



## Perceived gaps in provision of SEND services

December 2018

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### 1. Report Summary:

#### Overview

This consultation looks at provision of services for families who have children and/or young people with special educational needs and/or disabilities (SEND) living in Brighton and Hove.

Our aim was to find out if SEND families perceived their needs as being met by current services and activities, and if not, to better understand the gap between what SEND families would like to receive and what the Local Authority (LA), local NHS and other organisations are providing.

Findings and recommendations from this consultation will be shared with Brighton & Hove City Council (BHCC) and Brighton & Hove Clinical Commissioning Group (B&H CCG), and inform development of the new SEND Strategy 2019-2022.

Parent carers responding to this consultation may or may not have accessed particular services for their child/young person. This means that some will have a good understanding of services, whereas others may think a service sounds like something they might find useful, without necessarily having a full understanding of what the service is, whether their family would benefit from accessing it or be eligible to receive it.

#### Main findings:

- The majority of parent carers who responded to our consultation don't feel that current services satisfy their child and/or young person's needs
- Parent carers think that lack of service provision risks impacting upon their child and/or young person's social opportunities, quality of life, ability to live independently, chance to get in to employment and access to health care
- Services which are felt to be insufficient or lacking include:
  - Social, emotional and mental health support
  - Support for children and young people with the Autism Spectrum Condition (ASC)

- Sensory services including music therapy
- Wellbeing support services within schools
- Health care services such as hydrotherapy and alternative or complementary therapies
- Outreach from the children's disability team,
- Access to help and advice, including financial advice
- After-school activities including leisure and sporting clubs, social clubs and respite services, e.g. residential short breaks
- Education, training and employment services for young adults

**Recommendations:**

- I. BHCC and B&H CCG to map out provision of education, health and social care services to better understand and address perceived gaps in provision
- II. B&H Parent Carers' Council (PaCC) to work closely with BHCC and B&H CCG to ensure the perceived gaps in SEND services are reflected on and addressed in the SEND Strategy 2019-2022
- III. PaCC Parent Reps who sit on relevant Boards and strategic groups to take forward suggestions and recommendations from this consultation, e.g. for the Wellbeing Board to tackle shortage of wellbeing services
- IV. Amaze to continue to look for opportunities to respond to gaps in services and help ensure that families' needs and aspirations are met
- V. Amaze to continue to promote leisure activities and sporting clubs through the weekly Compass ebulletin and on the Compass website
- VI. Brighton & Hove SEND Employability Steering Group to develop a clear strategy around access to training and employment for young people with SEND
- VII. Amaze and PaCC to ensure referral pathways into Carers' Centre are clear and working well, for young people age 25+ and their families who are able to benefit from Carers' Centre services.

## 2. Report

### 2.1 What Amaze does

Amaze is Brighton and Hove's 'one stop shop' for families with children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze also manages the Compass Database and the Compass Card, a free leisure incentive card for 0 to 25 year olds with significant disabilities or special needs who live or go to school in Brighton and Hove.

Since 1997 Amaze has been engaging parent carers at all levels of services provision for their child or young person, for themselves and for the whole family. Their aim is to increase parent carers' resilience and confidence which in turn has a direct effect on the lives of their children. Since September 2014, in line with the new Children and Families Act, Amaze has been supporting families, and young people with Special Education Needs and Disabilities (SEND) themselves, up to the age of 25.

### 2.2 What PaCC does

The PaCC, hosted by Amaze, is a city-wide engagement group with over 380 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

PaCC also has ten partner organisations, some of them service providers, others community groups formed by parent carers. PaCC gives a voice to parent carers using different engagement methods, for example focus groups and forums to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve services for families.

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Investment Programme (TSIP), fund Amaze and the Carers Centre for Brighton & Hove to gather views and ideas from carers around provision and delivery of health care services. Amaze and PaCC specifically consult parent carers of families with children and young people with additional needs and/or disability – Amaze and PaCC engagement diagram ([See Annex 1 Amaze and PaCC Engagement Diagram](#)).

Some of these consultations are designed and planned in collaboration with the Carers Centre for Brighton & Hove.

