



Brighton and Hove Adult Autism Strategy Development

A contribution to the 2023 consultation from the Parent Carers' Council (PaCC), Amaze and The Hangleton & Knoll Project (HKP)

A) Summary:

This consultation was with parent carers of children and young people with special educational needs and disabilities (SEND) aged 0-25, and with SEND young people aged 14-25. It looked at how to improve lives of autistic adults without a learning disability and address current gaps. The consultation was carried out by PaCC, Amaze and HKP. Parent carers and young people told us that:

1) What's working well:

Families said they value services which are providing support, including:

- Amaze's Mental Health counselling, Face 2 Face service, the Compass Card, and support with making DLA and PIP applications
- PaCC coffee mornings, including the multi-cultural parent/carer group with HKP
- Grace Eyre's housing brokerage for young people in Brighton (although we heard how the model needs to expand)
- Autism lead specialist from the BHISS team, the Cullum Centre and the Swan Centre in Falmer school and special nurseries
- Home To School Transport (HTST) offer
- Local parks – those that are fully accessible

Parent carers underlined the fact that there is plenty of support available, but you need to know about it. Parent carers enjoy provision of safe spaces where they can express themselves, connect with other services and do fun things at the same time.

2) What can make life difficult:

- Lack of PAs, accessible housing and long waiting lists to access services
- Some families feel that the Education, Health and Care Plan (EHCP) is a challenging process, even more so for families who don't have English as first language
- Some public services are not fully accessible to autistic CYP, for example public disabled toilets are always locked and public transport can be difficult to access because of difficulty of communication with drivers. The anticipated cut to post 16 HTST has a major impact on families when the children transition to supported living.
- A&E department at The Royal Sussex is not neurodiverse friendly, with long waiting times to be seen and a very noisy environment. Some services don't give a choice to the child to see a male or female professional or consultant.

- Some parents highlighted the stigma attached to social care and social work and as a result parents are afraid of involving them. Many parents feel that the judgement is on them, and they get questioned about their parenting.
- Too frequent changes with key workers make life very difficult and some school staff do not fully understand or respond to the individual needs of neurodiverse children
- Many parents felt that they had to educate themselves on how to access and navigate services, which can be quite challenging.

3) What would make things better

- To be able to access information about services as early as possible
- Early identification and intervention
- Activities that help autistic CYP express themselves
- More joined up working between Neuro Development (ND)/MH and physical health teams, with services more ND friendly.
- A multi-disciplinary specialist team focused on autism which includes OT could help more young people get the support they need
- To be able to access a 'specialist rental support team' to help autistic YP access housing and independent living, eg facilitation between a YP and letting agencies and/or /landlords.
- To have a named/individual keyworker who supports the CYP and to be able to choose between a male or female.
- More awareness and knowledge around neurodiversity; ND training to be offered to service providers, including GPs, practitioners, social care staff, mainstream school staff, police, staff in police stations and the youth offending service. There should be more promotion of the Pegasus card.
- 'Feeling safe' workshops and feeling safe at school as a theme in lessons
- A navigation system to be in place when a young person reaches 16 years to support their transition into adulthood. This would offer more access to life skills opportunities, not just offer catering, computers, and IT, but also mental health support. More vocational courses in secondary schools, and colleges should offer more training and support so that young people know what's out there
- More diverse mental health support for YP, for example art therapy or surf therapy which could be accessed earlier (waiting lists are huge).
- Wellbeing services for neurodiverse adults with diverse mental health support and friendly couple/family therapy
- Opportunities for neurodivergent young people to socialise in 'safe spaces', for example Amazing Futures.
- More indoor entertainment for autistic people but also more accessible public spaces, such as Hove Lagoon, with more signage and more awareness in general about older autistic adults, eg in local parks
- More supported volunteering, work experience and apprenticeships. Overall, the job market and recruitment processes need to be more neurodiverse friendly.
- More information about what support is out there
- More awareness around neurodiversity within different cultures and communities, eg ASC awareness workshops for parents with English as their second language.

B) Background:

The Brighton and Hove Autism Partnership Board consulted on the city's new Autism Strategy May-June 2023. The Autism Partnership Board is a partnership led by autistic people involving the NHS, police, BHCC and voluntary and community sector organisations that work to improve the lives of autistic people across the city.

The consultation focused on autistic adults without a learning disability so to address current gaps. The city already has an Adult Learning Disability Strategy and a Special Educational Needs and Disability Strategy.

The consultation gave autistic people, their carers, family members and staff who work with autistic people the opportunity to share their views on services available in the area and how partners can work towards Brighton & Hove becoming a city that recognises and values neurodiversity.

