
To: Health and Social Care Scrutiny Board (5)

Date: 1st December 2021

Subject: Coventry and Warwickshire All Age Autism Strategy 2021-2026

1 Purpose of the Note

- 1.1 Local Authorities and CCGs have statutory responsibilities to support autistic people as outlined in the Autism Act 2009, Equality Act 2010, Care Act 2014, Children and Families Act 2014, SEND code of Practice 2014 and NHS Long Term Plan 2019. In recognition of these statutory responsibilities and the inequalities faced by autistic people, the Coventry and Warwickshire Collaborative Commissioning Board approved the development of a joint all age strategy for autistic people. This is a joint five-year strategy which is owned by the following organisations:
- Warwickshire County Council
 - Coventry City Council
 - NHS Coventry and Warwickshire Clinical Commissioning Group
- 1.2 The Strategy builds on the previous joint commissioning plan developed by Warwickshire County Council and Coventry City Council in 2017. Publication of the local strategy was delayed while the national strategy was being developed, however, work has continued to work towards delivery of the strategy in the meantime. Significant progress has been made since the previous joint commissioning plan 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, autistic people continue to experience inequalities due to gaps in services and support, hence the need for this strategy.
- 1.3 This autism strategy is informed by a range of co-production and mapping activity which was completed in 2019 and 2020 with experts with lived experience and key professionals, 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. An accessible & easy read version of the strategy is being developed and will be published following sign off of this Strategy.
- 1.4 The strategy gives the overarching objectives for the next 5 years. These will be delivered in a coordinated way across Warwickshire and Coventry and some elements will be delivered differently in the different places to take account of the different services and communities across the area.
- 1.5 In line with the Coventry and Warwickshire Special Educational Needs and Disability (SEND) and Inclusion Strategies, the Autism Strategy emphasises the importance of promoting inclusive practice and supporting young people to access their full potential through education. Delivery of the strategy will therefore be aligned with the Warwickshire

SEND change programme and the Coventry SEND Strategy 2019 to 2022 'Lifting the Cloud of Limitation'.

- 1.6 The new national Autism Strategy (2021-2026) launched in July 2021 builds on the previous national Strategy's pre-existing duties placed on commissioners and service delivery providers in relation to adults; and through the SEND Code of Practice in relation to children and young people. Overall, there is close alignment between the local and national strategies, although the priorities are described differently between the two documents.
- 1.7 A year 1 strategy delivery plan has been developed to describe activities that have been initiated while waiting for the publication of the national strategy. Priorities identified within this plan are funded and are deliverable. The year 1 plan focusses on reducing waiting times for a diagnosis and pre and post diagnostic support, as well as reducing the numbers of autistic people admitted to MH hospitals. In year 2 priorities will reflect the wider scope beyond health, social care and education.
- 1.8 In reflecting on the national strategy priorities, there is the opportunity to strengthen the focus on workforce development in our local delivery plan for year 2 and building the links with education, criminal justice, and public health as well as with our own organisation's employment practices in promoting the employment of autistic people. For example, greater consideration needs to be given in the local delivery plan to improving the experience of autistic people in accessing public transport and advocacy services and improving support in and environments of services working with autistic people.

2 Recommendations

- 2.1 Health and Social Care Scrutiny Board (5) and Education and Children Services Scrutiny Board (2) are requested to:
 - (i) Consider the report and submit any comments to Cabinet for their consideration on the content of the strategy

3 Information/Background

- 3.1 Local Authorities and CCGs have statutory responsibilities to support autistic people as outlined in the Autism Act 2009, Equality Act 2010, Care Act 2014, Children and Families Act 2014, SEND code of Practice 2014 and NHS Long Term Plan 2019. A new national strategy for autistic children, young people and adults was published in July 2021. In recognition of these statutory responsibilities and the inequalities faced by autistic people, the Coventry and Warwickshire Collaborative Commissioning Board approved the development of a joint all age strategy for autistic people. This is a joint five-year strategy which is owned by the following organisations:
 - Warwickshire County Council
 - Coventry City Council
 - NHS Coventry and Warwickshire Clinical Commissioning Group

4 Options considered and recommended proposal

- 4.1 Autism is a term used to describe a neurological difference in brain development that has a marked effect on how a person develops. 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.

