A Parent Carer Perspective

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

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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.

Summary Report

A summary of this report, outlining the Parent Carer Perspective can be viewed **here.**

Background information

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 with all relevant professionals. You can read this report **here.** We have continued to build on dialogue with parent carers and young people to ensure those with lived experiences are at the forefront of shaping local provision.

Joint conversations have taken place across a range of partners to develop a new pathway for children with autism and ADHD (Attention Deficit Hyperactivity Disorder), aged between 5 and 18, which will replace the current autism pathway from 1 April 2021. Tees Valley Clinical Commissioning Group (TVCCG) are leading these changes.

New ways of working will involve a 'needs led' approach, providing a 'Bubble of Support' for families, from the point of referral and throughout this age span. TVCCG provided information about the new pathway which you can access **here.**

As an independent stakeholder within these partnerships, we were asked to engage with parent carers about their experiences of the current pathway, so that family experiences directly influence the new pathway. This work was undertaken during October 2020.

Current Landscape

This section of the report provides a brief overview of the current autism pathway from a parent carers perspective, the main features of the new pathway and significant differences.

Current Autism Pathway

During this consultation, parent carers frequently talked about how difficult and slow it was to get an autism diagnosis on the current pathway and often other coexisting conditions were not picked up as part of the assessment process.

They said professionals may refuse to support families to make a referral, so parent carers frequently self-referred.

Many children were refused an assessment on the basis there was not enough evidence of needs, only to re-enter the pathway later. This was the case especially for children who masked traits at school, the majority of which were girls. For some families this went on until the child reached teenage years.

During the assessment process, there was a lack of information and communication, and in some cases, this was experienced over many years.

Having received diagnosis, families told us it was commonplace to send families on their way, with no follow up or support offered.

This position is reflective of the national picture that has prompted wider developments across the NHS, with new approaches adopted by other authorities across England.

New Neurodevelopmental Pathway

The new pathway is referred to as the Neurodevelopmental Pathway and will be for children and young people between the ages of 5 and 18 (From here referred to as children). Information provided by TVCCG about the pathway states: “Neurodevelopmental is the name given to a group of disorders associated within the functioning of the neurological system in the brain”. Initially, we understood the new pathway would cover a range of neurodevelopmental disorders, but it has since been clarified, it will specifically cover Autism and ADHD (Attention Deficit Hyperactivity Disorder).

Further discussions with TVCCG indicated a multi-disciplinary team will assess information presented on referral. The team will identify any underlying or co existing conditions, alongside autism and ADHD and refer on as appropriate.

Information stating the Neurodevelopmental Pathway is for children with autism and ADHD, was not provided to parent carers as part of this consultation. Although our focus group discussions did not therefore cover this area during the consultation period, there has been some discussion since. Responses and comments have been added to this report in the recommendations and conclusion sections.

The new pathway is described as an ‘improved and sustainable’ method of meeting current and emerging needs, with ‘better use of resources and improved outcomes for families’. It is a ‘needs led’ approach that does not rely on diagnosis and provides support for children and families from the point of referral until the child is 18 years old, as required.

The new pathway will:

1. Introduce a generic referral form which will capture information, preventing unnecessary delays.
2. Remove the option for children to be referred in through core CAMHS by reviewing all referrals at a multi-agency panel, with representatives from CAMHS, Speech & Language, Education and Early Help.
3. Determine what support the child could access to have their needs met, based on the information provided and make these recommendations to the parent and the referring agency.
4. The multi-agency approach will ensure that relevant support/provision is in place for the child.
5. If there is enough evidence to suggest there could be a neurodevelopmental condition (Autism/ADHD) the referral will be passed to the Specialist team.
6. If there is not enough evidence at this time, parents will be asked to access ‘the bubble of support’ to see if their child’s needs can be met.
7. Training will be rolled out across all schools, health and front-line local authority professionals to increase knowledge and understanding of autism.
8. Professionals will be better informed to identify existing services that could offer support to families where their child is displaying traits associated with neurodevelopmental conditions. This will be known as the ‘bubble of support’ and will work alongside the diagnostic pathway.

TVCCG have informed us that this consultation with parent carers will help to shape what is required from the ‘Bubble of Support’ and inform commissioning.

Specific Differences with the New Pathway

The new pathway is proposed to cut waiting times, co-ordinating a range of timely multi-agency assessments and identify coexisting neurodevelopmental conditions. It will do this by moving away from the current health / TEWV responsible body and be dependent on a cultural change with health, care and education, working closely together to meet the needs of children and their families. There will be a clear protocol for education and health professionals to refer onto the pathway and there will no longer be the option for self-referral.

The new pathway will provide ‘A Bubble of Support’ at the earliest opportunity, from the beginning of the process, for both the child and the family, which is not dependent on diagnosis as it was on the previous pathway. This will address the current lack of support, before and during the assessment process, and after diagnosis.

What we did

We created a digital survey and disseminated information about the new pathway, with survey questions and information provided by TVCCG. We provided parents and carers with opportunities to engage through online focus group meetings. We also offered a range of other engagement options, taking account of those not digitally connected e.g., telephone conversations. We recorded conversations with 16 parent carers engaged in the 6 online video discussions, many representing broader parent carer groups and forums. We also received data from 91 survey respondents.

Presentation of findings

A vast amount of information and raw data was collected from the variety of engagement options and is presented in two separate reports – Survey Responses Report and Focus Group Dialogue Report. We refer to this information throughout this report.

This report, follows the issues and challenges families with neurodiverse children have told us they experience on their journey:

1. Before entry onto the pathway.
2. During referral, assessment, and diagnosis.
3. Through transition out of the pathway at age 18.

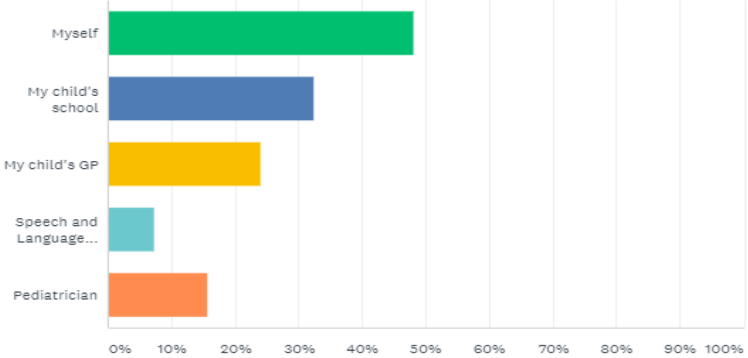
We explored and analysed data from the consultation and checked back with focus groups, to ensure we truly represented parent carer views and experiences. We are confident, the information in this report, presents a clear picture of what life can be like for families experiencing neurodevelopmental conditions, living in South Tees.

Within each section, we summarise what works, what doesn't, what needs to change and any gaps in services. We have chosen quotes from parent carers to depict key messages.

Our recommendations for implementing the new pathway are outlined at the end of this report. These recommendations are to be considered within the broader context of the more detailed feedback. Our report will be presented for consideration to relevant decision makers within South Tees responsible for directly contributing to the development of this provision.

Referral onto the Pathway

Parent carers commonly described ‘self-referral’ as the only route onto the current pathway. They are worried, that for some children, referral onto the pathway may be extremely challenging with the elimination of the self-referral option.



Data from the survey shows a significant number of self-referrals onto the current pathway.

Parent carers are also concerned there will be a reliance on schools and health professionals to recognise neurodevelopmental conditions in children and, to refer them onto the pathway.