Feedback and input to the consultation will help shape the strategy. Working groups around key themes identified will then be developed and help influence the autism action plan for the next five years. It is the ambition of the Autism Partnership Board that autistic people will be able to see improvements in their lives from year one.

C) Introduction

PaCC and Amaze run different projects and activities for parent carers who have CYP from 0 to 25 years of age with SEND in B&H. HKP is a community development organisation working in partnerships to access and develop opportunities and resources which facilitate positive change, as identified by the residents of communities in the west of the city.

Together we are aware of the many challenges and barriers that families and their children experience every day and we periodically run sessions to inform families about services available in the city and to pass on useful information. Many families who are supported by us have children on the Autistic Spectrum and many parent carers are on the Autistic Spectrum themselves.

PaCC, Amaze and HKP worked together to gather information and feedback from parent carer / CYP communities. The consultation looked at 9 areas identified by the Autism Partnership Board:

- physical health services
- social care
- mental health
- feeling safe police and the justice system
- parenting and relationships
- housing
- jobs and volunteering
- feeling part of the community
- diagnosis and support from the Neurodevelopmental service

D) Methodology

In addition to promoting the citywide online consultation we ran two parent carers coffee mornings, in East Brighton and the west of the city, we carried out 4 one-to-one interviews with parent carers from minoritised communities and we invited input from PaCC and Amaze staff – those who are parent carers themselves and staff who are supporting our YP groups.

Families were asked what is working well, what can make life difficult and what would make things better for autistic people in Brighton and Hove?

E) Feedback

Feedback from PaCC coffee mornings and PaCC and Amaze staff

Each coffee morning session was introduced by Lorne Power, Commissioning and Performance Manager (Autism Lead) Health and Adult Social Care Commissioning, and facilitated by Paolo Boldrini, PaCC Engagement Coordinator. The 2 coffee mornings were advertised as a space - *‘to hear your views and experiences on what needs to change locally particularly for autistic adults without a learning disability so that your children will have a better future. This coffee morning is specifically for parents who have autistic children without a learning disability or who are themselves on the autism spectrum’*.

The 9 areas were written on flipcharts on the wall, attendees were asked to record their feedback/experiences/ideas. A total of 22 parent carers attended the two sessions.

This is what parent carers shared.

Physical health services

- **More information about services needs to be available as early as possible**, for example for parent of 16 to 25 years old, navigation more than social worker.
- Referrals from doctors to wellbeing is good. A parent expressed concern around checking a young person's MH, e.g. are they danger to them or others?
- Better links into support, referrals though GPs and education can be slow. Could a specialist team support the referrals process better?
- **More joined up working between Neuro Development (ND)/MH and physical health teams; ND friendly and accepting services.**

Social care:

- **Social care should be involved with families as early as possible** so to not have a child becoming an adult and them still not be connected with the disability service, direct payments or PAs.
- **A navigation system in place for when a young person reaches 16years**, which perhaps could be part of the Education Health Care Plan (EHCP) review so to let parents know what services are available and what they can be referred to.
- A parent pointed out that there is a **stigma attached to social care and social work and as a result parents are afraid of involving them**; perhaps we a new name and/or title.
- The **lack of PAs** (recruitment) puts parent carers in a very difficult situation and many families at a crisis point.
- Life skills should not just look at catering, computers and IT, but **also provide mental health support** based around interests.
- Social care should focus more on need instead of diagnosis. To have a **special autism team, which can help more young people get the support they need**, something in place before the crisis.
- **Social care staff need to be trained around ND and transition to adulthood** which should be person centred, information on pathways, assessments carried out in time. And more support is needed for those hidden additional needs and for those children who are masking.

Mental Health (MH):

- **Greater awareness and knowledge around neurodiversity** and that many children are not able to access services when they need them because of the **long waiting lists**. And when therapies are not provided on time can lead to crisis, eg self-harm and breakdowns.
- CAMHS's CBT sessions, which are usually offered for 6 weeks, are not enough as most of the time the child doesn't warm up to it until the 5th session. It would be good if **art therapy could be accessed earlier as at the moment the waiting list is huge or even surf therapy**.
- Service providers, including GPs and practitioners, should be provided **training around Autism** and how best support children and adults who are on the Autistic Spectrum and **better prepared to signpost** to the right service.
- **Early identification and intervention** and **activities that help CYP expressing themselves**. Better diagnose of MH disorders and Autism and links between addition and Autism.
- In relation to education and the impact it can have on children's MH, **parents would like to see more vocational courses in Secondary schools**, not just maths and English, **with more focus on confidence and small steps**; exams can be very stressful for children and young people with additional needs.
- **Colleges should provide more training and support so that young people know what's out there and generally more support for young children to navigate everyday life from the moment they get diagnosed**. For example, some neurodiverse teenagers or adults are not able to tell the time or knowing concept of time; and that's important as affects life skills.
- Many young people who have accessed the **MH counselling support through Amaze**, feel that they've found it easier to talk to counsellor as they say '*she treats them like an adult, not like a child*' which they've experienced in other services.
- Important for young people to **socialise in 'safe spaces' for neurodivergent young people, for example Amazing Futures project**.
- Many parents feel that the judgement is on them and they get **questioned about their parenting**.
- A better provision of **wellbeing services for neurodiverse adults** is needed. It would be good also to **vary mental health support**; change services to fit individuals. What parents would like to see are more family groups, like coffee mornings, and child services and adult services that are linked to each other.

