

Analysis of the Amaze Parent Carer Questionnaire 2011/12

Introduction

Amaze holds The Compass database of children with disabilities or special needs, on behalf of Brighton and Hove City Council. In order to make the database as useful as possible we ask parents for very detailed information about their children, which we collate and use to inform and lobby commissioners and service delivery managers about what those children need to live as happy and inclusive a life as possible here in Brighton and Hove.

However, as the Compass database is about the children themselves, we haven't previously asked parent carers for information about their caring needs. In autumn 2011 we decided to survey local parent carers to gather some of this information, which we could then use to further inform commissioners and service providers locally about what services and support local families with disabled children need.

We designed an in-depth questionnaire, which we included in the October 2011 edition of Amaze's newsletter, Out of Amaze. This newsletter has a circulation of approximately 4200. We also provided a link on the Amaze website to an online version of the questionnaire, for parents who preferred to complete it electronically.

Who responded?

69 (60.5%) parent carers completed paper questionnaires and a further 45 (39.5%) filled it out online, giving us a total response of 114. We currently have approximately 1300 families registered on The Compass database, so we are hopeful that the 114 respondents represent almost 10% of our survey group. The full results can be found in the Appendix at the end of this report, but the key points are covered below.

We received responses from all of Brighton and Hove's wards apart from Regency and Wish (see Table 1 below), but when we compared the results with The Compass, some wards such as Withdean, Queen's Park and St Peter's & North Laine are over-represented, whereas the more deprived wards of East Brighton and Moulsecoomb & Bevendean are greatly under-represented:

Table 1: Geographical spread of survey results compared with Compass membership

	No. of respondents	% of total	Compass membership
Brunswick and Adelaide	1	0.75%	1.00%
Central Hove	2	1.75%	1.50%
East Brighton	3	2.75%	10.50%
Goldsmid	2	1.75%	3.00%
Hangleton and Knoll	7	6.00%	7.50%
Hanover and Elm Grove	8	7.00%	7.00%
Hollingdean and Stanmer	9	7.75%	6.50%
Hove Park	5	4.25%	3.00%
Moulsecoomb and Bevendean	3	2.75%	12.50%
North Portslade	10	8.75%	7.00%
Outside Brighton and Hove	1	0.75%	5.50%

Patcham	9	7.75%	5.00%
Preston Park	4	3.50%	3.50%
Queen's Park	8	7.00%	3.50%
Regency	0	0.00%	0.50%
Rottingdean Coastal	5	4.25%	2.50%
South Portslade	7	6.00%	5.00%
St Peter's and North Laine	8	7.00%	3.00%
Westbourne	3	2.75%	1.50%
Wish	0	0.00%	2.50%
Withdean	11	9.50%	3.00%
Woodingdean	3	2.75%	5.00%
Unknown	5	5.25%	0.00%
Total	114		

This disparity between the respondents group and Compass membership should be kept in mind when looking at the survey results as we believe that some hard to reach groups, such as more deprived families, will be under-represented.

89.5% of respondents were female and 10.5% male. 8% reported that they have special needs and 3% are registered disabled.

85.5% of respondents described themselves as being White British. This closely follows the local population – 2007 population estimates say that 84% of Brighton and Hove residents are of White British origin (State of the City report, Brighton and Hove City Council 2011), which is also the same as the national average.

We asked respondents about their usage of the Internet. 97.2% reported that they have the Internet at home. According to the Office for National Statistics, 77% of households nationally have home Internet access (Internet Access – Households and Individuals Aug 2011), which may be another indicator that the respondents' group under-represents deprived families.

Who do the respondents care for?

92% of respondents were birth parents of children with disabilities or special needs; 6.5% were adoptive parents and the remaining 1.5% were grandparents or aunts/uncles. 14% reported that they care for more than one child with a disability or special need. This is slightly higher than the 9% of families on The Compass database who have more than one disabled child.

Table 2: Age range of respondents' children with disabilities or special needs

Age of child with disability or special need	No. of respondents	% of total	Compass membership
0-4	10	9.70%	12%
5-10	21	20.40%	30%
11-16	51	49.50%	46%
17-19	17	16.50%	12%
20+	4	3.90%	0%

As seen above, the 5-10 age range is under-represented compared with Compass membership.

Table 3: How respondents describe their child(ren)'s condition or disability

	No. of respondents	% of total
Physical disability	32	23.50%
Learning disability	98	72.00%
Sensory impairment	34	25.00%
Mental health condition	35	27.70%
Long term health condition	23	16.90%
Autism spectrum condition	44	32.40%
Other	21	15.40%

60% of respondents' children with a disability or special need currently have a statement of special educational needs (SENs).

What is the impact of caring for a child with disabilities or special needs?

We asked respondents to calculate how much care they provide over and above a parent carer's usual duties – 57% said that they provided 30 or more extra hours a week and 14% of those felt that they were providing care 24 hours a day, 7 days a week.

Table 4: The kinds of extra support that parent carers provide

	No of respondents	% of total
Extra support/reassurance/confidence building	122	89.70%
Additional help with behaviour	113	83.10%
Additional help with communication	110	80.90%
Additional help with leisure activities	103	75.70%
Personal care	92	67.70%
Extra support with homework	89	65.40%
Additional help with health	63	46.30%
Physical help	40	29.40%

72% of respondents have a partner who lives with them and 63% have supportive friends, family or neighbours living nearby. Even so, 63% of parent carers said that they sometimes feel isolated and 21% feel isolated all the time.

