

29 June 2021

Lisa Bosomsworth
Healthwatch South Tees
Carers Way
Newton Aycliffe
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Dear Lisa,

Re: A Parent Carer Perspective - Replacing the Autism Pathway report

Thank you for sharing this report with us. Feedback from parent carers is valued by the CCG and will help to inform the way future services are shaped.

We acknowledge that engagement with parent carers outlined in this report was the result of a request from Tees Valley CCG for Healthwatch South Tees to explore the barriers and gaps in the existing Autism Pathway, as well as the proposals for the new, yet-to-be-implemented Neurodevelopmental Pathway across South Tees. We would like to thank you and all those involved for the time taken to do this and we will continue to use the feedback received to inform our work and communications. On reflection, it would have been more appropriate to focus on the barriers and gaps in the existing Autism pathway, as the elements which have focused on the new pathway needed additional reassurance to parents that the pathway was to be a partnership between all partners, with the family at the core. The concerns that parents have expressed relating to the new pathway will be addressed through a series of communications, which we will work with the Parent Carer forums from Middlesbrough and Redcar & Cleveland to develop.

As the report contains recommendations on a range of subjects related to the pathway (such as access, schools, treatments, mental health, training, communication etc.), we have provided a joint response from multiple teams within NHS Tees Valley CCG (TVCCG) and Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV). Our response has been compiled with, discussed and agreed by Dominic Gardner, Director of Operations at TEWV.

| Recommendation | TVCCG Response | TEWV Response |
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| Culture | | |
| Elimination of discrimination and provision of a fair system with equal access based on needs, not poor parenting or socio-economic factors. | The services provided in the 'bubble of support' will be available to all families living in the South Tees area. | |
| Treat parent carers and children with compassion, dignity and respect. Listen to what they are saying and take the information seriously. | Families will be asked to access training and support where the multi-agency triage panel feel this will benefit the family and child. | The parents view is captured as part of any assessment their child is part of. |
| Provide ongoing opportunities and actively seek the views of parent carers and children about their experiences on the new pathway and the provision within 'The Bubble of Support'. | <p>There will be an ongoing review of the needs led pathway with the views of parent carers being regularly sought.</p> <p>A more formal review will take place 6 months after launch and then 12 months afterwards.</p> | <p>The views of parents will be collected on the referral form alongside those of the professional and the child.</p> <p>The Parent carer forum are involved in working with TEWV to pull together newsletters and other communication.</p> |
| The New Pathway | | |
| Provide clear and user-friendly information about the new pathway and what is in 'The Bubble of Support'. Consider changing the name of 'The Bubble of Support' due to negative connotations related | <p>The term 'Bubble of Support' is used in Neurodevelopmental Pathways in other areas of the Tees Valley, therefore it would not be appropriate to have a different named approach in each area.</p> <p>South Tees will have a designated Neurodevelopmental Webpage</p> | All communication relating to the new Specialist Assessment Pathway are being developed and discussed with the Parent Carer Forum in both Middlesbrough and Redcar & Cleveland. |

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| to Covid-19 and lockdown. | which will contain all this information. | |
| <p>Consider parent carer concerns about the new pathway and provide feedback on issues raised in relation to:</p> <ol style="list-style-type: none"> 1. Removing the self-referral option. 2. The ambiguity over diagnosis. 3. Transitional points including Age 5, primary to secondary school and age 18. 4. Limiting the pathway to only include autism and ADHD. | <p>Parents have never been able to refer onto the ASD pathway. They have been able to refer their child into CAMHS and as part of that assessment the CAMHS clinician can consider the child for ASD/ADHD; however that is part of a much wider initial assessment. The clinician then determines if a child could possibly have ASD/ADHD and they are then referred to the relevant specialist pathway.</p> <p>The change is the creation of a Neurodevelopmental Team and the introduction of a referral form. This is due to the best-practice models' focus on referrals being made with supporting evidence from practitioners and parents to speed up the assessment process. The referral form includes the parent carer's views as it is completed with them, and also the views of the child if they are able. TVCCG is aware of parent carers' concerns that sometimes they have different views to the child's teacher, therefore the focus is not just on SENCOs being able to send in referrals, but also other professionals who are linked to the family. If families aren't linked to other professionals, they can seek advice from TEVV.</p> <p>The pathway will be able to consider children for ASD and ADHD during the same assessment process without the need for separate referrals</p> | <p>Removal of self-referral – we recognise the concerns around this however the remit is that any professional can complete the referral form alongside the parent. This will expand to the family support service once this is in place from December 2021. Where the family feel they are not being supported by a professional they can call the Neurodevelopmental Assessment Team for advice on how to move forward.</p> <p>The ambiguity over diagnosis – this new Specialist Assessment Pathway is not to prevent people from getting a diagnosis. It is there to ensure children get the support they need to meet their needs whilst they are on the diagnostic journey. Under the current pathway, not all children who are referred for a specialist assessment receive a diagnosis – this new pathway will ensure that the needs</p> |

