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RE: Views & Experiences of People Accessing or Requiring ADHD Support Services

Dear Natasha,

Thank you for sending us your latest report, which provides lived experience and insight from service users, carers and professionals on their concerns regarding Attention Deficit Hyperactivity Disorder (ADHD) services. We recognise from the feedback featured within the report that there are challenges regarding awareness and understanding of ADHD, referral pathways for support, and extensive waiting times, as well as the potential impact that peer support can have in improving outcomes for patients.

We have provided a response to your recommendations below:

	Recommendation	Comments
1.	<p>Communication – Clear, timely and appropriate information to be made available at the point of first contact, providing easy read information about the potential impact of ADHD, reasonable adjustments that can be made and highlights coping strategies and signposting to appropriate sources of support.</p> <p>Information made available to families and friends would also help to provide a positive approach to awareness raising, social understanding and support, to help alleviate feelings of isolation.</p>	<p>Your feedback will help us to work with our providers to ensure that information is available to everyone at first referral and includes the asks made throughout this engagement.</p> <p>As part of the standard process for supporting families who are waiting and from the point of acceptance onto the pathway, the services (Tees Esk and Wear Valley NHS Foundation Trust (TEWV)) send a 'Keeping in Touch' (KIT) letter, every three months, to communicate waiting times and provide signposting to local support.</p> <p>In addition, for Children and Young People under 18 years a needs-led pathway was implemented several years ago, with the aim of supporting the needs of children and families with or without a diagnosis and at the earliest point. Parents and carers helped to develop resources and literature to support</p>

		<p>communication. More information is available here: https://northeastnorthcumbria.nhs.uk/our-work/workstreams/children-and-young-people/needs-led-neurodevelopmental-pathway/.</p> <p>NHS North East and North Cumbria Integrated Care Board (NENC ICB) is currently working with local partners and parent carers to understand what else would be helpful to support families, friends and the wider community earlier in their journey, which includes access to digital and peer support. We will ensure the views within this report are taken into consideration.</p> <p>The specialist adult ADHD Team provide assessment, diagnosis, immediate diagnosis support and titration of medication. If additional care and treatment is required patients are transferred back to their local community team.</p> <p>Community Teams currently provide a keeping in touch process for patients waiting for assessment (with no additional assessed needs) which includes a minimum annual contact to consider any change in needs and / or risks.</p>
2.	<p>Training – Feedback received highlighted a broad lack of awareness of the impact of ADHD from professionals within health and care services, schools and employers. GPs were reported as being inconsistent in their approach and information and advice shared was sporadic. Clear training and messaging demonstrating an inclusive, consistent approach to information and support needs to be embedded within recovery plans to continue to raise awareness of the growing issue. As local wellbeing services continue to develop, including the planned Stockton-on-Tees Wellbeing Hub – robust training plans for frontline staff should include the awareness of ADHD, impact, referral pathways and</p>	<p>TEWV commission a training offer which includes training for parents and carers and leadership skills for people with lived experience: https://www.tewv.nhs.uk/get-involved/training/.</p> <p>There is an integrated offer available through schools to support emotional health and wellbeing at an earlier point, which includes Mental Health Support Teams. The teams work together with the Neurodevelopment Services to help provide an earlier response to support.</p> <p>In line with community mental health transformation, Adult ADHD and Autism are areas of specific focus. Local community mental health transformation groups have embedded representatives from specialist Adult ADHD services to ensure all partners are made aware</p>

	<p>coping strategies to support the development of a community approach to wellbeing.</p>	<p>of the developments and issues arising in this area of work.</p>
<p>3.</p>	<p>Parent Classes and Peer Support Groups – It was clear throughout our engagement that people felt that they would benefit greatly from having the support of like-minded people who could support them on a personal level, to help alleviate isolation and build positive relationships. This could provide a positive learning platform that communities could develop at a local level.</p>	<p>NENC ICB commission jointly with all five Local Authorities across Tees Valley (including Stockton) a Neurodevelopmental Family Support Service. This service aims to provide early support and access to services for families (with or without a diagnosis), and to help navigate, (what can be, a complicated system of support) and provide access to peer support: https://www.daisychainproject.co.uk/family-support-service/.</p> <p>Stockton Parent Carer Forum works closely with NENC ICB to help identify needs of families with Special Educational Needs and Disabilities (SEND). Part of the parent carer offer encourages peer support with other SEND families: https://stocktonparentcarerforum.co.uk/.</p> <p>TEWV are rolling out a programme to support families whilst waiting for assessment and diagnosis. This is an evidenced-based programme for earlier support and written specifically for parents of children aged up to 16 years: https://www.barnardos.org.uk/get-support/services/parent-factor-adhd-service.</p> <p>From an Adult Mental Health perspective, the value that peer support offers is fully recognised. Peer support and lived-experience forums are embedded into community mental health and crisis work portfolios. There have been Peer Support Services introduced across Durham, Darlington, and Teesside (including Stockton), this is in addition to the internal TEWV Peer Support Team and these services are provided by Humankind: https://humankindcharity.org.uk/service/teesside-peer-support-service/</p>
<p>4.</p>	<p>Exercise and Mindfulness – Many people told us that their main sources of coping were exercise, mindfulness techniques and activities within the</p>	<p>We will seek to promote information on the importance of exercise and mindfulness.</p> <p>We have Social Prescribing Link Workers (SPLW) within Primary Care Settings which will</p>

<p>community to alleviate isolation and empower them to manage their condition.</p> <p>As the cost-of-living crisis continues it is important that consideration is given into how community activities can be developed and maintained with appropriate support and funding.</p> <p>Supporting people to develop positive relationships and alleviate isolation, while feeling happy and safe within the environments that best caters for their individual needs, is the way forward.</p>	<p>support and signpost to already existing community activities, supporting with isolation and relationship building.</p> <p>Examples of Social Prescribing newsletters have been attached alongside this response, and the 'Youth United Stockton' website has information on Youth Provision and their strategy for growth: https://www.yus.org.uk/.</p>
<p>5. Joint Working – As current health and care systems are changing there is a strong focus on better collaboration and joined up care to improve outcomes for people. The Integrated Care Systems (ICSs) have been set up to make this happen – with a focus on prevention, better outcomes and reducing health inequalities. These systems include NHS organisations, local councils, the voluntary sector, social care providers and other partners with a role in improving local health and wellbeing. In order to facilitate community development adequate funding and support needs to be available to promote positive system change while improving outcomes in population health, tackling inequalities in outcomes, experience and access.</p>	<p>The demand placed on autism and attention deficit hyperactivity disorder (ADHD) services for children and adults at a national level has increased notably over recent years and as with other areas across the country, NENC ICB is experiencing widespread challenges in our efforts to meet this increased demand for assessments, diagnosis and any subsequent treatment. We are working together as a local health, education and social care system to tackle these waits and support children, adults and families whilst waiting.</p> <p>NENC ICB is currently working with local partners and parent carers to understand what else would be helpful to support families, friends and the wider community earlier on, which includes access to digital and peer support. We will ensure findings from this report are taken into consideration.</p> <p>Joint working and multiagency collaboration underpin the community mental health transformation agenda. A key aim of this is to create a core mental health service which is aligned with specialist services, General Practice, Local Authorities and Voluntary Care Sector organisations whereby dedicated services and functions can be embedded.</p>

Thank you very much for sharing this report and we look forward to reading the next one.

Kind regards,

Alex Sinclair - Director of Place (Stockton)
North East and North Cumbria Integrated Care Board

Cc David Gallagher – Executive Area Director (Tees Valley and Central)
North East and North Cumbria Integrated Care Board