



## **1. 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 also need to regularly survey parent carers for information about their caring needs. This ensures that Amaze continues to be able to 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 posted to every family in Brighton and Hove with a child registered on the Compass database (a total of 1275 families). We also provided a link on the Amaze website to an online version of the questionnaire, for parents who preferred to complete it electronically, and in addition we emailed a direct link to the online version to all of the Compass parents on our ebulletin list (800 in total).

## **2. Focus for the questions**

The last Amaze parent carer questionnaire was carried out in autumn 2011. In the intervening years there have been numerous changes nationally and locally to areas such as health, education and the benefits system and whilst we asked one question to assess the demand for social care personal budgets, we didn't feel it was the right time to ask all parent carers about their views on the pathfinder and incoming changes like the new Education, Health and Care Plans.

Our main focus was to consider the impact of caring for a child with disabilities on the carer themselves – including the carer's **mental health** and feelings of depression or isolation. During spring 2013, the Department for Health (DoH) issued a national Carers Survey for local authorities to use locally with their carers of adults (18+) population (Brighton and Hove's is called the 'Caring for Others Survey'). Amaze continues to make the case that the needs and voice of parent carers should not be forgotten when devising our local Carers' Strategy and services for carers and we secured some funding from the local authority to design and evaluate our second parent carers' questionnaire using many of the same questions as the DoH one for carers of adults. We have compared some of our results with those from the 'Caring for Others Survey' as many of the needs of parent carers are the same as those caring for adults, but some needs are specific/different too and need to be recognised as such.

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Parent carers frequently report that the adequate provision of good quality **short breaks/respice** is one of the most important factors in them being able to cope. Given we know the pressures on local authority funding for 2014 are going to be considerable, we wanted to find out how many families were reliant on these services and what the impact may be of any reduction in them, so this was our secondary focus.

### **3. So Who Responded?**

255 (75%) parent carers completed paper questionnaires and a further 86 (25%) filled it out online, giving us a total **response group of 341** (up from 113 respondents in 2011). As we sent the questionnaire to 1275 Compass parents, we are confident that the 341 respondents represent at least 26% of our survey group.

We received responses from all of Brighton and Hove's wards (see Table 1 below).

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

	No. of respondents	% of total respondents	Compass membership
Brunswick and Adelaide	8	2.3%	1.2%
Central Hove	7	2.1%	1.3%
East Brighton	20	5.9%	11.7%
Goldsmid	9	2.6%	2.7%
Hangleton and Knoll	22	6.5%	8.1%
Hanover and Elm Grove	22	6.5%	6.0%
Hollingdean and Stanmer	21	6.2%	6.5%
Hove Park	9	2.6%	3.7%
Moulsecoomb and Bevendean	27	7.9%	11.5%
North Portslade	22	6.5%	7.3%
Outside Brighton and Hove	10	2.9%	4.6%
Patcham	24	7.0%	4.5%
Preston Park	14	4.1%	3.4%
Queen's Park	10	2.9%	3.7%
Regency	2	0.6%	0.9%
Rottingdean Coastal	13	3.8%	3.1%
South Portslade	20	5.9%	4.9%
St Peter's and North Laine	13	3.8%	2.2%
Westbourne	6	1.7%	1.9%
Wish	12	3.5%	2.5%
Withdean	16	4.7%	3.4%
Woodingdean	12	3.5%	4.9%
Unknown	22	6.5%	0.0%

Most of the city's wards are well represented in the respondents group, although slightly less so for the two most deprived wards in Brighton and Hove: Moulsecoomb & Bevendean and East Brighton (highlighted in yellow above). These two areas are slightly under-represented

with a total of 14% of the respondents group, compared with 23% of the Compass membership.

Although this does indicate that we still need to do more to reach these two parts of the city when surveying parents, the results are still far better than for the previous questionnaire in 2011, when only 5.5% of respondents came from these areas, so we are confident that we are increasing our reach in those wards. However, this disparity between the respondents group and Compass membership should be kept in mind when looking at the survey results.

