

Child Disability Mapping Project Survey Report

Tim Martin

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Child Disability Mapping Project Survey Report

1 Background

This report presents the results of a questionnaire-based postal survey of families who were known to have disabled children in West Sussex. The survey asked parents and carers about their experience of services for their children. This survey forms part of a wider mapping project of child disability in the county.

Some questions used in the questionnaire were based on those used in the 2009 national Aiming High survey, which generated the performance indicator NI 54.

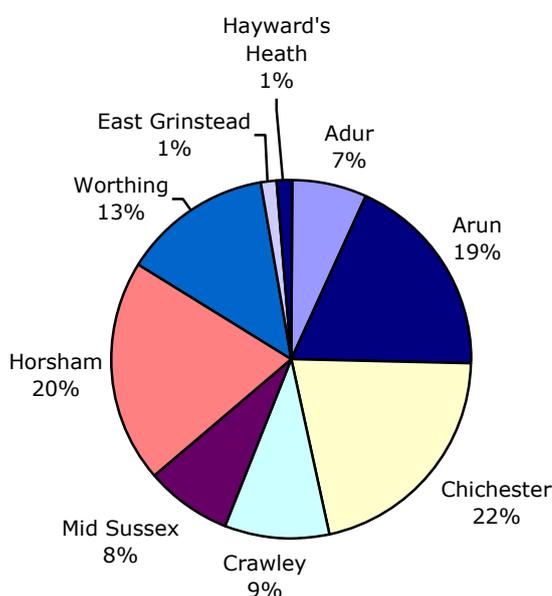
Parents and carers returned their completed questionnaires directly to the West Sussex Research Unit.

1.1 Number of responses from families and where they lived

A total of 645 questionnaires were sent out to families. Three were returned uncompleted due to the families having changed address. This gave a potential response of 642 questionnaires. By the end of the survey period, 153 questionnaires were completed and returned, giving a response rate of 24%.

The chart and table below show that most respondents came from Chichester, Horsham or Arun.

Chart 1: Responses by area



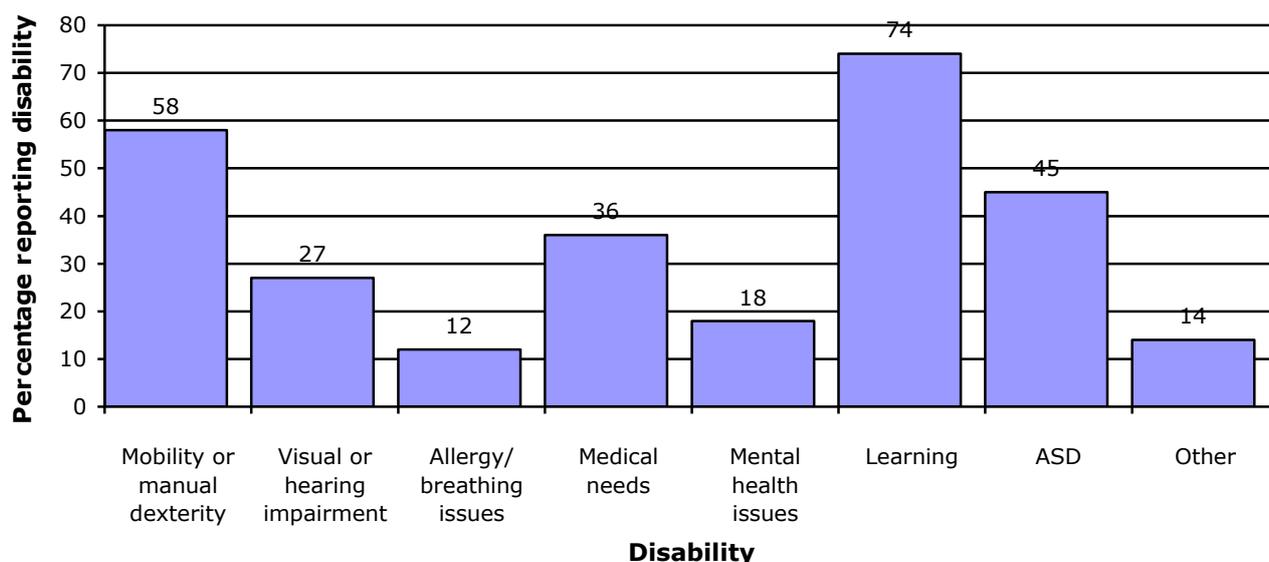
Area	Number
Adur	10
Arun	28
Chichester	32
Crawley	14
Mid Sussex	12
Horsham	30
Worthing	20
East Grinstead	2
Hayward's Heath	2
Not recorded	3
All	153

