthen the enablement offer by ensuring this community support is autism friendly.
3.2 Develop local specialist education provision to meet the needs of autistic young people with high support needs. This includes both school age and increasing local options for post 16 provision for autistic young people.
3.3 Develop the market for community and accommodation- based support for autistic people (including short breaks, respite, supported living and residential services) ensuring a personalised approach which promotes independence, autonomy and self-care
3.4 With housing leads and housing providers, develop suitable housing options to enable people with autism to live independently, supported by skilled staff where needed. This will include developing a joint approach to commissioning autism friendly physical environments, using tools such as NICE endorsed checklist, to respond to sensory needs of autistic people.
3.5 Connect organisations and people who provide support through regular conferences and training opportunities and develop pathways of support that are easy for people to navigate.
3.6 Develop a systemwide workforce development plan for autism, including identification of training needs within education, primary care, acute hospitals, mental health services, community services, and for unpaid carers and families and development of new roles.
3.7 Work with Universities and Colleges to include learning objectives relating to supporting autistic people in training programmes and professional qualifications for all health, social care and education staff groups.

#### **Priority 4: Develop the all age autism specialist support offer**

**Commission and deliver a coordinated and personalised offer of support for autistic people across all levels of need, promoting early intervention and enabling people to navigate this offer as their needs change. This includes redesigning the autism diagnostic pathway and focussing on all age pathways to better support transition from children's to adult's services.**

This objective is about ensuring that autistic people (or people who think they have autism) are able to access the right level of support at the time they need it. It aims to ensure the offer of support is based on what they say they need to live a good life and not about 'fitting' them into services that aren't suitable or accessible to them. We want to support autistic people when they need it rather than leave them until their needs escalate. The offer will promote early intervention and prevention, with the ability to escalate where required to specialist assessment, treatment and crisis support services. Capacity and capability to diagnose autism and adjust support plans appropriately will be built across services. A key principle in delivering this objective is the ability of front line staff from health, social care and education to work together to solve problems and arrive at pragmatic solutions supported by integrated teams and budgets.

#### **I Statements**

- I am in control of planning my care and support.
- I can access specialist support to help me to understand my autism and support me with my social, communication, sensory and emotional wellbeing.
- The support available to me to help with my autism is easy to understand and I have someone I can contact to help me get the right support when I need it.
- My support is coordinated, co-operative and works well together.
- I feel safe, I can live the life I want and I am supported to manage any risks.
- I can plan ahead and get extra help and support when my needs change and before I am in crisis.
- I am supported to manage my mental health so that I don't need to be admitted to hospital.

<b>Priority 4 – What We Will Do</b>	
4.1	Redesign the neurodevelopmental diagnostic pathway to address length of wait for diagnosis and ensure the pathway is co-produced with people and families on the waiting list in order to deliver the support they require to meet social, communication, sensory and emotional needs while awaiting a diagnosis. Build capacity and capability across existing services that work with children and adults, to support and undertake diagnosis.
4.2	Clarify where responsibility sits within social care and health services for care coordination for autistic people with no learning disability so that people do not fall between services. This will include clarifying responsibilities for transition from children's to adults' services.
4.3	Develop a "Keyworker" role which will remain a contact point for autistic people and families to help them to navigate the system and access extra support when they need it, including at times of transition between children's and adults services.
4.4	Develop an offer of specialist assessment and treatment in the community for autistic people with more complex needs. This will include a holistic assessment of needs and functioning and the development of an individual autism profile which will inform care and support plans. The service will deliver appropriate therapeutic interventions as well as provide a source of specialist advice for parents and care workers when changes to care and support plans are required.
4.5	Provide specialist and ongoing outreach support to autistic people who are in the criminal justice system or at risk of developing criminal behaviours to avoid them entering the criminal justice system or becoming victims of exploitation.
4.6	Ensure that the needs of autistic people are appropriately met within the development of New Care Models for mental health, eating disorders and CAMHS, including clarifying the pathway and offer of support for autistic people at risk of mental health crisis in order to prevent admission to hospital.

## **Priority 5: Co-produce, work together and learn about autism**

**Co-produce solutions and services with autistic people and their families and collect and share the information that will enable us to learn and improve our offer to autistic people.**

This objective makes a commitment to continue to improve the whole systems' care and support offer for autistic people by collecting the information that will make service planning and delivery the best it can be. Through cooperation and collaboration between partners we will align strategies that overlap and support the objectives in this strategy. This objective reflects our commitment to ongoing co-production with people with lived experience, including measuring the impact of the strategy on the lives of autistic people living in Coventry and Warwickshire.

### **I Statements**

- I am asked how services and support are working for me, my response is listened to and my communication needs are recognised.
- The organisations responsible for my support work together, learn from each other and coordinate their resources effectively.
- People supporting me collect and share information that helps them deliver the right services to me and plan for better services in the future.