- 4.2 Autistic people have strengths over those without autism. For example, strong attention to detail and an ability to see patterns in data that can bring many advantages. Not all autistic people require support and 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.
- 4.3 The difficulties autistic people experience with communication, interaction and social imagination lead to inequalities in health, education and social outcomes for autistic people compared to non-autistic groups for almost all conditions studied. This includes mortality, obesity, smoking, bullying, social isolation, education, criminal justice, employment and homelessness. 80% of autistic adults and 70% of autistic children will experience mental health conditions including anxiety and depression, leading to higher rates of self-harm, suicide and admissions to mental health hospital. In Coventry, the largest proportion of children and young people with Education Health and Care Plans have a primary need of Autism. 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.
- 4.4 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 applied national prevalence estimates of between 0.8% and 1.1% of the population¹. This would suggest that in 2020 there are an estimated 4150 people living with autism in Coventry. Due to population growth alone, the total population of autistic people is expected to rise slowly over the next 6 years to 4,870 in Coventry by 2025.
- 4.5 Local data collected about referrals to the neurodevelopmental diagnostic service suggests that national prevalence may underestimate the true number of autistic people in Coventry and Warwickshire. 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. National autism charities such as the National Autistic Society suggest the true prevalence could be closer to 2%. 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.
- 4.6 The joint All Age Autism Strategy for Coventry and Warwickshire 2021-26 is informed by a range of co-production, engagement and mapping activity as outlined in section 3. The strategy gives the overarching objectives for the next 5 years. These will be delivered in a coordinated way across Warwickshire and Coventry and some elements will be delivered differently in the different places to take account of the different services and communities across the area.
- 4.7 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. A number of objectives have been developed against each of the priority areas:

Table 1. Coventry and Warwickshire All Age Autism Strategy Priority Areas and Key Objectives

Priority Area:	Key Objectives:
Priority 1: Support autistic people and people with social, communication and emotional	Improve early identification of characteristics linked to autism through wide ranging education and training and reduce the need for a diagnosis to access appropriate

¹ [Warwickshire and Coventry Joint Strategic Needs and Strengths Assessment 2019](#)

<p>health needs to help themselves pre and post diagnosis</p>	<p>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.</p> <p>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.</p>
<p>Priority 2: Reduce inequalities for autistic people and make Coventry and Warwickshire autism friendly places to live</p>	<p>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.</p> <p>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.</p>
<p>Priority 3: Develop a range of organisations locally with the skills to support autistic people</p>	<p>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.</p> <p>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.</p>
<p>Priority 4: Develop the all age autism specialist support offer</p>	<p>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.</p>
<p>Priority 5: Co-produce, work together and learn about autism</p>	<p>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.</p>

4.8 The new national Autism Strategy (2021-2026) launched in July 2021 builds on the previous national Strategy's pre-existing duties placed on commissioners and service delivery providers in relation to adults; and through the SEND Code of Practice in relation to children and young people. The new strategy introduces a new element of identification and provision of support to autistic adults in accordance with relevant legal duties.