Autistic traits in girls are frequently being missed by education and health professionals, but this is not solely related to girls. Many children go to considerable effort to mirror the behaviour of those not on the spectrum, and mask autistic traits in public. Some parent carers said their children mask traits especially within the structured school setting but families pick up the aftermath, describing the frequency and intensity of challenging behaviours being different at home. They said school staff often had little or no awareness of the impact of a school day on children and therefore refused to refer them onto the pathway.

Parent carers think that getting support from a health professional may also be challenging. They told us that health professionals such as GP’s no longer have relationships with families and often, their children avoid health professionals, surgeries, and clinical places.

“School tell me he’s OK. At home, it is a different story. On a bad day he is completely withdrawn and angry. He frequently has meltdowns after school.”

“Why have they taken the self-referral off the pathway. Who knows the children better than their parents or the people who look after them?”

“Strong opinions from school are likely to sway health professional decisions.”

We have listed data from the survey in relation to how children's needs and behaviours present at home, within our Survey Responses Report (Answers to question 13).

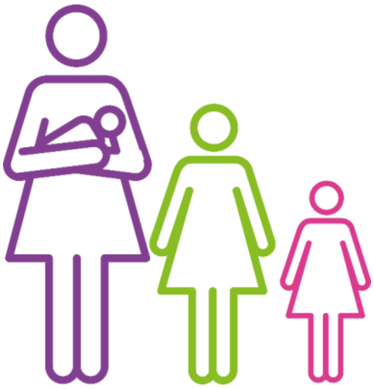
Referral onto the pathway:

What works well	What doesn't work	What needs to change	Where are the gaps
The option for self-referral on the current pathway.	Over reliance on education and health professionals to refer onto the pathway.	Reconsider keeping the self-referral option on the new pathway. Increased compassion towards parent carers. To actively listen and take what they say seriously.	Professionals recognition of parent carers being experts by experience. Professional training and awareness and increased understanding about neurodevelopmental traits and their presentation in children.

Autism in Girls

Parent carers stated that girls are being failed by the system. Neurodevelopmental traits are often missed in females because they can present very differently than in males.

Girls are generally much better at masking behaviours by copying their non-autistic peers. They are therefore less likely to draw attention from schools and other professionals.



Families face significant challenges when trying to get professionals to acknowledge the issues, often to be told their daughters do not meet the assessment criteria. This can result in home schooling and/or suffering declining mental health.

Girls later come back into the same system that failed them, to be diagnosed with mental disorders such as anxiety, depression, or anorexia instead of the neurodevelopmental conditions that underly these secondary disorders.

“The difficulties getting school or childcare to understand ASD in females. The fact we couldn’t just have the GP refer, there had to be information from school or childcare who were both in denial at the time which stopped us being assessed. Also, when being asked to describe the difficulties our child had we missed loads as we ourselves didn't know about ASD. If professionals are thinking it is a possibility, then they need to ask more specific questions.”

“I'm so upset with the current system and how it has let my daughter down. I knew nothing about SEN, ASD or dyspraxia. I've had to educate myself to try and get my daughter the help she needs and deserves. The pathway is far too slow and its flawed. It is letting children down who could be still in the education system but instead have to be removed for their health. So many home educated children have autism, I wonder why that is?”

“Autistic traits are commonly being missed in girls and assessment tools are not suitable for diagnosing girls on the spectrum. Professionals need training to recognise traits in girls.”

Autism in Girls:

What works well	What doesn’t work	What needs to change	Where are the gaps
There is a lack of information about what works well for girls	The system is not set up to recognise autism in girls. Late diagnosis of females for secondary mental health conditions because their neurodevelopmental issues have never been acknowledged or diagnosed, leaving them with unmet needs.	Professionals need to listen to parent carers when they come to them for help about their daughters. Referral and assessment criteria should be addressed to recognise Autism and ADHD in females.	Appropriate training and awareness in professionals to recognise autism in girls. Assessment processes that can identify neurodevelopmental issues in females.

Professionals Attitudes

What parent carers said about their children was frequently not given due weight by professionals. Poor parenting or living in deprived/poverty areas was frequently blamed for children's difficulties, shifting the focus away from referring the child onto the pathway. Families living in such circumstances, explained how they were forced to go through a process of eliminating other causal factors relating to their child's difficulties before anything else could be considered. They said a diagnosis felt like 'confirmation or proof', they, or their life circumstances, were not the cause of their child's difficulties.

Parent carers discussed "unfairness" in the system, whereby families living in deprived areas had more negative experiences compared to those from more affluent backgrounds. They told us, some families are not able to articulate themselves and are faced with barriers to getting the help they need, whether they had a diagnosis or not. Often, these are the families that need most support because they are unable to afford things that might help their child.

When professionals have been approached for advice, it is common for parent carers to be given conventional parenting advice that doesn't work for their children. When parent carers explain they are not taking the advice because it doesn't work, professionals take the attitude that parent carers are not cooperating and make this the reason for dismissing them.

They said, front line professionals need more awareness and training and to respect the views and experiences of parent carers who have been repeatedly failed by the system, who are already very low and exhausted.

"I truly believe that the professionals thought the reasons for my son's behaviours and presentation was because he was from a deprived area. He was from a properly supported family who needed to fight all the way. I contacted all the health professionals and even though they believed us, they wouldn't go against the school."

"I've often felt like a failure… been given advice that doesn't help... It's a sort of grieving process, making comparisons with other parents and children."

"That first point of contact is a very important. These people must be extremely on board to avoid alienating parents."

Professional Attitudes:

What works well	What doesn't work	What needs to change	Where are the gaps
A non-judgemental approach based on mutual respect. Reassurance for parent carers that their self-help parenting measures are benefiting their child.	Making assumptions about a child and family based on where they live or family background.	Elimination of discrimination from the system.	Provision of a fair system with equal access based on needs not assumptions and socio-economic factors. Training for professionals to recognise neurodevelopmental traits and to improve the way the work with families.

Assessment

Often parent carers said they were kept on the pathway for extended periods of time, with little or no contact, information, explanation, or communication from professionals. 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.

Assessments can be heavily focused within education, particularly in structured classroom settings, not considering some of the more challenging contexts for children on the spectrum. During assessment, not enough emphasis is put on unstructured play, free time, the child's presentation at home/in the wider community, or the information parent carers provide about their child.

There were instances where the assessment process failed to diagnose children with complex needs, or those that mask neurological traits. Parent carers shared stories of children being 'ping ponged' back and forth, with little or no support.

They described children spending many years of their childhood crippled with declining mental health, anxiety, and depression, or diagnosed with other conditions such as separation / attachment disorders.

Families described how they desperately 'fought' the system to help professionals understand their children's needs, to rescue their child's happiness, wellbeing and development.