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| | <p>and without needing to have assessments repeated, which addresses parental concern around children being assessed multiple times. Regarding education, TVCCG is working with Local Authorities to determine what training can be offered to school staff so that all educational settings are trained to a consistent level across South Tees.</p> <p>The Neurodevelopmental pathway is limited to ASD and ADHD because it is a TEVV pathway and these are the conditions which they are commissioned to assess. The Family Support Service will be available for a wider number of neurodevelopmental conditions once it is available from December 2021. TVCCG has already advised the Parent Carer Forum that as part of ongoing work, the pathways for other neurodevelopmental conditions such as Foetal Alcohol Syndrome will be reviewed. We have started with ASD and ADHD based on need and waiting times.</p> | <p>of all children are met.</p> <p>Transitions – all education establishments will receive training. The needs led approach, will over time, ensure that needs are met at the earliest opportunity and concerns around transitions will not be as prominent as they are now.</p> |
| <p>Explain how the diagnostic process will consider information about children in unstructured settings and take seriously information presented from parent carers about behaviours in the</p> | <p>The views of parents and carers are central to this process and are collected on the referral form and explored more once the child is on the pathway. If a parent feels they have not been listened to then we will develop mechanisms for this to be reported and addressed.</p> | <p>Listening to the parents' voice – the views of the parent are captured on the referral form alongside those of the referring agent and the child. The parent will be involved in the initial assessment with the child.</p> |

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| <p>home and wider community. Also explain, how the pathway will identify, diagnose and support children:</p> <ol style="list-style-type: none"> 1. That mask traits, especially girls. 2. With additional co-existing neurodevelopmental conditions, including sensory and regulatory dysfunction. | <p>TVCCG will work with TEWV to identify training that can be rolled out to front line professionals to enable them to better identify and support children who mask traits (especially girls). TVCCG is also working with South Tees Hospitals NHS Foundation Trust to improve the sensory offer available.</p> | <p>Masking – There are additional assessments that can be undertaken for girls that mask. Experienced clinicians conduct the assessments. Masking checklists are used throughout the assessment. Teaching and training within the team. We are involved with ongoing research regarding the topic.</p> |
| <p>Monitor and evaluate the new pathway, especially in areas where there are specific changes, including referral, assessment, diagnosis and the 'bubble of support'. It is essential to include parent carer and children's views on their experiences of the changes.</p> | <p>In order to monitor and evaluate the new pathway, it will be reviewed on an ongoing basis through communication with the Parent Carer Forums. The service will be formally reviewed after six months and again after a further 12 months. All organisations commissioned to provide services (such as the Family Support Service and Sensory Sunflower) will be reviewed in partnership with the Parent Carer Forums – this approach has been proven effective in the North Tees locality.</p> | <p>The pathway will be subject to ongoing review and tweaking to ensure it is more effectively meeting the needs and is working like we are intending it to work. We have already involved the Parent Carer Forum in aspects of the pathway including the service specification for the Family Support Service and in reviewing paperwork which the Neuro team will use.</p> |
| <p>Support in School</p> | | |
| <p>Improved wellbeing for children in mainstream settings by:</p> <ol style="list-style-type: none"> 1. Increased knowledge and understanding of | <p>As part of our work across children's mental health and emotional well-being, we are working with several providers and agencies to develop a whole system approach. Many of the providers we are working with are working into schools</p> | <p>Some of this will require a response by the Local Authorities (LAs) but from a Pathway perspective, we are working with the LAs to ensure that there is training</p> |

