

Joint Meeting
Adult Social Care and Health OSC
And
Children and Young People's OSC
26 October 2020
Autism Strategy Update

1. Recommendation

- 1.1 It is recommended that the Overview and Scrutiny Committees note the progress to date on developing the joint all age Autism Strategy for Warwickshire and Coventry.

2. Purpose

- 2.1 The purpose of this report is:

- to give an update to committee members on the development of the joint Warwickshire and Coventry All Age Autism Strategy, which is currently in draft form and being considered by all partners prior to publishing; and
- to outline activities being progressed in 2020- 2021 to support delivery of the strategy.

3. Background and Context

- 3.1 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.
- 3.2 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.
- 3.3 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 Warwickshire, 32% 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.

3.4 Local Authorities and CCGs have statutory responsibilities to support autistic people as outlined in the Autism Act 2009, Care Act 2014, Children and Families Act 2014, SEND code of Practice 2014 and NHS Long Term Plan 2019.

3.5 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 Rugby Clinical Commissioning Group
- NHS Warwickshire North Clinical Commissioning Group
- NHS South Warwickshire Clinical Commissioning Group

3.6 The Strategy 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 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, autistic people continue to experience inequalities due to gaps in services and support, hence the need for this strategy.

3.7 In line with the Warwickshire SEND and Inclusion Strategy, 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.

4. Prevalence of Autism

4.1 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, suggesting there are an estimated 4,770 people living with autism in Warwickshire². Due to

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

² [Warwickshire and Coventry Joint Strategic Needs and Strengths Assessment 2019](#)

population growth alone, the total population of autistic people is expected to rise slowly over the next 6 years to 4,894 in Warwickshire by 2025.

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

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
Warwickshire	570	4,200	4,770
Coventry	367	2,831	3,197
Total	937	7,031	7,967

4.2 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. 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.

5. Strategy Development

5.1 This strategy is informed by a range of co-production 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.

5.2 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.
- While autism is an eligibility criteria 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 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 (see page 30 of the attached draft strategy).

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 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.

5.4 The draft strategy has been endorsed by the Coventry and Warwickshire Learning Disability and Autism Transformation Board to be shared with partners for review prior to finalisation of the strategy.

6. Strategy Delivery

6.1 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. Once the strategy is agreed, the intention will be to work with partners to develop place-based delivery plans which describe in greater detail how the objectives will be delivered in each place. This work is beginning now, with commissioning leads identified in Warwickshire and Coventry.

- 6.2 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 using health and social care services in supporting them in relation to autism related needs. 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 Board with key workstreams assigned to leads from across the system to share ownership and ensure effective delivery.
- 6.3 There is a refresh expected of the national autism strategy, however there is no confirmed timeframe for this at present. The work to deliver the identified year 1 priorities in 2020/21 within the local strategy is already in progress as outlined in section 7 below and the Learning Disability and Autism Transformation Board have recommended that we proceed without waiting for a national strategy which may continue to be delayed.

7. Priority Actions for Delivery in 2020/21

- 7.1 A number of activities have been agreed with partners as priorities for the first year of the strategy (2020/21).
- 7.2 Demand significantly exceeds capacity of the current neurodevelopmental diagnostic pathways, resulting in long waiting times. People waiting for a diagnosis are not being offered the support they feel is required and report increasing need, for example non-attendance in school, loss of employment and mental health crisis. Without a diagnosis, people with ADHD are not able to access the medication required to help manage their condition. A system wide approach has been agreed, recognising the need to:
- redesign the all age diagnostic pathway and explore 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;
 - improve the offer of pre and post diagnostic support from health, social care and education for all people currently referred for a diagnosis, all of whom have social, communication and sensory needs even if they do not go on to get a diagnosis of autism.
- 7.3 Linked to the above, we will improve 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. We will deliver a mixed model of family support for families 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 of autistic children are reflected in local parenting strategies and offers.

- 7.4 Commissioners are working to develop the market for community and accommodation- based support for autistic people through training, re-procurement and growing new local support providers.
- 7.5 Non recurrent funding has been identified to pilot a specialist community service for autistic people aged 18-25 with more complex needs, building on the successful outcomes delivered by the CWPT children and young people's intensive support service. 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. Learning from the pilot will be used to inform the development of specialist autism services for adults and children.
- 7.6 Coventry and Warwickshire are one of 13 sites participating in a national pilot as part of the NHS Long Term Plan to develop a keyworker role for young people aged 0-25 with autism and/or learning disabilities who are in hospital or at risk of admission. The keyworker role will build relationships and access resources from across the system; provide a single voice to advocate and coordinate the right help across complex systems; to deliver better outcomes for young people and their families; and keep families together at home and not in hospital.
- 7.7 A systemwide workforce development plan will be developed to support delivery of the strategy by addressing workforce gaps in relation to autism
- 7.8 Partners will 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 to adult services.

8. Financial Implications

- 8.1 There is no new recurrent funding identified to deliver the strategy, however it is recognised that autistic people currently access high cost support from a range of specialist services once they are in crisis. 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 existing health, care and education services and pathways of support more accessible and effective for autistic people. For example, initiatives will aim to reduce the numbers of autistic people who go into care, access mental health crisis or inpatient services or access high cost specialist education placements. Non recurrent funding streams are available, for example through the NHS Long Term Plan to support pilot schemes and transformation activities.

9.0 Environmental Implications

9.1 None

10. Conclusion

10.1 The draft autism strategy is being considered by all commissioning partners prior to being published. Work has begun to develop place-based delivery plans for Warwickshire and Coventry to ensure the strategy is implemented in the context of local services and support.

10.2 There is no new recurrent funding identified to deliver the strategy. 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 existing health, care and education services and pathways of support more accessible and effective for autistic people.

10.3 The strategy delivery will be overseen by a new joint Coventry and Warwickshire Autism Partnership Board with representation from the social care, education and health sector, community and voluntary sector and autistic people, their parents and carers as experts in experience. Alignment with the Warwickshire SEND change programme will be maintained, recognising the overlapping objectives within the two strategies.

10.4 Priority activities for delivery in 2020/21 have been agreed and are being progressed through integrated commissioning arrangements, including system wide transformation to address waiting times for autism diagnosis.

11. Supporting Documents

11.1 Appendix 1 – Draft Autism Strategy

12. Background Papers

12.1 None

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