### 2.3 This consultation

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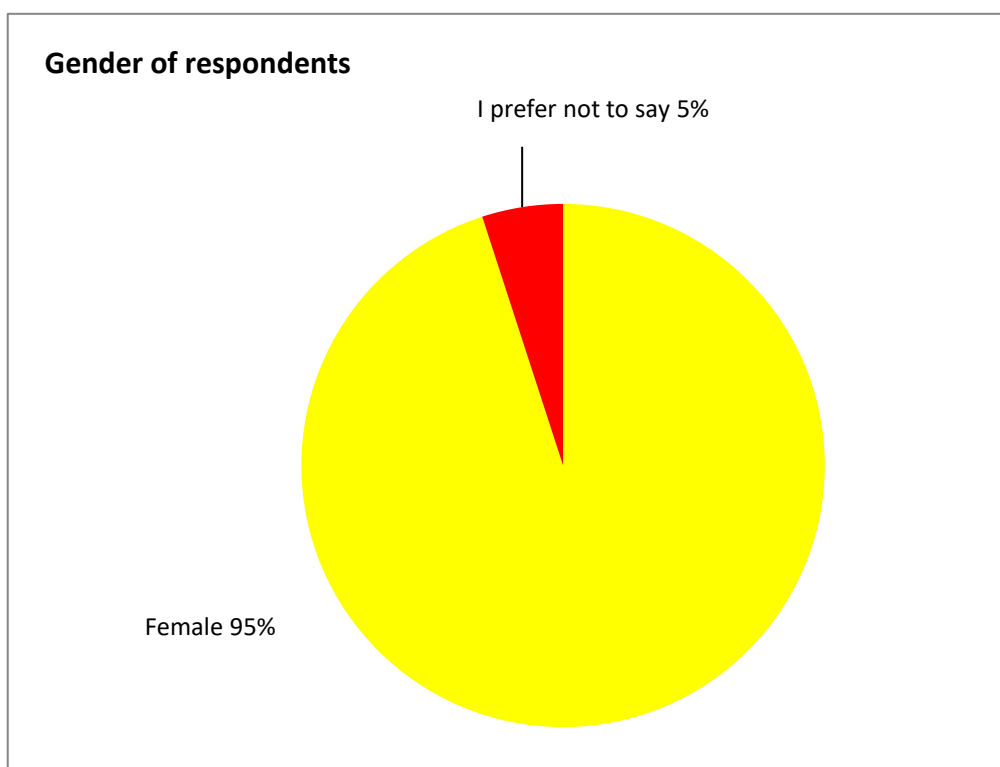
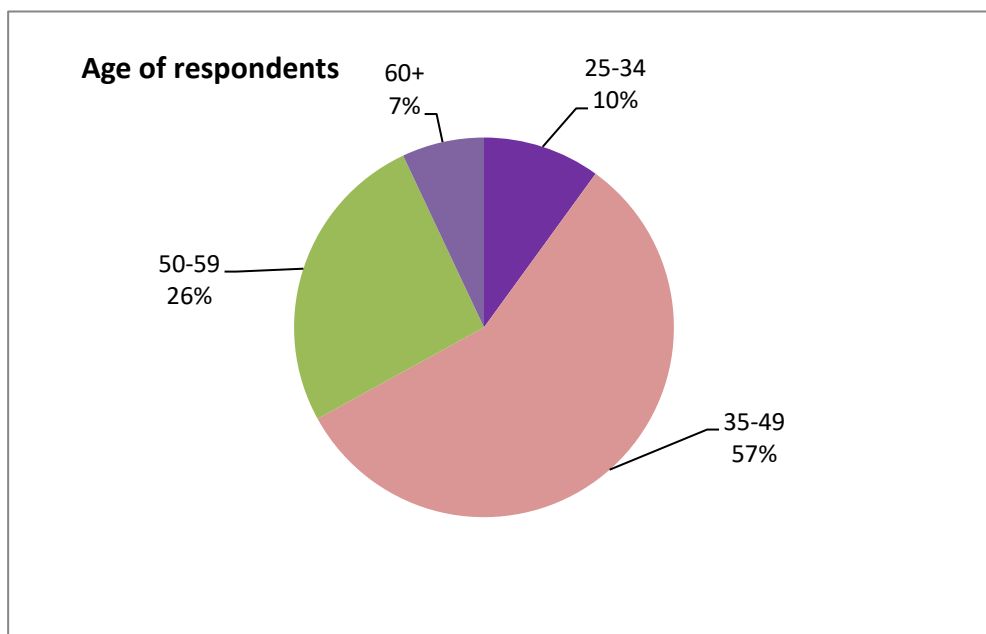
## 3. Methodology