90% of respondents were female and 9% male. **18% reported that they have disabilities or additional needs and 7% are registered disabled.**

93% of respondents described themselves as being white – a group which would include white British, Irish, Traveller of Irish Heritage, Gypsy/Roma and any other white background. We think that this is slightly higher than the local population as the Census 2011 states that 89% of Brighton and Hove residents are of white origin (Census 2011 Briefing on Equalities, Brighton and Hove City Council 2013).

This indicates that parents from BAME (Black, Asian or Minority Ethnic) groups may be slightly under-represented in the respondents group. Only 2% of respondents reported that they don't speak English fluently, but according to the Census 2011, English is not the first or preferred language for 8% of Brighton and Hove residents, so some parent carers may have faced a language barrier when given our questionnaire and not completed it as a result. We should seek funding to translate any future questionnaires into the top community languages.

#### **4. Who do the respondents care for?**

The 341 respondents care for a total of 407 children with disabilities or special needs. **11% of those children are fostered or adopted**, which is higher than we were expecting.

**16% of parent carers reported that they care for more than one child with a disability or special need.** This figure is more than double that of families with more than one child registered on the Compass database (7%), but we don't know how many of the respondents' children with disabilities would be eligible for Compass membership so we can't make a direct comparison between the two figures.

**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	58	14.3%	12.7%
5-10	120	29.5%	30.3%
11-16	163	40.0%	45.9%
17-19	49	12.0%	11.1%
20+	16	3.9%	0%
Age not given	1	0.2%	0%

As seen above, the age ranges fairly reflect that of the Compass membership, apart from those aged 20 or over, who wouldn't be eligible for Compass registration.

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**Table 3: How respondents describe their child(ren)'s condition or disability** (note: parents could select more than one descriptor)

	No. of respondents	% of total
Learning disability	253	62.2%
Autism spectrum condition	155	38.1%
Physical disability	108	26.5%
Mental health condition	106	26.0%
Sensory impairment	100	24.6%
Long term health condition	95	23.3%
Other disability/special need	109	26.8%

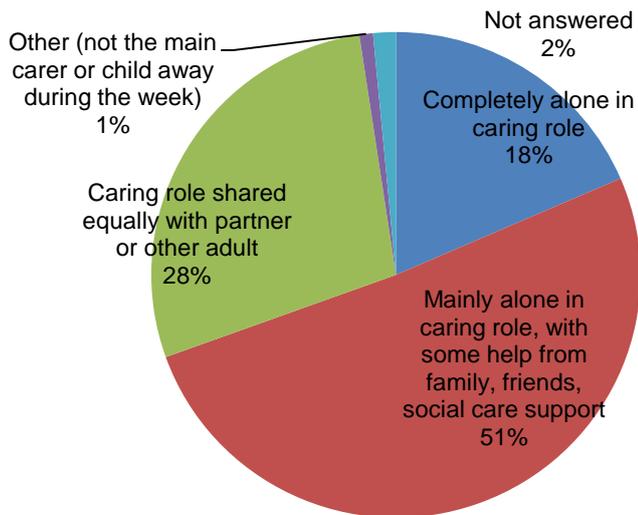
### **4. The Caring Role**

We asked respondents to calculate how much care they provide over and above a parent carer's usual duties. Answers varied considerably - **66% said that they provided 20 or more extra hours a week and 15% said that it was 100 or more hours.** Parents reported this is difficult to quantify, particularly if they don't have other non-disabled children to compare with. A higher number caring for adults (from 'Caring for Others') said they spent more than 100 hours per week caring - 36% - a likely reflection that children with disabilities are under the care of a school during the 'school-day'.

