

## Survey of the Information Needs of Parent Carers

### Independent report from Jim Simpson for Amaze & Reaching Families

March 2016

#### **Executive Summary:**

- ) Amaze and Reaching Families surveyed 275 families - involving 323 children with additional needs - across West Sussex and Brighton and Hove asking them about their information needs and more general, related needs and situations.
- ) Testimony from parent carers repeatedly demonstrates the need for good quality and easily accessible information and training. Access to both is essential to supporting the child with the additional need and the family.
- ) Respondents were asked about many areas of information and knowledge and whether they either a) 'already have good information' or b) 'they really need good information'. They had a 'not applicable to me' option as well.
- ) Thanks to a number of agencies working to provide information in both areas, parent carers already have good information in some areas such as 75% of parents having good information about their child's condition.
- ) Despite all current efforts and provision parent carers report continuing needs for more/better information in many areas especially<sup>1</sup>:
  - a. Supporting my child's confidence and self-esteem - 62% in both areas ; supporting my child's emotional well-being - 62% in both areas
  - b. Handling stress and building resistance - 67% West Sx., 54% B&H
  - c. Short breaks and respite - 60% West Sx.; 42% B&H
  - d. Transition to secondary school/FE - 52% West Sx., 50% B&H
  - e. EHC Assessments and Plans - 66% West Sx., 43% B&H

Information needs and demands were reported to be greater in West Sussex than in Brighton and Hove.

- ) Parent carers build their caring and support capacity in a number of ways – these include personal learning and research, mutual and peer support, training, social networks and through the advice of outside experts and support people. The need for good quality information services underpins the success of all these activities.
- ) Information provided by the two main information providers – Amaze and Reaching Families is well used and appreciated with comments like these commonly made about both organisations.

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<sup>1</sup> These are highlighted examples of need. The full 11 page report gives more detail and analysis of need and demand

*“Reading the guide (Making Sense of It All) is like having someone talk me through what I need to know rather than having to look for each topic elsewhere. Fantastic thank you!”*

*“They were a life saver when I first found out about them following my son’s diagnosis. I have contacted them regarding a multitude of different topics and have always been given excellent advice. As a parent I feel empowered to manage all aspects of my son's condition, thanks to the support I have received from Amaze.”*

- ) Parent carers in both West Sussex and Brighton and Hove most liked to use website information, handbooks, the helpline (in Brighton only) and factsheets to get their information.
- ) Parent carers need information to support them in their parenting role; with the development of their child; accessing external support services; and with accessing information about financial support and access to leisure opportunities.
- ) Parent carers get informed and learn in different ways – updating, improving and developing different ways of channelling information and knowledge is important.
- ) Information needs are ongoing and these needs vary with the age and stage of the child involved; the additional needs of the child; specific support needs; and the learning and development of the parent carers and families involved.
- ) Parent carers require information and support that is both general to additional needs and very specific to their child’s needs, condition, age and stage.
- ) Typically there continues to be peak moments of need for information and support throughout a parent carer’s caring journey. Key points include: the stages of formal assessment of need/condition/development; diagnosis (of the child’s condition); school starting; school finishing; and transition to adult age.
- ) Having good information does not equal being satisfied with the broad suite of services available. For instance parent carers generally know about school-based speech and language therapy but that doesn’t mean they are satisfied with the service (in West Sussex).

## 1. Introduction

This report details findings from a survey carried out in West Sussex and Brighton & Hove amongst parent carers of disabled children and children with additional needs and long-term conditions. The survey was thorough and gives very useful data on needs, preferences and use of services. It does not measure depth or intensity of view or need as a survey often does not. The survey was jointly run by Amaze and Reaching Families as they both provide various support, information, training and self help activities for parent carers in, respectively, Brighton and Hove and West Sussex. The survey is part of a process of improving information and other support to families by joint working in the two areas. For instance this survey will inform the development of a new and updated range of factsheets being co-produced by Reaching Families and Amaze.

