



Brighton and Hove Parent Carers' Council is the local forum representing parent carers of children and young people with special educational needs and disabilities (SEND)

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Hosted and supported by **Amaze**. Amaze provides information, advice and support for families of children and young people with SEND in Sussex



About PaCC

- We are an independent forum, running since 1998
- We provide a voice for parent carers of CYP with SEND aged 0-25 in B&H and are pan disability
- We work in partnership with organisations that provide services to families, to help raise and maintain the standard of support available, to maximise our children's opportunities to flourish
- We are made up of a steering group of parent carer reps, a membership of 600+ parent carers in B&H and a small staff team of 2.2 FTE staff

What we do

- Reach out to diverse families, to hear experiences and grow the PaCC community – through different activities including coffee mornings, focus groups, other events eg Awards, surveys/polls, social media
- Represent parent carers, sharing knowledge and expertise with decision-makers, with parent carer reps sitting on strategic boards
- Produce reports and position statements on key issues, to provide challenge, share good practice and make clear recommendations for change
- Co-produce communications, guidance, policies, letters and other documents with services and stakeholders
- Work collaboratively to improve services for CYP with SEND and their families
- Communicate through PaCC newsletter, social media, blog to keep families informed about our work and encourage their involvement

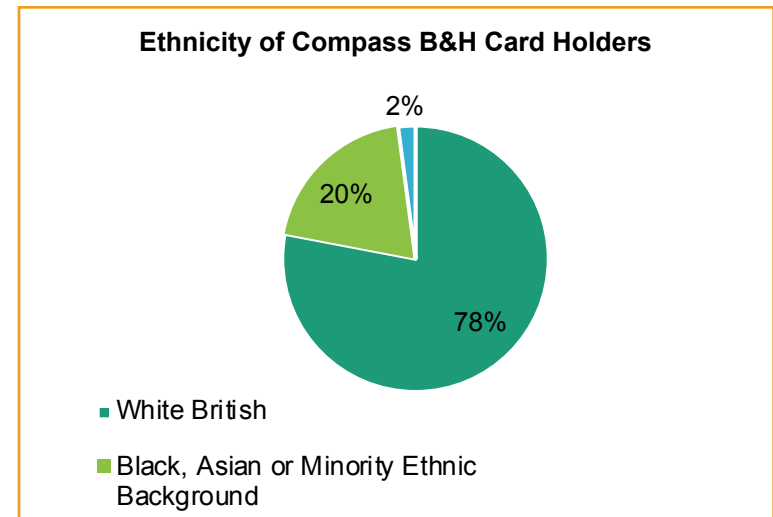
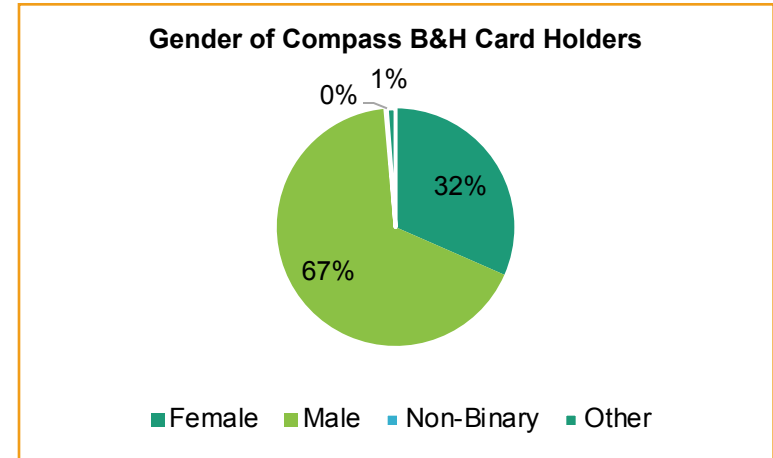
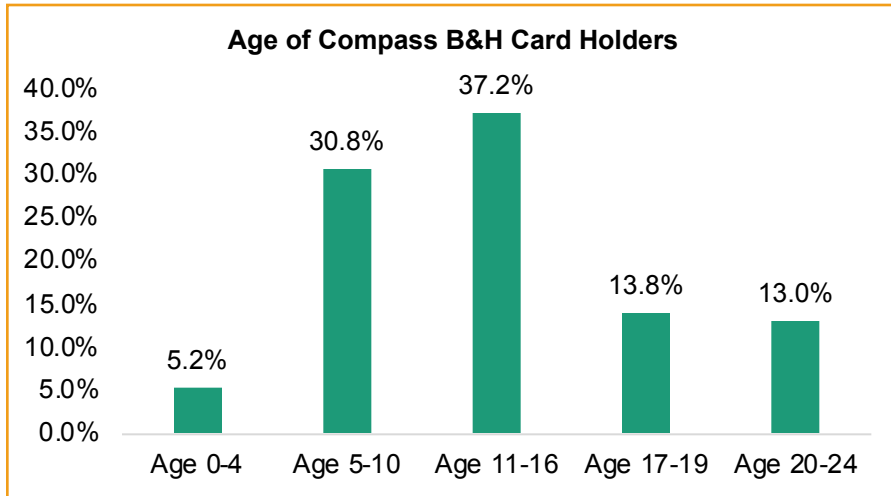