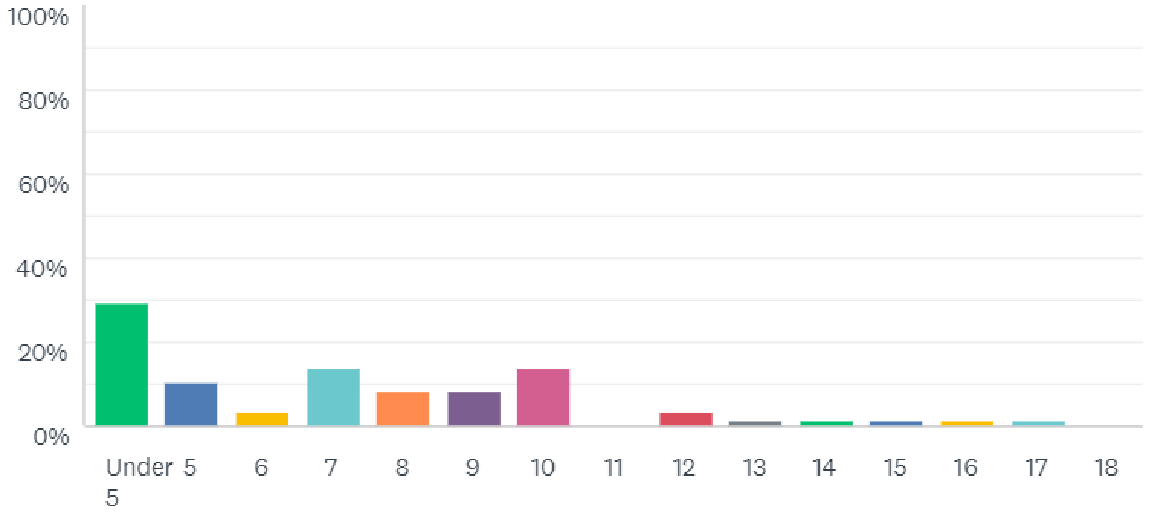
Sensory and regulatory dysfunction is commonly associated with neurodevelopmental conditions, yet children’s sensory needs are not being properly assessed to fully understand them. Some have paid for private assessment but have been told this will not be recognised by the local authority.

> “Children get referred into First Contact / Early help teams then back to school and this goes round and round. The children are not getting what they need. We are spending too much money picking up the pieces when a child hasn’t been picked up in early years and we are then dealing with bigger problems.”

Assessment:

What works well	**What doesn’t work**	**What needs to change**	**Where are the gaps**
Early assessments that take into consideration all contexts of children’s lives. Assessment procedures that recognise co existing conditions that provide the foundations for understanding and meeting needs.	Limiting assessments to structured education settings and not giving due weight to information parent carers provide about presentation at home and other out of school settings.	Parent carer information to be taken seriously. Due weight given to the child’s presentation in out of school settings. Families should not be ‘ping-ponged’ in and out of the system and left unsupported.	Assessments that identify co existing conditions including sensory and regulatory dysfunction. Review assessment processes to recognise traits in children that are very good at masking.

Diagnosis



The survey asked respondents if their child had a diagnosis of autism. Of those who responded yes, the graph shows the majority received diagnosis before the age of 5 or during primary school age. Some children were not diagnosed until their teens.

It is important to put the information in this graph into the wider context of this survey. These figures relate only to those children that received a diagnosis which was 54% of respondents. A further 34% of respondents describe themselves as on the pathway and 2% were unsure as to where they are within the process. Those unaccounted for, didn't complete this section, but some comments were raised as to 'who' the new pathway is for!

Parent carers were confused and concerned about whether formal diagnosis will be given when the new pathway is introduced. There was a reference to the flow chart, presented by TVCCG as part of parent carer information, questioning what was meant by the statement: *"Needs of the child are identified but further diagnostic assessment is not appropriate"*. The following quote sums parent carers concern:

> "…this feels like a gatekeeping / check point. We are not going to diagnose you, but we have somewhere to put you."

Parent carers commented on the importance of formal diagnosis. There was a clear link between the importance of a diagnosis and children's mental health; Parent carers described escalating and debilitating mental health due to a lack of understanding about their children's needs, which were never identified by effective assessment and diagnostic processes.

They described some of the benefits of having a formal diagnosis:

- Positive attitudes from others, appropriate adjustments, practical, emotional, social, and financial support.
- Prevent negative misinterpretation of challenging or personalised behaviours.
- Protective rights under the 2010 Equality Act.
- Continued formalised acknowledgement of needs at any age, and particularly into adulthood.
- Help family members understand their child or siblings needs and to work with these as a family.
- Provides a point from which a person may identify themselves, understand how they best function, build self-help and coping strategies.
- Offers opportunity to accept difference, embrace and celebrate it; to value individuality and to help build communities that thrive happily together.

> "If a child has no evidence, then they have no protective rights under the disability part of the equality act".

> "How are we supposed to put things in place for a child who doesn't have a diagnosis? A diagnosis helps to understand individual needs".

> "There are too many children/young people not getting diagnosed correctly for autism and other neuro conditions, developing mental health problems, and reaching crisis point as a result".

During one of our focus group sessions a parent carer offered her thoughts. You can hear what she told us **here**.

Diagnosis:

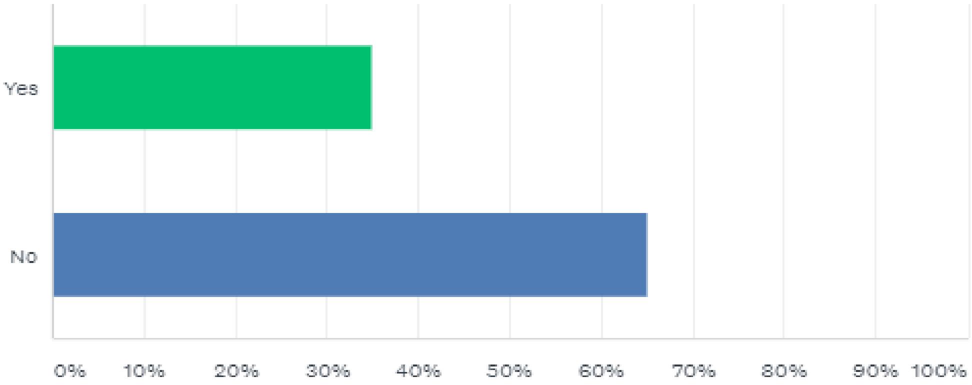
What works well	What doesn't work	What needs to change	Where are the gaps
Early diagnosis is essential to: • Help to identify and meet the child's needs. • Embrace and celebrating individuality and difference. • Offer protective rights against discrimination. Agencies working together with the child and family at the centre to identify and meet their needs.	Children and families struggling to get the help and support they need with or without a diagnosis. Late diagnosis, after a child and family have had traumatic life experiences because their needs have been misunderstood or not been recognised.	The new pathway needs more clarity in the area of diagnosis. Parent carers want clear, open and honest information about the new needs led pathway. Intervention, assessment and diagnosis should happen as early as possible to prevent unmet need and avoid escalation of mental health problems.	Monitoring and evaluation of the new pathway, particularly around diagnosis, to include parent carer, children and young people feedback.

Support

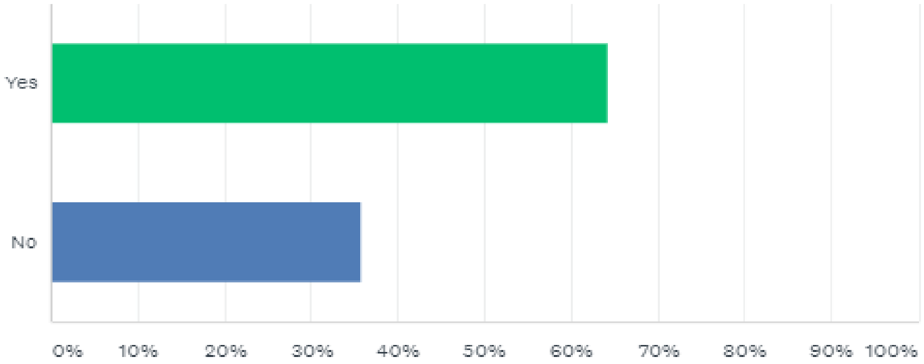
TVCCG asked questions in the survey about the support children received in school, outside of school and in the wider community. We have reported on these areas individually and refer the reader to detailed lists provided by survey respondents in the 'Survey Responses Report'.

