



PaCC Connect Report

Brighton & Hove Neurodevelopmental (ND) Pathway - Focusing on Autism, ADHD and Tics and Tourettes

All the quotes are from parent carers at the PaCC Connect and from the survey mentioned below. This report will be shared with the Brighton & Hove Neurodevelopmental Pathway Action Group, the SEND Partnership Board and the Amaze NDP Training and Navigation Family Support Service. The report will be posted on PaCC's social media and website and included in PaCC's November update to parent carers

Introduction

Long waiting times for ND assessments, exacerbated by the pandemic, have highlighted the crisis facing neurodivergent young people and their families, pre and post-diagnosis. The challenges facing children and families are broad, from simply understanding their child through to coping with school, access to mental health services and social care.

In Brighton and Hove, we have heard from families that they are facing waiting times of 2 years for an assessment for ASC and over 3 years for ADHD.

In 2019/20, PaCC carried out an extensive consultation about the support families wanted while their child is on the neurodevelopmental pathway, the results of which were written up in 3 linked reports.

<https://paccbrighton.org.uk/wp-content/uploads/2022/11/NDV-family-support-consultation-2019.pdf>

<https://paccbrighton.org.uk/wp-content/uploads/2022/11/ADHD-Family-support-consultation-2019.pdf>

[NEURODEVELOPMENTAL-SURVEY-FYP-2019.pdf \(paccbrighton.org.uk\)](#)

This consultation highlighted a real need around pre-diagnostic support, as well as the important role schools play in supporting neurodivergent children (and how this often goes wrong).

With the current catastrophic waiting times, and increasing number of children struggling to attend school, PaCC hosted a further PaCCConnect in the summer of 2022 on the neurodevelopmental pathway, plus an online survey, to find out parent carer views on the following specific questions:

1. What support could be helpful whilst waiting for next step (pre-diagnosis, post-diagnosis or after no diagnosis)?
2. What support could be helpful at school whilst waiting for next step?
3. What sort of communication could be helpful (individual about your child, about what is happening to improve the NDP, or anything else)?

PaCC know that NHS commissioners and providers are working to reduce the waiting times. However, long waiting lists continue and therefore it is essential that more is done to support families while their child or young person is waiting. PaCC also know that a diagnosis is not the magic bullet to help their child, so we also wanted to hear from parent carers whose child already had a diagnosis, as well as those who received no diagnosis following assessment.

This report should be read in conjunction with the 2020 reports, since it echoes and extends the themes highlighted pre-pandemic. The main difference now is that waiting lists are even longer, more children are out of or struggling with school, and families are even more desperate. Therefore the information within all these reports is more important than ever.

Themes and Comments

This section provides a summary of the views of parent carers around the questions they were asked.

Q1. What support could be useful whilst waiting for next step (pre-diagnosis, post-diagnosis or after no diagnosis)?

"Where to start..."

"There needs to be support for parents because you are heading into the unknown."

Five main themes came through. All of these were also identified in the 2020 consultation.

1. Support for children and young people
2. Access to services for children and young people
3. Support, training, information and strategies for parents and carers to help them understand and support their child
4. Support, understanding and hearing parents and carers
5. Understanding "the system"

1.1 Support for children and young people

Much of the feedback centred on anxiety and mental health, and that help only arrives when there is a crisis:

"It's much harder to help a child now out of school, burnt out, mentally distressed."

"Emotional help or support as I don't know how to help"

"Kids with ADHD being held back a year as if LD. 6 years of early life being 'told off'"

Other suggestions of what could help include:

- Social prescribing
- Not wait for a crisis
- Mental health team
- School nurse
- Wellbeing service
- An EHCP
- Look at child holistically first
- Psychoeducation (learning about and understanding mental health and wellbeing)
- Peer support
- Support to understand their diagnosis through the school setting

"Support for my child on the basis that they may be autistic – recognising that some of their behaviours may be driven by this and being sensitive to their needs."

"Therapy for my child – as with hindsight I believe my son was traumatised at school."

1.2 Access to services for children and young people

A lack of diagnosis can be a real barrier to support:

"Wellbeing service said no as SSV"

"Too young to screen" – years of suffering, wasted resources

"No access to support until diagnosis"

"My son has expressed many suicidal feelings ... but it is near impossible to get him to speak to a person about anything that he is feeling."

Not having a diagnosis creates barriers to children and young people being able to take ADHD medication. The lengthy waiting lists add to this, leaving some children and young people waiting years for medication that could be life changing for them. Some have a diagnosis but aren't prescribed ADHD medication because of the current shared care protocols between GPs and psychiatrists – especially private practitioners.

