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Title of meeting: Health, Wellbeing & Social Care Portfolio meeting

Subject: Working with Autism and Neurodiversity including Transition

Date of meeting: 5th December 2022

Report by: Liza Grainger, Transition Lead

Wards affected: All

1. Requested by

Councillor Matthew Winnington, Cabinet Member, Health, Wellbeing & Social Care

2. Purpose

To update the Portfolio holder and spokespeople of the developments in approaches and support being progressed in Portsmouth Adult Social Care for autistic and neurodivergent individuals.

3. Background & Context

In July 2021 the Government published the policy paper 'The national strategy for autistic children, young people and adults: 2021 to 2026.' This has 6 areas that is seen as having the opportunity to have a significant impact on autistic people's lives:

- improving understanding and acceptance of autism within society
- improving autistic children and young people's access to education, and supporting positive transitions into adulthood
- supporting more autistic people into employment
- tackling health and care inequalities for autistic people
- building the right support in the community and supporting people in inpatient care
- improving support within the criminal and youth justice systems

Portsmouth Autism Community Forum is a local open forum for autistic people, carers and professionals.

The purpose of the forum is to:

- work together to improve support for autistic people
- monitor and share progress against the autism strategy
- publicise and celebrate success for services and individuals

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- identify areas for improvement and take positive action
- work with key decision-makers to improve services
- discover and share evidence-based best practice

The Portsmouth Autism Strategy and Action Plan 2017-2022 refers only to Autistic people. Since this was published the scope of this work has broadened to include all Neurodivergent individuals. To clarify on the language preferred by the Autism Community Forum:

- Neurodiversity is a recognition that not all brains think or feel in the same way, and that these differences are natural variations in the human genome. A group of people are neurodiverse, an individual is not.
- Neurodivergent refers to an individual who has a less typical cognitive variation such as autism, ADHD, dyslexia, dyspraxia etc.
- Neurotypical refers to individuals of typical development and intellectual/cognitive functioning

Portsmouth Adult Social Care is working with the Autism Community Forum to co-produce new and improved services and support for Autistic and Neurodivergent adults in the local area. There is significant opportunity to prevent the deterioration of health and wellbeing for Autistic and Neurodivergent people which will be a focus in all of this work. It will require action from the Health and Care system as well as wider partners across the city to achieve meaningful change.

4. If not now, when? Autism and neurodivergence in Portsmouth: Evidencing the need for change

4.1 The Project

Published in May 2022, this report (Appendix 1) is the outcome of a project which took place over six months in the summer of 2021 to understand the experiences, challenges and gaps for neurodivergent individuals in Portsmouth. The project did not include people who have a learning disability.

Conversations were held with autistic and neurodivergent people, and those who support them. The project lead also completed a deep dive into Adult Social Care records of 10 autistic adults.

The project was supported by the Portsmouth Autism Community Forum (PACF) and the report was co-produced with the forum.

4.2 The findings

Key themes that were identified through the project included:

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- The potential to prevent worse outcomes
- Improvement required in the support through transition from Children's to Adult services
- Current lack of understanding and tailoring of offer from a wide range of public services including Primary Care
- Current lack of support for independent living, advocacy, practical skills, navigating services and finding appropriate housing
- Current lack of support for physical, mental and emotional health
- Need for better knowledge and understanding for autistic and Neurodivergent people and their friends and family
- Problems with interactions with mental health services, standardised approaches, potential misdiagnosis or not being able to access support due to autism diagnosis
- Stigma around autism and neurodivergence
- The need for accountability and co-production

4.3 The principles

The Portsmouth Autism Community Forum produced a set of principles using feedback from the project:

- We must develop understanding and acceptance – awareness isn't good enough
- We recognise that neurodivergence/autism is a rapidly evolving topic in terms of research and public debate and we commit to taking a broad viewpoint which prioritises people and not their diagnosis
- Most autistic and ND people are a mix of different neurodivergence, come from a range of backgrounds, and identify in different ways. We must recognise diversity and accept individuals for who they are, including those who have not sought or been offered diagnosis
- Autistic and ND people are more likely to have multiple physical and mental health conditions than neurotypical people. This is due to a combination of poor recognition by the individuals, late presentation, and poor management by health professionals, leading to significantly worse outcomes and earlier deaths, as detailed in a report written by Autistica¹ It is vital that we work to address these health inequalities.
- Where an autistic or ND person has more than one condition/diagnosis these should be viewed as distinct from autism unless it's useful to think of them together
- Co-production and collaboration are key – services must be jointly led by those who use or have an interest in them and work together where an autistic person needs access to several services e.g. mental health, physical health, social care
- Eligibility for support must be considered broadly to ensure wellbeing and prevention are at the core of our thinking – all too often autistic and ND people are left to reach crisis before support is offered

¹ (<https://www.autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf>).

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4.4 The recommendations

The recommendations from the report made to Portsmouth's Health and Care system are presented under 6 themes:

- Transition from children's to adult services
- Support
- Workforce development
- Building knowledge of what is needed
- Communications
- Health

The report has been presented to the Health and Wellbeing Board.