<b>Priority 5 – What We Will Do</b>
5.1 Develop a system to enable a greater understanding of the numbers people in Coventry and Warwickshire who have an autism diagnosis, and where these people are in health and care services and their needs, to ensure future commissioning plans are informed by local demand and needs.
5.2 Continue to ensure that commissioning plans and the design and delivery of services are co-produced by people with lived experience of autism, including both specialist and mainstream services.
5.3 Identify links to the strategies in the following areas and ensure their outcomes will support people with autism: <ul style="list-style-type: none"> <li>• Parenting</li> <li>• SEND and inclusion, including further education</li> <li>• Mental health/CAMHS</li> <li>• Employment</li> <li>• Housing</li> </ul>
5.4 Work with commissioners and providers across the West Midlands and nationally to share best practice and learning about support and services for people with autism.
5.5 Collect and share learning across the system and enlist autism specialist organisations and universities to help us grow our evidence base of what good looks like for people with autism in line with national developments.
5.6 Work together to understand the true cost of supporting autistic people locally, and identify opportunities to pool budgets and invest in early intervention and prevention services to reduce spend on supporting autistic people in high cost specialist services.
5.7 Evaluate the impact of Covid-19 on the lives of people with autism and commission services in the way that responds effectively to people’s needs during and following the COVID-19 pandemic.

**Glossary**

Word	Meaning

DRAFT

## Appendix 1 – Autism Services and Pilots in Coventry and Warwickshire 2020

Support	Description	Service / Provision	Detail of Service offer
Mainstream School Support	Support School are able to access	Dimensions Tool	<ul style="list-style-type: none"> <li>• Free online mental health self-assessment tool developed by CWPT for professionals/parents to complete with a child.</li> <li>• Involves a number of questions which are rated to indicate how the child or young person is feeling.</li> <li>• The tool analyses the responses, and provides a report of the submitted answers for a professional/parent to use in supporting a child's mental health where necessary.</li> <li>• Depending on the young person's score, the tool may signpost on to relevant services.</li> </ul>
		Information and Advice (FAQs)	<ul style="list-style-type: none"> <li>• Frequently Ask Questions (FAQs) have been developed in partnership with CWPT and the CCG to provide parents / carers / schools with information and advice</li> </ul>
		Extended non-attendance at School (ENAS) - Pilot	<ul style="list-style-type: none"> <li>• Pilot project with a small number of schools across Coventry and Warwickshire</li> <li>• Pilot is a 3 cycle process: <ul style="list-style-type: none"> <li>✓ Cycle one provides a quick response for young people who have been out of school</li> <li>✓ Cycle two provides specialist support for children and young people, families and schools in understanding the needs of the autism through specialist occupational therapy support and interventions, educational psychology and complex communication specialist interventions.</li> <li>✓ Cycle three includes support available through statutory processes including EHC plans</li> </ul> </li> </ul>
		Traded Service offer	<ul style="list-style-type: none"> <li>• Offer to schools which consist of specialist teachers, educational psychologists and higher level teaching assistants (HLTAs) to address individual, group and whole-school needs.</li> <li>• Schools are required to buy in this offer (traded).</li> </ul>
		Early intervention and assessment offer	<ul style="list-style-type: none"> <li>• In Coventry <ul style="list-style-type: none"> <li>• offer to families and school settings from Educational Psychologists and higher level teaching assistants (HLTAs) to address individual, group and whole-school needs.</li> </ul> </li> <li>• In Warwickshire <ul style="list-style-type: none"> <li>• Delivery of Autism Education Trust training to schools free of charge</li> <li>• Assessment of communication and interaction needs, recommended provision and proposed outcomes as part of the Education, Health and Care statutory assessment process</li> </ul> </li> </ul>

Support	Description	Service / Provision	Detail of Service offer
Special school support	Support for young people whose needs cannot be met in mainstream school	Specialist Education Provision	<ul style="list-style-type: none"> <li>• In Coventry, service is available at 2 Enhance Resource Bases (attached to Aldermore Farm and Alderman's Green Primary Schools) a Special School for children with complex communication needs (The Corley Centre) and a range of broad-spectrum provision.</li> <li>• In Warwickshire, the satellite provision (Exhall Grange Learning Pod) is a therapeutic and nurturing environment which caters for the educational and psychological needs of its students. This six place learning environment caters for a group of vulnerable pupils who present with a combination of mental health difficulties and social communication needs (including those with Autism). The Exhall Grange Learning Pod allows the pupils to reengage with a mainstream curriculum in a sensitively adapted environment. Further to this, Warwickshire hosts ten special schools, supporting a range of needs including autism, and eight resourced provisions for communication and interaction needs.</li> </ul>

