A Parent Carer Perspective

Summary Report

Replacing the Autism Pathway for 5 – 18 Year Olds Across South Tees

March 2021

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healthwatch Middlesbrough

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Introduction

There's a Healthwatch in every local authority area of England. We are the independent champion for people using local health and social care services. The role of Healthwatch is to listen to what people like about services and what they think could be improved and to share these views with those with the power to make change happen. We also share information with Healthwatch England, the national body, to help improve the quality of services across the country. Healthwatch helps people receive the right health and social care services locally by providing an Information and Signposting service.

In sum – your local Healthwatch is here to:

- Listen to what people think of services
- Use people's views to help shape better services
- Provide information about health and social care services locally.

Healthwatch Middlesbrough and Healthwatch Redcar & Cleveland have been working together across Healthwatch South Tees (HWST), since 1 April 2017.
If you would like to learn more about what we do, please click here to visit our website. If you require this information in a different format, please click here to be directed to our accessible documents, or you can contact us: healthwatchsouthtees@pcp.uk.net.

Background information

Healthwatch South Tees (HWST) adopted autism and learning disability as a local priority following our consultations in 2019 to support implementation of the NHS Long Term Plan. You can read our report here. In June 2019, we included our local intelligence in a consultation report, contributing to the development of a national Core Capabilities Framework to train and raise awareness of autism and learning disability. You can read this report here. We have continued to build on dialogue with parent carers and young people to ensure those with lived experience are at the forefront of shaping local provision.

Joint conversations have taken place across a range of partners to replace the current autism pathway from 1 April 2021. The new pathway is for children and young people aged 5 to 18 years old (referred to as 'children' in this report). It will be called the Neurodevelopmental Pathway because it covers Autism and ADHD. It is described as a 'Needs Led' approach, not dependent on diagnosis, that provides support to the child and the family from the point of referral, onward, and as required. You can read more about the new pathway here.

The new pathway will require health, care and education to work closely together to meet the needs of children and their families. TVCCG (Tees Valley Clinical Commissioning Group) are leading on this work and have involved a range of partners in the development of the new pathway.

As an independent stakeholder within these partnerships, we were asked to engage with parent carers to find out their views, so family experiences can directly influence the new pathway. TVCCG particularly want to hear parent carer views about what support is needed within 'The Bubble of Support' to develop existing provision and consider future commissioning.

What We Did

HWST disseminated a survey and received 91 completed submissions from parent carers across South Tees. We also hosted virtual focus group conversations with an additional 16 parent carers, some representing larger networks.

Presentation of Data

This summary presents key messages from our consultation and discussions with parent carers, about their experiences of the current autism pathway and the proposed changes. The full report and recommendations can be viewed **here**.

Referral onto the Pathway

Our survey data showed self-referral was the most common route onto the existing pathway.

Parent carers are concerned that the option for 'self-referral' is to be removed from the new pathway. They said, for many families, 'self-referral', was the only route onto the current pathway. The new pathway creates a reliance on schools and health professionals to agree to make appropriate referrals when currently, they frequently fail to recognise neurodevelopmental conditions.

Autism in Girls

Parent carers stated that girls are being failed by the system because neurodevelopmental traits are often missed in females. Girls are generally much better at masking behaviours by copying their non-autistic peers. Assessment criteria can fail to diagnose females, who later come back into the same system to be diagnosed and treated with mental disorders because they are struggling with unmet needs.

Professional's Attitudes

The way in which parent carers are responded to by professionals is fundamental to how supported they feel.

Many parent carers said information they shared about their children was not given due weight by professionals and poor parenting, or living in deprived areas, was frequently blamed for children's difficulties. They also highlighted that professionals are quick to judge and dismiss them, when conventional parenting advice doesn't work for their children.

Assessment

Respondents said they were often kept on the existing pathway for extended periods of time, with little or no information or communication. They said, not knowing what was happening, whilst they struggled at home, and to convince school to recognise their child's needs, put enormous pressure on families.

During the assessment process, families said:
Too much emphasis is put on assessing children in structured classroom settings.
Not enough emphasis is put on information provided by parent carers
Sensory and regulatory dysfunction should be part of the assessment.

"Can you provide an advocacy service for parents on this pathway? If we had something like this, it would cut down massively on the lack of information and support during the pathway".