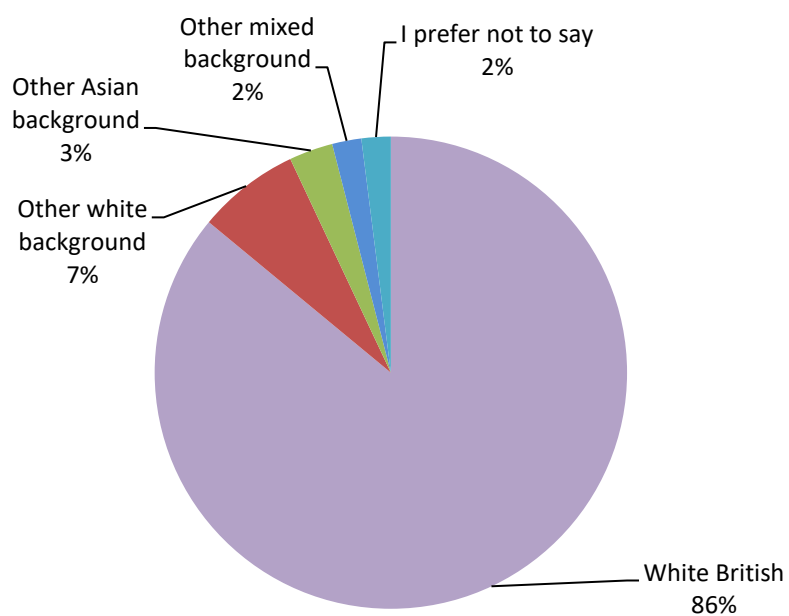
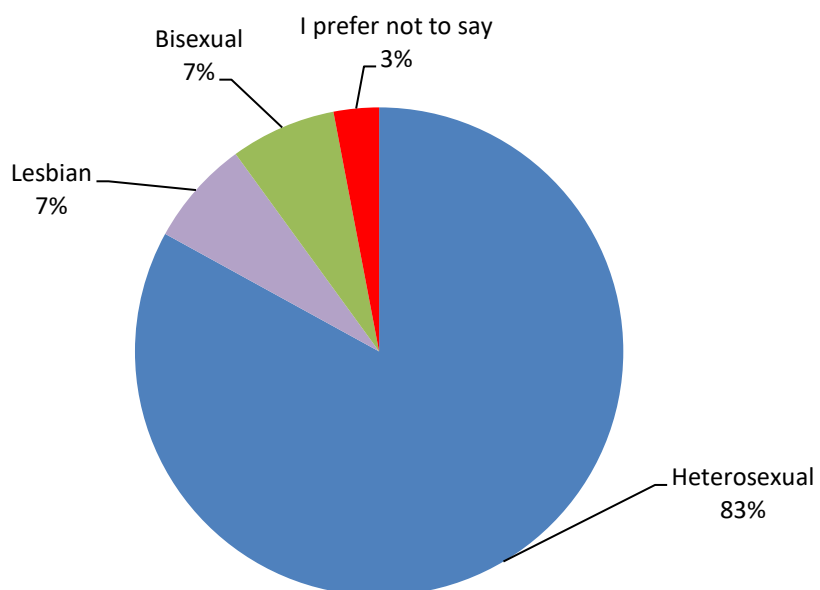
To gather data and information for this consultation we used an online questionnaire that was planned and designed with support from Amaze's Database Manager. The questionnaire included a range of questions with 'please select' and 'tick box' options and boxes to provide extra information and comments. The questionnaire was sent to all parent carers in Brighton and Hove on the Compass Database held by Amaze and it was also uploaded onto PaCC and PaCC Partners' social media. We received 45 completed questionnaires summarised into a report – Service Gaps Results ([See Annex 2 servicesgapssurvey](#))

We have extracted data from Compass questionnaire-renewal forms that are sent every three years to all the families on the Compass Database. This data was used to indicate service gaps identified by families at the time they renewed their Compass registration – Compass Brighton & Hove Services Data Report ([See Annex 3 Compass B&H Services Report](#)).

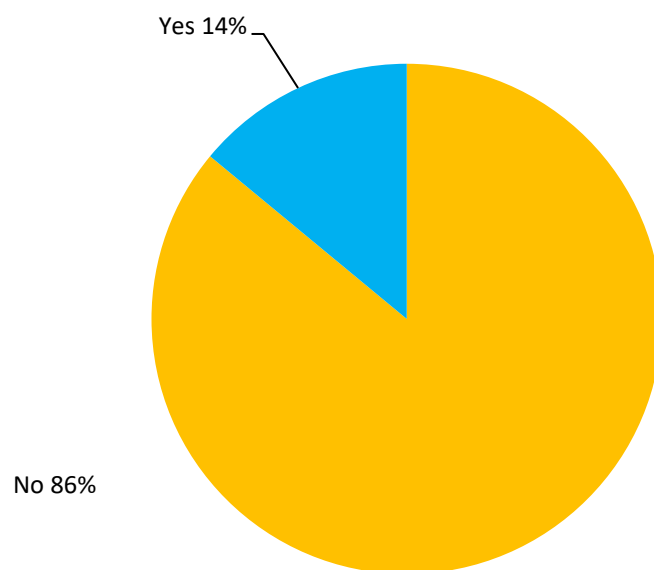
Parent carers' contributions to this consultation are reported in *verbatim* to ensure the detail of their experiences is captured and considered.