Local SEND Demographic

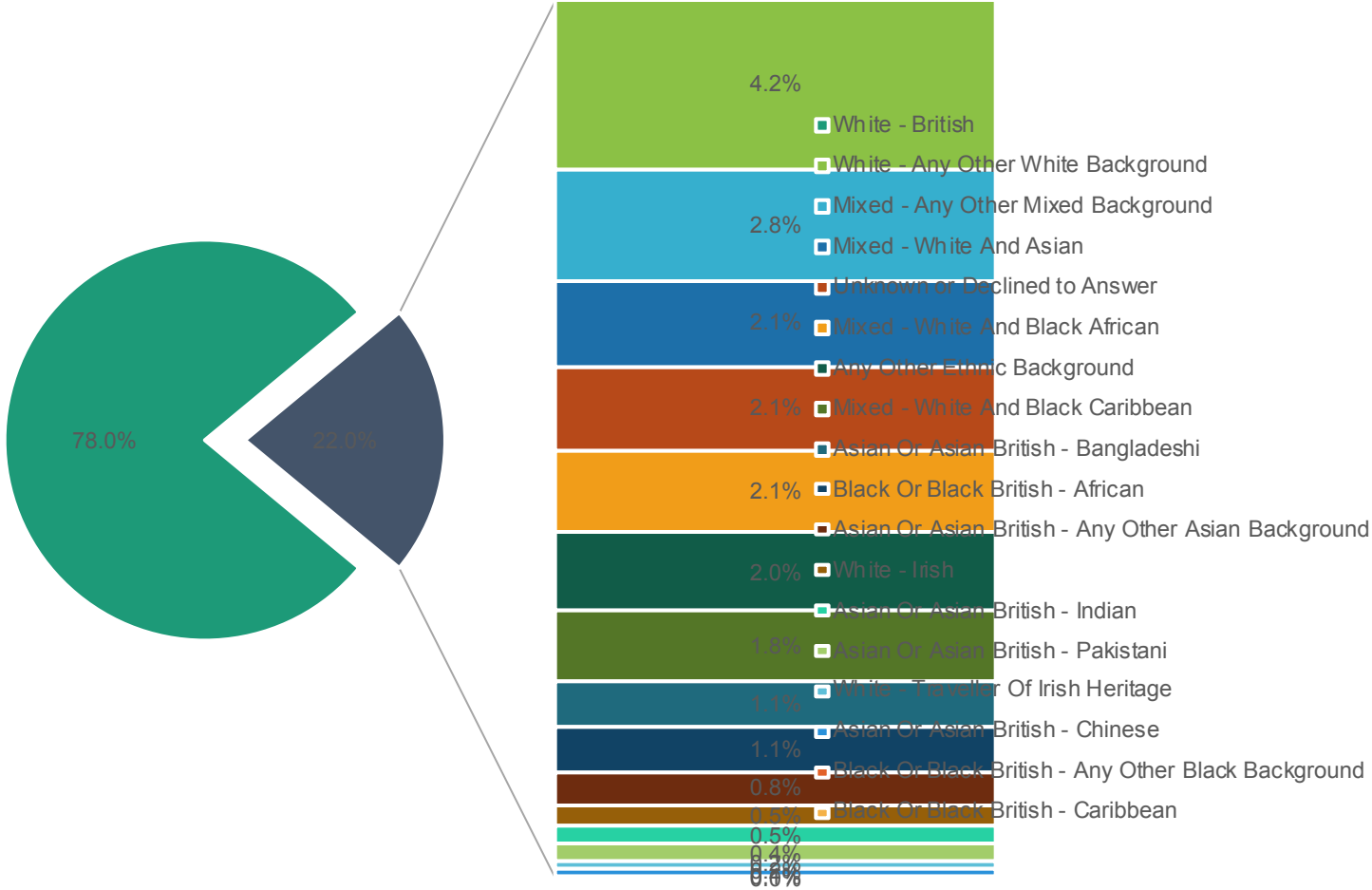
Compass Disability Register for Brighton and Hove

There are 2195 CYP aged 0-25 on the Register
(criteria SEND has significant impact on daily life, usually EHCP or DLA)

