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**Personal Social Services Physically  
Disabled and Sensory Impaired User  
Experience Survey**

**May 2004**

**Policy and Research Services  
Strategic Support Directorate**

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**Personal Social Services Physically Disabled and Sensory Impaired User  
Experience Survey  
2004**

**INTRODUCTION**

All local authorities in England are carrying out surveys to ask the views of Social Service users about the services they receive. The survey for 2003-04 covered physically disabled and sensory impaired users aged 18-64 (excluding those with learning disabilities). It is important that the Department of Health understands at the national level how well services are meeting users' and carers' needs. However, information about services is not intended to be used solely to monitor performance but will also be used locally by Social Services to inform service delivery and to monitor and develop standards. The overall response to the survey was good and 63% (220 out of 347<sup>1</sup>) of people in the sample took part in the survey. 45% (98) of respondents completed the questionnaire themselves. However, nearly half (47%; 103) of the respondents had help either from a family member, friend or a care worker. 10 users were interviewed on the telephone and 9 users were interviewed in person by an interviewer<sup>2</sup>.

**RESULTS<sup>3</sup>**

**Demographic details**

Amongst the respondents who had provided the information on their ethnicity, gender and age group; the majority 94% (207) of respondents were white, 57% (125) were women and 98% (215) of respondents were between 18-64 years old.

**Are you male or female?**

	No. of respondents	Valid Percent
Male	95	43.2
Female	125	56.8
<b>Total</b>	<b>220</b>	<b>100.0</b>

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<sup>1</sup> There were 355 eligible users, however, 5 users deceased during the survey and 3 users were excluded due to ongoing complaints.

<sup>2</sup> 3 interviews were in Punjabi and one in French

<sup>3</sup> Please note that percentages have been rounded and may not always total 100.

### How old are you?

	No. of respondents	Valid Percent
18-64	215	97.7
65 and over	5	2.3
<b>Total</b>	<b>220</b>	100.0

### To which of these groups do you consider you belong?

	No. of respondents	Valid Percent
White (British, Irish, any other white background)	207	94.1
Mixed race	1	.5
Asian or Asian British	8	3.6
Black or Black British	3	1.4
Chinese	1	.5
<b>Total</b>	<b>220</b>	100.0

### Direct payments

Direct payments are the option for service users to purchase some or all of the services they are eligible for directly themselves, using money provided by Social Services.

Less than half (46%; 102) of the respondents stated that they were told about direct payments by their social worker or care manager, however, another one in ten (11%; 25) did not know.

### Has your social worker or care manager told you about direct payments?

	No. of respondents	Valid Percent
Yes	102	46.4
No	93	42.3
Don't know	25	11.4
<b>Total</b>	<b>220</b>	100.0

22% (48) of all the respondents stated that they used direct payments.

### Do you use direct payments?

	No. of respondents	Valid Percent
Yes	48	21.8
No	153	69.5
Don't know	19	8.6
<b>Total</b>	<b>220</b>	100.0

Nearly three quarters (73%; 35) of respondents who had been using direct payments said that, overall, they were 'extremely' or 'very' well advised and supported in using direct payments. A few (4%; 2) respondents claimed that they were not very well advised and supported and one respondent haven't had any advice and support in using direct payments.

**Overall how well do you think you have been advised and supported in using direct payments?**

	No. of respondents	Percent	Cumulative Percent
Extremely well	16	33.3	33.3
Very well	19	39.6	72.9
Quite well	10	20.8	93.8
Not very well	1	2.1	95.8
Not well at all	1	2.1	97.9
I haven't received any advice	1	2.1	100.0
<b>Total</b>	<b>48</b>	100.0	
Not applicable	172		
Total	220		

Over two thirds (69%; 135) of users responding to the question said that their opinions and preferences were 'always' (32%) or 'usually' (37%) taken into account when decisions were made about what services to provide them. However, another one in ten (10%; 20) respondents stated that their opinions and preferences were 'never' taken into account.

**Do you feel that your opinions and preferences are taken into account when decisions are taken about what services are provided to you?**

	No. of respondents	Valid Percent	Cumulative Percent
Always	63	32.3	32.3
Usually	72	36.9	69.2
Sometimes	40	20.5	89.7
Never	20	10.3	100.0
<b>Total</b>	<b>195</b>	100.0	
Question does not apply to me	13		
Missing	12		
Total	25		
Total	220		

The majority (95%; 193) of the users who responded either strongly agreed (56%; 114) / agreed (39%; 79) with the statement, *'My life would be a lot worse if I didn't have help from Social Services or direct payments.* Another 5% (10) of respondents either disagreed (3%; 6) or strongly disagreed (2%; 4) with the statement.

**My life would be a lot worse if I didn't have help from SSD or direct payments**

	No. of respondents	Valid Percent	Cumulative Percent
Strongly agree	114	56.2	56.2
Agree	79	38.9	95.1
Disagree	6	3.0	98.0
Strongly disagree	4	2.0	100.0
<b>Total</b>	<b>203</b>	100.0	
Doesn't apply	10		
Missing	7		
Total	17		
Total	220		

Comparatively fewer (89%; 147) respondents who provided the information strongly agreed (43%; 71) / agreed (46%; 76) with the statement, *'The help I get from Social Services or using direct payments means that I can live in my own home'.* Another one in ten (11%; 18) either disagreed (10%; 16) or strongly disagreed (1% 2) with the statement.

**The help I get from Social Services or using direct payments means that I can live in my own home**

	No. of respondents	Valid Percent	Cumulative Percent
Strongly agree	71	43.0	43.0
Agree	76	46.1	89.1
Disagree	16	9.7	98.8
Strongly disagree	2	1.2	100.0
<b>Total</b>	<b>165</b>	100.0	
Doesn't apply	27		
Missing	28		
Total	55		
Total	220		

Similarly 83% (145) of respondents who provided the information strongly agreed (31%; 54) / agreed (52%; 91) with the statement, *'The help I get from Social Services or using direct payments has made me more independent than I was.'* Another 17% (23) either disagreed (23; 13%) or strongly disagreed (7; 4%) with the statement.