#### 4. Demographics from the online questionnaire

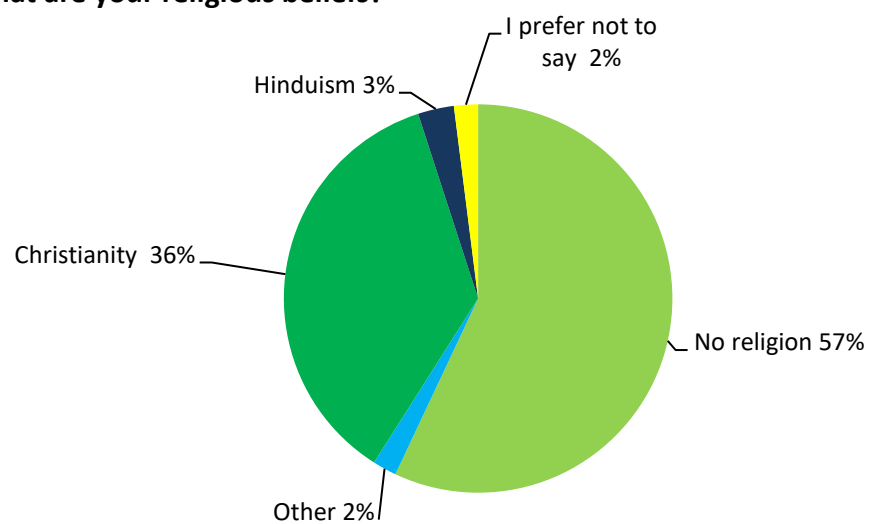


**How would you describe your ethnic origin?****Which of the following best describes your sexual orientation?**

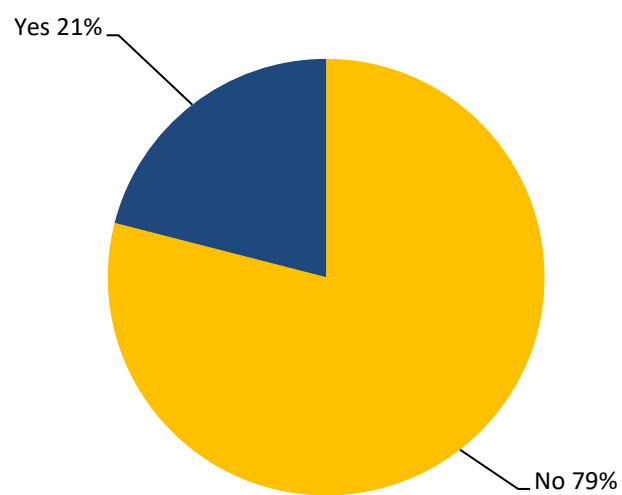
### Do you consider yourself to have a disability?