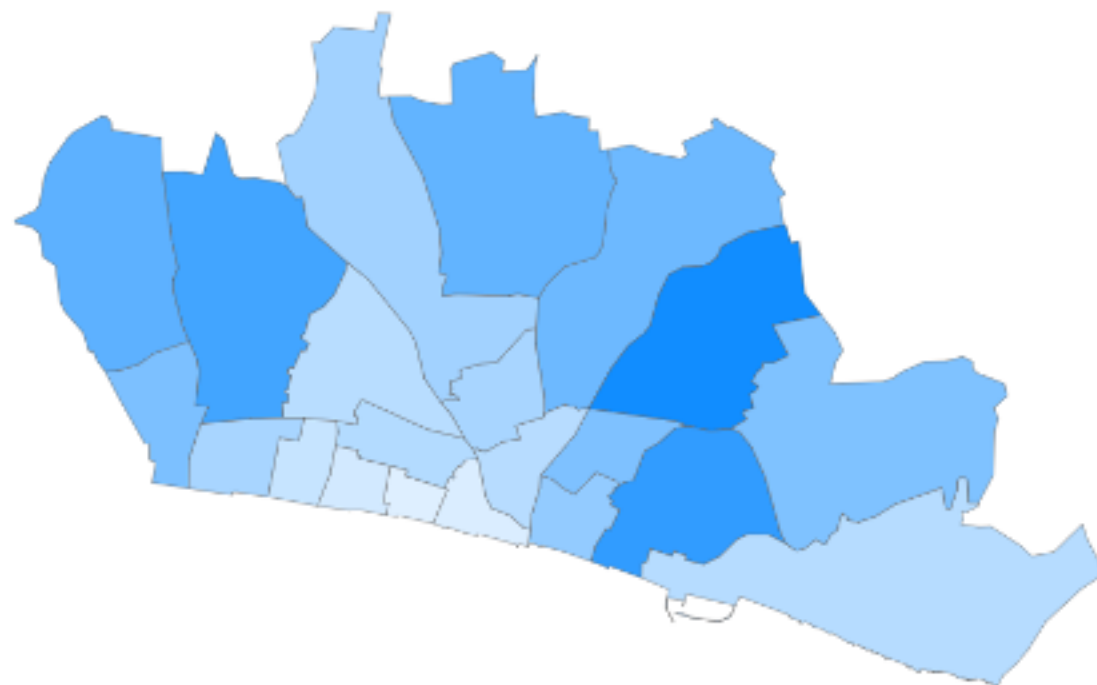
In receipt of DLA or PIP: 1864



Full Ethnic Breakdown of Compass B&H Card Holders

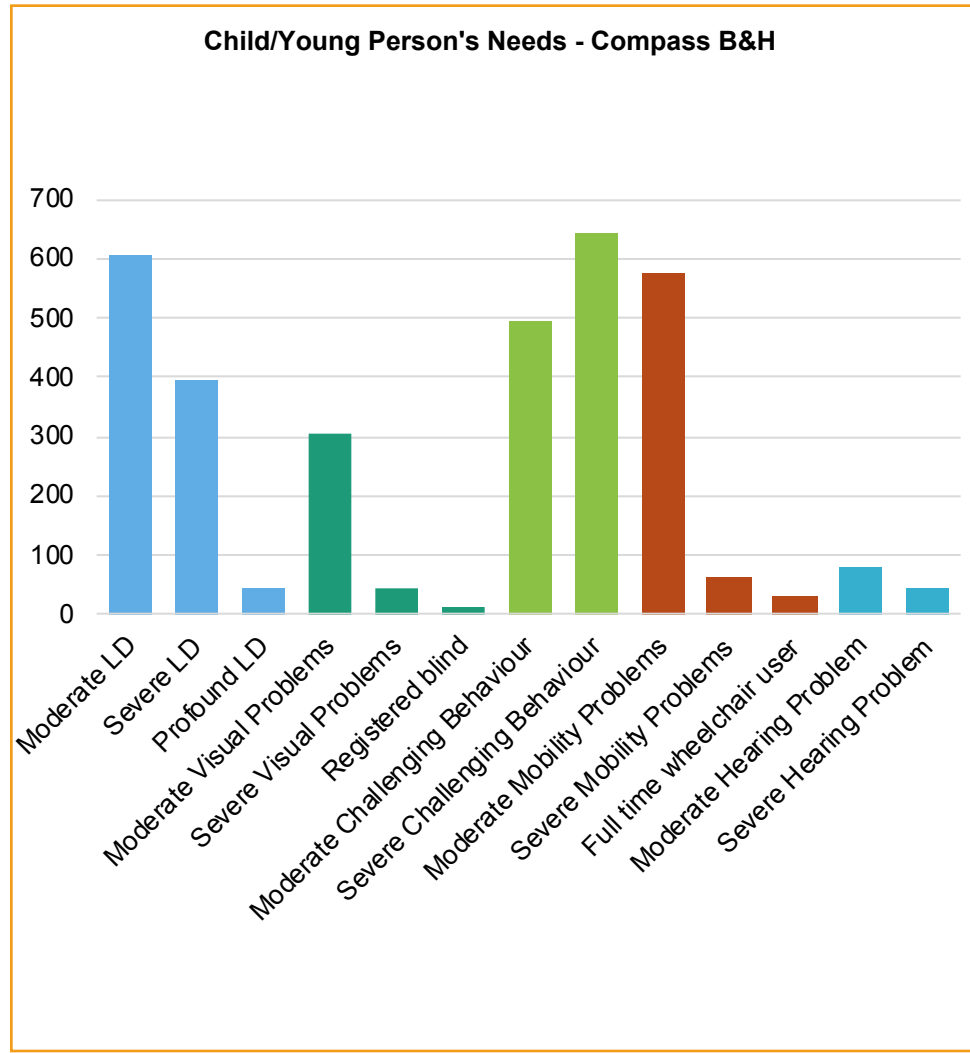


Distribution of CYP by Ward

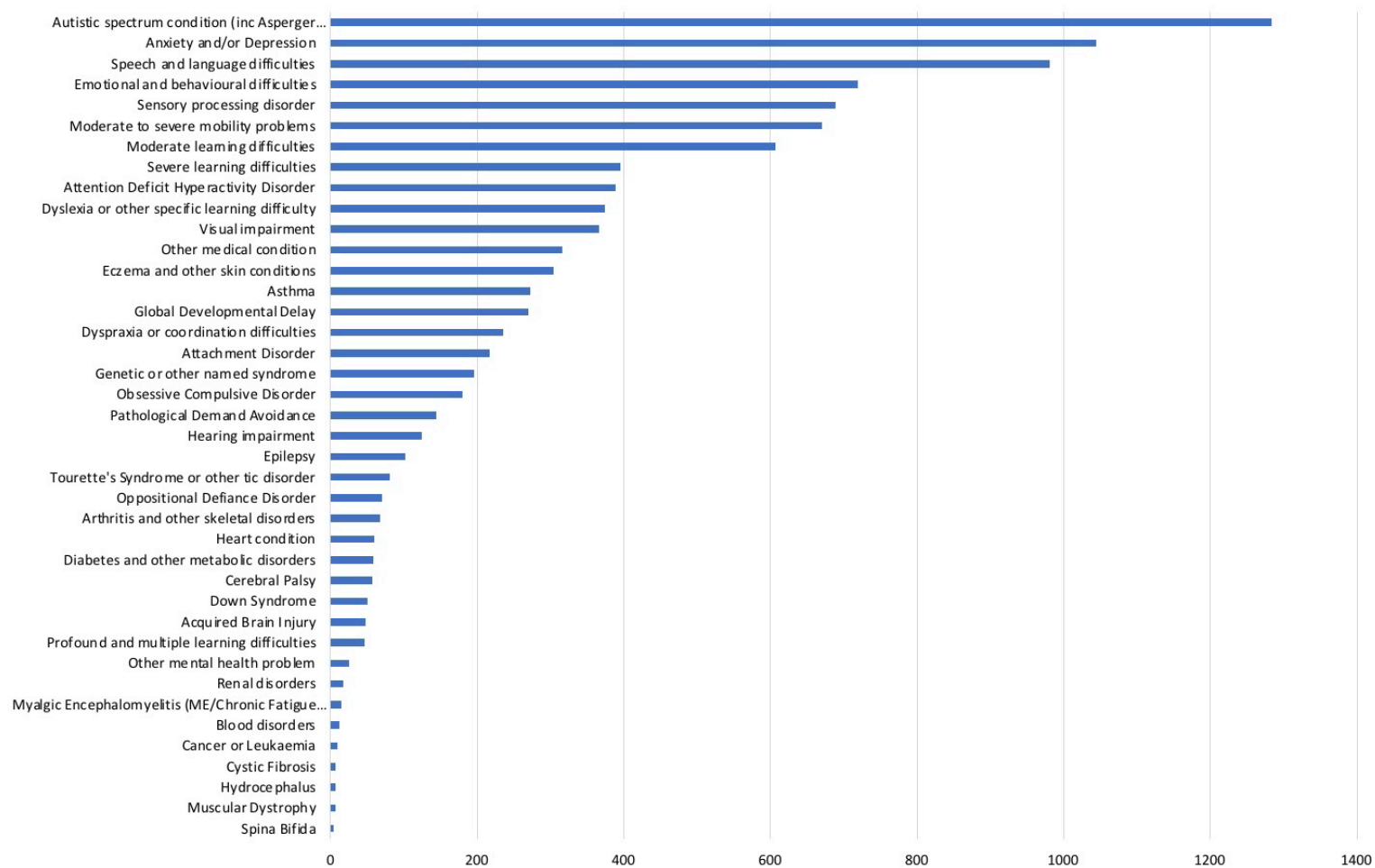


Ward	%
Moulsecomb and Beverdean	11.16%
East Brighton	9.54%
Hangleton and Knoil	8.68%
North Portslade	7.35%
Ratcham	7.11%
Hollingdean and Stanmer	6.54%
South Portslade	5.77%
Hanover and Elm Grove	5.69%