Support in Schools

The following graph shows survey results regarding the percentage of families **on the current autism pathway (those without a diagnosis)** for which school have made changes to improve how their children's needs are met.



This next graph shows survey results regarding the percentage of families for which school have made changes to improve how their children's needs are met, for those **with an autism diagnosis**.



The graphs show a higher percentage of those with a diagnosis have received changes in school to improve how their children's needs are met. Lists providing details of the change's schools have made is included in the Survey Responses Report. (Survey questions 8 – 11)

It could be ascertained from this information that schools are more likely to provide adjustments and support based on a child having a formal diagnosis, but we don't think the information is specific enough to confidently make this analysis.

One reason is that parent carers have stated children have other needs and/or conditions (Survey results, question number 12), which are likely to require adjustments in educational settings, irrespective of whether a child has a diagnosis of autism and/or ADHD.

Where specialist educational provision is accessed, it appears that this is working well for families. Some felt it unnecessary to identify adjustments within specialist provision because specialist schools already catered for their children’s needs.

Frequently, parent carers raised the issue of mainstream primary schools failing to refer children for formal assessment. This issue became significant when children moved from primary to secondary schools with little or no information about their needs. Comments stating children ‘can’t cope’ and therefore ‘suffer the consequences’, explaining ‘behaviour’ was subject to mainstream school policy. Children were constantly in trouble, ‘mental health declines, and some became NEET’ (Not in Education, Employment or Training) or forced into home schooling.

The information from survey questions related to adaptations in schools (survey questions 9 and 11), must be read in conjunction with other data within this consultation. Parent carers have answered the questions literally about whether changes were made in schools and what they are. They were not asked how satisfied they were about the changes or how effective the changes were. If we explore other data collected as part of this consultation (survey questions 19 and 20), we can see there are other factors to consider such as:

- Professional attitudes.
- Training and awareness.
- Links with other agencies such as CAMHS.
- Information for parents.
- Transition support.

As school is one of the main referrers into the new pathway, and significant in terms of supporting children and families, further in-depth exploration of this context would be beneficial. Ideally, this would include analysis of training needs and how agencies work together to meet the needs of children with additional needs. Children and families’ views on how schools are meeting needs should be monitored as part of this, particularly in respect of Academies, which parent carers claim, ‘have their own rules’. Comparing mainstream with specialist provision might help to identify interventions that work and help improve adaptations in mainstream provision where most children with neurodevelopmental conditions are taught.

> “My son was labelled as naughty and… was constantly punished and didn’t know why… my son become very confused, started wetting the bed every night, he would hit his head, his intrusive thoughts got really bad, he was very demanding… I had to take him out the school because it got so bad I thought we would have a nervous breakdown, he behaviour changed and he stopped wetting the bed as soon as he was in his new school”.

> “I was just very lucky school recognised this and were so supportive, schools & teachers play such an important part in the diagnostic process”.

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

Support in Schools:

What works well	What doesn’t work	What needs to change	Where are the gaps
Flexible, creative, and adaptable approaches to meet individual needs from an understanding and supportive perspective. Specialist school provision. Schools working closely with other agencies to understand and meet the support needs of children.	Rigid application of policies and procedures in mainstream settings. Punitive approaches to discipline, particularly for neurodevelopmental traits. Primary schools failing to refer children for assessment. Poor transitions, particularly into secondary school.	Improved wellbeing for children in mainstream settings by: • Increased knowledge and understanding of neurodevelopmental conditions. • Understanding and implementing reasonable adjustments, particularly within behaviour policies. • Greater accountability from health and care to work more closely with education to improve individual outcomes for children.	Mental health / counselling support in mainstream schools. Training and awareness about recognising and meeting needs including ‘needs led’ approaches. Bridge the gap between mainstream and specialist school provision to improve the school experience for those outside of specialist provision. Increased accountability for children’s overall wellbeing in school, to include the perspective of students and their families.

Access to Specialist Treatments and Therapies

The consultation data references the importance of specialist assessments, treatments and therapies. It is not clear where this aspect of support fits in the new pathway, but parent carers told us that should be a very important part of it.

Survey question 19, asked “What help have you asked for, but not been able to access”. Parent carers want reassurance these things will be available within the ‘Bubble of Support’:

- Sensory processing assessment, and training for parents to understand and look for triggers. Also, a sensory library for families on low income.
- Emotional regulation therapy.
- Speech and language therapy.
- Physiotherapy.
- Occupational therapy.
- Psychological and mental health support, including help with anxiety, anger and behaviour management.
- Social Interaction skills development.
- Sleep etc.

Parent carers want their children to flourish. They said therapies and treatments should be available as needed and not provided on a ‘time limited’, ‘closed case basis’. They want easy access to this kind of support, with provision that can respond quickly and effectively to needs as children grow and develop, have new experiences and new challenges.

“They should not be discharged but kept in the system and be able to access support according to their needs throughout childhood and into adulthood”.

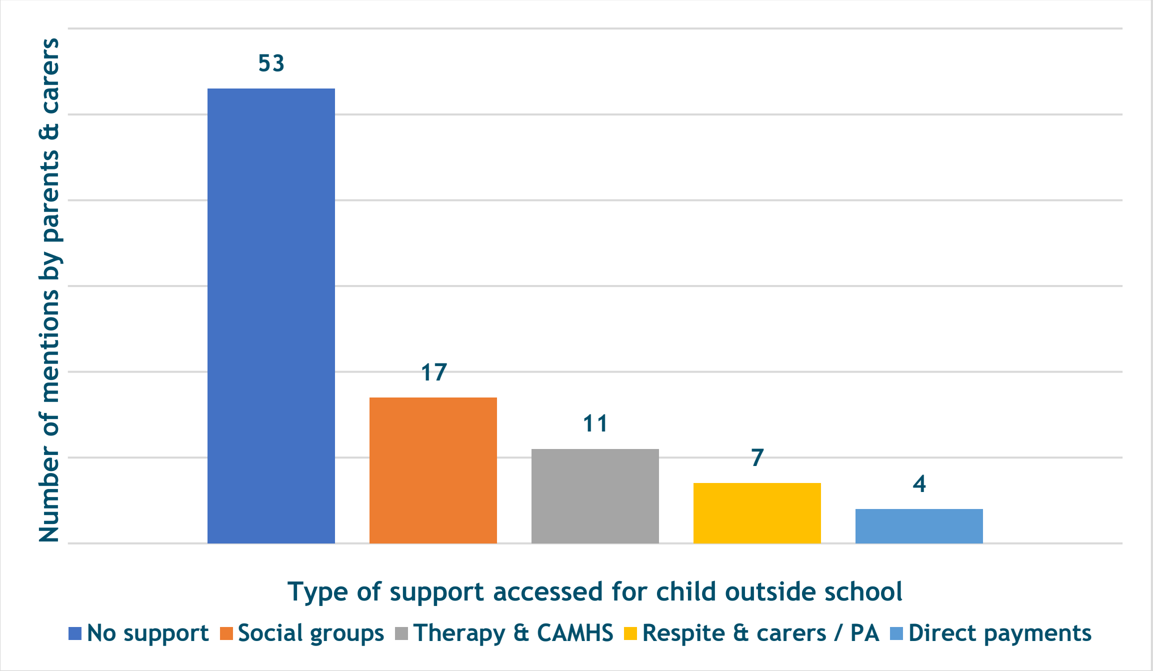
“Teenagers represent a large client-base because they haven’t been able to express themselves in the past”.