### What are your religious beliefs?



**Are you the carer of an adult (that is, someone aged 18 or over)?**

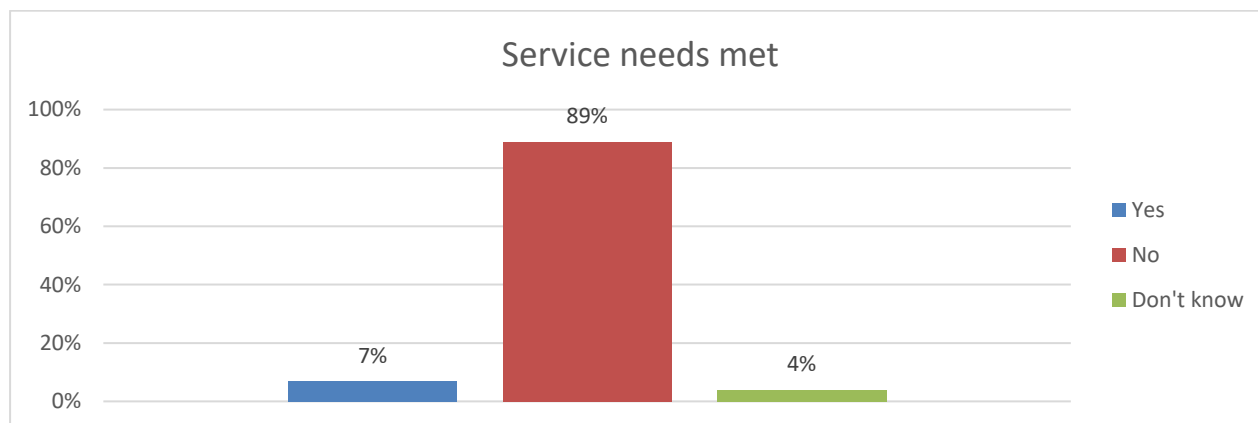




## 6. Findings from online questionnaire

### 6.1 Current service provision

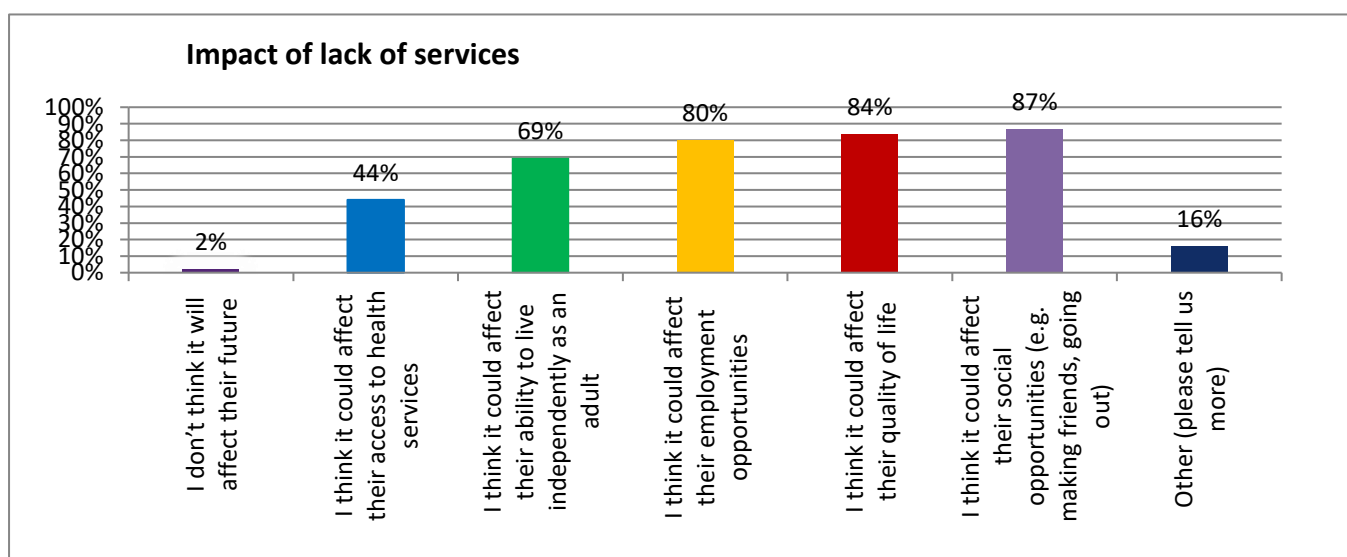
Firstly, we wanted to find out how parent carers felt about current services for their child and/or young person. To the question, *'Do you feel that your child or young person's service needs are fully met?'* - respondents told us:



The majority of parent carers, 89%, who responded to our questionnaire did not feel that services currently provided satisfy their child or young person's needs. Only 7% of respondents felt that services provided are meeting their needs.

### 6.2 Impact of lack of services

Secondly, we wanted to know what parent carers thought about how a lack of services potentially impacts upon their child or young person's future. To the question *'How do you feel that a lack of services might affect your child or young person's future? Please tick all that you think might apply'* – respondents told us:



Under 'Other' parent carers commented that a lack of services risks affecting family wellbeing, mental health and their child or young person's ability to live at home or in the community, and that it could lead to family breakdowns.

A parent commented *'I think it could affect their general progress and getting the right diagnosis'* whilst another stated *'the lack opportunity post 23 is frightening. Everyone seems to be shunted off to Grace Eyre. I personally knew a young person who literally died of boredom without post 19 services – not in Brighton & Hove'*.

One respondent added *'it is much more serious even than the list given'*.

### 6.3 Where the gaps are

Data for this section was collated from the Compass Database questionnaire December 2018 report. The Brighton and Hove Compass Database has currently 2,055 children and young people registered. Services and corresponding gaps are listed in accordance with children and young people's age (0-25 years old, 0-17 and 18-25). The 'red' column indicates percentage of families who don't receive certain services but perceive they need them, the 'green' indicates those who receive them and the 'amber' indicates those who would like to receive more. Only those services where there is perceived to be gap by more than 40% of parent carers are discussed and commented on in this report – Compass Brighton & Hove Services Data Report.