**The help I get from Social Services or using direct payments has made me more independent than I was**

	No. of respondents	Valid Percent	Cumulative Percent
Strongly agree	54	30.9	30.9
Agree	91	52.0	82.9
Disagree	23	13.1	96.0
Strongly disagree	7	4.0	100.0
<b>Total</b>	<b>175</b>	100.0	
Doesn't apply	21		
Missing	24		
Total	45		
Total	220		

Nearly three quarters (73%; 147) who responded either strongly agreed (16%; 33) / agreed (56%; 114) with the statement, *'Social Services provides me with all the information I need'.* However, another quarter (27%; 55) either disagreed (21%; 43) or strongly disagreed (6%; 12) with the statement.

**Social Services provides me with all the information I need**

	No. of respondents	Valid Percent	Cumulative Percent
Strongly agree	33	16.3	16.3
Agree	114	56.4	72.8
Disagree	43	21.3	94.1
Strongly disagree	12	5.9	100.0
<b>Total</b>	<b>202</b>	100.0	
Doesn't apply	5		
Missing	13		
Total	18		
Total	220	100.0	

Significantly more respondents (86%; 178) either strongly agreed (35%; 71) / agreed (52%; 107) with the statement, '*I can always contact Social Services if I needed to*'. Another 14% (28) either disagreed (7%; 19) or strongly disagreed (4%; 9) with the statement.

**I can always contact Social Services easily if I need to**

	No. of respondents	Valid Percent	Cumulative Percent
Strongly agree	71	34.5	34.5
Agree	107	51.9	86.4
Disagree	19	9.2	95.6
Strongly disagree	9	4.4	100.0
<b>Total</b>	<b>206</b>	100.0	
Doesn't apply	5		
Missing	9		
Total	14		
Total	220		

Of the 181 respondents who responded, the majority 92% (167) either strongly agreed (40%; 73) / agreed (52%; 94) with the statement, '*I get up and go to bed at times which suit me*'. A few (8%; 14) either disagreed (7%; 12) or strongly disagreed (1%; 2) with the statement.

**I get up and go to bed at times which suit me**

	No. of respondents	Valid Percent	Cumulative Percent
Strongly agree	73	40.3	40.3
Agree	94	51.9	92.3
Disagree	12	6.6	98.9
Strongly disagree	2	1.1	100.0
<b>Total</b>	<b>181</b>	100.0	
Doesn't apply	25		
Missing	14		
Total	39		
Total	220		

Comparatively fewer (82%; 150) respondents strongly agreed (40%; 73) / agreed (52%; 94) with the statement, '*Social Services have provided me with the adaptations and equipment that I need*'. Another 19% (34) either disagreed (12%; 22) or strongly disagreed (7% 12) with the statement.

**Social Services have provided me with the adaptations and equipment that I need**

	No. of respondents	Valid Percent	Cumulative Percent
Strongly agree	65	35.3	35.3
Agree	85	46.2	81.5
Disagree	22	12.0	93.5
Strongly disagree	12	6.5	100.0
<b>Total</b>	<b>184</b>	<b>100.0</b>	
Doesn't apply	25		
Missing	11		
Total	36		
Total	220		

The majority 86% (154) of respondents who provided the information said that their care workers or personal assistants<sup>4</sup> 'always' (53%) or 'usually' (34%) came at times that suited them. Very few (2%; 4 out of 179) stated that their care workers 'never' came at times that suited to them.

**Do your care workers (or personal assistants you employ using direct payments) come at times that suit you?**

	No. of respondents	Valid Percent	Cumulative Percent
They always come at times that suit me	94	52.5	52.5
They usually come at times that suit me	60	33.5	86.0
They sometimes come at times that suit me	21	11.7	97.8
They never come at times that suit me	4	2.2	100.0
<b>Total</b>	<b>179</b>	<b>100.0</b>	
Q is not relevant	6		
I Don't have a care work or personal assistant	25		
Missing	10		
Total	41		
Total	220		

<sup>4</sup> Employed using direct payments

42 respondents specified that they had bought services with direct payments in the past year. These included short breaks (10); help in home (9); personal assistant or enabler (6) and a day center/day time activities (2). Another 15 respondents used direct payments for buying two or more of these services.

**Which of the following services have you bought with your direct payments in the past year?**

	No. of respondents	Valid Percent
Help in your home	9	21.4
Personal assistant or Enabler	6	14.3
A day centre/ day time activities	2	4.8
Short breaks	10	23.8
Other - please specify	15	35.7
<b>Total</b>	<b>42</b>	<b>100.0</b>
Don't know	5	
Missing	1	
Total	48	

**Specify other services you bought with your direct payments in the past year**

	No. of respondents
All the above	4
Enabler & short breaks	2
Help at home & short break	3
Help at home & enabler	2
Day centre & short break	3
All and a leisure activity	1
<b>Total</b>	<b>15</b>

Two thirds (66%; 137) of users responding to the question said that they had as many visits as needed from the person that arranged help for them. However, another one in ten (21) respondents said they needed a few more visits and 5% (10) said they needed a lot more visits. 7% (15) of these respondents stated that they arranged their own care using direct payments.

**Do you have as many visits from the person that arranges help for you as you need?**

	No. of respondents	Valid Percent
Yes, I have as many visits as I need	137	65.9
No, I need a few more visits	21	10.1
No, I need a lot more visits	10	4.8
I arrange my own care using direct payments	15	7.2
I Don't have a social worker or care manager	25	12.0
<b>Total</b>	<b>208</b>	100.0
Missing	12	
Total	220	

**Support in looking after children**

The majority 88% (172) of respondents said that either they had no children (79%; 153) or didn't need support from Social Services in looking after their children (10%; 19). However, another 8% (15) of respondents said that Social Services had given them either a great deal of support (8) or some support (7) in looking after their children. 4% (8) of the other respondents claimed that Social Services had given no support to them in looking after their children.