**Table 4: The kinds of care or support that parent carers provide which is over and above a parent's 'normal duties':**

	No. of respondents	% of total
Reassurance/confidence building	293	85.9%
Help with behavioural issues	271	79.4%
Help with leisure participation	261	76.5%
Help with personal care	256	75.1%
Help with communication skills	250	73.3%
Support/guidance with homework	237	69.5%
Help with health matters	163	47.8%
Physical help	105	30.8%

19% of parent carers reported that they care for their disabled child(ren) completely on their own, with no help from anyone else. A further **51% said that they are mainly alone in their caring role**, but with some help from partners, other children, relatives or social care support. Only 28% have an equally shared caring role with a partner or other adult (see Chart 1).



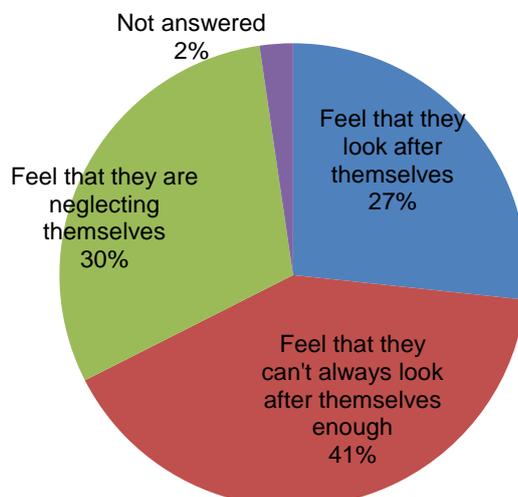
**Chart 1: Do Parent Carers Care Alone Or With Back-Up?**

22% of parent carers responding to our survey told us they hadn't had a single day or even an evening off from caring in over 6 months. **14% have never had an evening off from their caring role.** This increases to 36% who have never had a weekend off and 58% who have never had a full week's break from caring.

**71% of parent carers feel that they don't look after themselves well enough or are in fact neglecting themselves. This increases to 85% if the parent has disabilities or additional needs.** The corresponding figure for carers of adults ('Caring for Others' survey) was 42%.

27% of parent carers felt they had enough time to look after themselves, compared to 58% of carers of adults, and we think the reasons for this should be further investigated but we know that parent carers feel overwhelmed with the needs of their child(ren)/siblings/partner/household etc such that their own needs fall off the bottom of the list.

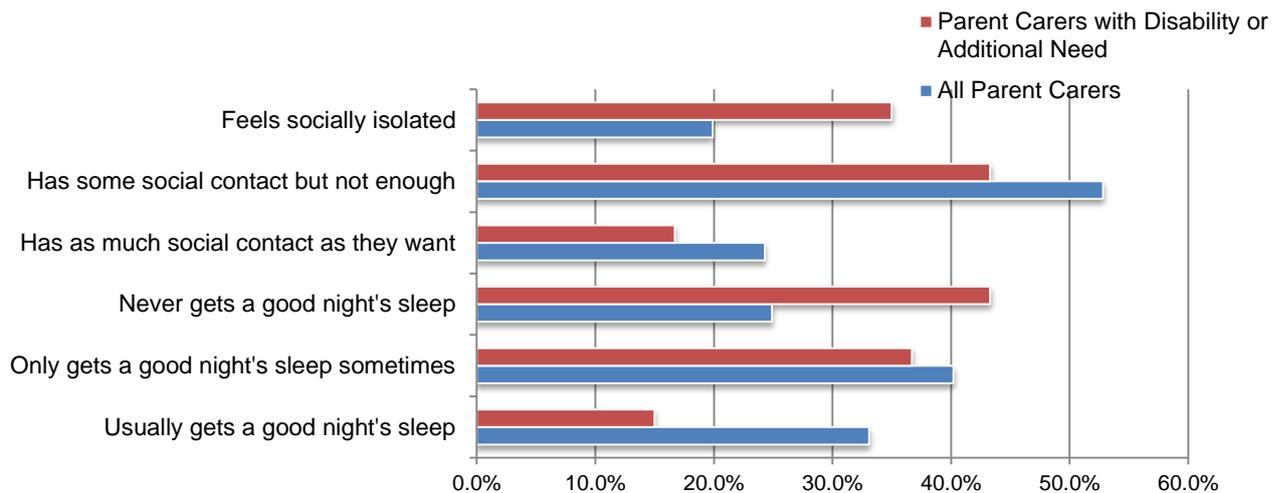
**Chart 2: Do Parent Carers Look After Themselves?**



**86% of parent carers spend none, or not enough, of their time doing things they value and enjoy. 20% feel socially isolated and this increases to 35% if the parent carer has disabilities or additional needs.** A further 53% of parent carers don't get enough social contact.