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| <p>neurodevelopmental conditions and the role of education in referring onto the pathway.</p> <p>2. Reversing punitive approaches by understanding and implementing reasonable adjustments, particularly within behaviour policies.</p> <p>3. Offering personalised, creative and effective support.</p> | <p>already and will also be part of the 'Mental Health Support Teams (MHSTs)' for school's roll-out. These providers have close ties with TEWV-CAMHS and will be developing processes to facilitate effective referrals into the pathway for any appropriate young people they become involved with. The ongoing support and training on offer to school's mental health leads will also help to facilitate increased knowledge and understanding regarding access to the pathway.</p> <p>The 'whole school approach' that will be developed alongside the MHST roll out can also be used to facilitate awareness raising, improved practice and culture change within schools and their connected services with regards to neurodevelopmental conditions.</p> <p>This recommendation will also be considered as part of wider work which TVCCG will pick up alongside LAs and Schools.</p> | <p>available for education settings to ensure they are upskilled in identifying and better supporting neurodevelopmental conditions.</p> <p>Across Tees there is a multi-organisational whole system approach to children/young people's emotional/mental health needs which include specialist CAMHS (TEWV), but this is in partnership with other VCS providers as well as the Mental Health Support Team (MHST) development. The whole system is using the iTHRIVE framework to organise the mental health offer.</p> <p>Getting Help (Targeted) interventions for mild to moderate emotional/mental health needs will be provided by a multi-agency approach which will include some resource from specialist CAMHS (TEWV). Specialist CAMHS will be providing interventions for complex mental health presentations in the Getting More</p> |
| <p>Greater accountability from health and care to work more closely with education to improve individual outcomes for children.</p> | <p>As above</p> | <p>to moderate emotional/mental health needs will be provided by a multi-agency approach which will include some resource from specialist CAMHS (TEWV). Specialist CAMHS will be providing interventions for complex mental health presentations in the Getting More</p> |
| <p>Mental health / counselling support in mainstream schools particularly around transition</p> | <p>Counselling is not typically commissioned by the CCG. However, we are working with several non-NHS providers who are experienced in counselling provision as part of our whole system approach</p> | <p>to moderate emotional/mental health needs will be provided by a multi-agency approach which will include some resource from specialist CAMHS (TEWV). Specialist CAMHS will be providing interventions for complex mental health presentations in the Getting More</p> |

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| <p>and adolescent stages.</p> | <p>and MHST roll out and are now able to build elements of this into our offer going forward.</p> <p>We commission Kooth across South Tees, which offers emotional and mental health support for children and young people. https://www.kooth.com/</p> <p>This recommendation will also be considered as part of wider work which TVCCG will pick up alongside LAs and Schools.</p> | <p>Help part of the framework.</p> <p>As a specialist mental health provider, TEWV would provide targeted/specialist interventions as per individual need. General support would come from LA/other providers.</p> |
| <p>Mainstream and specialist schools could work together more closely to improve wellbeing and outcomes for children in mainstream schools.</p> | <p>This recommendation will also be considered as part of wider work which TVCCG will pick up alongside LAs and Schools.</p> | |
| <p>Increased accountability for children's overall wellbeing in school, to include the perspective of students and their families.</p> | <p>The national rollout, mandated by Dep. Education, to have mental health leads in schools should bring this. We are also instructing our providers to facilitate regular engagement and co-production to inform ongoing delivery of support into schools.</p> <p>This recommendation will also be considered as part of wider work which TVCCG will pick up alongside LAs and Schools.</p> | |
| <p>Specialist Treatments and Therapies</p> | | |
| <p>Ensure access to an appropriate range of specialist treatments and therapies, that take account of the needs of children</p> | <p>Therapeutic interventions provided by the NHS are offered in 'episodes of care / intervention' and may be delivered by either the Acute Trust (i.e. sensory / SALT) or the Mental Health Trust (i.e.</p> | |