## 2. Research Sample and Methodology

An online survey was developed by Amaze and Reaching Families and was distributed in Brighton and Hove via Amaze's mailing list and in West Sussex via Reaching Families' mailing list, the Short Breaks for Disabled Children (WSDC) mailing list and via parent support groups on Facebook.

Prizes were offered as an incentive to parents completing the survey. In total 275 respondents completed the survey from the two areas. This is fairly substantial especially in view of the survey being relatively long. Below was the split across the two areas:

West Sussex:	157 respondents, 57% of the total
Brighton and Hove:	118 respondents, 43% of the total
<b>Total families:</b>	<b>275 respondents</b>
<b>Total children with additional needs:</b>	<b>323*</b>

\*some families have more than one child with additional needs

In the results reported below the higher frequencies of response are emphasised with grey shading. These higher numbers show a higher incidence of need. This does not mean lower numbers should be ignored and in some cases the meeting of needs amongst these areas may be very impactful. For instance, the data shows about 1 in 4 parents needing better information on their child's condition. Though this is a lower scoring area information about 'my child's condition' will still be a very important need for this smaller group of 1 in 4. 59% of parents said they had needed more information on their child's condition at the moment of diagnosis. This illustrates the point that it is best not to read too much into one statistic on its own, but the range of data should be read together.

It should be noted that as Amaze and Reaching Families sent the on line survey to all families known to, or in touch with, them, so respondents will invariably be families already in receipt of a service(s) provided by them and are also parent carers who are IT literate and happy to complete surveys on line. These factors need to be taken into account when looking at the answers below.

### 3. Profile of respondents

Most families have one child with additional needs 88% BH 83% WSX. The remainder have 2 or more children with additional needs. There are some differences as regards the ages of the children represented.

a) Age range of children with additional needs	BH		WSX	
Under 5	10	7.5%	19	10.0%
5 to 10 years	41	30.8%	107	56.3%
11 to 16 years	52	39.1%	48	25.3%
17 to 19 years	14	10.5%	6	3.2%
20 to 25 years	13	9.8%	4	2.1%

Age variation is not necessarily due to the whole population but other factors. For instance Reaching Families has met demand more from parents in the early stages. Amaze has been established much longer and works with parents of children in the older age categories too, approaching transition into secondary school years and those entering adult life.

Children have many kinds of additional needs. Again the differences in areas of need are explained by higher demands and needs of the particular families that the two organisations support and other factors other than the make-up of the whole population:

b) What kind of additional needs do the children have?	BH		WSX	
Learning difficulty	71	53.4%	79	41.6%
Autistic spectrum condition	54	40.6%	104	54.7%
Physical disability	24	18.0%	35	18.4%
Sensory difficulty	45	33.8%	74	38.9%
Behavioural or emotional difficulties	60	45.1%	84	44.2%

In many cases children had a number of additional needs such as sensory and physical disabilities or behavioural/emotional difficulties and ASCs. The statistics above record all the additional needs reported by parent carers (i.e. a child can have multiple needs). Both organisations have experienced a steep increase in needs and demands for services from parent carers of children with an ASC plus more need for support with behavioural and emotional difficulties, which is being reporting as increasingly more challenging. . For instance increasingly parents are requiring help with managing extreme behaviour more routinely and they need to learn things like restraint techniques and other means of control and behaviour management.

#### 4. Information needs

Parents were asked to rate their information needs under various categories as either 'I **already have** good information on this' or 'I **really need** good information on this'. They could also opt for a 'not applicable to me'.

From talking to parents it is reasonable to assume that in many cases a significant support need beyond only 'information' will apply in the majority of cases and will include support, advice and training. For instance information will be part of the need in the area of 'strategies to help my child at home' or 'meeting other parents in a similar situation'.