In order to improve access to services for children and young people, there needs to be more joined up thinking: *“Joining up between services - E.g. if Seaside View can't help, who can in the meantime?”*

Suggestions of what could help include:

- Services to be more joined up
- Not wait for crisis
- Can services be commissioned differently?
- Not pigeon-holing
- Being able to contact CAMHS
- Communication to understand criteria for acceptance onto the ND pathway

1.3 Support, training, information and strategies for parents and carers to help them understand and support their child

Parents want more knowledge, regardless of where their child is on their neurodevelopmental pathway.

While waiting for assessment, parents feel they are making it up themselves

“I feel like I am trying to diagnosis her myself to try to work out what is wrong with her because I really want to help her”

“How to support them while you don't know what or how to do it”

“I've felt at crisis point not knowing what or how to help her”

Parents report feeling in limbo while they wait, lacking the understanding and strategies to help their child: *“so much uncertainty”*. They need *“advice and support for families about what to do in the meantime – and for schools.”*

Meanwhile children and young people struggle, with impacts on their mental health and wellbeing.

“Things collapse for child while we wait”

However, it isn't a magic bullet following diagnosis, with parents reporting lack of support post-diagnosis:

“No support post-diagnosis; just needs”

“Nothing changed after diagnosis for Tourette's (until returned to tic clinic)”

Parents said they wanted to find out more about how to respond to behaviours, supporting sensory needs and understanding conditions. They also want to know about the links between different conditions: *“If links between conditions are known, why aren't we made aware?”* *“Need better linking up between diagnoses, we spend years finding out the links ourselves, ONE CHANNEL!”*

Other comments about what could help include:

- Accurate identification of needs
- Information and support around co-recurring conditions
- Understanding the role of Neuro behaviour management
- Training on understanding autism – e.g. proprioception, specialist clothing

- Educating us parents about ASC
- Advice about adaptations to make life easier – e.g. clothing
- Advice on sensory
- Youtube video by occupational therapist
- Educating about anxiety
- How to help sibling and the broader family understand
- How I should talk to a child about it – e.g. not identifying it
- Access to ADHD coaches
- Dedicated email/telephone response line with access to a nurse/psychiatrist
- Help with violence, self-harm and concurrent mental health issues while waiting for assessment
- Help with keeping a child in school

1.4 Support, understanding and hearing parents and carers

Parent carers need to feel supported and listened to. Where there is no diagnosis, it is even more difficult to get professionals to understand and listen.

“Made to feel like a fraud.

“Knowing what to say to the college as they don’t seem to listen”

“Mainly you need people to listen and hear your concerns.”

“...respect for parents’ views. We were ‘told’ numerous times by our son’s previous primary school that he wasn’t on the spectrum. We knew he was, and we were right.”

“Listen to carers.”

“Parent support was helpful because I didn’t feel so alone, and I felt listened to and heard.”

“We didn’t reach out when we were in crisis, and I wish we had.”

“Parents need to be listened to and services more joined up. Schools need to listen. Families are not being heard and apart from Amaze who were great when I was supported, no- one has ever said sorry, sorry the waits are so long, sorry we didn’t listen, sorry that we got things wrong.”

“1:1 should be non- judgemental and knowledgeable about the family situation. Sadly previous support offered has been agenda based and therefore not actually supportive.”

“When a family needs one-to-one support, provide that within a timescale that is proportionate to the need. There should never be more than one month, if a family needs one-to-one support, the family would’ve collapsed nine months later.”

Suggestions of what could help include:

- Being listened to without judgement
- Support for parents: Parenting support; Education about autism; Mental health support; Education about services. Support workshops. Online workshops. One to one support
- Family conference
- Parental Family support and Family Support Work based on the needs of the child
- Support groups. Peer to peer support. Seaside View drop in is really helpful, meeting other families in similar situations
- Increase FISS-ASC type service.
- Parent counselling service
- Feel heard earlier
- Getting advice on strategies
- Support to move forward
- Someone with expertise who can step in and help manage the situation
- Respite for siblings, a break for parents and 1:1 support for the child

- SSV and CAMHS confirming with school that a child is on the assessment pathway as there are significant indicators. Regular contact between SSV or CAMHS and the child's school, while on the waiting list

1.5 Understanding the System

When parenting a child with SEND, parent carers are faced with a mass of services, pathways and jargon which brings its own set of challenges for families. Clearer information, communication and signposting would really help. Some parents received no acknowledgement of their referral for an ADHD diagnosis, so didn't even know if their child was on the pathway.

Parents said they want:

"It would have been useful to have been signposted to services and information whilst waiting for assessment. This did not happen."