“What I needed was to be able to rely on a service if and when I needed them and not to have to jump through hoops so that I might get it”.

Access to specialist treatments and therapies

What works well	What doesn't work	What needs to change	Where are the gaps
Children and families benefit from a range of specialist treatments and support therapies.	Services that provide a set number of sessions, then discharge. Having to "fight" for access to treatments and therapies. Lack of provision in some areas.	Families need easy access to treatments and therapies that takes account of a child's developing needs and growing experiences. Treatments and therapies should be provided according to need and not based on a set number of sessions.	A range of easy access specialist provision that has capacity to meet needs, including sensory and regulatory treatments. Information about the range of provision and how to access it.

Support for children in the wider community



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

A young adult with autism, who had a social care package in place as a child, told us, "He feels more secure at home." He said, "I would struggle to go to the shop without getting bullied." and went on to say how this impacted on his confidence when he was younger. As an adult, he can do some things on his own, but it's all part of a learning process and about having experiences that he can relate to. He also said how important it is to have a trusted group of friends.

Parent carers told us their children often liked taking part in group sessions and planned activities, but some didn't like to do this without a friend. Children wanted and enjoyed friendships but there is often lack of opportunities for this to happen. Some friendships were formed through support groups during time limited sessions and children were unable to maintain these after support ceased.

Parent carers identified some provision that worked well in the past, including getting together with other parents and children through planned social groups, short breaks and voluntary sector activities. Those that accessed support by using a direct payment said it is essential to support children to access social activities, yet parent carers say this is never routinely offered and they must find out how to access this themselves. Where direct payments have been accessed, the benefits of having a carer or assistant to support children to access the wider community and mainstream activities, has helped children to develop independence outside the family and prepare them for adulthood.

The quality of provision must be taken seriously. It must meet individual needs as well as provide a safe, stimulating environment for the child, with opportunities to learn and develop. A parent carer told us.

> "we used to go to a local fun club but he was stuck in a room with a 'variety pack'. There were no facilities for changing, stimulation, interaction or engagement. Kids were just being pushed round in wheelchairs. It was boring so he didn't want to go back!"

> "Support and services need to be in place for children and young people to access leisure/social activities safely without the fear of bullying or negative responses from the public".

> "Some families don't have that support (direct payments) and the young person won't have opportunity or reason to leave their room"

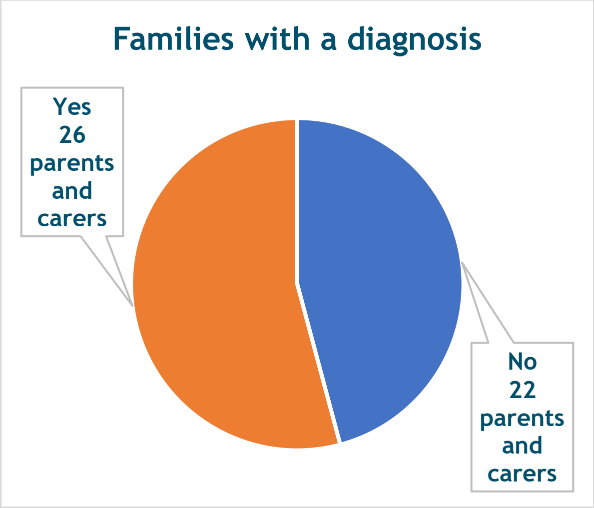
> "There is currently a 'mish mash' of support given by lots of different services providers that parents find difficult to navigate or are aware of".

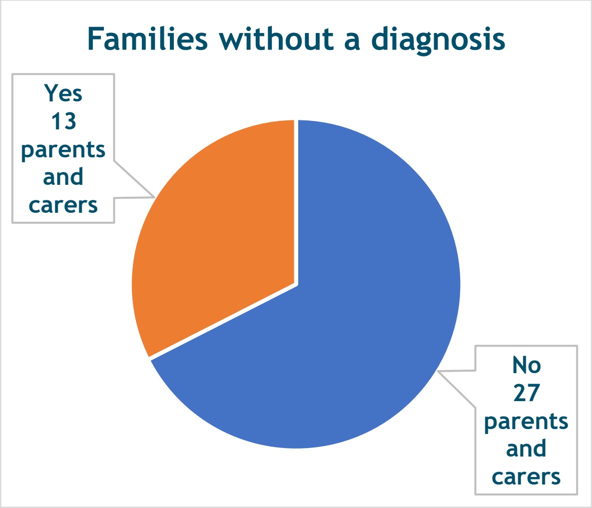
Support for Children in the Wider Community

What works well	What doesn't work	What needs to change	Where are the gaps
Some children enjoyed and benefited from planned activities provided through short breaks and voluntary sector provision. Direct Payments have offered supported opportunities to access and benefit from a range of leisure and social activities in the wider community. Opportunities for families to get together for outings and activities.	A one size fits all approach will not cater for everyone's needs. Expecting that parent carers are aware of what might be available and how to access it.	Families need to know what options are available for social development and inclusive activities, and how to access these, from the point of referral onwards. Families need to be confident that their child can access their community or activities safely, without the fear of bullying. Quality assurance needs to be taken seriously.	Increased emphasis on the importance and benefit of positive social interaction, interests and activities, for children, independent from families. Involving children with neurodevelopmental conditions in designing and monitoring the future of support for leisure and social activities.

Support for Parent Carers and Families

The following charts contain information drawn from our survey results (Question 16, asking 'Are you in touch with other families who are having a similar experience to you?'). They provide a breakdown of the number of parents and carers connected to peer support networks, split between those with a diagnosis and those without:





The charts show many parent carers benefit from peer support by being in touch with other families with similar experiences. The greatest number of families that didn't have this connection were those on the diagnostic pathway (those without a diagnosis).

It could be that parent carers with children on the pathway are not yet 'in the system' and therefore have not made these connections. We know that having a child with disabilities "can be a very lonely place." Peer support is one form of support that may relieve that level of loneliness from the point of referral onto the pathway.

Parent carers told us there is a good network of peer support across South Tees. Together with the Parent Carer Forums, other groups have become established and interlinked, providing a range of support such as:

- Coffee mornings.
- Opportunities to "offload, laugh and cry".
- Having people to talk to with shared experiences
- Sharing information.

> "We (parents) didn't have the support needed so we created our own. We also have a private chat group where we share our problems and support each other".

Parent carers explained that the whole family is impacted when there are siblings with neurodevelopmental conditions. The likes and dislikes of one child can dictate how the family functions at home and outside. A focus group discussion highlighted how important it is to consider a whole family approach to support:

"Siblings are losing a parent to the disabled child/ren needing 24/7 attention from the parents – Siblings and parents' mental health and wellbeing is affected and not focused on in direct payments".

"You don't only have an autistic child, you have an autistic family, because we are autistic by proxy, based on the way my child needs to live. We're an autistic family and we are in this together!"

Direct Payments, personal budgets or short breaks can be of great benefit to families. As well as supporting children to access activities independent of their family, they give parent carers chance to take a break, to spend valuable time with their spouse/partner, other child/ren, or find some much-needed respite to recharge.

The way in which parent carers are treated and responded to by professionals is fundamental to how supported they feel. A good, open, and honest relationship with a professional can provide a positive outcome, whether it leads to accessing a service or not. Sometimes parent carers just need to feel informed, or reassured, or need help to navigate what is already out there.

