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6a Additional Information - Autism in Schools Task and Finish Group (Pages 3 - 24) This page is intentionally left blank

To: Health and Social Care Scrutiny Board (5)

Subject: Report back of the Autism Task and Finish Group

1 Purpose of the Note

- 1.1 To inform the Health and Social Care Scrutiny Board (5) of the recommendations identified by the task and finish group established from members of the Education and Childrens' Services Scrutiny Board (2) and the Health and Social Care Scrutiny Board (5) to initially consider issues around the assessment process and support for children and young people who are referred for an autism assessment, and their families. As the task and finish group progressed, it expanded to include transition into adult services, inclusion and other aspects of neurodiversity.
- 1.2 Education and Childrens' Services Scrutiny Board (2) with support from Health and Social Care Scrutiny Board (5) are recommended to undertake further work 2022/23 municipal year to look at the in-depth challenges facing schools in providing support to children, young people and their families who are on the autism assessment pathway.
- 1.3 Throughout this report, 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. More information on this is provided in paragraph 5.4.

2 Recommendations

- 2.1 The Health and Social Care Scrutiny Board are recommended to make the following recommendations:
 - 1) The Council to work with partners to identify sustainable, long-term funding as there is currently only funding available for the first year of the All Age Autism Strategy delivery plan.
 - Ensure tackling health inequalities for autistic people is prioritised for delivery as part of the All Age Autism Strategy implementation plan to improve physical health, mental health and emotional wellbeing.
 - 3) Partners to accelerate and build on existing workstreams, to reduce the unacceptably long waiting times for diagnostic assessment
 - 4) The Council and health partners to work with schools, colleges and universities to ensure that all educational professionals (teachers, senior leaders, early career teachers, support staff) have a good understanding of the needs which may present for autistic and neurodiverse pupils and provide



Date: 23rd March 2022

Briefing note

appropriate Continuous Professional Development (CPD) to ensure high quality provision at both whole class and individual intervention level.

- 5) All partners work to strengthen data sharing between organisations to enable evidence gathered through assessments to be used by other professionals as part of the autism assessment process, to assist and expedite diagnosis with the necessary data protection safeguards put in place.
- 6) That the Education and Childrens' Service Scrutiny Board undertake a task and finish group during the 2022/23 municipal year to look at the in-depth challenges facing schools in providing support to children, young people and their families who are on the autism assessment pathway.
- 7) Health partners review the referral process for diagnosis to simplify it and enable electronic submission of referral forms.
- 8) Health partners to include schools in correspondence about appointments where schools were involved in the referral process. This will enable schools to support pupils and families through the diagnostic process.
- 9) Partners to ensure information on referral and support pathways is accessible to parents, carers, young people and professionals.
- 10)Community support services should be offered in the wider context of neurodiversity rather than limited to those with an autism diagnosis. Services should be titled and described to reflect that not all services require a diagnosis to access them.
- 11)Partners to develop a holistic approach to support for families post diagnosis which includes emotional as well as clinical support and access to training.
- 12)To continue the Council's participation in the Employ Autism scheme, or the development of an inhouse equivalent and ensure there is appropriate resource for it to be delivered.
- 13)For the Council to lead by example and become an inclusive employer including for autism and neurodiversity.
- 14)That SCRUCO include a future item on skills resilience pathways into employment for those with disabilities, including neurodiversity
- 15)The Council works towards Coventry becoming a city which celebrates, supports and accepts autism and neurodiversity. This would include
 - a) the introduction of more inclusive spaces and autism friendly environments throughout the City including in the City Centre, Parks and Open Spaces
 - b) safe spaces/low sensory stimulus areas to enable autistic people to decompression throughout the City.
 - c) public realm designs should include inclusive spaces including Autism friendly environments.
- 16)The Council resource and pursue digital opportunities including the development and rollout of a Neurodiversity Support App for Coventry
- 17) That Health and Social Care Scrutiny Board receive an update in 6months time on progress towards the recommendations, particularly the impact of measures to reduce waiting times for diagnostic assessments with regular briefings to the Chair in-between.

3 Background and Information

- 3.1 At the start of the 2021/22 municipal year, the Health and Social Care Scrutiny Board (5) agreed to set up a task and finish group to look at support for children and young people, and their families, who had been referred for an autism assessment. This work was prompted by concerns raised regarding the wait times for assessments and diagnosis. The Task and Finish group wanted to understand the reason for the lengthy waits and what support was available during that time, particularly for children and young people.
- 3.2 At their meeting on 11 March 2020 the Health and Social Care Scrutiny Board considered an item on the Autism Pathway and Support to Children and Young People in Coventry. The Board identified that more in-depth consideration needed to be made of some of the issues and invited Members to join a task and finish group
- 3.3 Due to delays caused by Covid-19 the task and finish group had their first meeting on 11th October 2021 and met 5 times.