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| <p>with neurodevelopmental conditions. Consider ways to improve current provision that has long waiting lists and is often time limited. Identify where the gaps are in provision through ongoing parent carer consultation and liaison, and plan to improve the range on offer, to include sensory and regulatory treatments and therapies.</p> | <p>Anxiety). The length of each child's intervention will differ depending on their needs.</p> <p>As part of the work programme of the CCG we are reviewing Children's therapies to ensure they can meet demand and that children are seen in a timely manner. Where possible we are looking to see if these services can increase their capacity through looking at joint commissioning opportunities. There is also work ongoing to look at the gaps we have in NHS provision and to see how the NHS offer differs from the provision offered by private providers.</p> <p>We are working specifically with the Occupational Therapy Team within South Tees to look at a Sensory offer to become part of the needs led bubble of support.</p> | |
| <p>Mental Health</p> | | |
| <p>Embed a preventative, whole family approach to mental health by:</p> <ol style="list-style-type: none"> 1. Treating children and families with compassion, respect and understanding. 2. Promoting widespread understanding of neurodevelopmental conditions and the impact on children and families, | <p>When working with our providers we would expect compassion and respect as a minimum standard and where this has not happened, for appropriate process to be followed and lessons learnt.</p> <p>Our whole schools approaches mentioned above will provide us with an additional tool to raise awareness, provide training and influence culture and practice.</p> <p>The roll out of MHSTs will improve the offer into schools, we will coordinate this with the support that schools</p> | <p>Please see response above under 'Support in School' heading.</p> <p>The whole system approach mentioned above will bring about a viable, quality and significant 'alternative to CAMHS' offer for mild-moderate mental health issues and help to bring about efficiencies in CAMHS specialist services.</p> <p>Workforce and retention is of national</p> |

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| <p>through awareness and training.</p> <p>3. Encourage and enable professional understanding about appropriate adjustments and coping strategies to meet individual needs.</p> <p>4. Provide access to mental health services in schools especially during transition and adolescent years.</p> <p>5. Consider a new model for providing mental health services that offers low level preventative support as well as accessible and appropriate specialist provision when needed.</p> <p>6. Personalise all mental health services to provide consistency in practitioners, needs based provision (rather than time limited), quick and easy access etc.</p> <p>7. Provide specialist parent carer support where necessary and encourage peer support networks for emotional support.</p> | <p>themselves commission so that the total offer is enhanced and not just replaced.</p> <p>The Family Support provision will encourage parent carer networks and peer support networks once it is live in December 2021. The CCG work on an ongoing basis with the Parent Carer Forums to improve services and the Forums work tirelessly to promote their organisation and encourage new membership.</p> | <p>concern. We do see ongoing therapist/practitioner turnover, however we are engaged in regional strategic work to look at this. The national policy with regards to workforce development in children's mental health is largely centred around Improving Access to Psychological Therapies (IAPT) type practitioners (for mild-moderate mental health issues</p> <p>However, the added benefit we get from working with some of our voluntary sector providers is access to other therapies, including counselling. We would expect that any specialist CAMHS involvement would continue for as long is necessary to facilitate the best possible outcome for the individual.</p> |
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Training and Awareness

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| <p>Promote and provide appropriate training and awareness to all front-line professionals. Ensure this includes:</p> <ol style="list-style-type: none"> 1. Appropriate understanding about neurodevelopmental conditions in children, how this may present and what the process is for making a referral onto the pathway. 2. Identify signs of neurodevelopmental traits in children that mask, especially girls and ensure front line professionals have a good awareness of this issue. 3. An awareness of discrimination within the system, treating families with compassion and respect in an open, honest and supportive manner. | <p>Although, due to COVID we are not currently undertaking GP Time-out sessions for Practices, the CCG's Primary Care and Children's Team will work together to:</p> <ul style="list-style-type: none"> • Develop communications to Practices covering these recommendations, and any additional information that may be helpful; and • Develop a specific session for primary care colleagues for when Time-out sessions are reinstated, hopefully during 2021/22. <p>The Local Authorities are identifying front line teams who will require additional training.</p> <p>We are looking at opportunities as to how we can make training available to schools, local authority front line staff to enable them to be upskilled in recognising and supporting children who are neurodevelopmentally diverse.</p> <p>Training will also be made available to families. Until the Family Support service goes live in December 2021, we have worked with Contact who will be providing support and training to families across South Tees. The training which they will be providing has been discussed and agreed with the Parent Carer Forums.</p> | |
| <p>Promote a public awareness of neurodevelopmental</p> | <p>This is something we can work with Healthwatch to look at how we can do this across South Tees in terms of expectations</p> | |