#### 6.3.1 Education 0 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
ASC support	224	42%	257	48%	56	10%	537
Early years support (presens off-site)	37	19%	144	75%	12	6%	193
Educational psychologist	176	33%	315	59%	41	8%	532
Language support	102	24%	277	65%	45	11%	424
Literacy support	139	32%	256	58%	44	10%	439
Sensory needs support	135	41%	173	53%	20	6%	328
Social, emotional and mental health support (previously Behaviour Support Team)	233	52%	186	42%	29	6%	448
Use of special educational equipment at school	95	23%	275	66%	49	12%	419

In the 0-25 year old age range, it was identified that children and/or young people need to be able to access more support services in the areas of social, emotional and mental health (58%) ASC (52%) and sensory needs (47%).

One parent who participated in the online consultation commented – *‘More in school support for autism, more support for children who are school refusing and for parents who are coping with homeschooling because of this, more social clubs for autistic young people who cannot attend school...’*

Another parent suggested – *‘I think educational services need to work more side by side to help children and keep each other informed of problems or things they have noticed regarding the child in question. I think schools and nurseries should have a legal obligation to have a guideline plan in place that is reviewed regularly with both the parents and other services involved. I also think that schools and nurseries should be assessed (separate service to Ofsted) to make sure that they are fulfilling their duties with children that have extra learning needs especially with providing 1 to 1 sessions. All SENCOs should display what training they have had and their qualifications on their website/notice board/information pack and provide clear information about the help they provide regarding children with extra needs.’*

## 6.3.2 Education 0 - 17

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Transport (or transport and escort) to school (0-17)	167	28%	384	65%	41	7%	592
Schools wellbeing service	23	51%	18	40%	4	9%	45

In the 0-17 year old age range, it was identified that a significant number of children and young people's needs are not being met by existing schools wellbeing services (60%).

One parent observed – *'My daughter has been ignored by CAMHS and the education services due to lack of funding. 10 years I've been fighting for a full mental health assessment. She's now 15 and addicted to Xanax with an alcohol problem. She's been held by the police and charged on numerous occasions because she can't manage her emotions. She's going to end up in prison or dead and then I'm going to sue the hell out of Brighton and Hove City Council and the NHS trust. Money is the only thing they understand and I think the community needs to fight back as one and take them to court. Lack of services is ruining generations of lives.'*

Another respondent to our online consultation commented on difficulties around transport – *'SEN transport has unfair rules, such as if a child is sick whilst at school, the parent has to pay for a taxi home; they usually won't collect children from after school clubs; they usually won't transport around medical appointments. Respite care is almost impossible to receive. Due to negative attitudes/detrimental behaviours and autism ignorance in social services, parents can feel averse to asking them for help so therefore don't get respite.'*

### 6.3.3 Education, Training and Employment 18 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Dialogue therapeutic and family services	9	56%	6	38%	1	6%	16
Independent training or apprenticeships (18-25)	30	73%	9	22%	2	5%	41
Other independent info, advice and guidance (18-25)	41	70%	16	27%	2	3%	59
Supported employment team (18-25)	52	80%	11	17%	2	3%	65
Volunteer programme (18-25)	29	80%	5	14%	2	6%	36

In the 18-25 year old age range, a significant need for education, training and employment services for young adults was highlighted.

One parent described – ‘*Since moving to adult services NO support in any area has been offered!*’

Meeting the threshold for some services was also identified as a barrier- ‘*If you don't have an EHCP then you can't seem to access any support. I don't know where to go with my 21 year old. They don't meet the threshold for statutory services and they will not engage with voluntary services and they can't force them to engage due to being voluntary.*’

## 6.3.4 Health 0 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Wellbeing service for children and young people age 4-25	67	69%	26	27%	4	4%	97%
Alternative or complementary therapies	183	54%	123	36%	32	9%	338
Bladder and bowel service	58	36%	94	58%	9	6%	161
Community paediatric nurse	51	18%	213	76%	15	6%	279
Community paediatrician	94	14%	534	79%	48	7%	676
Dietician	57	35%	98	60%	7	5%	162
Family health visitor	38	14%	229	83%	9	3%	276
Hospital paediatrician or consultant (0-17)	39	8%	434	88%	23	4%	496
Hydrotherapy	29	69%	11	26%	2	5%	42
Occupational therapy	209	35%	316	53%	68	12%	593
Physiotherapy	112	26%	275	64%	42	10%	429
Specialist CAMHS at Aldrington Centre	161	28%	352	62%	58	10%	571
Specialist health visitor	44	27%	111	68%	9	5%	164
Speech and language therapy	148	17%	628	71%	112	12%	888
Wheelchair and special seating service	17	12%	110	79%	13	9%	140

In health services for 0-25 year olds, wellbeing services, hydrotherapy and alternative or complementary therapies were identified as the most needed.