Woodingdean	5.65%
Queen's Park	4.63%
Withdean	3.86%
Preston Park	3.50%
Wish	3.58%
Goldsmid	3.01%
Rottingdean Coastal	2.86%
St. Peter's and North Laine	2.81%
Hove Park	2.77%
Westbourne	2.05%
Central Hove	1.48%
Regency	1.05%
Brunswick and Adelaide	0.86%

Child/Young Person's Needs - Compass B&H



Compass B&H Number of Child/Young Person's Diagnosis



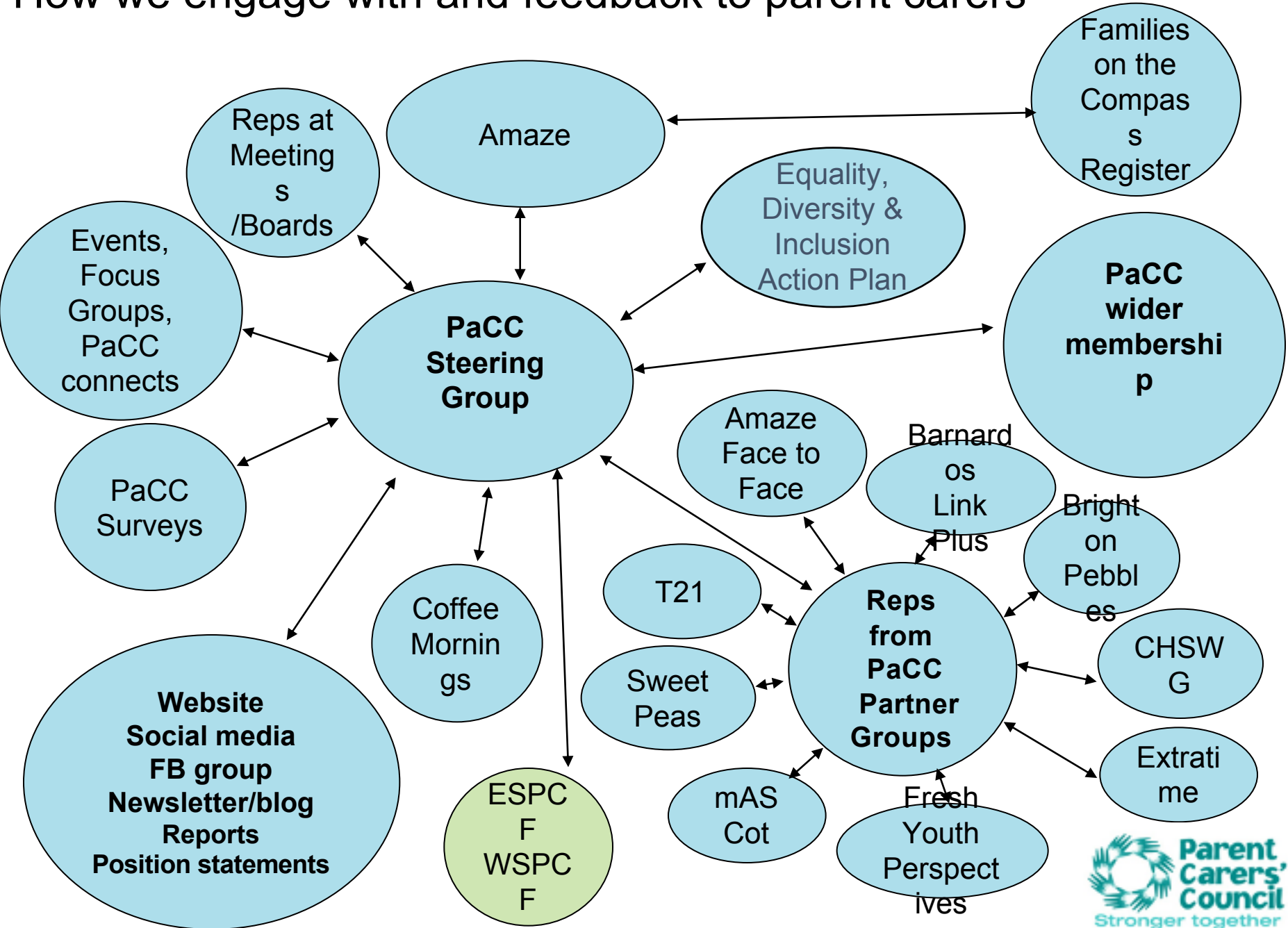
Some of the meetings PaCC attends in B&H