**How much support do Social Services give you in looking after your children?**

	No. of respondents	Valid Percent
I Don't have any children	153	78.5
I Don't need support from Social Services in looking after my children	19	9.7
Social Services have given me a great deal of support	8	4.1
Social Services have given me some support	7	3.6
Social Services have given me no support	8	4.1
<b>Total</b>	<b>195</b>	100.0
Missing	25	
Total	220	

A quarter (26%; 53) of users responding to the question stated that they didn't get practical help from family and friends. However, another 71% (146) said that the help they got from Social Services fitted extremely well (11%; 23); very well (40%; 82) or quite well (20%; 41) with practical help from family and friends. Only a very few (3%; 7) mentioned that the help didn't fit well.

**How well does the help you get from Social Services fit in with practical help you get from family or friends?**

	No. of respondents	Valid Percent
I Don't get practical help from family or friends	53	25.7
Help from Social Services fits in extremely well	23	11.2
Help from Social Services fits in very well	82	39.8
Help from Social Services fits in quite well	41	19.9
Help from Social Services doesn't fit in very well	4	1.9
Help from Social Services doesn't fit in at all well	3	1.5
<b>Total</b>	<b>206</b>	100.0
Missing	14	
Total	220	

**Support in keeping a job**

Over two thirds (70%; 153) of all the respondents were either unable to work or were past retirement age. A few (6%; 14) were either in a part-time (8) or full-time (6) work and another quarter (24%; 52) of respondents were not in work.

**Are you in paid work at present?**

	No. of respondents	Valid Percent
Unable to work/past retirement age	153	69.9
Yes, in full time work	6	2.7
Yes, in part time work	8	3.7
No, not in work	52	23.7
<b>Total</b>	<b>219</b>	100.0
Missing	1	
Total	220	

A third (34) of respondents said that their carers were either unable to work or were past retirement age. However, half of the respondents said that their carers were either in a part-time (18%; 18) or full-time (32%; 33) work and another 17% (17) of respondents said that their carers were not in work.

**Is your carer in paid work at present?**

	No. of respondents	Valid Percent
Unable to work/past retirement age	34	33.0
Yes, in full time work	33	32.0
Yes, in part time work	18	17.5
No, not in work	17	16.5
<b>Total</b>	<b>102</b>	<b>100.0</b>
Not applicable	1	
Missing	117	
Total	220	

A very few respondents said that they would like Social Services to help either them (6) or their carer (5) to get a paid job.

The majority (10 of the 14) of respondents who were in a paid job said that they didn't need Social Services to help them keep a job. However, the other 4 respondents stated that Social Services were very useful (1) or useful (3) in helping them to keep a job.

**How useful have Social Services been in helping you to keep a paid job?**

	No. of respondents
Don't need Social Services to help keep a job	10
Social Services have been very useful in helping to keep a job	1
Social Services have been useful in helping to keep a job	3
<b>Total</b>	<b>14</b>

Similarly, 18 respondents who provided the information said that their carer didn't need Social Services to help them keep a job. However, 20 respondents stated that Social Services were very useful (15) or useful (5) in helping their carers to keep a job. Only one respondent claimed that Social services were not useful at all in helping their carer to keep a paid job.

**How useful have Social Services been in helping your carer to keep a paid job?**

	No. of respondents
Don't need Social Services to help keep a job	18
Social Services have been very useful in helping to keep a job	15
Social Services have been useful in helping to keep a job	5
Social Services haven't been at all useful in helping to keep job	1
<b>Total</b>	<b>39</b>
Total	220

**Complaints**

Over two thirds (68%; 147) of users who responded said that they knew how to complain about Social Services. However, 7% (15) of these respondents said that although they knew they felt they could not complain if they wanted to. Another third (32%; 68) said they did not know how to complain.

**Do you know how to make a complaint about Social Services?**

	No. of respondents	Valid Percent
Yes and I feel I could if I wanted to	132	61.4
Yes but I do not feel I could if I wanted to	15	7.0
No I do not know how to make a complaint	68	31.6
<b>Total</b>	<b>215</b>	<b>100.0</b>
Missing	5	
Total	220	

### **Overall satisfaction**

The majority 84% (178) who responded to the question said that, overall, they were 'extremely' (30%; 63), 'very' (16%; 33) or 'quite' (39%; 82) satisfied with the help they receive from Social Services. A very few (4%; 9) respondents were either 'very' or 'extremely' dissatisfied with the service provided.

#### **Overall, how satisfied are you with the help you receive from Social Services?**

	No. of respondents	Valid Percent	Cumulative Percent
I am extremely satisfied	63	29.6	29.6
I am very satisfied	33	15.5	45.1
I am quite satisfied	82	38.5	83.6
I am neither satisfied nor dissatisfied	17	8.0	91.5
I am fairly dissatisfied	9	4.2	95.8
I am very dissatisfied	6	2.8	98.6
I am extremely dissatisfied	3	1.4	100.0
<b>Total</b>	<b>213</b>	100.0	
Missing	7		
<b>Total</b>	<b>220</b>		

63% (138) of all the respondents said they would like to have feedback on the outcome of this survey.

#### **Would you like to have feedback on the outcome of this survey?**

	No. of respondents	Valid Percent
Yes	138	62.7
No	82	37.3
<b>Total</b>	<b>220</b>	100.0

Over half (56%; 124) of the respondents said they would like to take part in further consultations to improve services.

#### **Would you like to take part in further consultations to improve our services.**

	No. of respondents	Valid Percent
Yes	124	56.4
No	96	43.6
<b>Total</b>	<b>220</b>	100.0

**If you could change one thing about the help you get from Social Services what would it be?**

A wide range of comments emerged (see Appendix I), however, most of the respondents either would like to have more hours of care, help with adaptations and equipment, more information or help from same carer all the time. Actual comments made by some of these respondents are given below.