1.2 Age of children and disability recorded

The ages of the children on the returned questionnaires ranged from one year old to 18. The average age was 10 years and five months.

Parents/carers were asked to record their children's disabilities. Most recorded a combination of disabilities as illustrated in the following chart. The most frequently recorded disability was 'learning', which was associated with 74% of children. This is demonstrated in Chart 2.

Chart 2: Disability recorded



2 Care and family support services received in the last 12 months

Note: discrepancies in percentages are due to rounding.

2.1 Satisfaction with the various services received

Parents and carers were asked to rate their satisfaction with various care and family support services that they may have received in the past 12 months (Tables 1 to 7). As can be seen from the tables, the highest levels of satisfaction were recorded for Direct Payments. Lower levels of satisfaction were recorded for help with housework from an outside agency and emotional support/counselling. This may reflect that parent/carers were not receiving these services rather than dissatisfaction with the services per se.

Table 1: Satisfaction with social worker services

	2012	
	Number	%
Very satisfied	49	34
Satisfied	57	40
Neither satisfied nor dissatisfied	19	13
Dissatisfied	8	6
Very dissatisfied	11	8
Total	144	100

Table 2: Satisfaction with home adaptations

	2012	
	Number	%
Very satisfied	18	44
Satisfied	13	32
Neither satisfied nor dissatisfied	3	7
Dissatisfied	1	2
Very dissatisfied	6	15
Total	41	100

Table 3: Satisfaction with respite care or short breaks

	2012	
	Number	%
Very satisfied	39	39
Satisfied	36	36
Neither satisfied nor dissatisfied	9	9
Dissatisfied	8	8
Very dissatisfied	7	7
Total	99	100

Table 4: Satisfaction with help at home for your child's care

	2012	
	Number	%
Very satisfied	27	32
Satisfied	32	38
Neither satisfied nor dissatisfied	11	13
Dissatisfied	7	8
Very dissatisfied	8	9
Total	85	100

Table 5: Satisfaction with help with housework from an outside agency

	2012	
	Number	%
Very satisfied	1	7
Satisfied	6	43
Neither satisfied nor dissatisfied	0	0
Dissatisfied	2	14
Very dissatisfied	5	36
Total	14	100

Table 6: Satisfaction with emotional support or counselling

	2012	
	Number	%
Very satisfied	7	22
Satisfied	12	38
Neither satisfied nor dissatisfied	2	6
Dissatisfied	6	19
Very dissatisfied	5	16
Total	32	100

Table 7: Satisfaction with direct payments/individual budgets

	2012	
	Number	%
Very satisfied	45	39
Satisfied	49	43
Neither satisfied nor dissatisfied	10	9
Dissatisfied	7	6
Very dissatisfied	4	4
Total	115	100

2.2 The extent to which the services used met children's needs

In more than 70% of cases parents/carers said that the services that they used either fully or mainly met their children's needs, as illustrated in the table below.

Table 8: To what extent have the services (in Tables 1 to 7) met your child's needs

	Number	%
Fully	43	29
Mainly	62	42
Partially	39	26
Not at all	5	3
Total	149	100

2.3 Rating of the quality of social care and family support services

More than six in ten parents thought that the quality of the services that they received were either good or very good. Meanwhile, 5% said that it was difficult to rate the quality of services as their experiences were varied. This is illustrated in Table 9.