*One parent pointed out the long waiting lists for many services – ‘CAMHS’ waiting times are still too long. Young people have to be in crisis before they meet thresholds, by which time schooling, psychological well-being, family relationships are adversely affected. Long waits for Ed Psychs, need to push very, very hard to get access to things that were once far easier to get. It feels like crisis management at times rather than a proper effort to support children to 'achieve their full potential' which is what those with additional needs deserve. Connections between health needs and those who deliver therapies, e.g. TAs could be strengthened. When speech therapy is delivered in schools there needs to be more differentiation between children with different needs, e.g. social language groups tend to put all children in together when they might need different therapies due to different diagnoses. There is a huge gap between primary and secondary which means that ideas that work in primary for inclusion often don't work well in much larger and more anonymous secondary schools’*

*One parent fed back on a positive service impact – ‘My young person loves education, has made progress with SALT even though he is 20, and benefits hugely from being with his friends. It is vital that they remain social, with their peers and with opportunity to be properly integrated into the community. Our young people have so much to give and need to be able to show that.’*

*Another reported – ‘Individual speech therapy was stopped 2 years ago. Have a 15 year old with severe learning difficulties who has unclear speech and sentence structuring’*



## 6.3.5 Health 18 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Adult mental health (18-25)	51	43%	60	50%	9	7%	120
Community health team	7	32%	11	50%	4	18%	22
Hospital consultant or specialist (18-25)	5	6%	76	84%	9	10%	90
Physical disability service (18-25)	1	11%	7	78%	1	11%	9
Sexual health services (18-25)	8	33%	14	58%	2	8%	24
Substance misuse services (18-25)	4	40%	5	50%	1	10%	10
TAPA - supporting young people aged 14 - 25 with emotional wellbeing (18-25)	30	93%	2	6%	1	1%	32

In 18-25 year olds, more support around emotional wellbeing was highlighted by 94% of Compass respondents.

## 6.3.6 Social care 0 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Adaptations or special equipment	73	32%	130	58%	22	10%	225
Children's disability service social worker	72	31%	145	63%	14	6%	231
Children's disability team outreach	60	65%	29	31%	3	4%	92
Community family worker	56	46%	54	45%	11	9%	121
Direct payments or personal budgets	118	36%	190	58%	21	6%	329
Family coach (integrated team for families)	35	41%	47	55%	4	4%	86
Family support worker	37	42%	50	57%	1	1%	88
Foster placement	2	8%	19	76%	4	16%	25
Help or advice (including financial)	105	73%	28	19%	11	8%	144
Link plus	22	45%	24	49%	3	6%	49
Other social worker	15	11%	112	83%	8	6%	135
Residential short breaks	157	77%	36	18%	10	5%	203
Sensory services team (sensory loss)	85	67%	40	31%	3	2%	128
Belltree music therapy	32	80%	7	18%	1	2%	40

In social care for 0-25 year olds, many parent carers identified needs for more outreach from the children disability team (69%), more help and advice, including financial advice (81%), support from sensory services team (69%) and music therapy (82%). 82% of parent carers identified a need for more respite / residential short breaks. One parent observes - *The lack of periodic overnight respite is putting great strain on parents' health & well-being. I have not received any overnight respite for over a year and can feel the negative effects of this on a daily basis. I think of placing my child into care more frequently now as I am totally exhausted and wonder how long I can continue. I suffer with anxiety and panic attacks now - it's a huge worry.*

### 6.3.7 Social care 0 - 17

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Transport (not to and from school) (0-17)	40	63%	21	33%	2	3%	63

In social care for 0-17 year olds, the need for more transport for children and/or young people was underlined by many parents (66%).

### 6.3.8 Social care and Housing Support 18 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Adult social care social worker (18-25)	30	29%	64	61%	11	10%	105
Community learning disabilities team social worker (18-25)	19	32%	37	62%	4	6%	60
Community support (18-25)	17	37%	25	54%	4	9%	46
Support through care team (previously 16+ support) (18-25)	16	61%	9	35%	1	4%	26
Learning disability service (18-25)	26	46%	26	46%	5	8%	57
Residential care (18-25)	4	21%	12	63%	3	16%	19
Transport including college/day centre (18-25)	24	24%	67	66%	10	10%	101
Support to live in own flat (18-25)	29	78%	7	19%	1	3%	37
Supported living (18-25)	17	34%	28	56%	5	10%	50

Shared lives (18-25)                      9 43%                      10 48%                      2 9%                      21

For 18-25 year olds, social care and housing support needs were identified as being more support from the care team (65%) and for young adults to live independently (81%).