'Waiting well' – signposting to support services – One stop shop please! – clear pathway"

"More and clear post diagnosis information from different services"

"There is no support aside from parent led and charity, this is appalling."

"What are the risks of not getting local support if you choose to go private for an assessment?"

"Knowing that the wait will not be years whilst your child deteriorates in front of you and life falls apart."

Parents didn't always know about the services that exist to provide support, eg. BHISS and Amaze, suggesting these services need to be promoted more, particularly to those waiting for diagnosis.

A parent felt that being on the pathway itself can be a barrier to accessing support:

"Pathway concept may not help. Other services step away because they are 'on pathway'"

What would help:

- Visual timeline with phases and interconnected services. Flowchart of pathways
- A visual map of Sussex relevant services to explain who does what + how they interact (on Amaze website)
- Clarity about which professional is responsible for what
- Streamline process
- When a referral has been acknowledged, a list of crisis numbers be provided and strategies
- Shared knowledge and information around cancellation lists
- A 'What to Expect' course
- Information to help understand the possible diagnosis and the implications
- Information available of how to access the pathway
- Transparency about waiting times
- Improved waiting times
- More explanation to parents of what appointments involve so they can prepare themselves and their child
- Signposting around what to do next and how to support the child's difficulties without a diagnosis
- Clarity around position on private diagnosis, recommendations of who to use, and who is accepted in order to access ADHD meds
- Parents would like information about how they can appeal a diagnostic decision or ask for it to be relooked at, as well as the legal position around this.

Early Years

"I find that early years BHISS support work much more to support the family than the schools' teams."

Things that would help:

- Peer groups of what to expect going forward
- Play support
- Avoid behaviour-based approaches
- Recognition that a child does not always want to join in

Transition point (e.g. from primary to secondary school, preparing for adulthood)

“Absolutely do not start the assessment at Seaside View and then transfer them when they get to 11 to CAMHS where the wait starts again for two years.”

Things that would help:

- A What to Expect course or workshop for parent carers and children and young people
- Workshops – BHISS, AMAZE and Local Authority courses were all mentioned
- Access to information that the child or young person can also participate in
- A 1:1 or mentor for the child or young person to help guide them through big transitions
- Extra settling in days and staff contact for the child or young person

Post-16

There was a lack of information around processes and post-diagnostic support post-16. Parents would like information about how to help their child and where to go for help. It is also essential that the young person has assessment and diagnosis information that they can properly understand, in order to give informed consent.

Q.2 What support could be helpful at school whilst waiting for next step?

The 2020 consultation highlighted the importance of schools in the wellbeing of children and young people and their families, but this wasn’t the primary focus of the report. This time, we therefore included a question around schools to get more information around the challenges for families around education, and what could be done to help. Parents of children with ADHD in particular highlighted the challenges for their children in school.

Main themes identified:

1. Accessing support in school and learning
2. Understanding the child and their individual needs
3. Whole school approaches
4. Communication with families
5. Working together
6. Training needs
7. Gaps in support: post 16 and home educated
8. ADHD

2.1 Accessing support in school and learning

Parents described a lack of support for their child, both in school and support for the child and school from outside agencies such as BHISS. Sometimes SENCOs can be a barrier to support from external services or the ND pathway, particularly if the child masks in school: *“SENCO holds power to block access to support “I know you’re worried but she’s fine at school””*

Parents acknowledged the lack of resources in schools but children *“needed help sooner”* and needed to *“refer to BHISS sooner”*. A parent described how her daughter *“Internalised her experiences... how bad does something have to get before addressed when not visible?”*, and many parents agreed with the need for *“More support around mental health; without it the child fails”*.

Lack of this support leads to many children being unable to access learning. This could be because they are out of school completely, on part time timetables, or are unable to access the learning even though they are in school.

“Has half days but not really learning.”

“Sitting under the desk – no problem to teacher so leave them there.”

2.2 Understanding the child and their individual needs

Stereotypical views of neurodivergence remain very common. Many parents stressed the importance of seeing their child as an individual with individual needs. This includes staff having a knowledge of the breadth of neurodiversity, including the impact of co-occurring conditions, masking and understanding the individual child rather than their label or diagnosis. Sensory profiles or passports can help with identifying individual sensory needs. The value of a needs-led approach is made even clearer when children are waiting so long for a diagnosis.

“Understand ND broadly rather than compartmentalised: Not “is it autism?” but “what are the issues/needs of their child?”. Will exist regardless of which exact eventual diagnosis or none.”