The results demonstrate significant differences on the scale of need between different categories as well as differences between the two geographical areas:

a) <b>Diagnosis and my child's condition:</b>	I <b>already have</b> good info on this		I <b>really need</b> good info on this	
	BH	WSX	BH	WSX
My child's specific condition	75.4%	74.50%	22.9%	26.1%
Relevant local services to help with my child's condition	57.6%	47.80%	39.0%	52.9%
Strategies to help my child at home	56.8%	45.20%	36.4%	55.4%
Coming to terms with my child's condition	59.3%	53.50%	24.6%	30.6%
Meeting other parents in a similar situation	51.7%	54.80%	38.1%	37.6%
Managing healthcare appointments and hospital Admission	61.0%	56.70%	15.3%	21.7%
(Note: not applicable choices are not included in the above)				

Hard facts and information on children's conditions is felt to be available to 75% of parents in both areas. This still leaves a quarter of parents needing more information. This does not reflect parent's experience of access to information when their child was diagnosed. This does not measure severity of conditions or additional needs and so this 25% is likely to include parents, carers and children with very high support needs as well as information needs. In both areas the need for information about local services and about strategies to help children at home remains high. Even though high quality information is available in a variety of formats, it is still not enough to meet need. There is a continuous need for information about meeting other parents in similar situations. It is important to recognise that the sample of respondents is likely to include parents already with support networks and possibly fewer parents not yet hooked into the Amaze/Reaching Families networks.

#### b) **Benefits and financial support:**

Information needs regarding Disability Living Allowance, Carers Allowance and tax credits is fairly low but not insignificant with 20% of parent in both areas needing more good information about carers allowance and 23% needing information on tax credits in West Sussex.

In Brighton and Hove a highly successful project on accessing DLA is responsible for 86.4% saying that they 'already have good information on this'. In West Sussex this rate is also fairly high at 77.7%.

	I <b><u>already have</u></b> good info on this		I <b><u>really need</u></b> good info on this	
	BH	WSX	BH	WSX
Work-based benefits	27.1%	21.0%	27.1%	37.6%
Direct Payments	27.1%	28.0%	44.1%	45.9%
Personal Budgets	17.8%	21.7%	44.1%	54.1%
Grants*	11.0%	15.3%	62.7%	72.6%

\*though information on grants is an area of high demand few grants are actually available. Information on direct payments and personal budgets are also areas of high demand/need and both areas should review how provision could be increased here, especially given the new SEND reforms and focus.

The above 4 areas had higher information needs. Also some parents who say that a given area is 'not applicable' to them may well be misinformed and may be missing out on financial entitlements. Elsewhere in evaluation work in West Sussex cases of parents wrongly believing they were not entitled to a benefit were found, as were also families who knew nothing of certain entitlements.

c) Education:	I <b><u>already have</u></b> good info on this		I <b><u>really need</u></b> good info on this	
	BH	WSX	BH	WSX
Choosing childcare	31.4%	27.4%	12.7%	29.3%
Choosing a school	49.2%	52.2%	27.1%	33.1%
Additional support for my child at school	47.5%	43.3%	39.0%	46.5%
Handling school meetings	55.1%	49.0%	33.9%	43.3%
EHC Assessments and Plans	38.1%	28.7%	43.2%	65.6%
Transition to secondary school and/or further education	20.3%	19.1%	50.0%	51.6%
Bullying	23.7%	22.9%	35.6%	43.3%

Information needs about Education topics in West Sussex seem to be greater than in Brighton and Hove - in particular the areas of EHC assessment and plans, choosing childcare and handling school meetings. This may be because respondents in Brighton and Hove may have had previous support from Amaze's IAS/IS service on these topics.

In both areas about half of parents say they need information on transition to secondary school and further education. In several cases some differences are due to a larger scale of support services, and information about them, in Brighton and Hove compared to West Sussex. However even with this in mind Brighton and Hove still has high information needs in the area of education. Concerns about bullying and information about what can be done are at a high level. Again this figure

represents how many parents are concerned about the issue not the scale or level of bullying that is taking place.