Feeling safe police and the justice system:

- **ND training should be offered to the police, staff in police stations and the Youth Offending Service**. Also, police should offer reasonable adjustments in custody. To improve communication between the police and young neurodiverse person, there should be **more promotion of the Pegasus card**, which is a scheme for people who find it hard to communicate with the police.

Parenting and relationships:

- **Young people need to learn how to build relationships and make choices**; it would be great for young people to have role models and attend meetings where young people lead the meetings. Neurodiverse young people need to explore sexuality, different identities, masking, being accepted.

- **Training should be offered to GPs and other service providers around ND** so that situations where a neurodiverse person get asked by the GP - *'how is your sex life? drugs? alcohol?'* – don't happened again.
- **For families to be able to access neurodiverse friendly couple/family therapy;** seeing a parent carer being neurodiverse as a strength and also training on double empathy and how best understand each other.

Housing:

- Parents underlined the **lack of accessible housing** and the need for **more OT assessments** to evaluate the safety of the house/flat. Children and young adults with neurodiversity need their own room, that means **bigger houses are needed in Brighton and Hove.**
- Unaffordable housing and very high rent in the city. Parents mentioned that some young people do move back to live with their parents because they cannot afford their own place; **Grace Eyre offered housing brokerage in Brighton but the model needs to expand.** It is difficult for young people to leave home and start renting; it's harder still for those with ND needs to move away from home.
- A parent said that 'supported living' costs £427 per week without staff costs and bills and that housing associations can charge whatever they want to. Access to support is for people who have quite complex needs; but they also need to have a safety net to support them around mental health.
- **More information about what's available** - finance, employment, benefit/financial support – and not being told what they are entitled to despite years of involvement in various services. **To set up a multi-disciplinary team which includes OT.**
- It would be good **to have a 'specialist rental support team'** that could liaise between the young person and letting agencies and/or /landlords.
- **Colleges could provide specific training and support at college**, i.e., around lived experience of renting, independent living. Autistic young people living in hostels lack the support needed around independent living, i.e. knowing how to budget. It would be good to train staff to offer lived experience support.

Jobs and volunteering:

- **More supported volunteering, work experience and apprenticeships for young people** is needed.
- **Ability for neurodiverse young people to observe other job roles**, not just catering, so to create a social environment and a cultural shift towards how people see additional needs and what jobs ASC people can apply for and do. To set ambitions for neurodiverse children and young people who often think that no organisation will employ them.
- **More information about what support is out there**, i.e., the BHCC supported employment team at BHCC is available but not many people know about it.
- **The job market and recruitment processes need to be more neurofriendly.**

Feedback from parent carers from Face 2 Face and the HKP Multicultural Group

Amaze's Face to Face service and HKP work in partnership supporting parent carers from minoritised communities to come together once a month for peer support with guest speakers from specialist services to meet their needs and to overcome barriers to enable them to access the support they need. We conducted 1-1 interviews with four members of the group on the strategy and the responses are captured below; the feedback has been anonymised. Each interview has been transcribed in the parents' own words.

Parent A has a 22-year-old son diagnosed with autism, ADHD, learning difficulties, speech and language difficulties and anxiety. Parent A has been attending Amaze groups for several years and is now attending the multi-cultural coffee morning. The family live in Hove and are from a Brazilian background.

What is working well for autistic people in Brighton and Hove?

- **There is plenty of good support for parent carers in the Face 2 Face support groups, charities, and WhatsApp groups.** My son loves the **special college he attends**, and they are very supportive. We also receive direct payments which enable us to pay for a PA to take him out which is very useful.
- We have a **Compass Card** which has lots of different activities available so we can choose ones he likes, and it makes it affordable for us i.e., the cinema and swimming.
- **Local parks with SEND equipment he likes to access.** I think that local shops/businesses and restaurants are becoming more aware and accommodating, for example, if there was a lengthy queue in a shop and I told staff that my son is autistic and would find that a struggle they are willing to listen and adapt.