Support	Description	Service / Provision	Detail of Service offer
Pre and post Diagnostic Support	Support available to children and adults and their families on the waiting list for a diagnosis and immediately post diagnosis	GPs	<ul style="list-style-type: none"> <li>Support children and young people and their families to complete the Dimensions tool.</li> <li>Signpost children and young people onto appropriate services such as CAMHS to support their wellbeing.</li> </ul>
		VIBES	<ul style="list-style-type: none"> <li>A service in Coventry provided by CW Mind that provides: <ul style="list-style-type: none"> <li>✓ Support for children and young people with autism</li> <li>✓ Helps develop confidence, social skills, self-esteem and understanding of their own emotional health</li> </ul> </li> </ul>
		Community Outreach support for children, young people and adults	<p>Two services provided by CW Mind for children and adults that provides:</p> <ul style="list-style-type: none"> <li>Targeted outreach community support to children, young people, adults and families who are on the waiting list for an autism diagnosis, or who have had a diagnosis.</li> <li>Focused and practical support to the child, young person or adult and their family around sensory integration and processing, behaviour, boundaries and routines, understanding and communicating feelings, managing relationships, eating and sleeping. This could be provided within the home, a community setting or school.</li> <li>1:1, paired or small group support to children and young people or adults with a diagnosis of autism.</li> <li>Parent coaching with development of a network for peer to peer support</li> </ul>
		Website	<ul style="list-style-type: none"> <li>Coventry and Warwickshire RISE website <a href="https://cwrise.com/parent-and-carer-resources">https://cwrise.com/parent-and-carer-resources</a> provides a lot of useful information and resources available pre-assessment and post diagnostic</li> </ul>
		Neurodevelopmental service	<p>A service provided by CWPT that provides</p> <ul style="list-style-type: none"> <li>Diagnostic assessments for autism, ADHD and other neurodevelopmental conditions across pre-school, school age and adult pathways</li> <li>Online information sessions for individuals, parents and carers, whilst waiting or following a diagnosis</li> <li>Post diagnostic education sessions for parents / carers and/or child groups to provide support around understanding neurodevelopmental disorders.</li> <li>Ongoing support for people with ADHD to manage their medication</li> </ul>
		Parent Training	
Together with Autism Conference			

Support	Description	Service / Provision	Detail of Service offer
Specialist and intensive support	Support to those at risk of admission to hospital	Intensive Support Service for children and young people	<ul style="list-style-type: none"> <li>• Assessment, treatment and support for children and young people who display behaviour that challenges</li> <li>• Provision of support, and person specific training for other agencies supporting those individuals</li> <li>• Coordination of transitions from inpatient and other settings</li> <li>• Autistic young people in mental health crisis are referred to the intensive support service where appropriate for further intervention and support.</li> </ul>
		Adult autism specialist pilot	<ul style="list-style-type: none"> <li>• Pilot for a small sample of autistic adults at high risk of admission.</li> <li>• Specialist autism expertise used to create an individual autism profile by working with an individual and family/carers, illuminating strengths and difficulties and providing an opportunity to educate.</li> <li>• The profile has the potential to support access and use of services in health, social care and education.</li> </ul>
		Care (Education) and Treatment Reviews	<ul style="list-style-type: none"> <li>• Autistic people at risk of admission to mental health hospital are referred to the Autism and Learning Disability Admission Avoidance Register.</li> <li>• A Care and Treatment Review (CTR) is a meeting to check that a person's care and treatment is meeting their needs. A CTR may be held for anyone with learning disabilities, autism or both who may be at risk of admission to, or who is already in, a specialist learning disability or mental health hospital.</li> <li>• There are two versions of the Care and Treatment Review. One is for adults and is still known as a Care and Treatment Review (CTR). The other is for children and young people and is called a Care, Education and Treatment Review (CETR). Each has its own code and toolkit.</li> <li>• The review is led by the responsible commissioner with support from two independent expert advisers whose role is to bring an additional challenge and an alternative perspective. The review team makes recommendations to improve the individual's care with follow-up checks to ensure this is happening.</li> </ul>

## **Appendix 2 Policy documents and reports used to develop the strategy**

- Autism dividend; Reaping the rewards of better investment, National Autism project, 2018
- Improving lives: the future of work, health and disability, 2017
- Autism in adults Evidence Update May 2014. National Institute for Health and Care Excellence (NICE) guidelines, 2014
- Autism: recognition, referral, diagnosis and management of adults on the autism spectrum. NICE, 2012
- Autism spectrum disorder in under 19s: recognition, referral and diagnosis NICE guidelines, 2011
- National Autistic Society Statistics: how many people have autistic spectrum disorders?, 2011
- Transforming Care: A national response to Winterbourne View Hospital, 2012
- Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey ,2009.
- Green Light Toolkit, 2013