#### **d) Supporting my child's development:**

Support needs in both child development and family support are the two areas that show the greatest information and support need.

	<b>I <u>already have</u> good info on this</b>		<b>I <u>really need</u> good info on this</b>	
	BH	WSX	BH	WSX
Support to help my child's speech and communication	45.8%	43.3%	24.6%	36.9%
Support to help my child's confidence and self esteem	32.2%	27.4%	60.2%	63.1%
Support to help my child's emotional wellbeing	33.1%	28.0%	58.5%	65.6%
Support to help my child sleep	33.9%	34.4%	22.0%	42.7%
Support to manage my child's behaviour	33.9%	25.5%	43.2%	65.0%
Support to help my child with sensory issues	39.0%	26.8%	32.2%	52.2%
Support to help my child's physical development (inc equipment)	22.9%	24.8%	21.2%	29.3%

In both West Sussex and Brighton and Hove support with 'children's confidence and self-esteem' and their 'emotional well-being' have high information needs. Managing behaviour was high scoring in terms of need as well, particularly in West Sussex. Developing and catching confidence and building self-esteem is the key underpinning to many important areas of cognitive development, esteem building and progression as much research has shown.

There is a marked difference between West Sussex and Brighton & Hove as regards need for information about sensory issues, behaviour support, children's sleep and speech and communication. West Sussex parents have particularly higher needs in these areas and it may be interesting to explore the reasons for this in more detail. Again, just because a given area has a lower comparative score this does not mean that there is not a potential acute and substantial need. For instance information needs about support for children's' physical development is lower scoring at 21% BH and 29.3% WSX – this is still a substantial number of families and has the potential to represent a substantial amount of need.

#### **e) Support for me and my family:**

Information about support for parents and families is an area of high information need particularly in the area of handling stress and building resilience. It must be pointed out that just because information about a given support or activity is made available this obviously does not mean that the broader support activity is available. For instance there is a particularly high need for information about respite – just over 60% WSX and 42% BH.

	I <u>already have</u> good info on this		I <u>really need</u> good info on this	
	BH	WSX	BH	WSX
Support for siblings	25.42%	17.83%	38.14%	52.87%
Parent carers support groups	45.76%	52.87%	37.29%	39.49%
Handling stress and building resilience	33.05%	26.11%	54.24%	67.52%
Relationship counselling	18.64%	15.92%	27.12%	35.03%
Short breaks and respite	16.95%	24.20%	42.37%	60.51%
Home adaptations	11.86%	10.83%	18.64%	19.75%
Disability equipment	16.95%	14.65%	20.34%	18.47%

West Sussex has particularly high information needs about short breaks and respite; handling stress and resilience; and support for siblings. One of Amaze's core values is about building the resilience of parent carers and their frequent Insiders' Guide and Looking After Yourself courses and recent siblings support groups may have influenced some of these scores.

#### f) Social and leisure activities:

Again these are areas with high information needs but are noticeably higher in West Sussex. Social groups and holidays are the areas of largest information need and may reflect a hope on the part of parents that these activities are available. It also reflects an on-going need for families to have the opportunity to participate in informal, supportive groups of people in a similar situation; and participate in meaningful social activities in general with their children.

	I <u>already have</u> good info on this		I <u>really need</u> good info on this	
	BH	WSX	BH	WSX
Inclusive leisure opportunities	46.6%	26.8%	41.5%	67.5%
Disability-specific leisure opportunities	24.6%	15.9%	23.7%	28.7%
Discounts for sports and leisure activities	49.2%	14.6%	44.1%	77.7%
Holidays	23.7%	7.6%	59.3%	76.4%
Playschemes	25.4%	21.7%	25.4%	48.4%
Social groups	28.8%	24.2%	49.2%	60.5%

It is likely that a larger proportion of parents in Brighton and Hove felt they already had good information as Amaze has the well established Compass Card (providing information and financial discounts to social/leisure opportunities) plus a weekly e-bulletin that goes with this and some well used fact-sheets all about leisure opportunities. There is an equivalent e-bulletin provided by WSCC (worth putting in how frequent this is.. and does it have the same leisure focus?) and it is hoped the new Compass Card West Sussex development will meet some of the information needs in this area over time.