- Children and Young Person Skills Committee
- Children and Young Person Health Oversight Board
- SEND Partnership Board
- Children and Young Person Mental Health and Emotional Wellbeing Board
- Neurodevelopmental Action Group
- Early Years Strategic Action Group
- PAN Sussex CAMHS Neurodevelopmental Pathway Co-Production Group
- Early Help Strategy
- Hidden Children Steering Group
- Learning Disability Board/Strategy
- Primary and Secondary SENCO forums
- SENDIASS and Local Offer Steering Group
- All SEND Strategy Workstream Lead Meetings
(Five in total)

Health meetings PaCC attends

- Neurodevelopmental Pathway Co-Production Group
- Neurodevelopmental Pathway Operational Group
- Learning Disabilities and Health Inequalities Board
- Neurodevelopmental pathway deep dives
- Planned Care
- Health Strategies – physical health, mental health

How we engage with and feedback to parent carers



Next steps for PaCC engagement

- Reaching out to key target groups:
- Ethnically Diverse Communities,
- LGBTQ+,
- Families home educating,
- Looked After Children
- Foster carers and adoptive parents

What makes PaCC successful

- Reach into and connection with the SEND community
- Steering group made up of volunteer parent carer reps with lived experience and from partner organisations, plus Chair and 3 part time staff
- Trusted relationships with families and professionals
- Commitment to challenging conversations
- Co-production Policy across a wide range of workstreams
- Reports and position statements



Our 'outputs'



Stronger together

The difference we make to services

Good joint working with BHCC and Health has led to the following:

- Maintaining a good Home To School Transport service
- Designing and creation of all aspects of the Social Communication Resource (with mASCot)
- Information for parent carers about the Dynamic Support Register
- Increasing the number of specialist ASC places in the City
- Creating the Hidden Children Officer role with the Local Authority
- The Amaze Neurodevelopmental Pathway (NDP) service was a result of coproduction between PaCC and health, designing the service and ongoing input into the training and support provided
- Co-producing the EHCP Quality Assurance Framework parent carer feedback survey

What is going well in our area for families

Feedback from families highlight below the value of key services:

- Parents have spoken highly of the ADHD CAMHS nurses and how helpful they are
- BHISS and the Home to School Transport team attend Face 2 Face groups, which parents find helpful
- Parent carers who are eligible, are aware of group sessions they can attend at Seaside View
- Parent carers have said that the Hidden Children officer has had a positive impact with their child's educational experience, attendance and relationships between families and schools
- Increase in different school provision for autistic children and young people who find mainstream education a challenge
- Parent carers have positive experiences of the Social Communication Resource and value the coordinators working with them
- Parent carers of deaf children and young people tend to be satisfied with the provision their children receive
- Parent carers appreciate the expertise within the BHISS ASC Team
- Home to school transport - significant strides in increasing quality and parental confidence in the service
- Schools being innovative with the flexibility of educational provision for pupils unable to attend school
- Positive feedback about secondary school parent carers groups
- CVS support for young people and families, eg Amazing Futures, Mascot groups, Face2Face groups, Brighton table tennis club, some very active family forums and support groups

What creates successful co-production

- Everyone be willing to listen.
- PaCC being respected for their knowledge and skills, of parent carer expertise.
- Regular meetings between PaCC and the Assistant Director for SEND.
- When PaCC's involvement with workstreams isn't just focussed on engagement but includes strategic planning, implementation and evaluation.
- Multi-layered, working at all levels, from co-production of letters/comms through to representation on top strategic boards.
- Setting priorities, agendas, workplans and timeframes together.
- PaCC position statements and BHCC responses being published simultaneously.
- Having honest, constructive conversations and providing challenge when needed and it being received without defensive.
- Inviting PaCC to team meetings so staff can learn more together.
- Being honest and open about barriers that may impact on workstreams so we can problem solve together and work can continue.
- PaCC having knowledge of local and national themes, to understand the context, issues and pressures.