“Deal with needs, not wait for diagnosis - working memory, executive function, sensory function”

“School assumes child’s needs based on their experiences of another child. ALL CYP are different”

Parent carers reported that a lack of diagnosis made it more difficult for their child’s needs to be recognised, eg. *“School prioritising those with diagnosis for referrals for Education, Health and Care Needs assessments”* and *“Getting school to acknowledge needs – pegged as a child without needs is difficult to change”*

2.3 Whole school approaches

Parents highlighted the importance of whole school approaches and flexibility. This includes identifying how school policies could impact neurodivergent children and being flexible around their use. Other suggestions of helpful practice included:

- Schools being prepared to be a bit different/flexible/creative/listen properly
- Whole school approach to ND + inclusion, less focus on diagnosis; support + manage the symptoms
- SENCO department to be an active leading support system, teach executive functioning
- All teachers knowing/updated with what’s going on
- Teach all children about ND
- Weekly support sessions with child/parents families community
- No exclusions

2.4 Communication with families

Positive communication and understanding between families and schools has obvious benefits for children and young people, and negative impact when communication is poor. There also needs to be recognition that keeping up with paperwork and support for your child is a full-time job and parents need the skills and time to do this.

Suggestions about what could help included:

- Communication from school about where the child is at / which stage
- Clear information about who to communicate with/speak to – especially important if the child doesn’t communicate well
- What can I ask for/information
- To know more about how things work at the school

- Support parents to work together to explore possible needs.
- SENCO listening to me and not having an agenda or barriers up!
- Listening to parents as experts about their child
- Easy communications with SENCO and being able to call when you need them
- Regular updates between school and parents

Parent carers frequently talk about “parent blame” and this can take many forms, from directly blaming parents for their child’s behaviour to considering parents to be over-anxious and not taking their concerns seriously. A parent fed back their experience of school using the *“Attachment” label to hold parenting to blame – “You’re anxious”*

Masking is increasingly recognised by professionals and is a common area of difficulty for families. One parent described their child having *“meltdowns outside school”*, and the response from teachers: *“He’s fine at school”*. A lack of recognition of masking by schools remains a barrier to a child getting their needs met in school, lack of support outside school, and can lead to parent blame and consequent strain on relationships between home and school.

2.5 Working together for the child

The benefits to children of strong partnership working are recognised by all, but families do not always feel this happens. Central to this is including, valuing and respecting the voice of both the child and their parent carers, *“using lived experiences as well as professional expertise”*: *“It is essential to have the opportunity for parent view to be heard - it felt like they’d listen to teacher, more than me”*.

Parents highlighted the importance of multi-disciplinary and Team around the Family meetings, and a parent thought it would help to *“Remove silos and pathways completely”*. Parents would also like schools to link them with other parents of children with SEND to share strategies and provide peer support.

2.6 Training

Parent carers identified a broad need for more training in schools. This covers general training around neurodiversity for school staff, other parents and children across the school. The need to understand individual needs was also discussed, and just having an autism award for the school does not mean they are equipped to support your child’s needs. So individual staff training for those supporting a child is also essential. Lack of training in other staff who work with children can be very detrimental to the child, eg. school counsellors.

Comments and suggestions about training included:

- More support/training for staff around additional needs/different conditions
- Educating peers and parents about ND/everybody to be thinking about inclusion
- The whole system to be more aware/more training for professionals
- Intersectionality (race, gender, etc.) in training, e.g. homophobic teachers still exist despite training
- No untrained school counsellors for potentially autistic children it is damaging
- More training for schools.
- CBIT training – using this in the city
- Parents need opportunity to learn + be educated
- Teachers not educated! They need support + training e.g. TICS accredited being paid for by parents as school wont

2.7 Gaps in educational support

Gaps were highlighted for young people in further education, age 16-18, and for those who are home educated, which a parent described as a “*black hole*”. With the very long waiting times for assessment as well as the barriers to identification of need during the pandemic, PaCC identify an increased need for more support for young people over the age of 16.

Gaps were also highlighted for support for Tics/Tourettes, with the suggestion that Support Tourette’s in Sussex (STICS) could help with this.

PaCC are also aware that the numbers of children and young people out of education or being home-educated has massively increased. The reasons behind this are broad, and the needs of these children and support for families needs to be considered to ensure home educated children are not disadvantaged.

There needs to be “*Organised and proactive service/s for children who are missing from school*”.

2.8 ADHD

The impact of undiagnosed and diagnosed ADHD on children’s education and experience in schools was particularly marked on the ADHD table at the PaCConnect. Below are a selection of comments from this table regarding their experiences, and what could help.