"Social care has been brilliant for us. They have held us up. If it hadn't been for social care I don't know where we would be."

"All parents want is straight, honest answers".

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

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

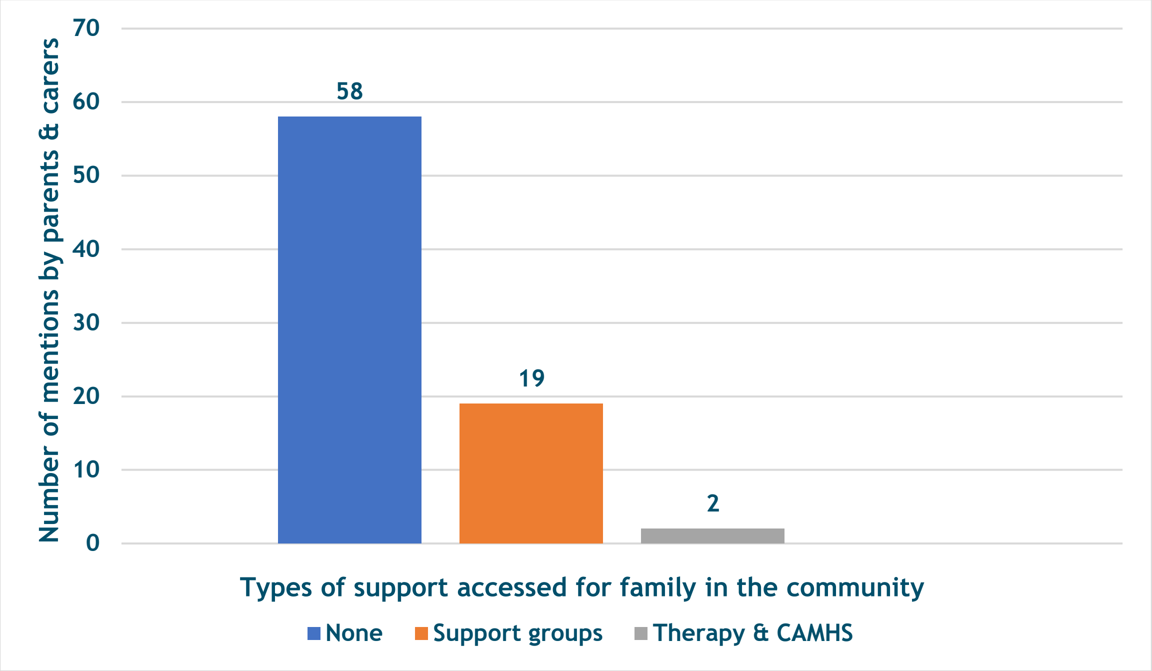
> "CAMHs and school need to work better together. Communication needs to improve, and professionals need to take responsibility to support us. I get exhausted with looking after my son, my nights are consistently disrupted, and my son is anxious before the school day even begins".

> "You have to fight every day to get the help your child needs It's wrong I don't understand how teachers can let this happen. No support no help".

Support for parent carers and families:

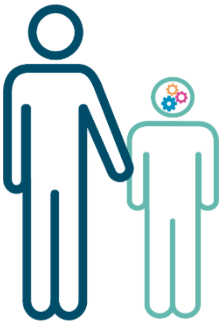
What works well	What doesn't work	What needs to change	Where are the gaps
Open, honest and supportive relationships between professionals and families. Clear information about what support is available. Easy access to support services when they are needed. Peer support for parent carers with a range of options for engaging with others.	Poor relationships between families and professionals. Lack of information and communication about what support is available and how to access it. Poor quality provision that isn't meeting needs.	Parent carers need to feel that professionals are working with them to ensure their child is happy and thriving. Increased awareness of direct payments as an option for children's social care and parent carer / family respite. Better marketing of accessible information about support that is available for families.	Robust, easy access pathways that identify needs and provide support for children to be happy and thrive, now and in the future. Exploration of a family advocacy support service. Whole family approach support model.

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.

Parent carers frequently spoke about their feelings and the impact of caring for children with neurodevelopmental conditions, sometimes under extremely challenging circumstances. Some displayed periods of intense emotions during discussions. Parent carers are the cornerstone of everything positive in the lives of children with neurodevelopmental conditions and because life can be so demanding for them, their own mental health suffers. Therefore, the fundamental importance of care and support for parents and carers is an extremely important aspect of the new pathway.



Parent carers told us children's unmet needs and being overwhelmed by everyday life were the main causal factors for their children's poor mental health. They referred to flawed assessment and diagnosis processes that had not properly identified their children's conditions or assisted with understanding needs. They also referred to the general lack of awareness or understanding about neurodevelopmental conditions or refusal to acknowledge individual 'hidden' needs in everyday life, particularly in mainstream schools.

They said, widespread information and awareness training is needed for front line professionals, alongside increased scrutiny of provision. 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.

Parent carers were frustrated with services that currently support their child's mental health. They told us that waiting times are extremely long, by which time their child's behaviour and wellbeing has declined, needing more intensive interventions and support. Some offers of support are time limited and situations aren't always resolved in this time frame. Parent carers said they needed options to 'dip in and out' as and when needed and not have to start the lengthy referral process and re-join the waiting list from the beginning each time.

Parent carers suggested that improved links between schools and CAMHS to support their child is essential, especially during the previously mentioned difficult times of transition and teenage years. They want professionals to understand that when you have a child with neurodevelopmental conditions, mental health often comes hand in hand, because these children can't cope with everyday life, particularly when they hit adolescence. They said, this is because they can't process life experiences in the same way as their non-disabled peers and can be emotionally immature.

The removal of mental health services from secondary schools has had a negative impact on some children and some parent carers felt that mental health support should be compulsory, as part of a transition package. They also suggested that a separate mental health service is required to run alongside the support bubble as, in their experience, CAMHS are unable to cope and something else needs to be in place.

Ultimately, families indicated poor mental health in children with neurodevelopmental conditions could largely be prevented if attitudes and understanding improved, personalised adjustments and support was in place as well as an increased accountability for children's mental health, especially by mental health services particularly in education settings.

"We need long term support from CAMHs. They need Health Care Assistants within mental health to provide some consistency and follow up".

"Mental health is brushed under the carpet and after convincing my son to finally talk to someone the counsellor was not consistent (different people) and so this made it impossible for him to build up trust and confidence to speak the truth".

"Now my child is receiving specialist support in a special unit her needs are being met. The damage to her mental health during her time in mainstream secondary school may be too severe for her to recover from".

Mental Health:

What works well	What doesn't work	What needs to change	Where are the gaps
Care and support for parent carers. Preventing poor mental health and escalating issues by ensuring appropriate strategies are in place to meet needs. Easy to access mental health services, when they are needed for as long as they are needed. Mental health services and schools working together to improve outcomes for children.	The general lack of confidence and consistency in existing provision. Flawed assessment and diagnosis tools and processes that may not effectively identify children's conditions or needs. Long waiting lists and pre prescribed number of sessions, leading to escalating mental health issues.	Overall improvements in mental health services. Compassion and consistency in care and support. Improved understanding of children's needs so that appropriate adjustments and coping strategies can be put in place. Improved collaboration to support children's needs, especially in education settings. Discrimination and bullying within the wider community.	A new model for mental health services that provides low level preventative support and better access to all mental health provision. Health Care Assistants within mental health to provide consistency and follow up. Provision of appropriate mental health services in secondary schools

Information & Communication

Parent carers highlighted the importance of receiving regular and clear information from professionals as well as needing improved communication between the professionals involved in their lives. Being involved in discussions about their child is crucial in addition to getting information about relevant conditions and support options available to them. They want to be in the best position to help their child, be able to make informed choices about what support is right for them and know how to access it.