Table 9: Overall rating of the quality of social care and family support services that were received over the past 12 months in relation to your child

	Number	%
Very good	40	27
Good	52	35
Fair	35	23
Poor	8	5
Very poor	8	5
Difficult to say as experience varied	7	5
Total	150	100

2.4 Services for families with disabled children that parents are aware of

Parents/carers were given a list of services that parents/carers might be aware of (see Chart 3 below and Table 10 for more detail). Nearly all were aware of Disability Living Allowance (99%) and a good proportion were aware of West Sussex Parents' Forum (84%). However, only around four in ten were aware of the Reach Out website (40%) and the Specialist Benefits Adviser (43%).

Chart 3: Services for families with disabled children that parents are aware of

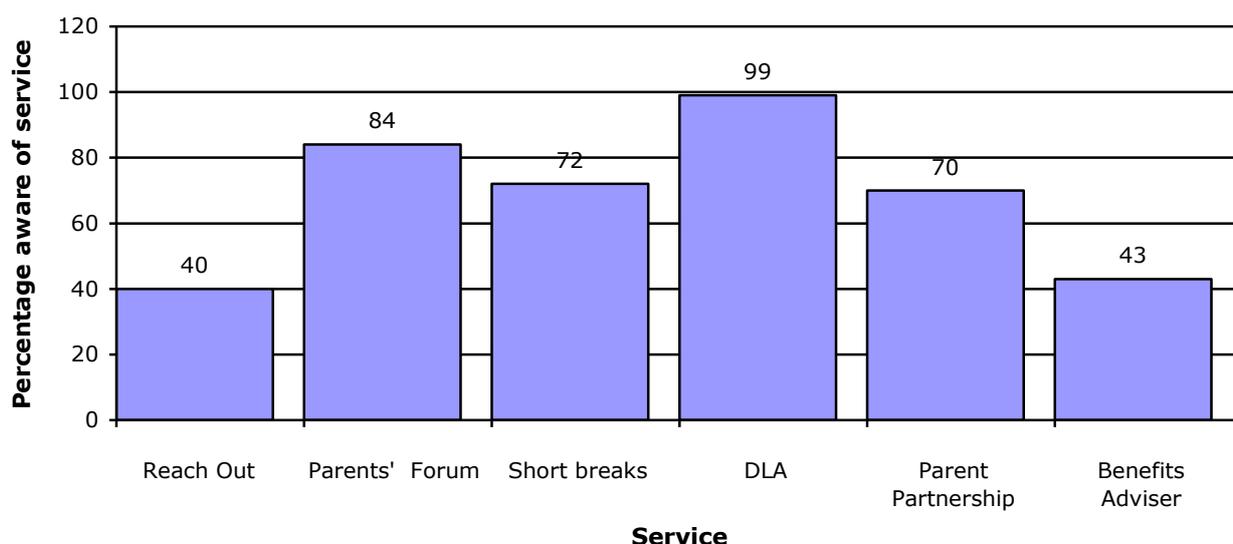


Table 10: Services for families with disabled children that parents are aware of

	Aware of		Not aware of		Not sure	
	Number	%	Number	%	Number	%
Reach Out (website)	60	40	56	37	35	23
West Sussex Parents' Forum	127	84	16	11	8	5
Short breaks for families with disabled children	109	72	30	20	12	8
Disability Living Allowance	149	99	1	1	0	0
Parent Partnership	105	70	25	17	21	14
Specialist Benefits Adviser	65	43	66	44	20	13

3 Information and advice about your child's care

3.1 Getting information and advice about care services for children with disabilities

Parents/carers were given a list of statements associated with obtaining information and advice about care services for children with disabilities and asked to say whether or not they agreed with them.

Of those who answered this question, 58% said that they had someone they could go to for help and support in getting social care services. However, 32% felt that they had not been given enough information about the social care services that their family is entitled to.

Table 11: Please indicate whether you agree or disagree with the following statements relating to information or advice about care services for children with disabilities

	Agree		Neither agree nor disagree		Disagree	
	Number	%	Number	%	Number	%
Given enough information about our social care needs	60	41	58	40	28	19
Given enough information about the social care services that my family is entitled	53	35	49	33	48	32
Given enough information about how to get social care services	58	40	50	34	37	26
Have someone I can go to for help and support in getting social care services	86	58	38	26	25	17

3.2 Information that families received about social care services for their child or family

3.2.1 In the last 12 months have you received any information about social care services specifically for your child or family

A total of 108 people (71%) said they had received information (either written or verbal) about social care services specifically for their child or family.