What are the barriers to successful co-production

- Inconsistency, where co-production isn't embedded effectively across all services and within teams .
- Inconsistency with communications to the parent carer community: when comms aren't coproduced with PaCC, aren't released in a timely manner, or aren't created as and when needed.
- Variable co-production with health, only resourced in NDP, DSR and keyworkers.
- Lack of clarity around SEND structures, of staffing, leadership, commissioning and governance within the CCG/ICB.
- Frequent changes with staff, especially within health and in key roles, creating instability with workstreams as well as needing to build new working relationships. Eg of impact on NDP work.
- Capacity within services/teams, pace of work in different areas, heavy workload.
- Groups working in silos leading to work not being coproduced, joined up with other areas of work or duplication of work.
- Uncertainty around PaCC's funding (affecting staff retention and planning abilities) and level of resource inconsistent with rising demands for PCF input and co-production.

Key challenges: themes from families

- Social care – PaCC position statement.
- Adult social care for autistic young people age 18-25 and lack of autism strategy
- Transition to adulthood across education, health and social care for all cohorts
- ND and mental health waiting lists, services and provision, PaCC NDP report
- The need to prioritise specific pathways for smaller cohorts of need eg Specific learning difficulties, Downs Syndrome, ADHD, PDA, etc
- Education – provision, experience, attendance, EBSA and EOTAS, AP
- Therapy provision
- Local Offer development
- EHCP processes (under development)
- Parent carer experience across all services, including education impacting on their mental health

Feedback From the Parent Carer Community

The following slides contain feedback from the Brighton & Hove parent carer community.

As most parent carers are unable to meet with inspectors during the process, it's important that this feedback is shared with them.

PaCC would like to thank our partner groups and associated groups for their contributions, ensuring that a broad range of parent carer views and experiences were included.

Themes from PaCC coffee mornings in Moulsecoomb and Hangleton & Knoll

- Education – behaviour sanctions when SEND is not taken into account, funding barriers to provide sensory and learning aids, BHISS ASC specialist teachers are unavailable to CYP without a diagnosis, school reports do not always reflect school experience, masking not being recognised, not listening to parents
- Parent carer experience – experiences of blaming and shaming, not listening to parent carers, inconsistent coproduction with parent carers and not including them during assessments and gathering feedback from them.
- Long ND waiting lists and with little information while you wait.
- Getting an EHC Plan still a challenge and many families find the process difficult.
- More and more families would like to be able to access some sort of one to one/face to face support. Complexity of needs, both children's and parent carers' needs, means that receiving support in the form of an email/links/signposting is insufficient and confusing. This is in relation to the service and support provided by SENDIASS, which funding was considerably reduced.
- Transition to adulthood – families report uncertainty of services across education, health and social care for 16-19 year olds; and a higher level of concern for those with severe learning disabilities (SLD) who report all aspects of social care are hard to navigate and provision is difficult to access.

Minoritised Communities

- Professionals (eg teachers) can misunderstand children's behaviours when they come from minoritised communities, meaning they can miss additional needs; this can be because children are stereotyped
- Understanding that when parents are at the beginning of their parent-carer journey (or there's a change in legislation) it can be hard to understand what is already a confusing and complex system (even for people who are familiar with it and speak English as their first language). Interpreting and translation services must be in place to help people navigate a multi layered system.
- Parent-carers from minoritised community can sometimes be labelled as very aggressive or not listening. Consequently, such approaches mean that professionals need further training to reveal unconscious biases.
- Need for professionals to understand how additional needs are seen differently by communities/cultures and that they need to have a more nuanced approach such that people don't get stereotyped or imagine that all people from a particular group hold the same views.
- Misunderstandings in terms of how some young people present when they have mental health challenges (eg 'aggressive' 'confident', 'street wise' and adultification.

Early Years

- Lack of specialist early years places
- Parent carers feel supported by BHISS EY team
- High caseload numbers for BHISS EY teams
- Transitions difficult for EY children due to COVID
- Increase in number of EY children with SEND in nurseries and schools vs reduced funding and staff
- Impact of COVID on early identification/intervention, social opportunities for EY children
- Regular and successful coffee mornings at Jeanne Saunders
- Reviewing EY SEND training and process for initiating statutory assessment request
- Clearer pathways needed, particularly around speech and language therapy
- More information for parent carers around services, pathways and processes, services and support
- More support and training for families

Health transitions for Young People with complex physical needs.

- Lack of joined up planning and communication between children's and adult services.
- Families are really distressed and confused at the lack of information and support, It's a real cliff edge
- Some children's services 'discharge' and stop the care they provide before the equivalent adult services have started. If the right referrals aren't made at the right time this can be disastrous. There may be no equivalent adult service.
- No named professional to oversee the transition or communicate what will happen.
- There are no clear time frames for service transitions, apart from the information that the Young Person will be discharged by the time they reach 19.
- Families need to know that different services require either GP referral or self-referral.

CONCERNING OUTCOMES:

- **Lack of monitoring of physical health, alongside a higher prevalence of co-morbidities leads to pain, loss of function, poorer quality of life, greater pressure on services, poorer adult health and life outcomes.**

NEXT STEPS:

- The Local Offer must include the gaps in information, following the CQC/ NICE guidelines.
- Commissioners and providers **MUST** listen to, involve and learn from young people and their families and understand what they want from their care, and services must be tailored to meet the needs of the community.
- GPs should be more involved at an earlier stage in planning for transition.