Diagnosis

Parent carers were concerned about the ambiguity around formal diagnosis as part of the new pathway.

Formal diagnosis was considered critical to help understand and meet individual needs at any age, and to provide protective rights under the 2010 Equality Act. Diagnosis can also be fundamental to building a positive identity, develop self-help strategies, embrace diversity, and value difference.

Support in Schools

Our survey revealed children with a diagnosis were more likely to receive adaptions in school to improve how their needs are met, but more focused exploration is needed to fully understand this position.

They are concerned about the lack of staff skills to recognise neurodevelopmental traits and this will result in children not being referred for assessment.

It was common for parent carers to be concerned about their child's mental wellbeing in mainstream school due to:

- The lack of awareness and understanding of neurodevelopmental conditions
- Unmet needs
- The punitive focused approaches to managing behaviour.

Parent carers want increased accountability for children's wellbeing in mainstream school through:

- Health and social care working more closely with schools.
- Monitoring children and parent carer perspectives by actively seeking their views and opinions.

Access to Specialist Treatments and Therapies

Survey data referred to the importance of specialist assessments, treatments, and therapies which parent carers want to see available within the 'Bubble of Support'. They indicated how they would like current provision to be extended and improved, to include sensory and regulatory therapies. They said they need information about what is available, with easy access to treatments and therapies when they are needed for as longs as needed.

Support for Children in the Wider Community

Most parent carers said their children didn't receive any support outside of school despite bullying, and their children's vulnerability preventing them from safely accessing the wider community.

Some families had accessed community activities including getting together with other parents and children through planned social groups, short breaks and voluntary sector provision. Although families had mostly enjoyed these activities, they said there can be inconsistency in the quality of what is on offer.

Children often liked taking part in activities and enjoyed friendships but there is a lack of opportunity for this to happen.

Support to access the community and universal activities through direct payments has proved very effective and improved overall outcomes for children; Yet parent carers say this is never routinely offered and they must find out how to access this themselves.

“There is currently a ‘mish mash’ of support given by lots of different services providers that parents find difficult to navigate or are aware of”.

Support for Parent Carers and Families

Parent carers want positive relationships with professionals, that treat them with respect and value the information and expertise they have about their child.

They explained that life can be demanding, and respite or breaks were an important element of support, which gave them chance to recharge or spend time with other members of their family.

“Siblings are losing a parent to the disabled child/ren needing 24/7 attention from the parents…”

Peer support helps relieve that level of loneliness that can be a part of family life with neurodiverse children. Survey results identified; it is common for families on the current pathway (without diagnosis) not to have contact with families like theirs, whilst families with diagnosis commonly accessed peer support.

An important element of parent carer support is to ensure there are robust easy access pathways, that provide their children with the right services, to be happy and to thrive, now and in the future.

Mental Health

Mental health was a common thread throughout many aspects of this consultation, yet only a small number of respondents had received support from CAMHS. (Child & Adolescence Mental Health Services)

Parent carers said caring for a child with neurodevelopmental conditions, can have a huge impact on their own mental wellbeing.

They told us, children’s unmet needs and being overwhelmed by everyday life were the main causal factors for their children’s poor mental health, which could largely be avoided. Flawed assessment and diagnosis processes and a lack of awareness and understanding were identified. They would like increased accountability for children’s mental health, especially by mental health services and particularly in mainstream education settings. Mental health support is needed in mainstream secondary schools, as well as an improvement in the way schools and CAMHS / mental health services work together, to better meet the needs of children.

“No access to mental health services in secondary schools is a problem considering suicide rates for people living with autism”.

The way in which families are treated in the wider community was mentioned, being judged by others, being subjected to negative verbal comments and the effect of their children being victims of bullying.

Information & Communication

Parent carers said they want regular, open and honest communication from professionals. This is especially important during assessment and diagnosis processes. They want easy access to information to be aware of options available to them. They suggested information about direct payments should be offered as an option, along with support for how to manage these.

It would be useful if more professionals were better informed of where to signpost families for relevant information, including how to engage with local groups, community activities and peer support.