What can make life difficult for autistic people in Brighton and Hove?

- **Public disabled toilets are always locked so this is very difficult. There are not enough ramps on sidewalks which makes wheelchair access tricky.**
- The disabled parking on Kingsway, especially near Hove Lagoon is a problem due to cycle lane right next to it making it very dangerous. My son has no danger awareness and I worry there will be a terrible accident soon. **Cutting post 16 home to school transport soon will have a major impact on us from September when my son transitions to supported living.**

What would make things better for autistic people in Brighton and Hove?

- **We need more indoor entertainment for autistic people;** for instance many soft play areas promote SEND friendly sessions but these are always at unsuitable times i.e., early morning or late evening which are not practical for our families.
- **We need more accessibility at Hove Lagoon** as it is not good for wheelchair users, plus my son loves using the disabled swing there and this is always in use by neurotypical teenagers. This can be tricky as my son doesn't understand the need to wait so it could do with **more signage in these areas or even sectioned off so that it is not accessible to non-autistic wider public members.**
- And maybe **more awareness in general in local parks about older autistic adults** like my son that love to use swings and play areas, so we don't feel judged.

Parent B has a 16-year-old son diagnosed with autism, speech and language difficulties, dyslexia, and anxiety. The family live in Hove and are a Farsi speaking family from an Iranian background.

What is working well for autistic people in Brighton and Hove?

- I get lots of help and support from the **autism lead specialist from the BHISS team**, every time there is a problem in school, she sorts it out very quickly. As well as dealing with my son she also offers us check ins and family support. My son attends Hove Park School, and the **Cullum Centre staff** are really helpful and understanding. We have lots of help and support from **Amaze from the Face 2 Face** service, meaning I can access WhatsApp groups and meet other parent carers in person to gain advice and support. Plus, I have had a lot of help from the **DLA service** to do forms as it wasn't easy with the language barrier.
- We also have a **Compass Card** and have taken my son to Washbrooks Farm and Saltdean Lido but now he is getting older doesn't always want to go out with me.

What can make life difficult for autistic people in Brighton and Hove?

- **Some wider school staff are not very understanding or helpful to my sons needs**, which makes life difficult. They **have placed him in isolation several times** which is not good for an autistic person. It doesn't happen so much now that he's almost ready to leave after GCSES.
- **Buses have left him behind before as he struggled to communicate with drivers**. We had a **difficult incident at the A&E department at The Royal Sussex Hospital** recently when my son broke his hand. It was very busy in the department, and **he struggled with the noise**. After **2 hours of waiting**, he walked out, and I had to follow and return the next day.

What would make things better for autistic people in Brighton and Hove?

- I feel that all **school staff in mainstream schools should have autism awareness training** as when they haven't, they can make situations worse. I also feel that **police officers need to have autism training** too after an incident with my older son who has autism traits.

Following this interview, the Face 2 Face project worker informed parent B of support available: Helping Hands lanyards and disabled council bus passes for juniors; Health passports and Pegasus Card.

Parent C is a 70-year-old single mum living with two sons. She has a 35-year-old son diagnosed with autism, ADHD and learning difficulties. Parent C has been using Amaze services for many years and is now attending the multi-cultural coffee morning. The family live in a privately owned home in Brighton Hove and are from a Chinese background.

What is working well for autistic people in Brighton and Hove?

- He's an adult in a very good place right now. **There is plenty of support available but only if known about and if you know where to go to seek help.**

- If parents are aware of the special needs, they need to seek help. Having the 'gut feeling'/early detection, my son was almost one year old. Recognising the signs, looking out and being aware - he was 'anxious. Being aware of Amaze and their services.
- **Amaze is brilliant! The space of coffee morning is helpful** to find out more about services and seek advice and ask questions. It is good to see Amaze working in the community with HKP. To raise awareness and have these conversations as I see families in in denial which makes it worse for the children and delays support.
- With my first son, I first noticed at a hearing test at age 5. He was not listening, being in the world of its own, unsettling behaviour and high-pitched screaming. Took the opportunity to get my second son looked at, he was almost two.
- Referred to Mcketh centre at the children's hospital. Son was assessed once a week. Found out he was in the Autistic spectrum. **After diagnosis he was referred to a special nursery. Not sure if such services still exist but that was very useful and helpful at the time and felt supported.**
- He didn't like going to school but we used the **taxi service**, which was a great help.

What can make life difficult for autistic people in Brighton and Hove?