**Positive Comments**

*"I would just like to say how thankful my mam and I are for having (Care Connect) the Care service. They are a big help to us both; without this help I just don't know what we would do. Added to this we are so grateful for the adaptations provided to help us both. All of this has improved our quality of life. Thank you so much from us both."*

*"My care worker and social worker are both great. They have made a significant difference to my life. I would, in an ideal world, like more home help but understand the implications of budget and financial limitations."*

*"We are very grateful for the help of .....She is only a phone call away and is a great help and support to all our family."*

*"I am very happy with the help that I receive from Social Services. To be treated with respect and dignity by the carers I receive on a daily basis is paramount to my health and well-being. I could not ask for a better service. I do not need any additional services at present. Thank You."*

*"I have a girl who comes to my home to do my shopping as I am semi-disabled and she has always been very helpful and pleasant towards me."*

*"Overall I am happy with the help I get and find my carer very homely and caring in my home and respectful to my wishes and needs."*

*"They have done a lot of things for me and there is nothing I would like to change."*

*"The Social Services have and still do extremely well."*

*"My present and so far only designated social worker has proven exceptionally helpful to adjusting to my condition, MS."*

*"Thanks for the services but would like more visits."*

*"For years I have received no help from Social Services as I didn't need any. I recently needed to contact ..... as I am having problems due to new obstacles. He was extremely helpful even though I am still waiting for the work to be carried out. I think I really need a re-assessment of my needs."*

*"Satisfied with the service so far."*

*"I'm very happy with all the help I've been given and have no complaints."*

*"Happy with the service."*

*"Happy with it, my needs have been considered."*

*"Happy with the service I receive from Social services."*

*"I feel that a basic bath lift could help us all. I need to note I am most grateful for all the aids."*

*"I cannot really think of anything at the moment, but I am now more confident to ask for help and advice due to my Social worker."*

*"I am satisfied with Social Services that provide me with a carer for 1 hour per week."*

*"I am quite happy with the way things are at the moment."*

*"Nothing, very happy with help received."*

*"Would not change get plenty of help."*

*"Get good help from social worker."*

*"Not applicable as all is working well for me."*

*"We are very satisfied with the help from our social worker."*

*"I am happy with the care I get."*

## **More help needed**

*“As my condition worsens my home environment makes me less able to be independent. I should be able to voice my own needs and where possible have that done – but decisions are taken, not by me but a group of people that have never met me and are used to dealing with older people who may or may not have different needs.”*

*“I am filling this form in for my husband; after 2 very bad strokes doesn't talk so we don't know what he knows. I would like him to have respite care to give me a break as he is so frightened of everyone and everything he clings to me for everything. I am his main carer and have been for 4 years. The only break I get is 5 days when my son and daughter look after him for me; that is all they can manage for me.”*

*“Need help with daily things like housework, shopping and someone to call in regularly 2-3 times a week as I'm often bedridden. Don't get help or support I need due to cut backs suffering from this. Care workers slap dash and no time or care to detail or just flick through things; no real help, just quick tidy up in no time at all.”*

*“I used to get 4 hours a week that was reduced to 2 hours. I feel like I need the 2 hours back as the carers do what they can in the 2 hours but I feel I need more.”*

*“As myself and mother are both disabled, it is quite difficult doing the garden and any jobs like decorating in the house. It would be a big help if the garden could be put into an easy way to do i.e. Landscaped. I get very frustrated with not being able to do the things I want to do like I have previously stated. It would mean a great deal to us both if you could help with the garden or decorating.”*

*“I would like help to cope at home”.*

*“More help/visits from Social Services.”*

*“I would like more than 4 hours help a week as my care worker is my only regular visitor.”*

*“To get some help in first place. I get no help whatsoever.”*

*“To get more help as I don't get any at all.”*

*“More hours.”*

*“Change of bed times.”*

*“More help with agoraphobia.”*

*“I really like going to the Minorities day centre. I would love one more day.”*

*“I would like to go up to Kielder for a week this summer please as I have not been away on a holiday for nearly 7 years! Mainly because of disability and my husband needs a break from me as he looks after me. I go to the Minnories day centre in Jesmond.”*

*“Social services are unable to give me the help I really need. It’s not even adequately covered. Need care with things cannot manage and don’t rate as priority so not much help to resolve and address my needs due to lack of funding. Very frustrating coming up against so many things.”*

*“I would like to be provided with services that make me a fully active and included member of society. Social services works to the medical model and therefore fails disabled people. I would like social services to work with organisations of disabled people e.g. Disability Action North East and British Council of Disabled People, not just one local group that it funds and therefore has control over.”*

*“I do need more frequent help from podiatry nurse (at present help is irregular and for between 3 months to 6 months intervals and transport is another problem). My mother’s hands are shaky. My father who used to help me cutting nails is unable to do so because his eyesight is failing especially when his recent cataract operation ended in failure. I have nobody else to help me.”*

*“Help with carer, help with mounting debt. I am immobile a lot of the time and unable to sort my debt out. I am quite medicated which leaves me forgetful and I don’t manage to sort problems out through memory loss.”*

*“Move to bungalow.”*

*“When regular care workers are on holiday or sick, the replacement should be a lot better in their work.”*

*“That my care workers time be extended, she currently gives me 2 hours, to 3 or 4 hours to help me with shopping. The MS has left me unable to carry heavy weights and prevents me from driving.”*

*“I should like more assistance with personal shopping.”*

*“Would like more baths a week (only get 1).”*

*“More hours (visits). I would like more help to enable me to get about more.”*

## **Adaptations and equipment**

*“To have my bathroom fitted with a shower that my wheelchair would push straight into – then I could do a lot more of my personal self care myself – have been waiting since October 2003 for an assessment!!!”*

*“Quicker at delivering large/expensive equipment once it has been agreed there is a need.”*