> "Nobody explains to families what is going to happen. Families are not informed about the procedure. More information would be a good thing. Once you are on a pathway you are just there waiting. You get to the end (of the pathway) and given a bit of paper and that is that"

Awareness and Training

Professionals

Parent carers explained training and awareness for professionals is critical to understanding and meeting the needs of children, early recognition of traits, and referral onto the pathway. They said they can often feel criticised by professionals who can be dismissive or judgmental, and don't understand why conventional methods of parenting don't work. They are concerned that currently, professionals can have a very poor understanding of neurodevelopmental conditions, yet they are going to be the linchpin for referring children for assessment.

The Public

Negative experiences for children and families in the community can have a devastating impact. Bullying and feeling judged, reduces options to be part of community life, to develop confidence and independence and has a negative impact on mental health.

Parent Carers

Parent carers welcome training opportunities to develop understanding of their child and how to help and support them. However, they don't want to feel like training sessions are a 'punishment' for 'bad parenting', or that they have to prove to anyone that they are a 'good parent'.

Transition

More needs to be done to support children and families around transitional stages. Parent carers explained the move to secondary school is very challenging for their children. Some children's needs in primary school are not being formally recognized leading to poor transitions to secondary schools. Transitions to adults services at age 18 can also be very challenging. There were instances whereby reassessments were undertaken at age 17 and their child's 'disability' was changed to a 'difficulty', impacting on the support they can access from adult services.

> "Autistic children become autistic adults. What happens at the end of the children's pathway"?

Living with Autism – A Better Life

Parent carers shared their perceptions of autistic friendly communities and had some great ideas for local decision makers to consider, including awareness raising campaigns, community hubs and advocacy support.

> “You don’t only have an autistic child; you have an autistic family… based on the way my child needs to live.”

Recommendations

Following the engagement of parent carers in this work, HWST is suggesting recommendations under the following headings. The full account of these is in the main report **here**:

Culture
The New Pathway
Support in School
Specialist Treatments and Therapies
Support to access activities and the wider community
Mental Health
Training and Awareness
Care of Parent Carers and their families
Communication & Information
Transitions
Autistic Friendly Communities

Conclusion

Many families are currently struggling to get the support needed for their children and themselves. What they want is to be listened to, treated with respect, get open and honest answers and to access fundamental support, treatments and therapies for their children to thrive. In essence, they want the best outcomes for their children and to work with professionals to achieve this.

Some support provision is already in place, but parent carers want increased accountability for the quality of delivery. They want more choice and control to access support services that are right for their family when they need it, for as long as they need it.

They welcome multi-disciplinary teams working alongside each other, picking up on co-existing conditions, to give a fuller picture of their child’s needs. They stressed the importance of early assessment and diagnosis to help to understand their child, to adapt how they live and to prevent mental health becoming an issue.

They emphasized the importance of training and awareness, advocating it is especially important for those who have a duty to be fully aware of children’s needs, to avoid misinterpretation of ‘masking’ and challenging behaviours. Diagnosis is currently relied on as ‘evidence’ required to make sense of behaviours and needs, which explains why parent carers are concerned about proposals to remove the ‘self-referral’ option, and the current ambiguity regarding ‘diagnosis, on the new pathway.

Information about limiting the new pathway to autism and ADHD has caused significant response after the consultation period. There is apprehension about not having a clear identified route for children with other neurodevelopmental conditions including Foetal Alcohol Spectrum Disorder. Parent carers are concerned there is a lack of skill within the system to recognise other neurodevelopmental conditions; Because of this, they feel the proposal to identify these conditions at referral stage is therefore fundamentally flawed and will not happen. There is a fear that children who don't fit the autism/ADHD assessment criteria will not be properly assessed with far reaching negative consequences.

Despite the issues and difficulties parent carers raised as part of this work, a positivity emerged. There was talk of 'autistic families' and 'autistic communities' that celebrate difference and strive for reformation.

> "Our communities will continue to strive for a society where families are part of a network of support from community level upwards; Truly involved in making decisions and shaping the future for our own children and families, and those that come after them."

Thanks & Acknowledgements!

We are grateful to have received a vast amount of data from our survey and focus groups and want to thank everyone for taking part. We acknowledge that although every journey is different, every individual and their experience is extremely important to us.

We would also like to thank members of TVCCG for their patience and support during the consultation and production of our reports.

We have valued the opportunity to be part of this work and look forward to receiving responses and actions relating to the recommendations linked to this report. We are anticipating a positive impact on the development of the new South Tees Neurodevelopmental Pathway, shaped by neurodiverse families.

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Working for you,
across South Tees

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