4 Task and Finish Group Membership

- 4.1 The Task and Finish Group membership was Cllr Clifford (Chair), Cllr Innes, Cllr Heaven, and Education and Children's Services Scrutiny Board (2) Co-optees, Sybil Hanson and Kellie Jones.
- 4.2 Cllr Brown and Sarah McGarry attended the meetings as Experts by Experience.
- 4.3 Officers from a range of Coventry Council services attended meetings to provide evidence including Childrens' Services, Education, Adult Services, Human Resources, ICT and in addition Officers from Warwickshire County Council and representatives from Coventry and Warwickshire CCG Joint Commissioning Team.
- 4.4 Coventry and Warwickshire Partnership Trust also participated in the meetings.
- 4.5 Task and Finish Group members attended a Special Educational Needs Coordinator (SENCo) Briefing. There were representatives of around 80 schools present who shared their views from an educational perspective about the support to autistic children and young people and their families including those awaiting assessment.
- 4.6 The Task and Finish Group would like to thank all those who took part in and contributed to the work of the task and finish group.

5 Defining Autism and Neurodiversity

- 5.1 Autism is not a medical condition with treatments or a "cure", but autistic people often need person centred support to varying levels across and within four main areas: social communication, social interaction, social imagination and sensory processing. No two people with autism will necessarily be alike or will necessarily benefit from the same type and level of support. Lack of appropriate support during childhood can result in the need for additional support during adulthood. There is a higher prevalence of anxiety, depression and Post Traumatic Stress Disorder in autistic adults then the neurotypical population.
- 5.2 This video from the National Autistic Society provides further information about Autism <u>https://www.youtube.com/watch?v=Lk4qs8jGN4U</u>

- 5.3 As the work of the task and finish group developed, it became apparent that many of the recommendations being made by the task and finish group would also apply to other neurodiverse people. Neurodiversity is a term used to describe a variation in normal human evolution which means some people think differently to others and experience the world in a different way. Neurodiverse conditions include autism, attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia, Tourette's syndrome and complex tic disorders¹.
- 5.4 Throughout this report, 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. This mirrors the language used in the Coventry and Warwickshire All Age Autism Strategy.
- 5.5 Partners referred to in recommendations include Council services, health service commissioners, service providers and third sector organisations involved in the delivery of services to autistic children, young people and adults.

6 Coventry and Warwickshire All Age Autism Strategy

- 6.1 The Coventry and Warwickshire All Age Autism Strategy was being developed and finalised during the period that the task and finish group met. The Health and Social Care Scrutiny Board scrutinised the draft strategy at their meeting on 2nd December, which was approved at Cabinet on 15th February 2022.
- 6.2 Members endorsed the aims of the strategy which are to:
- 6.2.1 **C&W Priority 1:** Support autistic people and people with social, communication and emotional health needs to help themselves pre and post diagnosis
- 6.2.2 **C&W Priority 2:** Reduce inequalities for autistic people and make Coventry and Warwickshire an autism friendly place to live
- 6.2.3 **C&W Priority 3:** Develop a range of organisations and services locally with the skills to support autistic people
- 6.2.4 C&W Priority 4: Develop the all age autism specialist support offer
- 6.2.5 C&W Priority 5: Co-produce, work together and learn about autism
- 6.3 Members appreciated that the strategy would help to address some of the issues raised throughout the task and finish group but were concerned that funding had only been identified for the first year of the delivery plan.
- 6.4 **Recommendation 1**: The Council to work with partners to identify sustainable, long-term funding as there is currently only funding available for the first year of the All Age Autism Strategy delivery plan.
- 6.5 Members were concerned about the extent of health inequalities and rates of premature death experienced by autistic people and welcomed priority 2 of the Coventry and Warwickshire All Age Autism Strategy. However, the task and finish group wanted to ensure that the importance of delivering on this priority for all organisations.

¹ https://www.oxfordhealth.nhs.uk/news/autism-

and/#:~:text=Neurodiversity%20is%20a%20term%20used,syndrome%20and%20complex%20tic%20disor ders.

6.6 **Recommendation 2**: Ensure tackling health inequalities for autistic people is prioritised for delivery as part of the All Age Autism Strategy implementation plan to improve physical health, mental health and emotional wellbeing.