*“I would like a care worker, also some adaptations, around the house. I am in a wheelchair but the door to the shower and toilet is too small for the chair to go through. I use the commode and have to wait for family to come and empty it.”*

*“I feel I have deteriorated so the bath bar (on my weak side) is dangerous/very inadequate to my needs. I feel that a slight bath lift would help me and my carer.”*

*“Have waited for months for OT assessment for kitchen and bathroom even although grant has been passed. Worried now as the end of the financial year is near and the grant may be void.”*

*“Would like less delay for necessary adaptations to my home.”*

*“I would like them to sort out the shower they had installed.”*

*“I have waited a long time for my shower to be installed. I am sick of getting bed baths.”*

*“I could really do with a stair lift as my legs and back are really bad.”  
“To ask for a bath lift which I am still waiting for.”*

*“A grant for a washing machine (at least) as being incontinent and having hand problems finger movement/grip etc. All my washing I have to do in my bath by hand. No one with this kind of disability should have to endure this pain and suffering.”*

*“Raised toilet seat is very uncomfortable so I struggle without it. My old settee was raised but I changed it and now it isn't and I am struggling with that. I no longer need bath bench as a shower with seat was installed.”*

*“I would like a shower installed.”*

*“I would also like to know about a shower as I have a bath lift but cannot use it as the buttons are too hard to push.”*

## Carer/Support worker

*“That the carers are appropriate for the tasks that are set i.e. capable of using lifting equipment safely. The carers need a lot more training and support from the management team. Carers should be CRB checked they are in contact with vulnerable people.”*

*“Would prefer later night call.”*

*“Have carer to do more cleaning in my home.”*

*“Pick my own carer.”*

*“Some times there is no replacement carer when normal carer is off.”*

*“If I could have a worker who is very good at computers, both software and hardware, and who can set up a computer for me at home and who can come 3 days a week, 2 hours each day coaching me to use the computer would be marvellous.”*

*“There needs to be more continuity. I have several carers calling in the last few years. If one has the same people they will understand one’s needs better.”*

*“If I could have one more hour of carer help it would help a great deal.”*

*“I would like to have help in order to attend social, religious, educational or leisure activities and appointments with dentist, optician etc.”*

*“Please try and help the same care workers always.”*

*“The timing of the evening visit by support workers would be later in the evening; currently 7pm.”*

*“That they assist Community Care, which employs the care worker, to organise themselves more efficiently. Both the care workers and clients would benefit.”*

*“Times which fit in more easily with my very limited social life.”*

*“To have more days from Care Concern as it’s hard for me to use my hands and even walking is hard as I have rheumatoid arthritis. I have a big house and 2 kids and it is hard to keep on top of. I get 2 hours 2 times a week and I could use 2 hours a day for washing, ironing, shopping and housework.”*

*“Not to be messed around changing carers, not having strange faces coming and going.”*

*“I would like the carers to come at times more suitable to my lifestyle.”*

*“To have all my care services from 1 supplier – rather than having to deal with 2.”*

*“That the care for both myself and my mother-in-law who lives under the same roof and share one carer – my wife – could be better co-ordinated and take into account that my wife cares for 2 people.”*

*“That I did not get 4 different people other than the 3 girls I usually get. A change in the agency providing the carer. My carer is very good and I get on really well with her but when she is on holiday I fail to get a replacement from Carewatch even if I contact them to remind them. I am very flexible for times within the constraints of school hours but Carewatch never send anyone or let me know what is happening until I chase them up by which time the times offer are unsuitable. I am not impressed with Carewatch at all and personally would not use that agency if I had a choice as their management is very unsatisfactory - even their workers complain about their lack of organisational skills.”*

*“I would like some respite please.”*

*“I would like to receive a better opportunity to get different and more chances of my total respite care allocation.”*

*I would like to get out more often, also easier contact and higher visibility of my social worker.*

*“To work in conjunction with health services to train my main carers to use my peg feed.”*

*“More commitments and speedier results from occupational therapist.”*

*“If I could change one thing I would make sure the same carer came for me instead of all different.”*

## **Information**

*“Better communications concerning services available and also the changes being made concerning disabled people and carers.”*

*“Are there any classes/courses or centres to help with improving communication, speech, reading and writing that cater for people with*

*disabilities/aphasia/learning difficulties or anything similar that deals with people on a one-to-one basis.”*

*“Happy but would like more information about aids and adaptations – hands free telephone sets.”*

*“More information and practical advice about the complications that arise with my wife’s illness maybe a visit from a health visitor to explain about this.”*

*“To be told more information when you first become disabled and living in your own home e.g. Who can help you? Where to get information, not left for years after being discharged from hospital and having a fall down stairs before help is offered you.”*

*“Give more advice on services available to disabled people i.e. Provide lists.”*

*“More information on financial assistance that I can get. My carer does not receive any payment for what he does.”*

*“I would like information (written) on what services are available i.e. Housework, gardening etc. and the conditions that you need to take up ie. do you need to be on income support etc.; also information about Direct Payments (written).”*

*“Be more aware of what is on offer.”*

*“Faster response to requests.”*

*“More information on what’s on or happening.”*

## **Direct payments**

*“Using Direct Payment more freely instead of being restricted.”*

*“I would like direct payments. I completed the relevant form, months ago, but I have heard nothing in return.”*

*“I would like social services to tell me about direct payments. I don’t get any at all – never have.”*

## **Transport**

*“Current transport facilities arranged via Nexus are not very good i.e. communication with Nexus is often difficult and timing is unreliable. I have one 4 hour “take out” per month at the moment’ I would like to increase it to 2.”*

*“Ambulance transport to hospital which would get me there on time for my appointment not up to three hours late and which would be able to pick me up for the return without having to wait for hours.”*

*“The taxis that take me to my Day Centre are unreliable and never on time.”*

## **Care too expensive**

*“My contributions to the care package are too high.”*

*“Increase more money (£23.67). There was no advance warning for a sudden change in my care.”*