Experiences:

- Teachers don’t understand why strategies are not working
- Uniform, rules, homework tough for ADHD kids
- Little knowledge of ADHD masking and suppressing hyperactivity/impulsiveness
- Lack of resources generally and therefore learning for ADHD
- Independent sector picking up the pieces from state schools
- Criminalisation of ADHD kids
- Schools aren’t as aware of internalised hyperactivity/impulsiveness
- ADHD like poor relation of ASC in schools

What could help:

- Coaching (not punitive)
- Relationship building
- An understanding of different presentations of ADHD
- Understanding sensory needs
- Understanding what the right setting is for ADHD kids
- All school staff to be curious/knowledgeable about ADHD
- Shake up school system to be inclusive for ADHD kids
- Awards for good practice in schools
- Raising awareness across all British schools about ADHD to identify early needs
- Sensory breaks, movement breaks, fizzy brain breaks

Q3. What sort of communication could be helpful (individual - about your child, about what is happening to improve the NDP, or anything else?)

Communication and clear information are important areas of focus, not only because they have a big impact on families, but also because they can be improved with a relatively small financial investment.

Parent carers discussed a variety of areas of communication, but consistent throughout was the need for was clear, timely and transparent communication from services. *“Communication is vital”*.

Key themes discussed included:

Communications:

1. While on the diagnostic pathway
2. Post-diagnostic reports
3. Between services
4. Inclusive communication
5. ADHD
6. With education providers

3.1 Communication While on Diagnostic Pathway

While waiting for a diagnosis, parent carers feel in the dark from the point of referral through to preparing for an assessment.

Is my child on the list? Parents sometimes don't know whether their child is on the list or not and only chase after many months of hearing nothing: *“Too often not in the system/ waiting when we think we are”*.

Once accepted: *“knowing what's happening”*: Once their child's referral has been accepted, regular update messages - by email, text- are needed to let parents know where their child is on the pathway, and how long they are likely to wait. Lack of communication means parents *“don't know whether to chase or wait.”* A flowchart of the pathway should be sent out with letters: a marker could show where the child is currently on the pathway. Where a referral for more than one condition has been made, joined-up information about both pathways should be included.

Waiting times: Parents want *“transparency and honesty about waiting times”*. This way they know what is happening and can make informed decisions. And they want to know where their child is on the pathway and approximate waiting times. They also want to know how the list is ordered, and why some people get seen sooner than others. *“Tell us what is happening!”*

Assessment and meetings: Knowing what to expect. Professionals live and breathe meetings and the assessment progress, but for most families, this is their first experience. Therefore clear information ahead of meetings and assessments is essential to explain the purpose of the meeting, what to expect, what will happen afterwards, and who to speak to about reasonable adjustments and any other queries about the assessment process. This will help parents and children to be as prepared as possible.

3.2 Post-diagnostic reports

Reports need to have a clear focus on how they will be used and *“what happens next”*. Clinicians should consider *“If you are doing a report, is it going to achieve the help or support needed?”*. Reports can be very helpful and used all the time when they have are focussed on what is needed to meet the child's needs. Some parents felt it would be more helpful to begin the report with strengths, difficulties and recommendations – rather than repeating what the parents had said during the assessment.

3.3 Communication between services

Parents said that there needs to be better communication between services, both across the NHS and with other ND partners such as BHISS. Parents reported having to repeat the same information over and over again. *“Services are not talking to each other”*

Children and young people are too often “*pinged between services, for example when looking for mental health support*”. Parent carers said that silo working must be avoided, and everybody needs to be at the table. Team around the family (TAF) meetings work well to improve communication.

3.4 Inclusive communication

It is not uncommon for parents and carers to be neurodiverse themselves, diagnosed or otherwise. Therefore the norm must be an inclusive culture for neurodivergent people, and to adjust the communication style to fit the parent carer’s needs, and neurodivergent-friendly communication. Another element of inclusivity is to ensure opportunities for parent carers to discuss their child without them being present: parents often try to focus on the positives of neurodiversity with their child, and prefer not to raise the more challenging aspects in their presence.

3.5 Communication and ADHD

Parents would like a more positive attitude towards ADHD in communications, as well as more information. Specific suggestions were:

- Less negativity ... taking a positive approach on ADHD – the plus points – creativity
- What support is available for ADHD kids – formal + informal
- What are the different presentations of ADHD and how each can be supported?
- A widely available pamphlet on how to recognise ADHD, and how to support parent/child needs

3.6 Communication with education providers

A few suggestions of helpful communication included:

- Clear liaison and communication with the SENCO daily
- Family liaison posts with schools needed in every school and CAMHS for 16-18s
- Knowing how your child’s day has gone (
- Communication system that is personalised for each pupil between school staff and parents

4. Additional information from the NDP survey

The PaCC survey asked additional questions providing useful information as follows.