**Only 33% of parent carers usually get a good night's sleep, and this drops to 15% if the parent carer has disabilities or additional needs.**

**Chart 3: Social Contact and Sleeping**



Given these results, it isn't surprising that **58% of parent carers feel depressed, anxious or stressed some of the time and a further 18% feel that way all or most of the time - this last figure rises to 42% if the parent carer has a disability or additional need.**

### **5. Balancing the Caring Role with Paid Work**

48% of parent carers are looking after the home and family full time. 47% of parent carers work either full or part time, in addition to their caring role.

**38% of respondents said that they can't be in paid work because of their caring responsibilities and a further 22% have had to reduce their work hours.**

### **6. Getting Support for their Caring Role**

We asked parent carers if their needs had ever been formally discussed in the form of a Carer's Assessment. **85% of parent carers said they haven't ever been offered a Carer's Assessment** but Seaside View Child Development Centre in Brighton have explained these are always carried out as part of a family's integrated assessment. 8.2% said they had received a Carer's Assessment but only half of those had been within the last 12 months. This would tend to indicate that parent carers aren't aware of having their needs assessed and this may need to be better communicated by staff at Seaside View.

**Only 53% of those parents who are aware of having been offered a carers assessment currently receive respite.** We would like to get a better understanding of what support services can be accessed by parent carers after an integrated assessment to support the carer's own needs e.g. counselling, respite etc.

**Only 15% of parent carers currently receive any support with respite or short breaks** and a further 24% feel that they need to. A further 5% of parent carers have received respite in the past.

The 15% (50 parents) survey sample receiving respite is proportionate with the total actual figure for parent carers receiving respite in Brighton and Hove, which is currently 395.

**We would like to know how many parent carers apply for short breaks and are turned down and what the current waiting list time is to access each short break provider.**

**17% of parent carers are currently on medication prescribed by their doctor and 15% say that they need, but don't receive, counselling.** We have been told that the average waiting time for counselling at Seaside View is 3-4 months. They are planning to hold a multi-agency meeting soon to collectively look at counselling services. **Again we would like to know how many parent carers self-refer/are referred for counselling but are turned down/signposted elsewhere.** We do know that Brighton and Hove have increased service capacity for parent carer counselling and have also developed mindfulness courses and parent support via CAMHS. Parent carers can also access counselling via their GP's wellbeing service. Amaze is planning to promote these opportunities in our October newsletter and to continue to identify levels of unmet needs for counselling.

**Only 19% of parent carers said they attended a parent support group.** Given how helpful many parents find peer-to-peer parent support, and that 12% of respondents said that they don't currently receive this but would like to, Amaze would like to do some more work to promote the parent support groups available in each area and ask families how these could be more accessible.

Of those parent carers currently receiving support with respite/short breaks, **50% feel that they weren't offered a range of options and 30% have seen their respite package change significantly in the last year.**

Three parents reported that their package had been reduced, and two reported that it had been removed altogether. Those parents' comments in full are:

'All short breaks/respite has been stopped'

'Hours reduced'

'Reduced'

'Stopped'

'Reduced – transition'

However, the local authority states that no respite packages have been reduced this year, and the number of short breaks hours provided has remained constant, so we need to investigate why some **families perceive that they are receiving less.** There is clearly still an overwhelming demand for **more** short breaks from the families responding to our survey. When asked how they feel about their current respite package, only 28% of parent carers

are happy with the level of support they receive. 26% feel that their package isn't enough and a further 18% just about manage with theirs.