*“Recent cutbacks have made life more difficult.”*

*“My contribution to Social Services was increased by over 200% but my short breaks was cut by one week. I would like this restored.”*

*“Domestic help is required as my carer looks after 2 very disabled people on her own, but both cases are assessed independently and the additional cost would be too expensive given the considerable increase in costs of care in 2003 for both patients.”*

*“Cost at £90 per week for our direct help which is at times very inadequate. We have decided to leave all care from Social Services and go it alone. This is despite all the many promises made when I left hospital of more or less free care and support.”*

*“Inadequate provision of disability equipment and adaptations in the home. Mostly I’ve had to borrow money to find adaptations I’ve desperately needed because your system is so slow, inefficient and humiliating e.g. endless forms, means testing and takes years.”*

## Other

*“I wish that there was a standard catalogue issued to all service users, where if we needed a piece of equipment or needed any adaptations done, all we would have to do is look at the relevant page and say that is item x y z. Because there must be other service users besides myself who have had strokes and find it extremely hard and almost impossible to describe what they may require by way of equipment or adaptations and in that way it would make it easier all the way round.”*

*“Ability to spend the money as we wish rather than as we are told. System is still very patronising.”*

*“Prefer confidentiality. My social worker gave private confidential information to another person.”*

*“When extra help is needed in an emergency situation that there would be a willingness to at least try to help, rather than the over used statement “we don’t have enough staff and other people are our priority”. This has been said on numerous occasions.”*

*“I would like someone to listen to me with respect and give me what I want/need. I’m just the same as them. I am made to feel stupid and inferior as what is said by them with a smiling face usually doesn’t get interpreted that way i.e. I don’t get what they say I will.”*

*“Lack of talks between agencies.”*

*“It would be needs led not budget led. I would be given my basic human rights in a social model perspective. My personal assistants would be paid a salary that reflects their importance and there would be a pool of personal assistants that I could call upon when needing emergency cover.”*

*“Change of day care centre to more active and appropriate stimulating day centre.”*

*“I don’t think I am given enough support from social worker. I would like to see them give more support to people like myself who have a lot of family support but would like to be independent.”*

*“Advice and help with my daughter and debt:- rent and council tax arrears.”*

*“Quite happy but initial response time could be better.”*

*“Friendlier and more flexible.”*

*“Treatment as a person and not as a commodity.”*

*“I would find it useful if I had the E-mail address of either Social Services or my actual Social worker, that way I could E-mail them whenever I had questions to ask, as I cannot always reach them via the telephone. Plus due to my many medical problems I am usually awake in the early hours and my brain is more receptive to what I want to ask or may require from Social Services et al.”*

*“Since my social worker, Jenny, left a couple of years ago I don’t know who my social worker is or even if I still have one. No one has been in touch and I don’t know where to phone if I needed to, other than Disability North.”*

*Please get me the funding for one more day at the Minorities. Please.*

*Respite care needs looking into so that everyone gets a fair chance of their respite care allocation.*

*“With a chronic, severe and deteriorating/progressive condition, funding has always lagged behind my level of care need by at least 2 – 3 years. I believe Social Services lacks a working knowledge of the very high level of care need of severe M.E sufferers. Also, one is discouraged from asking for increasing level of care needs to be met because at each level of deterioration you are told “there is no more funding”. This leads to unnecessary hardship.”*

*“That my short breaks were in the family name and not just mine. This makes break choices limited, as I’m a single parent and need to take the children with me as they help take care of me.”*

*“Not to be struck off the register when in hospital for over 3 weeks, then having to, perhaps, have a change of carers. Yes, you have to be re-assessed for change of care needs, but sometimes you cannot get Social Services carers back, you have to have a changed agency.”*

*“More proactive service would be useful.”*

*“I gave up work to care for Ann, I get the great amount of £43.15 per week; this is a disgrace for a civilised society. It equates to about 50p per hour. The government should be taken to the European court for Human rights; it is just a joke. My rates bill alone is £17.87 per week; this leaves me with £25.28 from the state to live on. This means I have to use my personal resources to survive.”*

*“Budget limitations have reduced available care to 2hrs. – this is by no means enough. At present I pay a training agency for 2hrs. care (Westgate Home Help Services). They are brilliant, flexible and far more human than agencies Social Services have put me with prior to going onto direct payments.”*

*“If others have to make decisions for me – these decisions should be taken as soon as possible.”*

*“Would like continuity of personal social worker to reassess my needs.”*

*“I would like them to listen to me with respect. I know what I need. They only think they do.”*

*“Having had help for approx. 7 years as a disabled person with a child, I feel the service has been greatly reduced/changed. Originally a manager knew each client and their needs and staff were willing to help out/change jobs. Now there are too many managers who don’t know clients well or even their staff.”*

*“Unhappiness of some staff often makes one feel more upset after they leave; though the children and young people workers are excellent and underpaid and undervalued for their excellent work. You cannot compare a person who makes lunch or tea to someone who deals and gives security and continuation of a normal life to children.”*

*“The initial contact with Social Services to help point me in the right direction wasn’t very good.”*

*“I was told 5 years ago that I wasn’t eligible for care worker to help with housework.”*

*“For several years I’ve wanted to move to a new home but am unable to do so because I can’t afford to make my new home wheelchair accessible and your system for providing help is inadequate e.g. you will not assess someone until they have moved into the new home. This is impossible, as I can’t manage to move in until there is a new kitchen, bathroom and other access provided. This system is useless for disabled people living alone who own their home but want to move elsewhere. Grant aid for adaptations should be provided up front. At the moment the people who need the most help do not get any if they move home.”*

*“More one to one with my Social worker to discuss any problems that might occur.”*

*Maintaining flexibility to suit needs is important.*

*“Make sure enough time is given to the service user for personal care tasks.”*

*“Some carers say they are in a hurry as they have extra jobs.”*

## **Health Services**

**If you could change one thing about the help you get from Health Services what would it be?**

The following comments were made by some of the respondents. For details see Appendix II.