They suggested specifically that information about direct payments should be offered as an option, along with support for how to manage these.

Informal peer support networks are an important aspect of keeping in touch, particularly for emotional support, but this needs to coincide with other forms of good quality information and communication from professionals.

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

> “The Early Help team is picking up on issues such as sleep problems. I find school can be trigger happy and refer into social services. Sometimes this isn’t needed, and that little bit of extra support can be gotten from elsewhere.”

> “What they say is going to happen doesn’t always happen.”

Information and Communication:

What works well	What doesn’t work	What needs to change	Where are the gaps
Good quality communication between professionals and families. Provision of accessible information to include support available to families, especially about direct payments. Low level, easily accessible services. Peer support networks.	Prolonged periods of no or little communication with families, coupled with barriers faced by families to reach professionals. Parent carers having to ‘hunt’ for information. Escalating issues when they can be dealt with at a lower level.	Increased value on quality communication between professionals and families. Inconsistencies in how people receive information. Everyone should be able to access the information they need when they need it.	Review of communication and information systems and processes. Cultural change in the way services are delivered that actively seeks to involve and empower families by providing access to information and positive communication.

Awareness and Training

Professionals

Parent carers said there needs to be mandatory training for all relevant professionals, particularly in mainstream schools, to raise awareness of neurodevelopmental conditions. Frontline staff need to be able to recognise and respond to children and know what to look for when children masks traits. It is vital children can be referred onto the pathway as early as possible, especially if the self-referral option to the new pathway is removed.

Professionals need a different mindset to actively listen to parent carers and children. It is important to learn from them and acknowledge how life is experienced from their perspectives. Families need to be valued for their expertise and be fully involved in making adjustments that embrace difference.

Parent carers described how often professionals can be disconnected from their family experiences. They can commonly give conventional parenting advice and criticise families when it doesn't work for children with neurodevelopmental conditions. This is usually at a time when parents carers are going through high levels of emotional turmoil themselves, when they need compassion and support from professionals.

> "What happens when a parent or carer goes to a professional because they want a referral, and they are not referred because that person doesn't have the training or knowledge they need?"

> "Everything we do tends to focus on alleviating anxiety for our children which can often be seen as pandering to their needs."

The Public

Educating the public is a much-needed priority. Negative experiences, including judgement and bullying, has a huge impact on mental health and decreases the desire for children and family to engage in activities outside of the home. It reduces the options to be part of the wider community and to develop independence, confidence, and self-worth.

Awareness raising of presentation and behaviours linked to specific disabilities could help to reduce negative responses from the public. Parent carers told us that these regular experiences can be devastating for the whole family.

"I would struggle to go to the local shop without being bullied!"

"There is very little understanding from the wider community."

Parent Carers
Parent carers welcome training opportunities to develop understanding of their child and how to help and support them to thrive. They suggested training in sensory dysfunction and emotional regulation would be beneficial. They said improving their skills and knowledge would better equip them to prevent crisis situations, offer coping strategies to support everyday functioning and transitions and potentially reduce the need to access relevant support services.

Options for the delivery of training sessions, would need to work around the family, could be done virtually; through social interaction and eventually face-to-face, when current circumstances change.

However, when delivering training to parent carers a positive approach is required. They told us they regularly question themselves as parents, and 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'.

"People seem to be getting much better at recognising autism. My family, friends, people in general will tell me, it's ok we get it! However, front line professionals seem to be held back with old fashioned training with focus on conventional parenting."

"Parenting courses can be great, but it depends on how they are delivered and how they make you feel. It is the manner in which the training is delivered that turns potentially good training into something else."

Awareness and Training:

What works well	What doesn't work	What needs to change	Where are the gaps
Training for professionals to: • Recognise traits and refer early. • Improve the way they respond to children and families and develop positive strategies to support them. • Value the family perspective. Empower families to understand and meet the needs of their neurodiverse children.	Critical, judgemental approaches towards families. Applying conventional methods to parenting advice. Training for parent carers based on the premise of correcting poor parenting skills.	Public and professional understanding and attitudes towards neurodiversity, specifically in mainstream settings.	Awareness training for more professionals to: • Recognise traits and refer early. • Value family perspective and respond compassionately. • Understand 'parenting' from a neurodiverse perspective. Training for parents in sensory dysfunction and emotional regulation. Campaigns to raise public awareness of neurodiversity, to value and embrace difference in communities and society.

Transition

Experiences of transitions were raised frequently during the consultation and questions arose about how the new pathway would support children and families around transition periods. Many respondents had children diagnosed before the age of 5 and questioned how they would enter onto the pathway at age 5?

Conversations took place about primary schools frequently failing to formally acknowledge children's needs, to document or share information, or support additional needs when transferring to secondary school.

Children with a diagnosis often had negative experiences when transitioning into secondary schools, leading to increased stress, anxiety, mental health problems and school avoidance.

Parent carers explained circumstances where their children were reassessed at age 17 when their ‘disability’ was changed to a ‘difficulty’. This impacted on what they could access in the transition to adult services, resulting in services ‘dropping support’. They described the whole assessment process as negative which left them fighting for access to support from the beginning again, at a time when their child should be developing a level of independence.

> “What happens at the end of the bubble? They get to 18 and get an assessment and the disability is taken away from them and made into a difficulty. They might get a social worker, but they are overstretched and don’t get the service they need.”

> “Somebody needs to stop changing diagnosis. Fast reassessment within a few weeks at age 18, changing disability to a difficulty, isn’t acceptable.”

> “Autistic children become autistic adults. What happens at the end of the children’s pathway”?

Transition

What works well	What doesn’t work	What needs to change	Where are the gaps
Formal acknowledgment of children’s needs and robust planning before, during and after transitions. Seamless links between this and other pathways	Ignoring the child and the family’s needs during transitions Schools and agencies failing to work together to meet individuals needs Changing diagnosis of lifelong conditions. Dropping support at age 18	Transitions need to be recognised as critical points in a child’s life and treated with the relevant importance. Diagnosis of lifelong conditions should not be subject to questioning at transitional changes.	Training and awareness for professionals Increased scrutiny across agencies, from a child/family perspective about transitions performance Information about how pathways will provide seamless links. Lack of support after age 18.

During our discussion with parent carers, they shared their own perceptions and ideas for local decision makers to consider:

"Everybody can be happy and live differently. We can start to build a society of acceptance."

"We are an equal team (parents and professionals) and we should be treat that way."

"Our lifestyle is our lifestyle. We champion difference and celebrate difference. We accept how the differences are part of our life and live on the outskirts of life that other people live."

"The local authority, the CCG, and professionals need to support us to create an environment where families feel like they aren't missing out."

"It hurts our head, because we have to carry all this information for families… We need honest and straight answers from professionals which we are not getting now."

"Community health hub for SEN families is ideal because if a young person has not had a diagnosis and gets to 18 struggling, there needs to be a community access point, as a safety net. A familiar place in the community would be somewhere a young person could go whether they need help or support or in crisis."

"Why can't we have somewhere where we can just pop in with any issues relating to our disabled children / families. Somewhere we can speak to someone and get some advice. A low-level intervention and support at community level model! Professionals can have drop ins for things like dieticians, sleep problems etc. Health messages can be promoted at this level, reducing the need for social work resources. Parents could provide peer group support. Referrals could be made from here if there was a need to do so. (Like a Sure Start model)."