The report makes some specific recommendations directed to Adult Social Care are:

- Ensure that family members or other people who are important to the young person are supported through the transition phase including with support from the Carers Service where needed - recognising that change can be challenging to manage for all parties.
- Specialist adult social care team offering Care Act assessment and acting as Lead Professional for the individual.
- Establish a virtual team/staff network across health, social care, criminal justice, voluntary sector providers, advocacy, acute settings and primary care to share knowledge, working practices and foster better cross-organisational working.
- Ensure community-based provision (Community Hub/commissioned diagnosis and support services) are seamlessly linked with the specialist adult social care team and the virtual team/network.
- Consideration should be given to using the model developed by the National Autism Implementation Team for staff and autistic people to determine what level of support would be most appropriate.
- The ASC specialist and virtual teams should make regular use of tools and resources to support individuals to understand their challenges/diagnosis and what it means for them as an individual.

5. Information, Advice and Support

Examples of actions already being taken to improve the access to and support available in Portsmouth include:

5.1 Room One

Room One is a new space managed by autistic people, for autistic people in Portsmouth, based at the Charles Dickens Centre (Lake Road, PO1 6HH).

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The aim is for the space to act as a one-stop-shop for autistic and neurodivergent adults, as well as parents, carers, friends of those adults, and the professionals supporting them.

Room One can be used as a source of information and advice, as well as a space where people feel they can drop-in, develop understanding, share challenges, and receive signposting or referrals to more appropriate services. This includes helping people to live as independently as possible and access resources that they are entitled to but may be currently struggle to access.

The team host lots of activities, including online and in-person peer support, as well as one-to-one and drop-in group sessions.

5.2 Autism Ambassadors

Autism Ambassadors have been appointed in the council to help raise awareness of autism and help staff and our customers living with autism. The ambassadors can work with staff to identify reasonable adjustments that can be made in the work environment to help them do their job, advocate for people with autism with their line managers and support line managers to understand what autism means in terms of the working environment so they can get the best out of their team members. This support will also help customers living with autism when using council services.

The ambassadors can also signpost individuals to additional information on autism, professionals and resources.

5.3 Employment Support

There has been a recent tender put out for an employment support service for autistic people in Portsmouth. Representatives from Portsmouth Autism Community Forum were involved in the bid proposal and the evaluation of the responses.

6 Transition into Adulthood

For those young people that may require support from Adult Social Care we want to make sure that they are supported by the most suitable team. If a Neurodivergent individual also has a learning disability it will be the Integrated Learning Disability Team that they are referred to.

We have recently recruited to some new posts in the Adult Care and Support service who will have a focus on supporting Autistic and Neurodivergent Young People who do not have a learning disability. These workers will operate initially as a specialist team, working closely with the other Adult Social Care Teams and colleagues in Children's and Education

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teams. A Social Worker, Occupational Therapist and Independence Support Assistant are currently completing their induction and will be starting to work with individuals.

A single referral pathway for young people transitioning into Adult Social Care is being developed to prevent young people falling between teams. This will use a form that professionals can complete, with the consent of the young person and will be sent to a central email address. Referrals can also be made via the Social Care Helpdesk in the same way all other referrals to Adult Social Care are made.

There have been significant changes in the Autism and ND pathway for children in Portsmouth, including the introduction of a profiling tool to help understand the strengths and challenges for a young person - see Appendix 2. These changes are relevant to Adult Services because we want to ensure that when these young people transition into adulthood, the support strategies that have been effective during childhood can be continued. Communications regarding the change in approach and pathway have been shared with colleagues in Adult Social Care. Adult Social Care is represented at the Children's ND Steering Group and ND Delivery Board to promote and plan for the transition into adulthood and into Adult Social Care where appropriate.

7 Workforce Development

Theme 3 from the report discussed about is about workforce development, with a recommendation for the 'development of a comprehensive programme of workforce development for public sector, voluntary and community sector staff. Training resources and sessions must be led or co-facilitated by autistic and ND people, building on the initial work of the PACF training project.'

This recommendation reflects a national need for better training, with mandatory training in learning disability and autism for those working in regulated activities becoming a legal requirement under the Health and Care Act 2022. Skills for Care have produced a Core Capabilities Framework for supporting Autistic People which was commissioned by Health Education England. The national programme, the Oliver McGowan Mandatory Training on Learning Disability and Autism, is currently being finalised following a programme of co-production, trial and independent evaluation.

The Portsmouth Learning and Development team are mapping and reviewing our current training offer. A small working group has been formed to support the roll out of the Oliver McGowan training across the H&IOW NHS and Local Authority system (including independent and voluntary sector employers).

Existing training on understanding Autism is available to PCC staff via e-learning and taught sessions with plans in place to extend and improve this offer.

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Portsmouth Autism Community Forum have been co-producing some training materials, including videos which will be used in both a standalone training package and as a resource to enhance other training packages.

8 Next steps

There is a need for a new strategic plan for Autism and Neurodiversity, with The Portsmouth Autism Strategy and Action Plan 2017-2022 now being out of date. A new strategy will be co-produced with the Portsmouth Autism Community Forum, using the findings and recommendations from the report discussed above. Part of this strategic work will inform the forward plan for operational support including a review of the Autism Hampshire contract which is currently being led by ICB colleagues.

Adult Social Care and the Portsmouth Autism Community Forum would welcome further involvement from Elected Members and would be happy to share more details on the findings from the report (Appendix 1) at a future meeting or event.

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Signed by (Director)

Appendices:

Appendix 1 - 'If not now, when? Autism and neurodivergence in Portsmouth: Evidencing the need for change.'

Appendix 2 - Communication re New Profiling Tool

Background list of documents: Section 100D of the Local Government Act 1972

The following documents disclose facts or matters, which have been relied upon to a material extent by the author in preparing this report:

Title of document	Location