4.1 Family support courses/workshops

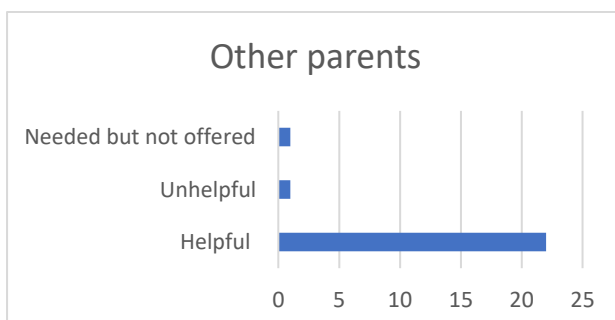
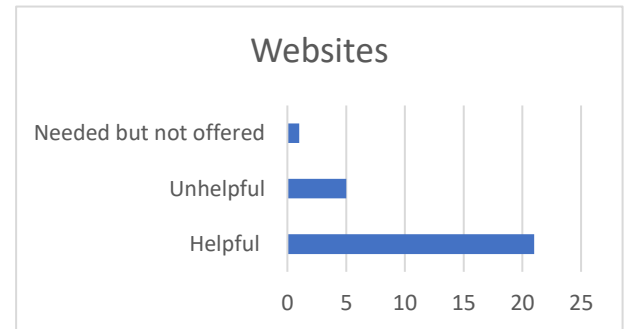
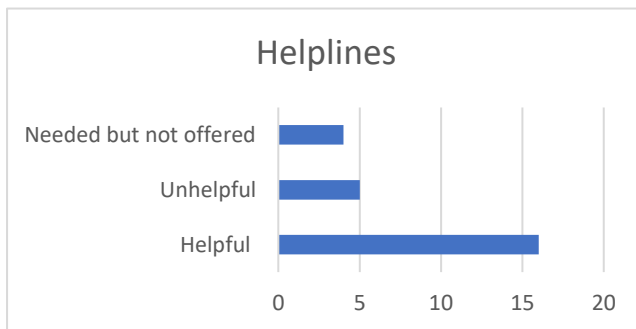
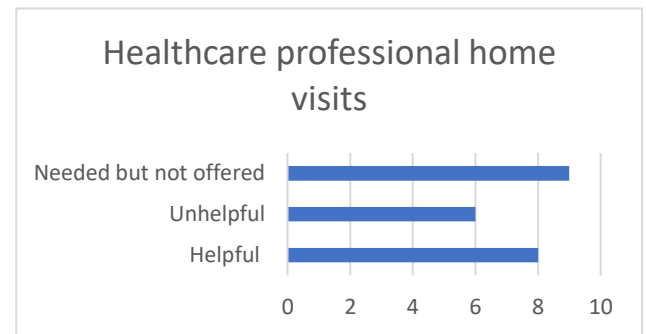
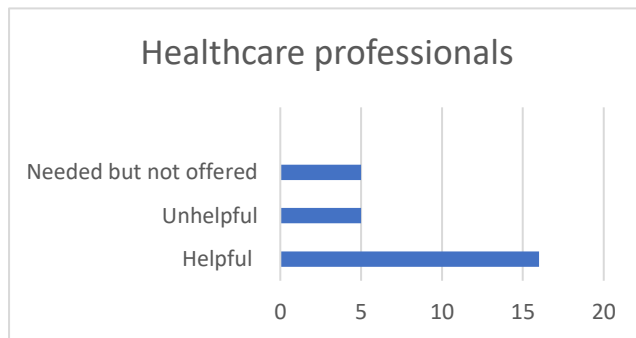
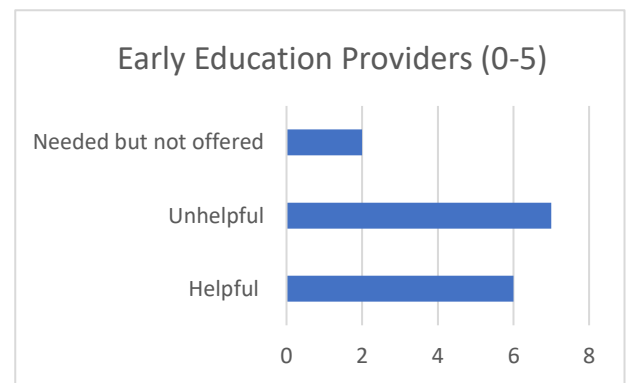
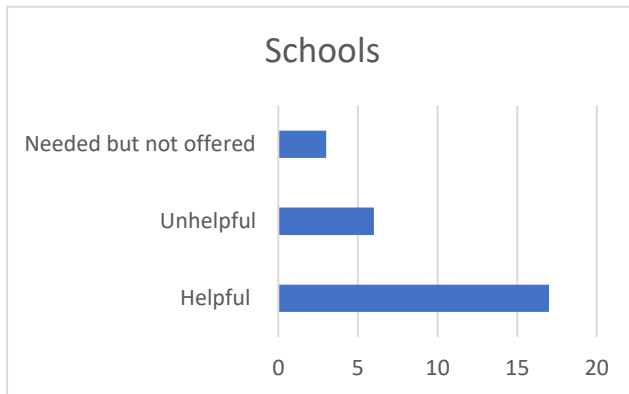
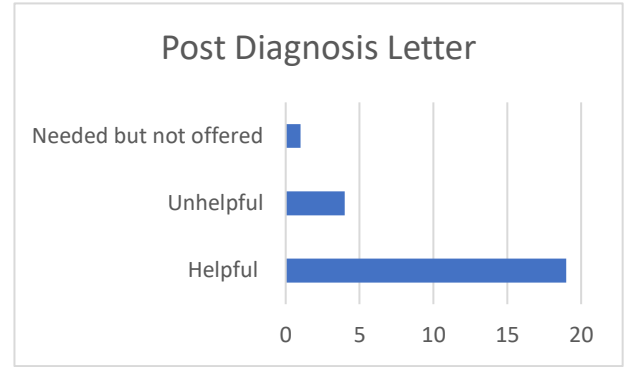
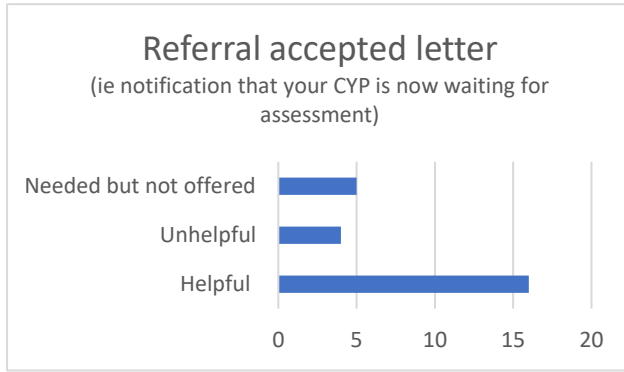
We asked if parent carers had accessed family support courses/workshops. 69% (20) had, 24% (7) had not, 7% (2) were unsure. Those who had, said this had included:

- Amaze insider's guide to under 4's,
- Amaze parenting a child with anxiety
- Amaze/Pacc etc
- AMAZE's DLA, and EHCP workshop
- Amaze Triple P
- Transition to Secondary School workshop from AMAZE/ MASCOT
- OT workshop and a Wellbeing workshop. Seaside View.
- Seaside View ASC support workshops
- SSV time out
- Resilience (social worker)
- Family conference (social worker)
- Founding for fathers (social worker)
- ADHD (CAMHS)
- Various BHISS ASC workshops.
- BHISS - most of them
- Various workshops from BHISS
- BHISS anxiety and demand avoidance course
- Elm Grove children's centre, Elm Grove school, Varndean school
- Triple P
- Managing child Anxiety
- Time out
- Sensory workshop
- Anxiety- (cannot remember)

Parents said access to learning opportunities could be improved by:

- Parents knowing about them
- Consideration to working parents with regards times and ensuring there can be online access.
- More support
- Out of work hours courses
- "We work full time so we couldn't find time to attend. But looking forward"
- An opportunity to do this out of work hours as I'm a full time teacher

4.2 Parent told us what helps them find out what family support is available



We asked parents if anything else would help them find out about what family support is available?

- BHISS
- mASCot / FB page
- Amaze / newsletter
- Support groups online
- Any other support for bullying trauma and anxiety mental health teen related

4.3 ADHD support

We specifically asked if parents felt there is a gap in courses/workshops/support for ADHD and that this area should be prioritised. 52% agreed there is a gap, 49% were unsure.

"There is not enough training around ADHD for families and schools. What is available tends to be around the stereotypical view of ADHD, not around the other presentations."

"Understanding ADHD in women/girls needs a lot of awareness."

"It feels like understanding and acceptance of ADHD is 10/15 years behind autism. Especially lacking is an understanding of when ADHD is internalised and how it presents."

"No information on how his medication might work, the process to go through this and pros and cons from real families' experience of this."

"I've seen no workshops or support relating to ADHD and how to manage a child's transition through adolescence and managing their school and homework."

"Please stop putting ADHD last, it's immoral."

4.4 Other training

We asked what are the other gaps in neurodevelopmental family support courses/ workshops?