- 4.9 Overall there is close alignment between the local and national strategies, although the priorities are described differently between the two documents. A year 1 strategy delivery plan has been developed for 2021/22, in line with the approach in the national strategy. Priorities identified within this plan are funded and are deliverable. The year 1 plan focusses on reducing waiting times for a diagnosis and pre and post diagnostic support, as well as reducing the numbers of autistic people admitted to MH hospitals. In year 2 priorities will reflect the wider scope beyond health, social care and education.
- 4.10 In reflecting on the national strategy priorities, there is the opportunity to strengthen the focus on workforce development in our local delivery plan for year 2 and building the links with education, criminal justice, and public health as well as with our own organisation's employment practices in promoting the employment of autistic people. For example, greater consideration needs to be given in the local delivery plan to improving the experience of autistic people in accessing public transport and advocacy services and improving support in and environments of services working with autistic people. A key difference is that the national strategy has a key focus on improving diagnostic waiting times and does not reflect our local ambition to ensure that while prompt access to a diagnosis is imperative, it is also of importance that people can access support without needing a diagnosis and are not excluded from services on the basis of their diagnosis.
- 4.11 Delivery of the strategy objectives will require system wide commitment to prioritise the needs of autistic people within wider programmes of work including education, primary and secondary mental and physical health services, social care and support, public health, communities, housing, businesses, police and probation.
- 4.12 In line with the Coventry and Warwickshire Special Educational Needs and Disability (SEND) and Inclusion Strategies, the Autism Strategy emphasises the importance of promoting inclusive practice and supporting young people to access their full potential through education. Delivery of the strategy will therefore be aligned with the Warwickshire SEND change programme and the Coventry SEND Strategy 2019 to 2022 'Lifting the Cloud of Limitation'.
- 4.13 A year 1 strategy delivery plan has been developed to describe activities that have been initiated while waiting for the publication of the national strategy. Activities identified within this year 1 plan are funded and are deliverable. The year 1 plan focusses on reducing waiting times for a diagnosis and pre and post diagnostic support, as well as reducing the numbers of autistic people admitted to MH hospitals. In year 2 priorities will reflect the wider scope beyond health, social care and education. The following paragraphs provide a summary of key activities within year 1.
- 4.14 **Priority 1:** Support autistic people and people with social, communication and emotional health needs to help themselves pre and post diagnosis
- The contracts for existing community-based autism support services are due to end October 2022. A proposed model of future support has been co-produced, building on the evaluation of existing services. The model includes the following elements which will inform the re-procurement activity during 2021/2022:
 - Improved and coproduced offer of information and advice provided in an accessible format, working in partnership with Coventry and Warwickshire Partnership trust to further enhance their Dimensions tool to be the one stop shop for information about the diagnostic process, signposting to support and provision of self-management resources.;
 - Support for children, young people and adults awaiting an autism assessment and those diagnosed with autism residing in Coventry and Warwickshire, their siblings and parents/carers/family members via a range of options for 1:1 support, social groups, peer support and mentoring;
 - Improved transition support including sessions for specific age groups and workshops for professionals;

- Autism awareness and peer networking sessions for parents and family members;
- The development of a housing action plan for learning disabilities and autism will improve access to suitable housing for autistic people living in Coventry and Warwickshire, by raising awareness of autism and improving access to housing that is designed to consider the sensory needs of autistic people.

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

- Autistic people and families highlighted that working with education and mental health and wellbeing services should be the priority in this area, along with improving access to employment.
- Two pilot projects have been funded by NHS England working with a small number of schools in Coventry and Warwickshire. One project aims to improve school attendance for autistic young people through a graduated offer of support and the other will focus on developing autism empowered school environments and developing positive self-identity of secondary school students, thus leading to improved outcomes around education and mental health needs. The learning from these pilot projects will inform the delivery of SEND support into schools across Coventry and Warwickshire.
- Coventry and Warwickshire Partnership Trust have developed autism training which is being rolled out to staff in emotional wellbeing and specialist mental health services (including CAMHS). Specialist roles are being created to build autism awareness in mental health services, including the employment of people with lived experience of learning disabilities and / or autism.
- Both Councils are working towards disability confident employer level 3 as part of the commitment to promote and support employment of autistic people within the Council.

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

- A systemwide workforce development plan will be developed to support delivery of the strategy by addressing workforce gaps in relation to autism and ensuring that training staff in relation to autism is a priority for all partners. The aim is to upskill the workforce to be able to identify characteristics linked to autism early on and provide reasonable adjustments within their service offer to avoid the need to access diagnosis in order to receive support.
- An introductory autism awareness e-module has been developed for professionals and Connections workshops have been commissioned for staff across Coventry and Warwickshire to ensure that workforce have an improved experience of and understanding of autism, feel empowered and skilled to meet the health, care and education needs of autistic people and provide support that is tailored to individual need.

4.17 Priority 4: Develop the all age autism specialist support offer, including redesign of the diagnostic pathway to address waiting times for a diagnosis.