### **g) Preparing for adulthood:**

About 40% of parents have high information needs with regards various 'transition' topics such as: further education, apprenticeships and paid employment, relationships and sexual health, independent living skills and advocacy. This figure is obviously much higher when we isolate the responses from parents of children aged 14. Taking the relevant-aged sample the high information needs increase to 54% across both areas, 50% in Brighton and 58% in West Sussex.

## **5. Accessing information:**

The survey responses show that most parent carers (would) prefer to use a variety of sources of information as opposed to a single source. Whilst many parent carers report already having good information on a number of topics and find accessing the information or training they need 'easy' or 'moderate' there is still 28%-30% of respondents who find accessing what they need difficult or very difficult so there is work to be done to identify and meet these access needs.

### **a) What sources of information do you like to use the most? (Ranked 1-10)**

	<b>BH</b>	<b>WSX</b>
Handbooks	6th	1st
Factsheets	3rd	3rd
Help lines	2nd	5th
Websites	1st	2nd
Your local authority's Local Offer	5th	6th
One to one advice	4th	4th
Training courses	7th	7th
Other parents	8th	8th

Though 'other parents' scores lowest here other data shows that this is often the first (informal) route into other sources of information and help. Other parents are an important source for getting new parent carers - at the start of their journey - hooked in who are not yet involved in support and information networks.

In West Sussex's case these preferences show the substantial use of Reaching Families' *Making Sense of It All* handbook. In Brighton and Hove's case choices reflect the availability of information on Amaze's website and its telephone helpline which are well known and well used. Other data suggests Amaze's equivalent publication, *Through the Maze* handbook is very well used, so this is worth exploring more.

Frequently cited sources of information and sign-posters to sources of information were schools and parent support groups – the later especially in West Sussex. Information-giving by GPs and Health Visitors was at a low level which should be an action to follow up with CCGs. The survey showed a wide range of other organisation, mostly third-sector ones, providing useful information, sign-posting and referral.

Below shows the more frequent places where people have been helped to access information:

**b) Which of the following organisations have helped you to access information?**

In Brighton and Hove:

Amaze Information, Advice and Support (IAS) Service	111	94.1%
Seaside View Child Development Centre	58	49.2%
Other Brighton and Hove CVS organisation/parent group	25	21.2%

In West Sussex:

Reaching Families or Making Sense of It All	79	50.3%
West Sussex Parent Carer Forum	60	38.2%
Child Development Centre	59	37.6%
SEND IAS (formerly West Sussex Parent Partnership)	37	23.6%

In general:

	Brighton and Hove Respondents		West Sussex Respondents	
Your Child's School	63	53.4%	82	52.2%
Parent Support Groups	35	29.7%	75	47.1%

The variance in use of the SEND IAS service in Brighton & Hove and West Sussex maybe a result of how the survey was originally circulated. For example, Amaze, who run the SEND IAS service in Brighton circulated the survey to their mailing list which is much larger than Reaching Families. Meanwhile, the SEND IAS service in West Sussex were not part of asking families they support to complete this survey

**c) Does anything prevent you from accessing services and support for your child?**

These, in order of the most cited, were the reasons why respondents were not able to access services.

	Brighton & Hove	West Sussex
1 Lack of relevant information	59%	47%
2 Waiting lists	36%	42%
3 Eligibility criteria	37%	34%
4 Cost	28%	28%
5 Mental health and well being	13%	11%

## 6. Key stages:

Respondents were asked to measure whether or not they got good information at key stages of transition where typically change takes place.