### **Positive comments**

*"I have always been quite satisfied with the help and care I have received from the Health services in the past."*

*"No complaints with health Service."*

*"Quite happy."*

*"Good service, no complaints about this service."*

*"Very happy with my support from Health service mainly Hunters Moor."*

### **Ambulance Service**

*"Better ambulance service. Re-think their pick-up service."*

*"The main thing I would like to change would be the ambulance service. What is the point of all the various clinics that I attend making appointment times if the ambulance bureau cannot get it right. If I have an early morning appointment i.e. say 09-30 hrs why does the ambulance turn up 2 hrs. later? Or if I have an afternoon appointment say 14-30 hrs why does the ambulance arrive so early, last time it was 11-30 hrs for a 15-10 hrs appointment plus the clinic I attended did not begin until 14-50 hrs and sitting in a wheelchair for that length of time is very uncomfortable!!!"*

## **Chiropody**

*“Chiropody service very poor.”*

*“A request for chiropody services has been requested twice recently but is still not forthcoming.”*

*“Monthly visit from podiatry nurse to help me cutting nails.”*

*“Would like chiropody service at home.”*

## **GP**

*“To receive the same treatment as other patients i.e. I am the only patient that can only receive repeat or other prescriptions when one named doctor has written and signed; other patients receive prescriptions from any doctor at practice.”*

*“I think my GP should visit routinely (once every 3 – 6 months perhaps?) to monitor my condition. I would also like help to access complementary medicine.”*

*“Too many GP’s – pig ignorant about blindness.”*

## **District Nurse**

*“More flexibility from District Nursing source – would suit me earlier.”*

## **Physiotherapy**

*“I would be given adequate physiotherapy, pain relief and equipment i.e. a wheelchair fit for the environment, bed and shower chair that are easy and safe to use and a method of transport that empowers me and compensates for the lack of accessible public transport. None of the hospitals in this area are accessible and few GP’s and dentists are.”*

*“I would like some physiotherapy.”*

*“More physiotherapy – personal if possible.”*

## **Hospital**

*“To know that if I go into hospital or to the doctors the environment and equipment would be accessible e.g. doors that can be opened, beds that are moveable to allow wheelchair users to be transferred easily with dignity.”*

*“I would like to not have to wait for so long for appointments.”*

*“Better Doctor’s appointment.”*

*“Hospital care appropriate to my disability.”*

*“Hospitals to adopt a holistic approach to separate symptoms/problems.”*

## **Nursing staff**

*“Attitude of the nurses who call at the house; normally the out of hours nurses. They work to suit themselves not their customers. If you question this they can become annoyed. I have complained – no difference.”*

## **Other**

*“For Health professionals to understand how it must feel not to be able to communicate easily for myself (I have Aphasia since my stroke and have developed Epilepsy since) and take more time to explain things, spell out information clearly, give me information about my health problems and not just assume that I know or understand. Realise the enormity of how my stroke has affected and traumatically changed my life and be just a bit sympathetic and understanding. Don’t fob me off or rush me through appointment sessions.”*

*“Make Health Services receptionist more disability aware (e.g. speech problems) so that you could be independent than having to telephone relevant services.”*

*“Help with transportation costs.”*

*“More regular health checks.”*

*“I feel I would like occasional checks on my foot (that has amputated toes) and my ankle/leg (left leg).”*

*“Yes, wish more specialist knowledge and understanding and support with M.E. - dreadful illness left on own no-one to help me medically. Very distressing and anxious don’t get help medically or physically. Lack of support, advice, understanding; lack of most things needed.”*

*“More concern over diagnosis/pain management/long term implications of disablement and how you’re meant to deal with things.”*

*“Improve the quality of Health service professionals (Guardian Report; get rid of 88% of health professionals).”*

*“To get help to walk about.”*

*“Proper help for people who have agoraphobia. It is a mental and physical condition. I’ve went blind, hardly unable to walk – dizzy through it.”*

*“More active continuity of care and more information as to what’s available.”*

*“They should know more about my problems. I have M.S. Have they tried a self-propelled wheelchair up a steep (legal?) short ramp with an outward opening door at the top. I have no carer! I want to be independent but sometimes it is very difficult therefore no-one is bothered.”*

*“I would like all my letters in Braille.”*

*“If you ask for a visit to sort out problems it shouldn’t take months for them to come.”*

*“I am excluded from receiving basic services – dental care, cervical smear tests, regular eye checks, physiotherapy etc. because I am bed bound. These healthcare needs are neglected and compound my difficulties. I believe the Health Service also lacks a working knowledge of the very high level of care need of severe M.E sufferers. Bed bound people should receive regular health checks/monitoring.”*

*“My carer is entitled to 6 weeks respite in any one year as she looks after myself with severe MS and her elderly mother who has had 4 strokes. Organising respite should be easier given the circumstances, only 2 weeks respite were used in 2003. The cases should be looked at together and not separately.”*

*“Not to let people slip through the net. To have frequent contact e.g. Health getting worse, more help if needed.”*

*“Lots of unnecessary paper work and meetings with no practical help. Care workers are paid so little that good staff are hard to find, if not impossible.”*

## **CONCLUSIONS**

This survey covered 18-64 years old physically disabled and sensory impaired service users. 63% of users in the sample responded to the survey. 46% of the respondents were told about direct payments and 22% of respondents used direct payments. Three quarters of respondents who had been using direct payments said that they were well advised and supported in using direct payments. The majority of respondents (between 83%-95%) appreciated the help they were getting from Social Services and agreed that their life would be a lot worse if they didn't have help from Social Services and the help has made them more independent. 86% of respondents agreed that they could always contact Social Services if they needed to. And 71% said that the help they got from Social Services fitted well with practical help from family and friends. 68% of users knew how to complain about Social Services. However, 7% of these said although they knew they could not complain if they wanted to. The majority 84% of respondents said that, overall, they were satisfied with the help they receive from Social Services.