7 National Autism Strategy (2021-2026)

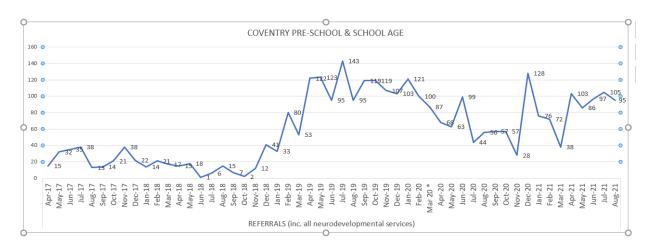
- 7.1 A National Autism Strategy (2021-2026) has also been published. The Local strategy is designed to complement the national strategy. The aims of the national strategy are:
- 7.1.1 National Priority 1: Improving understanding and acceptance within society
- 7.1.2 **National Priority 2**: Improving access to education and supporting positive transition into adulthood
- 7.1.3 National Priority 3: Supporting more autistic people into employment
- 7.1.4 National Priority 4: Tackling health and care inequalities
- 7.1.5 **National Priority 5:** Building the right support in the community and supporting people in inpatient care
- 7.1.6 National Priority 6: Improving support within the criminal and youth justice service

8 Coventry Context

- 8.1 There is no register of autistic people nationally or locally and so the true level of occurrence of autism in Coventry is unknown.
- 8.2 Autism predicted occurance by local place-based Joint Strategic Needs Assessment (JSNA) area indicates a higher density of expected cases in Coventry urban areas, compared with less densely populated areas of Warwickshire but more overall cases in Warwickshire than Coventry.
- 8.3 Evidence suggests that Coventry has a higher proportion of Special Educational Needs (SEN) support for autism across all state-funded school settings - primary, secondary and special schools – compared to England, the West Midlands, Warwickshire and Derby. The reasons for this are not clear but options to be considered include:
 - Higher occurrence of autism in Coventry than nationally or in similar areas, due to unknown factors or chance variation
 - Higher autism need based on wider socio-economic or a variety of other factors (e.g. training of teachers and approach within schools, support provided for families etc.), meaning autistic pupils in Coventry require more help than those elsewhere to manage their autism in an education setting.
 - A combination of higher occurrence and higher needs to thrive at school than other areas
 - A higher proportion of new autism cases receiving a diagnosis in school in Coventry compared with other areas, leading to increased access to support
 - A lower threshold criteria for SEN/EHCP support for Coventry pupils with autism than other areas.
- 8.4 Members were concerned that because there was no fully accurate register of autistic people in the city, it was difficult to plan services effectively to meet the needs of all people affected. It was thought that it would be useful if health partners developed of a process to record the numbers of autistic people diagnosised in the City to enable planning and service delivery.

9 Waiting Times for Assessment and Diagnosis

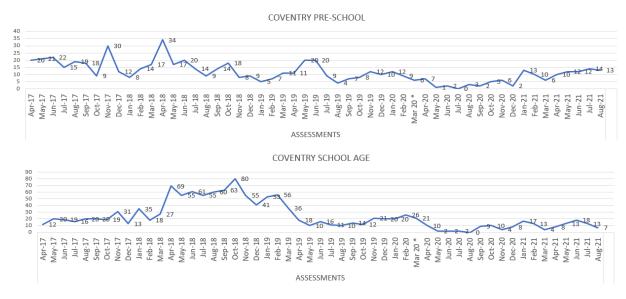
9.1 Information was shared with the task and finish group at their October meeting on the number of referrals made for pre-school and School age children (see graphs below).



Number of referrals made between April 2017 and August 2021 – Children and Young People

9.2

Number of assessments undertaken between April 2017 and August 2021 - Children and Young People

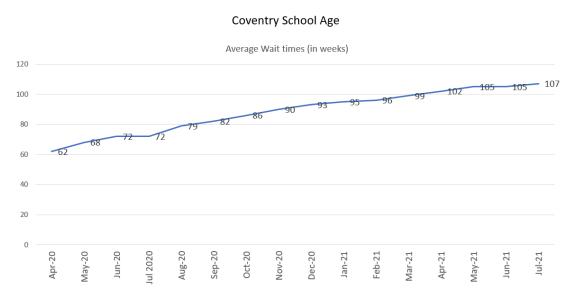


- 9.3 As of August 2021. There were 185 pre-school children in Coventry awaiting assessment and 1343 children and young people of school age. The system had identified priority groups via school years – these priority groups were pre-school, Year 6, Year 10 and Year 11.
- 9.4 As of July 2021, the average wait for assessment for a Coventry Pre-school child was 42 weeks which was a reduction from 56 weeks at its peak in March 2021. This reduction was being made as resource had been prioritised for pre-school assessments.

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9.5 However, there had been a steady increase in the average wait times of the Coventry school age children – up to 107 weeks as of July 2021. Across Coventry and Warwickshire, 598 children and young people had been waiting over 3 years for an assessment, with 10 waiting 4 years and 1 having been on the waiting list of 5 years, as per the graph below.

Current Referral Demand and Assessment Delivery



- 9.6 The Task and Finish Group heard about the work being done to reduce waiting times as well as the challenges which included difficulties in recruiting specialist staff. Whilst this work was acknowledged, Members stressed that the waiting times were still unacceptable.
- 9.7 **Recommendation 3:** Partners to accelerate and build on existing workstreams, to reduce the unacceptably long waiting times for diagnostic assessment

10 Early Intervention in Education and Statutory Support (including Education, Health and Care Plan)

- 10.1 The Task and Finish group heard about Early Intervention in Education and Statutory Support including Education, Health and Care Plans (EHCP). This includes a description of the targeted nursery support package and a group offer, parenting sessions for the carers focussing on the developmental profile for each child, plus interaction, play skills and strategies to use at home if required in Early Years.
- 10.2 There is transition support from Nursery into Reception provided by a Higher Level Teaching Assistant for the first term of the child's move into primary school.
- 10.3 The core offer for school age children and young people is outlined below in 4 key blocks.