Parents told us they wanted learning around:

- Specialist OT – sensory
- Anxiety for autism
- Developmental co-ordination disorder
- Puberty and diagnosis
- Accommodation in school
- Pre and Post diagnosis
- Bespoke support for individual children
- Transition to teenage
- Neuro affirmative approaches
- ADHD - internalised presentation
- Demand avoidance
- ASC and ADHD combined
- Violence and autism
- Co-occurring conditions anxiety etc
- Sensory needs
- Girls and diagnosis
- Multi neurodivergent families- managing different needs
- Teacher and school staff training
- Awareness of self and others
- Friendship and socialising support for Autistic children
- Managing emotions/regulation wtc
- Dyslexia
- Older Teenagers

We also asked about what helps with access to learning opportunities and whether parents prefer learning to be condition specific or topic based. This specific feedback has been shared with Amaze to inform development of their NDP Navigation and Family Support/Training service.

4.5 Mental Health needs of neurodivergent CYP

The PaCC survey explored the mental health needs of neurodivergent children and young people. 62% (18 parent carers) said their CYP had mental health needs, 31% (9) said they didn't, 7% (2) were unsure. Of those with mental health needs, 30% (6 CYP) were accessing mental health support, 67% said they knew where to look for mental health support, 33% being unaware.

Parents of CYP with mental health needs said support would be helpful:

- Changes in criteria so CYP are accepted for MH support
- ND and MH support not being siloed
- More psychotherapists who are knowledgeable about neurodivergent conditions
- A more responsive MH service
- Shorter waiting lists
- More than a set number of sessions
- Clear pathways and signposting
- More knowledge about how services (CAMHS, wellbeing service, BHISS and schools MH service) link
- More access to counsellors and life coaches in schools
- Pastoral support in schools being more focussed on MH and less about attendance and behaviour
- Seeing a private practitioner

Recommendations

Many of the themes within this report from the PaCC Connect and the survey reiterate messages heard time and time again and underline key changes that need to be made:

1. Strengthen communication, information and signposting – across all areas of the pathway and between services, parents and schools, resulting in better understanding of the system
2. Listen to parents and carers, ensuring they feel heard and respected, and their experiences and expertise valued and included
3. Improve access to support for children and young people - particularly around mental health, when there is no diagnosis, post-16 and when a child or young person isn't attending a school
4. Look where services aren't seen as helping families access support and understand why (eg healthcare professional home visits)
5. Provide more support, training, information and strategies for parents and carers to help them understand and support their child, especially around ADHD and ND conditions not included in current offers
6. Through services, PaCC and schools working more closely, better understand the barriers schools face with accessing training, as well looking at different training offers, themes and styles
7. Ensure that whole school approaches, working with families, understanding a child's individual needs and flexibility within school policies are included when creating the Brighton & Hove Inclusion Charter. Working in co-production with PaCC so the views and experiences of parent carers are included.
8. Increase the level of acceptance and knowledge around ADHD to help reduce stigma, increase understanding and to support positive experiences and outcomes for children and young people with ADHD
9. As a City, using neuro affirmative language in all that we do.

Appendix 1 – about the consultation process

Attendees

As well as inviting parent carers to attend the PaCC Connect, there was also representatives from:

- Amaze (including the NDP Training and Navigation Family Support Service),
- mASCot,
- TicToc Therapy,
- Brighton and Hove Inclusion Support Service (BHISS),
- Brighton and Hove CAMHS,
- Seaside View Child Development Centre,
- The Integrated Care System (ICS – then known as Clinical Commissioning Group CCG),
- The SEN Team at Brighton and Hove Local Authority

Format

PaCC Connects create the opportunity for everyone (parent carers and services) to be in the same room together. This helps to improve joint working for our children and young people and families and for guests to hear directly the experiences of parent carers. At this PaCC Connect, tables were organised roughly by condition and for those who have a child or young person with or without a diagnosis. Professionals joined the tables and circulated so they could hear directly from parent carers and answer any questions that they had.

The representatives from NHS Sussex (the Integrated Care Board, ICB – replacing the former NHS clinical commissioning groups) and CAMHS were also given the opportunity to provide an update to parent carers around recent work on the ND pathway.

During the main part of the PaCC Connect, parent carers were asked the following questions:

1. What support could be helpful whilst waiting for next step (pre-diagnosis, post-diagnosis or after no diagnosis)?
2. What support could be helpful at school whilst waiting for next step?
3. What sort of communication could be helpful (individual about your child, about what is happening to improve the NDP, or anything else)?

PaCC also created a survey for parent carers to fill in at the PaCC Connect and an online version was created for those who were unable to attend. The survey asked questions that will help to shape the parent carer training element of Amaze's NDP Family Training and Navigation Support Service, as well as questions around communication with ND services, ND and mental health and wellbeing and the current gaps in ND support currently.