### 6.3.9 Voluntary Organisations and Other Services 0 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
After school playschemes	203	60%	105	31%	33	9%	341
Amaze	185	15%	1013	80%	69	5%	1,267
Blue badge	185	41%	261	57%	10	2%	456
Childminder	78	68%	28	25%	8	7%	114
Counselling	135	51%	110	42%	18	7%	263
Crossroads	33	63%	17	33%	2	4%	52
Holiday playschemes	287	68%	111	27%	18	4%	416
Leisure and sporting clubs	357	71%	115	23%	31	6%	503
National or local support groups	167	60%	98	35%	11	5%	276
Triangle	56	81%	11	16%	2	3%	69
Social clubs or groups	62	57%	39	35%	9	8%	110

In other services outside education, health and social care, in the 0-25 year old age range, provision of after-school activities were identified as being needed (69%), as well as leisure and sporting clubs (77%), and social clubs or groups (65%).

One parent commented – ‘I would like to say how dismal afterschool & holiday club provision is for teenagers with learning difficulties. Woodys are good but are only able to offer about 5 days each summer holiday. Not only is it bad for these kids but it also impacts significantly on my ability to work. Direct payments do not extend to being able to pay a PA at £10.80 an hour for a full day for a large number of days over the holidays or after school. A woeful situation really.’

One parent suggested that more activities should be provided by statutory services – ‘I am fairly satisfied that our child's needs are met but much of this is through third sector provision like Whoopsadaisy and things we pay for. I think there should be more support from statutory services for these provisions and help for families who aren't in a position to access them as we are; signposting, financial help, support to problem solve how to get to these services.’

Some parents would also like siblings to be able to access more services – ‘I also think there is a gap with services for siblings. I think they can be affected a lot and there should be more support and understanding.’

### 6.3.10 Voluntary Organisations and Other Services 18 - 25

Service	Needed but not receiving	Percentage	Receiving	Percentage	Receiving but more needed	Percentage	Total families
Possability people (18-25)	21	40%	29	56%	2	4%	52
Other national or local charity	17	44%	21	54%	1	2%	39
Carers centre (18-25)	12	52%	11	48%	0	0%	23

In the 18-25 year old age range, some parent carers (52%) specified they would like more support from the Carers Centre.

‘My son should receive respite care once a month but hasn't for the last year because there are no carers available. Too many children are under social services care are only seen by a duty social worker, who does not know their case. Social workers are also now not obliged to attend ECHP meetings, even though their written input is essential, especially at age 16 transfers. Referrals to access Seaside

*view, CAMHS etc. used to be through the school or self-referral, now have been told (and other parents) that your GP will have to refer but most children with Autism, learning disorders, SALT problems do not see their GP for their conditions, this also is a problem with changing from DLA to PIP (or whatever). It's always been you have to fight for your child but now the fight is for things that are barely there. This is going to have a knock on detrimental effect on young adults' safety, mental health, housing, quality of work and life. We all know this but there is a tendency for services to shrug their combined shoulders and say the funding has been cut we can't do anything and that's just not good enough. Not to sound dramatic but in the end it will lead to the deaths of some young, vulnerable people in our local authority. I just pray I stay alive long enough so that it doesn't happen to my boy.'*

## **Recommendations:**

- I. BHCC and B&H CCG to map out provision of education, health and social care services to better understand and address perceived gaps in provision
- II. B&H Parent Carers' Council (PaCC) to work closely with BHCC and B&H CCG to ensure the perceived gaps in SEND services are reflected on and addressed in the SEND Strategy 2019-2022
- III. PaCC Parent Reps who sit on relevant Boards and strategic groups to take forward suggestions and recommendations from this consultation, e.g. for the Wellbeing Board to tackle shortage of wellbeing services
- IV. Amaze to continue to look for opportunities to respond to gaps in services and help ensure that families' needs and aspirations are met
- V. Amaze to continue to promote leisure activities and sporting clubs through the weekly Compass ebulletin and on the Compass website
- VI. Brighton & Hove SEND Employability Steering Group to develop a clear strategy around access to training and employment for young people with SEND
- VII. Amaze and PaCC to ensure referral pathways into Carers' Centre are clear and working well, for young people age 25+ and their families who are able to benefit from Carers' Centre services

**Annexes:**

Annex 1: Amaze and PaCC Engagement Diagram

Annex 2: servicesgapssurvey

Annex 3: Compass B&H Services Report