46% of parent carers said that caring has had a negative impact on spousal or romantic relationships and 27% reported that their caring role has been a contributing factor in a relationship breakdown.

43% of parent carers responding to our survey told us they hadn't had a single day off from caring in over 6 months. A staggering 25% say they have never had a day off. This increases to 43% who have never had a weekend off and 70% who have never had a full week's break from caring.

What is the impact on finances, health and wellbeing?

40% of respondents have given up work completely in order to care for their disabled child(ren). A further 32% have had to reduce their work hours and 27% have had to take a less challenging job. Less than 4% of respondents said that their caring role has had no impact on their capacity to work.

When asked how they were coping if they were struggling to make ends meet, 38% of respondents said that they use their bank account overdrafts, 24% use credit cards and 14% have taken out a loan or regularly borrow from friends or family.

30% of parent carers have cut back on heating, 25% have cut back on food and 60% on holidays/leisure/going out. Only 16% of respondents said that they haven't cut back on anything.

76% of respondents have experienced mental ill-health as a result of their caring role and 65% have suffered physical ill-health or injury. Only 29% of parent carers said that they usually get a good night's sleep.

What services have families received and how do they rate them?

Table 5: We asked parent carers what council or health services they have received and if so, how they would rate them on a 1-10 scale (10 being brilliant). We also asked if they hadn't received those services, but would like to:

	No. of respondents receiving or have received service	% of total	Average score (1-10)	No. of respondents wanting to get service
Presens	90	79%	7	4
School transport	53	46%	8	11
Learning support	32	28%	7	11
Direct payments	23	20%	8	15
Social worker	30	26%	4	14
Short breaks	9	8%	9	15
Paediatrician	86	75%	7	1
Specialist health visitor	27	24%	7	10
Occupational therapy	51	45%	7	14
Speech and language therapy	76	67%	7	7

CAMHS	54	47%	6	1
Physiotherapy	42	37%	6	2
GP	83	73%	7	1

We also asked parent carers what services they want their child to receive more of. The most popular answers were speech and language (24% of respondents) and occupational therapy (16%). The full list of answers given appears in the Appendix.

When asked which services parent carers would like to receive more of to help them in their caring role, the most popular answer was respite (28% of respondents), followed by information/advice or counselling/therapy (13% for each). The full list of answers given appears in the Appendix.

What other services could Amaze provide for parent carers?

We asked parent carers how they would prefer to receive information from Amaze. A very large proportion, 68%, said that they would prefer to get it by email. This needs to be looked at alongside the fact that 97% of respondents have home Internet, which is 20% higher than the national average, but it does reflect the fact that approximately three-quarters of Compass families receive information from Amaze already by email.

46% of respondents would prefer to receive information from Amaze via telephone, 39% would prefer to receive it at home and 20% would prefer it if they could come into the Amaze office.

We asked parent carers what other services they wish Amaze could provide, in addition to those that we do already. Only 21 respondents (18%) said that there were and they are listed below:

Table 6: Other Amaze services requested by parent carers

	No. of respondents
Education support	4
Transition Workers (more of)	2
Advocacy for Social Services	1
Behaviour management help	1
Counselling	1
Extended helpline hours	1
Help with professionals	1
Housing advice/support	1
Info on suitable groups for their child	1

Intensive interaction course	1
Leisure activities for children	1
Lists of specialists	1
Meetings support	1
More autism-friendly screenings	1
Take my children on holiday for me	1
Workshops on weekends	1
Youth groups list on website	1

How do parent carers feel about social inclusion, life satisfaction and the future?

64% of respondents told us that they do feel that they and their children are made to feel welcome at venues and amenities across Brighton and Hove. However, 20% also reported that they would feel their children were more welcome and included if venue staff, other parents and society in general had a much better understanding of disabilities and special needs.

50% of parent carers said that their child has experienced bullying at some point. This closely follows figures from The Compass database, which show that 48% of the children registered on it have experienced bullying at least once in their lives, either in or out of school.

We asked parent carers to rate their satisfaction with life overall, on a scale of 1-10, with 10 being brilliant. The average answer from respondents was 7 out of 10, and 73% gave a score of 6 or above.

We also asked how parent carers feel about their child(ren)'s future, bearing in mind their special needs. 63% of respondents were concerned or very worried about it, 30% had mixed feelings and 2% said that they couldn't think about it at all. Only 5% of parent carers said that they felt positive about their child's future.

Conclusion

The results detailed in this report are fascinating, but not surprising, and Amaze will be using them to further inform commissioners and service providers locally about what parent carers and their children need. Some of the key points are:

- The number of extra hours per week that parent carers spend looking after their child(ren) with disabilities or special needs is significantly higher than the time spent caring by carers of adults. It is believed that the economic value of the contribution made by carers is approximately £222m in Brighton and Hove alone.
- Less than 4% of parent carers say that their caring role has not affected their work/career in any way. We know that over half of disabled children live in (or on the margins of) poverty

and we know we need to do more to ensure families are receiving all the benefits they are entitled to, or are supported to return to work when they feel this is an option for them.

- Our survey results show that 65% of parent carers responding have suffered physical ill health or injury, and 76% have experienced mental ill-health, as a result of their caring role. Amaze will be feeding this information into the City's Carers' Strategy and to health commissioners to ensure appropriate medical and emotional support and care can be provided to parent carers when needed but more importantly that the necessary services are provided to them and their children at the right time to avoid any costly interventions required later down the line.