Quality First Teaching	Universal Provision Guidance	SENCo Network	Autism in Schools Project
 Reduce sensory stimulus Agree a regular seating position Clear and specific instructions Emotional Literacy Word Bank Visual cues and timetable 	 A local agreement about the support available across schools and settings without an EHCP. 	 Available for all maintained schools and academies. Peer support, training and resource sharing. 	 Developing resources to help Autistic young people develop their identity. Strengthening co- production between settings and families.

- 10.4 Following a discussion about how to improve and widen the support in schools, the Task and Finish Group discussed opportunities to work with schools, colleges and universities to encourage them to promote and deliver enhanced training for supporting autism in the classroom. This would help empower staff across the whole school to support autistic children and young people. The skills and knowledge of SENCOs within school could also be better utilised to help staff gain the skills to support autistic children and young people. This led to the following recommendation:
- 10.5 **Recommendation 4**: The Council and health partners to work with schools, colleges and universities to ensure that all educational professionals (teachers, senior leaders, early career teachers, support staff) have a good understanding of the needs which may present for autistic and neurodiverse pupils and provide appropriate CPD to ensure high quality provision at both whole class and individual intervention level. Good teaching for autistic pupils is good teaching for all.
- 10.6 Members heard there was a Complex Communication Team who provided training to whole settings on autism as well as bespoke training, including Lego therapy. This team also offered individual and group support.
- 10.7 The role of Education, Health and Care Plans (EHCP) was outlined. They were introduced in 2015 and were subject to review with a Green paper due to be published in Spring 2022. To be eligible for a plan the individual would have severe and complex needs requiring provision that is over and above what is 'ordinarily available' in the local area and focussed on the barriers to learning. A diagnosis of autism is not required to access the assessment which leads to an EHCP.
- 10.8 The Educational Psychology Team provide complex case support as well as assessment, formulation and consultation. They work in partnership with young people and their families. One of the issues raised was that the observations and findings from the work undertaken by educational psychologists did not contribute to the autism assessment process. It was discussed that there was an opportunity for the observations of other professionals to be included in the autism assessment process. This could help speed up the diagnostic process, reduce duplication in the system and potentially reduce undue stress on the young person and their family by them having to go through another observation process.
- 10.9 **Recommendation 5:** All partners work to strengthen data sharing between organisations to enable evidence gathered through assessments to be used by

other professionals as part of the autism assessment process, to assist and expedite diagnosis with the necessary Data Protection Safeguards put in place.

11 Education – Feedback from Special Education Needs Co-ordinators (SENCos)

- 11.1 Task and Finish Group members were invited to attend a SENCo meeting on 15th February. There were representatives from around 80 schools present.
- 11.2 This meeting was held virtually and participants were asked to submit their views on four questions via a Google Jamboard. The questions asked were:
 - 1. What works well in the system? Things that you value (keepers)
 - 2. What's missing or doesn't work well? (gaps, areas to improve, things we could stop)
 - 3. Thinking about the child's experience and the challenges they face in school if you could change three things to improve support, provision and outcomes, what would you do?
 - 4. Do you have any other comments?
- 11.3 The opportunity for SENCos to comment on this topic was well received with over 400 comments made in response to the questions above. This exceeded expectations and the quality and breadth of data collected was phenomenal. Therefore, the Task and Finish group recommend that this data is reviewed in depth by a separate task and finish group in the new municipal year.
- 11.4 **Recommendation 6**: That the Education and Childrens' Service Scrutiny Board undertake a task and finish group during the 2022/23 municipal year to look at the in-depth challenges facing schools in providing support to children, young people and their families who are on the autism assessment pathway.
- 11.5 In light of the above recommendation, high level data analysis has been done and a number of key themes identified. Key issues raised included
- 11.6 **The referral process** there were concerns that the form took too long to complete and by the time a young person was seen, it was out of date and therefore had to be filled in again. The referral form was a paper document which had to be returned by post/fax with no confirmation provided it had been received.
- 11.7 **Recommendation 7:** Health partners review the referral process for diagnosis to simplify it and enable electronic submission of referral forms.
- 11.8 There were significant concerns about the length of wait for assessments, and regarding the support received by parents both pre and post diagnosis. This is addressed in recommendation 4 above.
- 11.9 Concerns were raised about the communication between NHS services and schools it was difficult for schools to speak to health services about their pupils. A dedicated phoneline for schools was suggested as an option to explore. There were also issues whereby parents missed appointments, in some cases as they were unable to read the letter offering an appointment, and therefore the referral process had to restart. Issues such as this could be mitigated if the school was copied into appointment letters. Parents and schools struggled to get a dialogue with CAMHS even after a diagnosis.