"Parents are shooting all over across South Tees to access health services and support. Why can't professionals such as physio etc use the centralised health hubs to deliver services in communities. This will also deal with the issues many families have getting their kids to go into medical buildings that are unfamiliar to them."

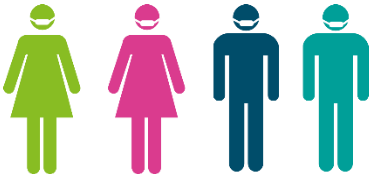
"We need something similar to the Domestic Violence system in place to protect our adults with learning disabilities. A carer should be able to apply to social care/police/duty care team etc. for a red flag to be put on the persons address with learning difficulties/disabilities/mental health issues. If anything comes in under that address, the response should be immediate."

"During lockdown, he was extremely anxious because I had contracted COVID (through my care work) and he had seen me become very ill and blue lighted to hospital. As September neared, his anxiety moved towards going to school."

"I'd like my son to have support to access the community and activities that he likes. It has been very difficult during lockdown and my own mental health has suffered. I'd like to be able to have a break and know that my son was happy and safe."

"We have had ADHD diagnosis for over a year now and we still have had no paperwork sent through. ASD assessment has stopped. Even after lockdown assessment has not begun. I've been given no reason for this or information about things starting up again."

COVID-19



This consultation never intended to capture experiences of lockdown during the COVID-19 pandemic. However, as the timing coincided within this period, naturally, parent carers comments were often related to their experience during this time.

Whilst we can't comment on behalf of all families taking part in this work, we can draw a general message that for some families, experiences of lockdown and the preceding months has been very bleak. The impact of families not being able to access the support mechanisms they usually rely on, has been exacerbated by increased isolation. Changes to daily routines, intense media coverage and changing rules for people who may be very literal, has a greater impact, causing increased anxiety.

Some messages received give an insight into families lives. Parent carers disclosed increased aggressive, violent, and explosive behaviours from their children, an increase in mental health issues with quotes about children wanting to "kill themselves". Parent carers described their situation as 'heart-breaking' and left to muddle through".

Other factors had a negative impact on families during this time. Returning to school in September after the long and uncertain break was difficult for some, especially for those who were returning to a new secondary school. Assessment processes had been halted during this time, so some families remained in limbo, without the required educational support, until services resumed many months later.

If we consider the overwhelming list of unmet needs generally experienced by these families, on top of a lack of contact with families with similar experiences, we may begin to understand comments from parent carers describing their experience as a "lonely place" and "we've been forgotten".

Recommendations

Information from parent carers suggests that ‘support’ should be an overarching ‘umbrella’ across the whole of the new Neurodevelopmental Pathway. They have given clear indication they understand the concept of ‘support’ is wide ranging, from how they and their families are treated, to the provision received by their children, themselves and their families within the system. The scope of information from parent carers provides an outline framework for influencing and shaping the new provision across South Tees and recommends consideration of the following areas:

Culture

- Elimination of discrimination and provision of a fair system with equal access based on needs, not poor parenting or socio-economic factors.
- Treat parent carers and children with compassion, dignity and respect. Listen to what they are saying and take the information seriously.
- 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’.

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 to Covid-19 and lockdown.
- Consider parent carer concerns about the new pathway and provide feedback on issues raised in relation to:
    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.
- 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 home and wider community. Also explain, how the pathway will identify, diagnose and support children:
    1. That mask traits, especially girls.
    2. With additional co-existing neurodevelopmental conditions, including sensory and regulatory dysfunction.
- 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.

Support in School

- Improved wellbeing for children in mainstream settings by:
    1. Increased knowledge and understanding of neurodevelopmental conditions and the role of education in referring onto the pathway.
    2. Reversing punitive approaches by understanding and implementing reasonable adjustments, particularly within behaviour policies.
    3. Offering personalised, creative and effective support.
- Greater accountability from health and care to work more closely with education to improve individual outcomes for children.
- Mental health / counselling support in mainstream schools particularly around transition and adolescent stages.
- Mainstream and specialist schools could work together more closely to improve wellbeing and outcomes for children in mainstream schools.
- Increased accountability for children's overall wellbeing in school, to include the perspective of students and their families.

Specialist Treatments and Therapies

- Ensure access to an appropriate range of specialist treatments and therapies, that take account of the needs of children 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.

Support to access activities and the wider community

- Provide every child with a choice of options to engage in safe activities within the wider community, without fear of bullying, that offer opportunities to develop social skills and increasing independence. These include organised activities, short breaks and increased use of direct payments and personal budgets. Provide help and encouragement for families to understand what provision is available and how to access it. Continue to monitor the quality of provision by involving ongoing engagement with families.

Mental Health

- Embed a preventative, whole family approach to mental health by:
    1. Treating children and families with compassion, respect and understanding.
    2. Promoting widespread understanding of neurodevelopmental conditions and the impact on children and families, through awareness and training.
    3. Encourage and enable professional understanding about appropriate adjustments and coping strategies to meet individual needs.
    4. Provide access to mental health services in schools especially during transition and adolescent years.
    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.
    6. Personalise all mental health services to provide consistency in practitioners, needs based provision (rather than time limited), quick and easy access etc.
    7. Provide specialist parent carer support where necessary and encourage peer support networks for emotional support.

Training and Awareness

- Promote and provide appropriate training and awareness to all front-line professionals. Ensure this includes:

    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.
- Promote a public awareness of neurodevelopmental 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.

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.
- 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.

Communication & 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.
- 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.
- Ensure communication and information systems and processes are regularly reviewed.

Transitions

- 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.

Autistic Friendly Communities

- 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.

Conclusion

Our consultation involved parent carers of children with a wide range of neurodevelopmental conditions, with and without diagnosis. Many are currently struggling to get the support needed for their children and themselves. The type of support parent carers asked for isn't necessarily related to more or different provision, unrealistic or unexpected demands. What they want is to be treated with respect, to get open and honest answers and to access the fundamental support and treatments 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 choices and control to access support services that are right for them when they need it. They recognise that support needs change as their child develops and that easy access is vital as opposed to the current "fight" to get what they need.

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.

Parent carers indicated; it is especially important for those who have a Duty of Care for children to be fully aware of children's needs. 'Hidden disability' can easily lead to unmet needs and challenging behaviours that can be misinterpreted as 'naughty' or negative in sentiment. A diagnosis is often relied upon as the 'evidence' required to make sense of behaviours, which explains why parent carers are concerned about the confusion around diagnosis within 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 that 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.

> It is unreasonable to entitle this service 'neurodevelopmental' and only serve the Autism and ADHD client group. You will be raising expectation amongst parents and contributing to a rise in mental health issues when they cannot access the service with other neurodevelopmental conditions.

> To design a care pathway without diagnosis is a failure of duty of care to both the young people but also the parent carers. Parents already endure a very unqualified, harsh attitude by education, mental health and social care services. With the prevalence of disability hate crime, the highest in the North East and with over one third of young people in the Youth Justice System having neurodevelopmental conditions, we have a collective responsibility to prevent harm.

Whilst undertaking this consultation, an unexpected positivity emerged which is enlightening and encouraging. 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 their 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 the production of this main and additional supporting reports.

We look forward to seeing new relevant services commissioned, improved support for local children and families developed in partnership as well as responses and actions relating to the recommendations within this report.

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across South Tees**

Healthwatch South Tees is the operating name for Healthwatch Middlesbrough and Healthwatch Redcar and Cleveland.

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