- A multi-agency Neurodevelopmental Diagnostic and Support Transformation Programme commenced in November 2020 in line with the Coventry and Warwickshire All Age Autism Strategy's priority to reduce waiting times for a neurodevelopmental assessment. Over the last 10 months, the programme has focused on redesigning the all age diagnostic pathway and exploring the potential to develop the wider workforce to be able to diagnose and appropriately support people with neurodevelopmental conditions, including in mental health, CAMHS and education services. Additional investment by the CCG and Coventry and Warwickshire Partnership Trust will create additional diagnostic capacity to contribute to reducing the waiting list. A number of projects funded by NHS England are being piloted to test a differentiated approach to the diagnostic pathway, enabling more straightforward diagnoses to be completed by

the wider workforce, without referral to a specialist service, thus further building the capacity for diagnosis.

- Specialist services are being developed to prevent unnecessary admissions to hospital, with a particular focus on young people age 14-25 as this is where the majority of admissions are seen.
- Coventry and Warwickshire are the most advanced system nationally in developing and delivering a Keyworker service for 14-25 year olds, which is now supporting over 70 young people and families, ensuring young people can navigate and access support from all agencies to prevent admission or facilitate discharge.
- The existing intensive support service for children and young people delivered by Coventry and Warwickshire Partnership Trust has been extended to age 25 to provide specialist intensive support for young autistic adults at risk of admission to hospital. CWPT are working to develop the model to further extend the offer to adults over 25 years. This is complemented by an emergency community outreach service delivered by Fine Futures which provides specialist care and support at home for autistic adults age 16 plus to provide additional wrap around support to prevent unnecessary admissions to hospital.
- A new community forensic service will be delivered by CWPT to support autistic adults in contact with or at risk of contact with the criminal justice system

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

- Coproduction is a key factor underpinning delivery of the Strategy. Coventry and Warwickshire Grapevine have been commissioned to facilitate delivery of a new Experts by Experience Coproduction service to support us to ensure all aspects of the Strategy are coproduced with people with lived experience. The model includes payments to 'experts by experience' for their time.

5. Results of consultation undertaken

5.1 The Strategy is informed by a range of co-production, engagement and mapping activity which was completed during 2019 and 2020 and 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. One Voice Coventry, the parent carer forum has also been involved in development of the strategy.

5.2 Particular issues highlighted through co-production and used to inform strategy priorities 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.
- While autism is an eligibility criterion for additional support, people will be driven to seek a diagnosis, increasing demand and waiting times for assessment. Support therefore needs to be available based on needs not diagnosis in order to have any meaningful impact on reducing the demand for diagnostic assessments.
- 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 (including CAMHS) 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. Support for autistic people therefore needs to be prioritised around periods of transition.
- 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 in Warwickshire. 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.

5.3 An accessible & easy read version of the strategy is being developed and will be published following sign off of this Strategy. A robust co-production approach will be used throughout all stages of strategy delivery to ensure that we build on strengths, experience and voices of individuals with direct experience of services and support. Parents and carers will be equally supported and will be recognised as experts by experience. This will be achieved through a multi-agency Coventry and Warwickshire Autism Partnership Group with key workstreams assigned to leads from across the system to share ownership and ensure effective delivery.

6. Timetable for implementing this decision

6.1 The following timetable indicates the governance process for signing off the strategy

Key milestone	Meeting Date
Strategy sign off by Warwickshire Parent Carer Voice forum	November 2021
Strategy sign off by Coventry OneVoice Parent Carer forum	November 2021
Strategy sign off by Coventry and Warwickshire Clinical Commissioning Group Governing body	17 th November 2021
Strategy sign off by Warwickshire Cabinet	25 th November 2021
Comment and assurance from Health and Social Care Scrutiny Board with Education and Children's Services Scrutiny Board invited in Coventry	1 st December 2021
Indicative date for strategy to be recommended to Coventry Cabinet for approval	January 2022

6.2 The delivery of year 1 implementation plan has begun while awaiting publication of the national strategy. The year 2 implementation plan is currently in development along with associated business cases and is due to be finalised by March 2022.

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