3.2.2 Information received in the last 12 months about social care services available to families

Most families felt that the information was either always or sometimes clear. They were slightly less sure about how relevant, accurate and up to date the information was. This is illustrated in Table 12.

Table 12: Overall, how would you describe the information you received in the last 12 months about social care services available to your family in relation to your child’s disability, illness or health condition?

	Always		Sometimes		Never	
	Number	%	Number	%	Number	%
Was the information clear to understand?	56	52	52	48	0	0
Was the information relevant to you and your child?	43	41	61	58	2	2
Was the information accurate and up to date?	54	52	47	45	3	3

4 Decisions made about your child’s care in the last 12 months

4.1 In the last 12 months have any social care professionals made decisions about your child’s disability, illness or services

In total, 101 parents/carers (66%) said a social care professional had made decisions about their child’s disability, illness or services in the past 12 months.

4.2 Aspects of any decisions made by social care professionals

The following tables (13 to 20) represent the extent to which parents agreed or disagreed with various statements associated with the care of their children over the past 12 months.

Around two thirds of parents/carers (66%) felt that that they had been listened to and their needs understood (see Table 14). However, 28% disagreed that the decisions had been made at the right time for them (see Table 17). Additionally, 54% felt that they had to give the same or similar information several times (see Table 13).

**Table 13: Do you agree or disagree with this statement:
We had to give the same information several times**

	Number	%
Agree	52	54
Neither agree nor disagree	23	24
Disagree	21	22
Total	96	100

**Table 14: Do you agree or disagree with this statement:
We were listened to and our needs were understood**

	Number	%
Agree	65	66
Neither agree nor disagree	23	23
Disagree	11	11
Total	99	100

**Table 15: Do you agree or disagree with this statement:
Our child was consulted about any decisions that were made**

	Number	%
Agree	26	52
Neither agree nor disagree	15	30
Disagree	9	18
Total	50	100

Some parents answered 'disagree', ticked 'not applicable' or did not tick any of the options in response to the question about the child being consulted (Table 15). This was because of their children's communication difficulties. One said, for example: 'My child cannot talk.'

**Table 16: Do you agree or disagree with this statement:
The decisions made were suitable for our needs**

	Number	%
Agree	52	55
Neither agree nor disagree	26	27
Disagree	17	18
Total	95	100

**Table 17: Do you agree or disagree with this statement:
The decisions were made at the right time for us**

	Number	%
Agree	46	49
Neither agree nor disagree	22	23
Disagree	26	28
Total	94	100

**Table 18: Do you agree or disagree with this statement:
We were confident in the skills of the social care professionals that worked
with our family**

	Number	%
Agree	57	59
Neither agree nor disagree	22	23
Disagree	18	19
Total	97	100

**Table 19: Do you agree or disagree with this statement:
Where necessary the social care professionals worked together to make
decisions**

	Number	%
Agree	48	55
Neither agree nor disagree	20	23
Disagree	19	22
Total	87	100

**Table 20: Do you agree or disagree with this statement:
On the whole we were happy with the decisions made**

	Number	%
Agree	57	59
Neither agree nor disagree	19	20
Disagree	20	21
Total	96	100

Table 21: To what extent did you understand the decisions made about the care or support for your child

	Number	%
Fully	61	60
Mainly	30	30
Partially	9	9
Not at all	1	1
Total	101	100

Table 22: To what extent were you consulted or asked for your opinion about the decisions made about the care or support for child

	Number	%
Fully	56	57
Mainly	29	29
Partially	13	13
Not at all	1	1
Total	99	100

Table 23: If you have been consulted or asked for your opinion, to what extent was what you said taken into account in any decisions that were made about your child's care

	Number	%
Fully	48	49
Mainly	28	29
Partially	17	17
Not at all	3	3
Not sure	2	2
Total	98	100

West Sussex Research Unit

West Sussex County Council
44-45 West Street
Chichester
West Sussex
PO19 1RP

Phone: 01243 815146

Email: social.research.unit@westsussex.gov.uk



West Sussex Research Unit