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| conditions and how they may present. | | |
| Provide information, training and awareness for families, eliminating the notion of 'bad parenting', that genuinely offers opportunities to better understand the needs of their children and helps them to thrive. Parent carers have particularly asked for training in sensory dysfunction and emotional regulation. | The training for parents either through Contact or the Family Support Service, when commissioned, will be built around the needs of the families in the Tees Valley. Regular meetings with the parent forums will ensure the training offer evolves as new needs arise | |
| Care of Parent Carers and their families | | |
| Treat parent carers with compassion, respect and understanding. Provide information about where they can get support, including carers assessments and peer support. | All families in South Tees will be able to access all of the information relating to the pathway and the Bubble of support on the Neurodevelopmental website once this has been created. | Letters sent to families, following receipt of the referral, and again following triage will detail local organisations who can offer this support. There will be a local 'neurodevelopmental' webpage which will also hold this information. |
| Consider the impact of raising a child with neurodevelopmental issues on the family and how support provision such as direct payments may extend respite to siblings as well as parent carers. | We recognise the fundamental role that parent carers have in supporting their children and part of the remit for the Family Support Service is to have some sessions for parents around their mental wellbeing. | The views of the parent are also captured within the referral form and the neuro team will have ongoing communication and a point of contact for parents to call if they need to speak to |

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| | | someone during the assessment process. |
| Communication and Information | | |
| Promote open and honest communication between front line professionals and families. Ensure there are systems in place to monitor accountability to families for keeping them informed and involved in decisions that impact on their family. | | Work has already commenced between the Neurodevelopmental Assessment Team Manager and the Parent Carer Forum to improve communications. |
| Ensure systems and mechanisms are in place so that families can access information about what support is available and how to access it. Ensure this includes information about social support options and specialist treatments and therapies. | Additional staff resource will lead to improved communication for families on the Neurodevelopmental Pathway. There will be a single point of contact and regular newsletters and updates which will be developed with the Parent Carer Forums and TEWV. | |
| Ensure communication and information systems and processes are regularly reviewed. | | Learning from work in North Tees there will be a different approach to communication and ensuring the parent remains involved in their child's journey through the pathway. |

| Transitions | | |
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| <p>Recognise transitions potentially as critical points in a child's life and respond with relevant importance. Increase scrutiny across agencies about performance at transitional stages and ensure agencies work together to better plan and support these periods.</p> | <p>Transition years are being factored in as a priority area to address as part of the MHST roll out.</p> | <p>The increase in training across schools and other professionals will improve this. The multi-agency triage will also help with the triangulation of information across statutory organisations at the earliest opportunity</p> |
| Autistic Friendly Communities | | |
| <p>Consider exploring the concept of autistic friendly communities and how the new pathway might fit with this. This may involve providing community hubs where low level preventative services could be delivered alongside a family advocacy support service. People and families with neurodevelopmental conditions could be involved in delivery, opening localised peer support networks and activity hubs around a 'whole family' model.</p> | <p>A key requirement of the Family Support service is that it will be delivered alongside other services provided by the Local Authority. The location of the delivery has yet to be determined. However, it will be discussed with the parent carer forum to ensure that it is as accessible as possible for all families.</p> | |

Some recommendations outlined in the report (such as access to specialist treatments and therapies, engagement in activities, recognising transitions and exploring the concept of autistic friendly communities) will be taken into account as TVCCG plans new services and reviews current services, and conversations will also take place with local authorities.

We hope that you find our response to the report's recommendations to be beneficial, and we thank you again for providing a platform for parent carers to have a voice and influence the way services are delivered in South Tees. We look forward to reading the next report.

Kind regards,

Alex Sinclair

**Director of Commissioning, Strategy and Delivery – Children and Young People
NHS Tees Valley Clinical Commissioning Group**

cc. Dominic Gardner

**Director of Operations – Teesside
Tees, Esk and Wear Valleys NHS Foundation Trust**