- 11.10 **Recommendation 8:** Health partners to include schools in correspondence about appointments where schools were involved in the referral process. This will enable schools to support pupils and families through the diagnostic process.
- 11.11 Schools wanted to be able to provide more support to parents whilst they waited for an assessment including how to help the young person at home for example with sleep, food and sensory issues.
- 11.12 SENCo's also flagged the need to improve understanding and support for mental health issues being experienced by pupils, some of which may co-present with autism and some which can lead to similar presentations, for example anxiety.
- 11.13 The recommendation identified by the task and finish group to become an Autism Friendly City, was supported by the schools. They wanted schools to become more autism friendly by increasing understanding amongst pupils, parents and all staff about autism to improve inclusivity and the introduction of quiet, low sensory spaces.
- 11.14 Concerns were raised about the lack of capacity in specialist settings for children and young people who would do better in specialist provision than a mainstream setting.
- 11.15 The increase in the numbers of children and young people presenting with autism was also flagged alongside concerns about the impact this has on resources within the school to ensure support is provided.
- 11.16 There was significant praise and support for the Council's Complex Communications Team who provide support whilst children and young people are awaiting assessment.

12 Pathways and Support Services

- 12.1 The complexity of the services on offer and the pathways to access support became clear as the task and finish group progressed. Sometimes the support was available but it was hard for the young people or their carers to know whether it was the right service for them to access or not. Some services could be accessed without a diagnosis if required. Therefore, it is recommended that:
- 12.2 **Recommendation 9:** Partners to ensure information on referral and support pathways is accessible to parents, carers, young people and professionals.
- 12.3 **Recommendation 10** Community support services should be offered in the wider context of neurodiversity rather than limited to those with an autism diagnosis. Services should be titled and described to reflect that not all services require a diagnosis to access them.

13 Impact of Diagnosis

- 13.1 The Task and Finish Group discussed the impact of a diagnosis on the child, young person and their families.
- 13.2 Members were told that whilst a diagnosis was not always required to access services, for some people gaining a diagnosis helped them to understand themselves better. It could provide families with a reason why their child/young person experienced the world differently to others.
- 13.3 However, for some families, a diagnosis brings a sense of grief as they worry about their child's or young person's future. In the past there had been emotional support

provided following a diagnosis as well as clinical support, however this was no longer offered. The task and finish group felt this was a gap and therefore recommended:

13.4 **Recommendation 11:** Partners to develop a holistic approach to support for families post diagnosis which includes emotional as well as clinical support and access to training.

14 Preparing for Adulthood

- 14.1 The Task and Finish Group heard about the transition process from Children's Service to Adult services. There was an agreed pathway for preparing for adulthood, outlined within a Transitions Protocol. Referrals were being more consistently sent to Adult Services from age 14 and there were monthly Pre-Transitions Panels supporting early identification and planning for all children and young people. There were regular transition meetings and a transition tracker to help monitor progress. Performance indicators were being developed to help strengthen service delivery.
- 14.2 Services available through Adult Services varied depending on whether the individual needs met Care Act eligibility criteria or not. Those who were eligible for services could access a range of services according to their needs including Promoting Independence Service; Home support; Supported Living; Employment Support; Day Opportunities; Care home; Aids and adaptations/digital solutions and Support for family carers.
- 14.3 Those who did not meet the nationally prescribed eligibility criteria were able to access information and advice/signposting/social prescribing; Mind; Grapevine; Employment Support (Disability Confident Employers); Support for Family Carers and Housing Related Support.
- 14.4 It was recognised by the Task and Finish group that the threshold for eligibility in Adult Services was much higher than that for children and young people through Education or Children's Services, and fewer autistic people would have the level of need required to access specialist provision as an adult.
- 14.5 Adult Services had been reviewing areas for improvement and had identified areas for development. They had undertaken a survey in December 2021 with young people and initial feedback identified that discussions around transition usually start at 14-16 years, but young people and families struggle to understand the changes to the service. There were still times when referrals to Adult Services were made too late. Adult Social Workers were not consistently identified early enough, although this had improved, in particular for children with complex needs and disabilities
- 14.6 There were a number of actions being implemented to improve the transition process. These included the weekly monitoring of performance indicators; completion of Preparing for Adulthood leaflet for children, young people and their families to support their understanding around changes to services; Care Act assessments to be consistently completed by 17.5 years; Adult Social Workers to be identified consistently at 16 years to support planning and enable families to understand the change in provision at 18 years.