	I <u>got good</u> info at this time		I <u>needed more</u> info on this		I'm not at this stage yet	
	BH	WSX	BH	WSX	BH	WSX
Assessment	34.7%	46.5%	55.9%	49.0%	5.9%	3.2%
Diagnosis	30.5%	36.9%	56.8%	59.2%	10.2%	2.5%
Choosing a school	47.5%	47.1%	42.4%	47.1%	5.1%	4.5%
Starting School	46.6%	51.0%	39.0%	40.1%	7.6%	6.4%

This shows that more than half of respondents needed more help at the assessment and diagnosis stages than they got. It also shows high information needs at choosing school and starting school stages despite the fact that there is considerable public sector information resource available about choosing and starting school. Qualitative data shows that parents need help and advice at this key, transition change as well as written factual information.

Respondents were also asked to rate information needs as regards transition to secondary school and adulthood. This proved to be less informative only because many respondents had younger children so were not yet at a stage where they were actively considering transition.

	I have <u>got good</u> info at this time		I <u>needed more</u> info on this		I'm not at this stage yet	
	BH	WSX	BH	WSX	BH	WSX
Transition to Secondary School	33.1%	20.4%	28.0%	28.7%	37.3%	49.7%
Transition to adulthood	7.6%	3.2%	21.2%	15.3%	69.5%	77.7%

## 7. Conclusion in brief

This survey was a useful and extensive piece of research that will enable better work in partnership to support families and children in Brighton & Hove and West Sussex. Amaze and Reaching Families need to identify the biggest gaps/needs for information and use this when prioritising their work over the coming months, starting with their review and updating of their suite of factsheets.

They, and other partner agencies working to support families, can use this analysis to identify other areas for improvement and hopefully can use this report as evidence for increased funding to meet some of these ongoing information needs.

**APPENDIX ONE - Search topics of parent carers.** Under new SEND legislation outlines in the Children's and Families Act, local authorities have a responsibility to produce a Local Offer – a central information portal outlining what is available to families with disabled children in their local area. The survey asked some supplementary questions to see how the Local Offer is viewed and being used in the two areas. Below is a useful data set that shows the various reasons as to why people search on the Local Offer websites and what they are searching for. This might be useful for those with an interest in further developing these information sources. There was an open ended question in this part of the survey and we received a great many free-text answers, too lengthy to go into here but these are available for sharing on request.

**19. Have you ever used the Local Offer website for your area?**

	BH		WSX	
Yes	28	23.73%	58	36.94%
No	89	75.42%	96	61.15%
Not answered	1	0.85%	3	1.91%

Again it should be noted that the respondent sample is more nuanced towards parent who are already in the support and information networks

21. What topics did you want to get info about?	BH	% of those who say they have used LO site	WSX	% of those who say they have used LO site
SEND activities	11	39.3%	35	60.3%
Activities open to all	3	10.7%	31	53.4%
Diagnosis	2	7.1%	6	10.3%
Finding support	11	39.3%	28	48.3%
Coping strategies/resilience	8	28.6%	15	25.9%
Money matters	3	10.7%	9	15.5%
Health and wellbeing	7	25.0%	9	15.5%
Transport and travel	5	17.9%	9	15.5%
Early years	4	14.3%	5	8.6%
Education support	12	42.9%	24	41.4%
Schools	18	64.3%	17	29.3%
Post 16 education and training	5	17.9%	10	17.2%
Moving to adult life	2	7.1%	10	17.2%
Keeping safe	3	10.7%	7	12.1%
Equipment and resources	2	7.1%	8	13.8%
Having your say and getting involved	0	0.0%	7	12.1%

**22. If you haven't used your area's Local Offer website, could you tell us why?**

	BH	% of those who haven't used it	WSX	% of those who haven't used it
I hadn't heard about it	65	73.0%	49	51.0%
I get all the info I need elsewhere	13	14.6%	23	24.0%
Other reason*	7	7.9%	24	25.0%
Not answered	4	4.5%	0	0.0%