Social care

- Acute difficulties children and young people and their families are facing around social care provision for children and young people with special educational needs and disabilities age 0-25 years.
- Families with CYP with LD are at breaking point due to a lack of respite from their caring responsibilities and children and young people are unable to access the activities their non-disabled peers enjoy. This has only been made worse by the pandemic.
- Families are in crisis as they are unable to access either an assessment or short breaks because their child does not fit the eligibility criteria.
- PaCC published a Social Care Position Statement in October 2022, and BHCC were quick publish a public reply- links below.
- The key areas of concerns from the community include the need for more - overnight respite, after school clubs and holiday clubs, a broader universal offer that includes CYP with SEND. Problems caused by DP processes, the lack of PAs, the impact of low PA pay rate. Eligibility criteria for CYP without an LD diagnosis, develop a pathway for this cohort. Increase in training needed for social workers around ND. Significant issues around timely Transition to adulthood assessments and developing meaningful social care opportunities for young people.
- In city solutions for shared care as a prevention to out of city residential
- Lack of clarity in the processes – how panel decisions are made, how to challenge them.
- Access to social workers – less allocated social workers and more work being done on “duty” which means lack of continuity for families
- Poor communication eg. if social worker is off sick
- PaCC recognise that senior leads are committed to make Social Care a priority area of work. However, progress is slow due to capacity in both Social Care teams and the commissioning team. Communication to families following engagement events is needed and regular updates from BHCC must be prioritised. PaCC hope that communication issues will be addressed by the AD for SEND, by her commitment to co-produce an urgent Communication Strategy.

T21

- A smaller community, by virtue of a CYP's specific diagnosis, and it feels to parent carers that they do not receive the same level of attention and resource that some other larger SEND communities do.
- A lack of clear Local Offer & T21 care pathway for this cohort.

Education:

- Support for CYP attending mainstream schools is inconsistent.
- More dedicated support from BHISS is needed, both for staff working with children (evidenced based DS specific literacy and numeracy support) and for parents, who could benefit from coffee & info sessions similar to those run for the ASC parent carer community.
- Secondary school options seem limited, and not all secondaries seem to actively welcome students with T21. As a result, CYP end up clustering, rather than being more naturally distributed across all the secondaries in the city and closer to their home communities.
- BHCC must track the education pathways for CYP with T21. Parent carer feedback suggests that CYP are being directed into special schools earlier in their pathway, hence our ask to analyse the data to understand the dynamics. This is especially pertinent with the recent passing of the Down Syndrome Act.
- Post 16 and Post 19 options for CYP are limited. Downs View Link College and the Life Skills College are not suitable for all CYP with T21. Out of city colleges have become a default choice for CYP attending mainstream schools until year 11. A pathway for secondary and further education and into the workplace for young adults with Trisomy 21 is urgently needed.
- For many, EHCPs peter out before young people reach 25, despite research stating that adults with Down Syndrome are capable of learning new skills into their 30s. We would like to see a Local Offer that can be accessed with a full EHCP until age 25.

T21

Health:

- SALT is an area of particular concern for the T21 community. All CYP will need EHCPs with SALT as a priority. We are asking for greater investment in early SALT for all families.
- Physio and Occupational therapy, families that achieve getting these therapies written into EHCPs report that provision is not reliably delivered.
- Transitions to adulthood, health pathways are inconsistent, and information are lacking for some families.

Social Care:

- Most families will reach the point when they need to access social care. This process is exhausting, and families feedback inconsistencies in allocated provision despite needs being very similar. Early help for many is denied risking and leading to family break up and crisis.
- Young people will usually need a Personal Assistant to enable them to enjoy leisure activities without being totally reliant on their parent/s. The lack of workforce is a significant barrier to respite, and this takes a huge toll on the family, further CYP lose the opportunity to develop skills of greater independence.
- There are families in the community whose child is now living hours away from home and from their home city as the family reaches the point of collapse. We strongly believe more support with more in city short break options could prevent this happening and families could stay together for longer.
- Planning for adult needs to begin earlier, and not at post 18 which most families report.

The Future:

- More focus on apprenticeships and employment is essential - young people have the same hopes and dreams as their neurotypical peers, and opportunities must be equitable.

Neurodevelopmental Differences

- Lengthy waiting times and limited information and support during this time.
- Support in schools being diagnosis led rather than needs led, only being able to access the BHISS ASC specialist teachers if there is a diagnosis.
- NDP workstream and Amaze's NDP service only covers ASC, ADHD and tics and tourettes.
- More support, training and services available for schools and families around autism and very little for other neurodevelopmental differences.
- Parent carers feel that ADHD needs to be prioritised more in the City, for there to be training offers for parent carers, young people and schools.
- Parent carers don't have access to much information about the assessment processes, support and services for dyslexia, developmental coordination disorder, developmental language disorder, dyscalculia. There is very little in place for these differences too.
- Services/teams specialising or focusing on a particular ND difference working in silo and not working jointly to create an overall profile of need and support for an individual child or young person.
- Educational experience is negative for a number of ND children and young people.