15 Employ Autism Higher Education Network Project

- 15.1 Coventry City Council had participated in the Employ Autism employability programme which offered 8-week summer internships for up to 5 autistic students and graduates per organisation.
- 15.2 This was a pilot programme which was delivered in partnership with Ambitious about Autism and Coventry University between July and September 2021. The pilot was a fully-funded programme with the intern's, who worked at the Council, having their salaries paid by Santander Universities UK, making it zero-cost for the Council.
- 15.3 The project included two free training sessions delivered by Ambitious about Autism on recruiting, onboarding and working with autistic students and graduates. This training was mandatory for all line managers and buddies participating in the programme.
- 15.4 Benefits for the Council included access to a pool of untapped, diverse talent; the promotion of diversity of thought and problem-solving; reflection on the diverse communities we serve; the removal of structural barriers to employment (traditional application and interview processes) and facilitation of a positive cultural change by raising awareness of conditions required for an inclusive team
- 15.5 The interns gained work readiness skills and ability to move into employment; enhanced confidence to contribute as an employee within a team; found barriers were broken down and they had a chance to expand their networks. It also empowered the interns to self-advocate in the workplace.
- 15.6 There was some learning from the programme which included the interns suggesting that they would like internships to last for 12 weeks rather than the 8 weeks offered, or to be paired up with other interns, if the programme were to run again.
- 15.7 Ambitious about Autism are currently evaluating the pilot programme using feedback from participating employers and interns and a decision is expected soon regarding the future of the programme and whether Santander Universities will continue to fund it moving forward
- 15.8 The Council is working with Ambitious about Autism and Coventry University to explore other ways to continue the project moving forward, if the funding is withdrawn.
- 15.9 The Task and Finish group were impressed with the opportunities offered by participating in the scheme and therefore made the following recommendation
- 15.10 **Recommendation 12:** To continue the Council's participation in the Employ Autism scheme, or the development of an inhouse equivalent and ensure there is appropriate resource for it to be delivered
- 15.11 Further to the recommendation above, Members felt that the Council should lead by example and become an autism friendly employer and showcase to employers across the City the benefit of employing autistic people.
- 15.12 **Recommendation 13:** For the Council to lead by example and become an inclusive employer including for autism and neurodiversity.

- 15.13 It was also discussed that barriers to employment are an issue for people with a range of disabilities. SCRUCO would be considering an item on skills resilience in 2022/23 and the task and finish group recommended that:
- 15.14 **Recommendation 14:** That SCRUCO include in a future item on skills resilience pathways into employment for those with disabilities, including neurodiversity

16 Autism Friendly City

- 16.1 There are already initiatives taking place to make the city autism friendly however, there is more that can be done to make Coventry a city which celebrates, supports and accepts autism and neurodiversity.
- 16.2 There is a proposal to develop a Coventry Autism App. The app would have a range of functions which could include information on autism friendly retailers, sign posting to green spaces and free of charge charging points, locations of disabled toilets, social stories to support travel, relaxation games, notification of autism friendly, low sensory sessions as well as identification of large events in the city such as carnivals which autistic people may wish to avoid.
- 16.3 Potential benefits of the app would be to increase independence of autistic people by reducing sensory overload, providing social stories for travel and reduce dependence on carers
- 16.4 Whilst the app has been scoped, to be able to develop it and roll it out, possible funding sources, partners, sponsors and suppliers need to be identified and resource allocated to make it happen.
- 16.5 Through forthcoming public realm works, there are opportunities to design inclusive spaces through the capital works which includes creating environments which are autism friendly.
- 16.6 Existing buildings and spaces could be adapted to become safe spaces which provide low sensory stimulus areas for autistic people to decompress. Any safe spaces which are introduced, need to be promoted and also included on the Coventry Autism App should development progress.
- 16.7 **Recommendation 15:** The Council works towards Coventry becoming a city which celebrates, supports and accepts autism and neurodiversity. This would include
 - a) the introduction of more inclusive spaces and autism friendly environments throughout the City including in the City Centre, Parks and Open Spaces
 - b) safe spaces/low sensory stimulus areas to enable autistic people to decompression throughout the City.
 - c) public realm designs should include inclusive spaces including Autism friendly environments.
- 16.8 **Recommendation 16:** The Council resource and pursue digital opportunities including the development and rollout of a Neurodiversity Support App for Coventry

17 Next Steps

17.1 If the Health and Social Care Scrutiny Board support the recommendations of the task and finish group a report will be taken to Cabinet on 12th April 2022 to consider the recommendations.

- 17.2 Health and Social Care Scrutiny Board will monitor progress on the implementation of the recommendations
- 17.3 **Recommendation 17:** That Health and Social Care Scrutiny Board receive an update in 6months time on progress towards the recommendations, particularly the impact of measures to reduce waiting times for diagnostic assessments with regular briefings to the Chair in-between.