- Had Problems settling in Mainstream school, went to unit attached to a school, with extra provision. Class is smaller. Providing one to one support. **Didn't like having one to one, didn't want to be singled out.** Anxious at playtime, peers giving hard time, feeling different. Felt safe in unit. At juniors mixed them in mainstream class. Teacher trained but not specialist in autism. He's very bright and manipulative.
- **Key workers change all the time** need to be soft, did not like attitude of keyworkers, caused him to play up.
- **When been seen by CAMHS son was seen by a male consultant. By not having a father figure he was quite anxious to meet men. At CAMHS got seen by a female nurse to really connect with him and felt supported.**
- He told in confidence to nurse that he was depressed and wanted to end his life! If wasn't for the nurse wouldn't have known!
- **Swan centre in Falmer school. Took him seriously.** When he's upset, he can run to 'the bridge'. He didn't feel safe at school. 'The Bridge' provided support, which was near his school and meant he felt safe, had reassurance and she was able get to him if something happened.
- **Came across a very helpful solicitor through Amaze who helped with school.** I battled to move from mainstream school. Had to get him privately assessed and identify the needs. Age 12/13
- **Had to educate myself to accessing and navigating services, which was a challenge.**
- Once the child was over 20 felt no support was available, came across a service called 'Connections' where received help for young adults

What would make things better for autistic people in Brighton and Hove?

- **Help/support services made available which fit in school environment, outside of school and in the community.**
- Separate units, an adjacent school and integrated. **School/staff aware and trained in autism, smaller classes, Benefits, transport, staff training in and out of school.**
- Half term, **outside school help and support. Peer groups. Activities during half term, clubs and social space.**
- Awful experiences with **police** etc. **systems being aware.**
- **Easily access and quick assessment. Financial help.**

- **Early detection.** Help with assessments. And support with EAL. Raising awareness in community - in denial.
- **Named/individual keyworker to support one child.**
- Knowing more about individual families and identifying barriers
- **Knowledge of services, help with accessing and navigating services – one place for help.**
- **Use of nurse.**
- **Raising awareness** - especially in different cultures and communities and more support for parents as carers and individuals. Peer support.
- **'Feeling safe' workshops, feeling safe at school. Autism friendly lessons.**
- **Having a choice of male/female key workers.**
- Help/support/Service throughout 'life hood'.

Parent D is living with her husband and two sons. She has a 7-year-old son who has Cerebral Palsy and is awaiting an ADHD diagnosis. She also has a 4-year-old son with an autism diagnosis. She is using Amaze services and is attending the multi-cultural coffee mornings. The family live in Hove and are from a Bengali Background.

What is working well for autistic people in Brighton and Hove?

- There are organisations that people have access to, to support them such as **Amaze and parent/carer support groups – including the multi-cultural parent/carer group.**
- I feel very supported and well connected by coming to the multi-cultural parent carer **coffee morning** and the HKP coffee mornings and through **WhatsApp groups**. They provide me with up-to-date information on services, events, and workshops which I can always opt in/out of. Also, they are a platform where I can go for help and advice through peer networks and service networks. It works really well to have them both on one platform as we get our answers instantly and get the necessary help and support.
- Feel both HKP and Amaze are doing brilliant work in the community in raising awareness and sharing information about help and services that are available.
- **I am able to connect with other services** outside of parent carer role and do something for myself and my family such as joining the multi-cultural women's group and activities and family events such as Big Munch. I feel better connected with everything and feel I can contact HKP about anything. I have referred a few people to different things and feel they listen to our needs.
- Having a **safe space to be able to express and be able to do fun things at the same time**, really liked the 'the bubble tea making session with the group and the pamper day and gifts. They help to focus on us even through the difficulties and the challenges.
- They have helped me to talk to certain services and professionals and helping me every step of the way of applying for the **Compass Card and benefits** etc as I wouldn't have known about this until I attended a session on benefits and entitlements. It is really useful and helpful for days out.

What can make life difficult for autistic people in Brighton and Hove?

- Education settings **not having much awareness** and not having SEN Support for ASD children
- There is a **long and challenging process for EHCP's** especially when English is one's additional language.

- Churchill Square and **shopping outlets should have a quiet area** for children with special needs

What would make things better for autistic people in Brighton and Hove?

- **More awareness of ASD.** Raising awareness, especially in different communities as some cultures are in denial and do not know the benefits and help and support available and that it is ok, being accepting.
- **Training in education settings.** More special needs schools and nurseries and more provision in place at every stage of life.
- **ASC awareness in and around Brighton,** for example informative posters etc
- **Separate ASC awareness workshops for parents with English as their second language.**