**58% of parent carers receiving respite/short breaks would like more choice or control over what respite they receive and 40% would be interested in managing a personal budget and direct payments in the next 1-2 years.**

**If their respite was reduced in the future, 82% of parent carers say that it would have a significant or devastating impact on their family.**

### **7. What Do Parent Carers Need More Of?**

We asked parent carers to imagine receiving more financial support for respite, in the form of direct payments, and to think about what they would spend them on. A staggering **99% reported that they would like more leisure activities or outings for their children** and for the whole family. Amaze is working hard to develop the Compass Card offers and inclusive activities but even with more options available there are still barriers to access e.g. affordable/accessible transport, need for independent travel training and buddies/befrienders to accompany young people, cost etc.

**23% would like to use any increase in financial support to pay for Befrienders** who could accompany their children to activities. This service, historically provided by the Children's Society locally, is closing in September and parents want to know how it can be replaced in the long-term. The local authority has used the funding that was previously allocated to this service to ensure that all families who are currently receiving it will have it replaced with something similar, e.g. Outreach or Cherish, at least up to the end of March 2014. But Amaze is keen to understand how new families who could previously have been offered befriending will be offered this or if this will be a real reduction in service.

**35% also reported that they would like more Extratime after-school and holiday clubs.** Extratime has had to reduce packages for families for the summer holidays 2013 as they are so over-subscribed. Extratime report that the majority of children/young people coming to the playschemes now need 1:1 support and the funding structure assumes more of a mix. So each child that needs 1:1 now gets fewer sessions. They say that the alternative would be to turn away some children completely. Extratime has been given some additional funding to cover the summer period, and they are using it to re-shape and spread services wider.

### **8. Amaze Services**

Finally, we asked parent carers which Amaze services they have used, and if so, how they would rate them on a scale of 1 to 5 (5 being excellent):

**Table 5: Amaze Services**

Amaze Service	% of respondents using service	% of service users who scored service at 4/5 or 5/5 for satisfaction
Compass Card (leisure discount card and targeted mailings)	74.8%	95%
DLA Benefits casework	45.1%	96%
Helpline – generic advice, support, information	43.4%	92%
Website – generic advice, support, information	38.1%	91%
Carers Card* (*not an Amaze-managed service, we only currently develop the offers)	31.4%	82%
Workshops – including Triple P, Insider’s Guide, Looking After You	26.4%	94%
IPS Education casework	13.8%	82%
Transition – information, training and some casework	7.9%	92%

We also asked parents if there are any services that Amaze could provide for parents, but don’t currently. Only 47 parents (13.8%) said that there were other services Amaze could provide, and answers ranged from anger management classes to holiday provision. There was general consensus, however, around the **need to make the helpline more accessible by increasing opening hours**, but parent carers also report that they are unable to get through when the helpline is open so Amaze is going to consider how call-capacity can be improved.

**Parent carers also want more training workshops**, on themes ranging from Makaton to stress management, and for more workshops to be available outside office hours.

### **9. Summary of learning points and next steps**

Although we have increased the proportion of respondents from the most deprived areas of Brighton and Hove (compared with the previous questionnaire in 2011), we need to do more to reach ‘seldom-heard’ groups of parent carers.

We also need to seek funding to ensure that future parent carer questionnaires can be translated into the main community languages in the city, so that we can reach more parent carers from the BAME community.

We would like to get a better understanding of which parent carers are routinely offered a carers assessment and what support services this can lead to.

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We would like to know how many parent carers apply for short breaks and are turned down and what the current waiting list time is to access each short break provider.

We would like to know how many parent carers apply to receive counselling and are turned down and what the current waiting list time is to access it.

Amaze would like to do some more work to promote the parent support groups available in each area and ask families how these could be more accessible.

We would like to make the Amaze helpline more accessible to parent carers and we will be exploring the best ways of doing this. We would also like to be able to offer more workshops outside of normal office hours, and will be trialling this later in the year.