18 Health Inequalities Impact

- 18.1 The following paragraph from the Coventry and Warwickshire All Age Autism Strategy outlines some of the health inequalities suffered by autistic people
- 18.2 "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."
- 18.3 Many of these adverse health outcomes are avoidable and can be addressed through appropriate levels of preventative care, support and lifestyle interventions. For this reason it is important that timely access to diagnostic assessments is provided so needs can be identified and addressed.
- 18.4 The recommendations in this report compliment the Coventry and Warwickshire All Age Autism Strategy 2021-26 and the National strategy for autistic children, young people and adults: 2021 to 2026 which strive the reduce the health inequalities experienced by autistic people.

Victoria Castree Gennie Holmes Scrutiny Team

Appendix A

Autism Task and Finish Group – Update on Recommendations

The Autism Task and Finish Group, jointly established by Health and Social Care Scrutiny Board 5 Education and Childrens' Services Scrutiny Board 2 took their recommendations to Cabinet on 12th April 2022 and these were approved. The purpose of this report is to provide scrutiny Members with a progress report on the implementation of the approved recommendations.

	Recommendation	Update - October 2022
1	That the Council work with partners to identify sustainable, long-term funding as there is currently only funding available for the first year of the All- Age Autism Strategy delivery plan.	Funding has been identified to support the commissioning of pre and post diagnostic support for years 2 and 3 of the Autism Strategy delivery. Coventry City Council have also contributed to the investment into additional diagnostic capacity.
		As future funding needs are identified, leads of the five priority areas of the strategy will develop business cases for investment. However, there is also focus on considering wider funding opportunities such as the system-wide health inequalities fund.
		Investment of £11m across the Coventry and Warwickshire system has been identified to address the diagnostic waits issue and to support the development of post diagnostic support provision.
2	Ensure tackling health inequalities for autistic people is prioritised for delivery as part of the All- Age Autism Strategy implementation plan to improve physical health, mental health, and emotional wellbeing.	This is a focus of Priority 2 of the Autism Strategy. Allison Duggal, Director of Public Health and Well-being for Coventry City Council has recently been identified as the lead for this Priority Area.
		A delivery plan for this Priority Area is currently being developed with key stakeholders.

		A new system-wide health inequalities lead for mental health, learning disability and autism across Coventry and Warwickshire has recently been appointed. The local Autism Partnership Board are liaising with the postholder to identify areas for focus.
3	Work with partners to accelerate and build on existing workstreams, to reduce the unacceptably long waiting times for diagnostic assessment	Significant investment has enabled CWPT to recruit additional internal diagnostic capacity and to source an additional 8 external "neuro partners" who can complete diagnostic assessments. This is enabling progression towards the reduction of the autism diagnostic waits as per a business case and trajectory that was developed to support the investment. Whilst progress is being made and we are currently ahead of plan in relation to reduction in the wait for an assessment, a new challenge has arisen as there has been a significant increase in the number of referrals for assessment – CWPT are currently undertaking analysis of this and revising the associated modeling to identify the capacity required to meet demand.
4	The Council and health partners work with schools, colleges and universities to ensure that all educational professionals (teachers, senior leaders, early career teachers, support staff) have a good understanding of the needs which may present for autistic and neurodiverse pupils and provide appropriate Continuous Professional Development (CPD) to ensure high quality provision at both whole class and individual intervention level.	 Extended Non-Attendance at School (ENAS) Programme is well developed in Coventry. A termly panel meets to consider individual cases and provides advice and signposting to schools. More information can be found here: https://www.coventry.gov.uk/attendance-inclusion/extended-school-non-attendance-advisory-panel-esnaap. Training on non-attendance regularly offered to schools by members of the ENAS Panel and Complex Communication Specialist Practitioners are in post and providing training and modelling of good practice to school professionals as part of a traded service managed by Coventry City Council

		Two Coventry secondary schools were involved in an NHSE funded Autism In Schools project during the 21/22 academic year, developing awareness and resources that can be shared across settings to improve the school experience of autistic pupils. During the 22/23 academic year, key learning from the project will shared with other schools in their MAT.
		Priority 3 of the Autism Strategy outlines a commitment to developing an understanding of training and workforce needs across Coventry and Warwickshire to identify gaps and enable consistency of workforce development – this will feature as part of years 2/3 delivery plans.
		The Community Autism Support Service, delivered by Coventry and Warwickshire Mind, leads monthly topic-based toolbox sessions for education, care, and health professionals with a focus on helping them to successfully navigate working with children and/or young people with autism and other neurodevelopmental conditions. Topics of focus have been agreed based on feedback from professionals.
		An e-booklet is now available for neurodiverse children, their families, and professionals. This includes resources and links to services who offer training in autism.
5	The Council strengthen data sharing, alongside all relevant partners, between organisations to enable evidence gathered through assessments to be used by other professionals as part of the autism assessment process, to assist and expedite diagnosis with the necessary data protection safeguards put in place.	The data sharing agreement was renewed in 2021 to enable the Key Worker pilot to function.