Neurodevelopmental Differences

- GPs not agreeing to shared care arrangements with private practitioners, for the prescribing of ADHD medication and unclear rules for parent carers around prescribing
- Private assessments – parent carers having no alternative but to arrange a private assessment for their child due to long waiting lists. Lack of clarity about acceptance of private diagnoses and unclear pathways for parent carers. Huge inequalities for families who cannot afford to go privately.
- The link between ND CYP and the criminal justice system.
- The numbers of ND children and young people who are unable to attend school or experiencing emotional based avoidance is increasing all the time.
- Behaviour policies and sanctions do not take into account ND.
- Difficulties in accessing MH health support, especially because of criteria in place or interventions not being adapted for a child or young person's ND.
- Lack of understanding, acknowledgement and acceptance of masking and the impact it can have on a child or young person over time and it leading to burn out.

Please see PaCC's NDP report for further details:

[PaCCConnect-and-supporting-survey-on-NDP-Dec-2022.pdf \(paccbrighton.org.uk\)](https://www.paccbrighton.org.uk/PaCCConnect-and-supporting-survey-on-NDP-Dec-2022.pdf)

Mental Health

- Slow progress on Foundations for our Future recommendations and SPoA
- Lack of access and provision for neurodiverse children and young people, including those awaiting ND assessment
- Parent carers value the BHISS Schools Wellbeing Service and SEMH Team
- Long waiting lists
- CYP struggling with their mental health post COVID, including self-harm
- CAMHS unable to help unless in crisis
- Need to link up between ND, Mental Health, eating disorders etc.
- Parent carers mental health
- SEMH is a broad category and provision doesn't meet the needs of all the different groups

Education health and care plans (EHCPs)

- Many parent carers find the EHCP process too stressful.
- Communication to parent carers by the SEN team isn't always timely.
- The process isn't clear and parent carers don't always feel that they have been kept informed about things.
- Coproduction meetings are no longer happening during the EHCP process, which is a big loss and could be contributing to the negative experiences.
- Parents feel that they have had to request a statutory assessment for their child through a lack of coproductive working with their child's educational setting.
- Parents feel that their child has received an EHCP too late and this has increased their child's support needs.
- The annual review process isn't robust enough, or ended in a timely manner with some parent carers waiting for an amended EHCP long after the annual review meeting. Paperwork not sent in advance.
- Parent carers don't always feel listened to during the process, which impacts on their child's finalised or amended EHCP.
- Some parents do have positive experiences.
- PaCC are aware of the SEN Team's restructure and hope this leads to positive experiences for the majority of parent carers.

Education

- The number of children and young people who are unable to attend school full time continues to increase.
- Emotional base school avoidance and the need for a guidance for families and schools with a focus around prevention, early identification/intervention and plans for support is greatly needed.
- There is a pressure on special school places/insufficient specialist school places as well as post-16, lack of provision up to 25
- Inclusive behaviour policies are not consistent across schools.
- Not all pupils experience an inclusive education.
- SEND support is a huge area of concern for parent carers – incl schools providing regular updates, plans and reviews
- SEMH provision - Inadequate provision both with Homewood and out of City placements. Nothing for post 16 in the City.
- Parent carers don't always feel that schools work in partnership with them and treat them as an equal, including their knowledge, expertise about the child when creating support plans, outcomes etc.
- Parent carers feel that the staff training within schools is inconsistent and gaps in what is available.
- There is some really good coproduction between schools and families, support packages for children and positive outcomes but this is not consistent.
- PaCC are aware of the issues around primary school admission numbers and the impact of budget challenges and staffing levels are having on children with SEND.
- BHISS do not always communicate with families, and assessments (eg dyslexia, EP) are delayed with children on SEN support then not receiving the support they need in school

Education Other Than School (EOTAS)/Alternative Provision

- EOTAS, the range of impact of EOTAS for CYP is mixed. For some, this has a positive impact and can be the best fit for attainment; some families and students report a contrast and that EOTAS can be a desperate low point.
- There is limited SEMH AP available locally.

INFORMATION.

- Information around EOTAS needs to be more overtly communicated, enabling CYP, parent carers and professionals to understand the range of circumstances when EOTAS/AP could or should be considered.
- Information must include clear information about processes around EOTAS/AP and a more defined pathway is needed
- The Personal Budget mechanism also needs to be much clearer in the Local Offer alongside the statutory differences between EHE and EOTAS.

TIMESCALES

- Significant concerns about how long it takes to get EOTAS/AP provision agreed, in turn this means lengthy periods of missed education and therapies. Eg: a term to organise SALT.

SENDIASS

- Whilst very satisfied with SENDIASS and the quality of the support and advice they provide, the capacity within the service is having an impact on parent carers.
- Parents are waiting longer for 1:1 advice calls and fewer parents get more extended help from a named advisor
- The impact on parent carers is made worse due to the capacity issues within schools and the SEN Team.

Parent Carer Experiences and Wellbeing

- Parent carers struggling with their mental health post COVID, including suicidal ideation
- Isolation for parent carers and their CYP
- Parents who are neurodivergent themselves struggling to navigate the system
- Parental relationship breakdown
- Lack of family support
- Cost of living crisis
- Feeling burnt out and/or despondent to carry out further surveys, as they have been asking for educational help and improvements with services over the last couple of years which they feel has gone unnoticed
- Dads wanting to be heard by services
- Dads wanting to be treated as an equal to their partner by services
- Instances of parent blame

Next Steps, After the Inspection

As well as providing this information as part of Brighton & Hove's local area inspection, we recognise that this information adds value for the review of the SEND Strategy. PaCC welcome this review and look forward to working alongside BHCC and Health to progress all citywide strategies relating to SEND 0-25.

The key themes will also help inform PaCC's priorities for the next year