6	Support the Education and Childrens' Service Scrutiny Board undertaking a task and finish group during the 2022/23 municipal year to look at the in- depth challenges facing schools in providing support to children, young people and their families who are on the autism assessment pathway.	The task and finish group has been established.
7	Health partners review the referral process for diagnosis to simplify it and enable electronic submission of referral forms.	Work in progress. Referrals currently submitted via email to CWPT who are the lead provider of diagnostic provision and hold the local waiting list. The referral process is under review as part of the neurodevelopmental transformation plan. Work is also underway to widen capacity and capability of the wider health workforce to be able to diagnose individuals, as part of a local differentiated diagnosis pilot.
8	Health partners to include schools in correspondence about appointments where schools were involved in the referral process. This will enable schools to support pupils and families through the diagnostic process.	Work in progress. Processes linked to this are being co- produced with parents/carers of children and young people with and awaiting diagnosis. There are a range of issues and concerns regarding consent and lengthy waits meaning that children may be attending different schools to that which they were attending at the time of referral – however, these instances should reduce as we progress to much shorter waiting times.
9	The Council work with partners to ensure information on referral and support pathways is accessible to parents, carers, young people, and professionals.	This is a feature of the information stored on the Local Offer website. CWPT also deliver the Dimensions tool which provides a range of self-care resources and hosts the recently published e- booklet providing information and advice for neurodivergent people <u>https://dimensions.covwarkpt.nhs.uk/Events.aspx</u> Further development of the information and advice offer will be progressed via Priority 1 of the Autism Strategy – this includes

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		further development of the e-booklet resource, video resources and an expanded offer of co-produced accessible resources.
10	Community support services should be offered in the wider context of neurodiversity rather than limited to those with an autism diagnosis. Services should be titled and described to reflect that not all	There is an increased focus on need across provision so that access to support is not diagnosis dependent. The Community Autism Support Service is commissioned to
	services require a diagnosis to access them.	provide support to people with and without diagnosis.
11	The Council, with partners develop a holistic approach to support for families post diagnosis which includes emotional as well as clinical support	As per update 9 above In addition, CWPT are developing a clinical model of care and
	and access to training.	plans for a community specialist neuro team who will provide additional post diagnostic support
12	To continue the Council's participation in the Employ Autism scheme, or the development of an inhouse equivalent and ensure there is appropriate resource for it to be delivered.	Although Coventry University and Ambitious About Autism had obtained funding for 2 interns this year this has not proceeded due to the participating service area being unable to proceed and too little time available to engage another placement area. Ambitious About Autism are currently in talks with Santander, regarding the future of the scheme and whether or not they will continue to fund it moving forward. Depending on the outcome, this is likely to affect our ability to be able to provide such employability opportunities, going forward, particularly given the current economic climate.
13	For the Council to lead by example and become an inclusive employer including for autism and neurodiversity.	The Council recently commissioned Enna, an organisation specialising in supporting neurodiverse individuals in joining the workforce, to deliver Neurodiversity 101 training as part of National Inclusion Week in September. The session was recorded and is available on the <u>intranet</u> for all staff to access. The Workforce D&I team do not have a specific neurodiversity project in progress at this time.

14	Support SCRUCO including a future item on skills resilience pathways into employment for those with disabilities, including neurodiversity	The Council were re-validated as Disability Confident Level 2 (disability Confident Employer) in August 2022 work has not yet started on achieving Level 3 (Disability Confident Leader). This item went to SCRUCO in September 2022.
15	 The Council works towards Coventry becoming a city which celebrates, supports, and accepts autism and neurodiversity. This would include a. the introduction of more inclusive spaces and autism friendly environments throughout the City including in the City Centre, Parks and Open Spaces b. safe spaces/low sensory stimulus areas to enable autistic people to decompression throughout the City. c. public realm designs should include inclusive spaces including Autism friendly environments. 	This is a focal area of Priority 2 of the Autism Strategy
16	The Council resource and pursue digital opportunities including the development and rollout of a Neurodiversity Support App for Coventry	Brain in Hand is an app tool used to help improve confidence and resilience when facing anxiety and stress. This was piloted across Coventry and Warwickshire during 2021/22 - evaluation suggested the app may not be appropriate for individuals who were in or approaching crisis. Coventry and Warwickshire are now entering into a 6-month self-referral model of Brain in Hand which will consist of 50 licenses made available to individuals aged 16+, who are autistic, or awaiting a neurodevelopmental assessment. The impact of use of the app will be evaluated to inform future commissioning decisions.

		The first iteration of the information and advice booklet for neurodivergent people was issued as an e-booklet, with a mobile phone compatible version created alongside a traditional booklet
17	Support Health and Social Care Scrutiny Board receiving an update in 6 months-time on progress towards the recommendations, particularly the impact of measures to reduce waiting times for diagnostic assessments with regular briefings to the Chair in-between.	This report is to update the Chair and the Board on the progress.

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