## APPENDIX I

**If you could change one thing about the help you get from Social Services what would it be?**

	No. of respondents
More hours of help/care	10
Same carer all the time/continuity of carer	6
Prefer a later night call	4
More help with housework	4
Better timing of visits/more precise times	3
More information about financial assistance	3
Faster response to requests	2
Better assessment of care needs	2
Better trained staff/train to use the peg feed	2
More days/hours at the day centre	2
I need a bath lift	2
More respite care needed	2
Help with garden	2
More influence over decisions that affect me	1
Service should be needs led not budget led	1
My contribution to Social Services has increased by 200%	1
Someone to come & train me how to use a computer	1
Quicker delivery of large expensive equipment	1
Convert bathroom to a shower with wheelchair access	1
Prompt visits when requested	1
Grant for a washing machine	1
Care workers agency is unprofessional	1
Social Services should have paid for my equipment	1
Be made more aware of whats on offer	1

More flexible friendlier service	1
More assistance with community care	1
Initial response could be better	1
Treatment as a person not a commodity	1
Being able to contact social worker via email	1
Make it easier to contact Social Services	1
Prefer 1 supplier for care rather than 2 different suppliers	1
More help to be able to attend social events	1
Provide more info of what is available to the disabled	1
Social workers to respect the client confidentially	1
More choice with short breaks	1
More regular health check ups	1
More personal care	1
Speedier results from occupational therapist	1
Less red-tape	1
Better cover when carer is sick/on holiday	1
Better communication between the agencies	1
Increase benefits to carers who have finished work	1
Direct payments	1
Social Services should keep its promises about service	1
More help from social worker	1
More financial advice/how to budget	1
Being able to choose my own carer	1
Better customer care/ to be treated with respect	1

I receive reduce care as my health deteriorates	1
less restrictions when using direct payments	1
Better emergency cover	1
More one to one contact with social worker	1
Better day centre with better activities	1
Shower installed at home	1
A more proactive service	1
Total	88

## APPENDIX II

**If you could change one thing about the help you get from Health Services what would it be?**

	No. of respondents
More help/ contact hours	6
More regular health checks	4
More physiotherapy/ more adequate physio service	3
Better access to chiropody	3
Quicker appointment system	3
Better ambulance service to meet my appointment times	3
Better diagnosis/ better pain management	2
Sort out my shower	2
Better provision of disabled equipment & adaptations at home	2
Better quality health service professionals	2
More information from health authorities	2
Monthly health visitors	2
Same carer all the time/continuity of carer	2
Better trained receptionists	1
More information provided in Braille	1
Grant for a washing machine	1
A regular supply of cannabis	1
Don't relocate Hunters Moor to Walkergate	1
More help with personal shopping	1
Bath lift is needed	1
Hospital care that is appropriate to my disability	1
More knowledge about disabled accessibility at hospitals	1
More regular visits from health visitors	1
Better timings for carer visits	1
Faster/ more responsive service re mobility problems	1

Service Doesn't have a working knowledge of high level care	1
Easier access to respite care	1
More time/hours/days at the day centre	1
To be treated the same as other people for prescriptions	1
Better trained staff/train to use the peg feed	1
Dental health costs	1
I would like a social worker	1
Visiting physiotherapists	1
Speed up the delivery of equipment	1
Hospitals to have holistic approach to separate problems/symptoms	1
There is too much unnecessary paperwork	1
Help with transportation costs	1
More flexible district health service	1
More help to walk about	1
Proper help for people with agrophobia	1
Doctors to understand blind people better	1
Better attitude from out of hours nurses	1
Total	65

### APPENDIX III

**18a. Please write any other comments you would like to make about the help that Social Services organises for you or any additional services that you would like to receive in this box.**

	No. of respondents
Very pleased with the level of care received	37
Need more hours/ would like more hours	7

My financial contribution to Social Services has increased	3
Same carer all the time/continuity of carer	3
Budget limitations have reduced availability of care	3
More information about services provided and costs	3
Quicker decisions on issues that affect me	2
Better access to chiropody	2
Initial contact with Social Services to help my needs was not very good	2
More financial freedom to spend money as we wish	2
Would like a shower	2
More access to transport	2
Would like to move to a bungalow	1
Grant for a washing machine	1
Social Services only provide me with taxis to day centre	1
More information about my rights to equipment	1
More help with personal shopping	1
Social Services medical model fails disabled organisations	1
Better timing of carers visit	1
Grant Aid to be paid up front	1
Stair lift is needed	1
Carer who looks after 2 patients need better assessments	1
Faster assessments	1
More respite care	1
Better communication of what services are available	1
More help with speech therapy	1
An outside window cleaning service needed	1
Better cover when carer is sick/on holiday	1
Maintaining flexibility to suit needs is important	1
Social workers should be easier to contact	1

I need a reassessment of my needs	1
More financial advice/how to budget	1
Better/ fairer respite care allocation	1
Listen to me with respect/ respect my opinions	1
Need more disabled adaptations to my home	1
I would like an evening call	1
Too many managers at S Services Don't know their clients	1
Would like a holiday break	1
More reliable transport to day centre	1
would like more baths a week	1
Information about aids & adaptations	1
Information in my own language	1
<b>Total</b>	<b>91</b>

**18b. If you need additional services can we give your name to the Social Services.**

	No. of respondents
Yes	100
No	45
<b>Total</b>	<b>145</b>
Missing	75
<b>Total</b>	<b>220</b>

#### **APPENDIX IV**

**Do you have a learning disability?**

	No. of respondents	Valid Percent
Yes	27	12.6
No	187	87.4
<b>Total</b>	<b>214</b>	<b>100.0</b>
Missing	6	
<b>Total</b>	<b>220</b>	

**Did you fill in this questionnaire by yourself or did you have help from someone else?**

	No. of respondents	Valid Percent
I filled it in myself	98	44.5
I had help from a family member/friend	81	36.8

I had help from a care worker	22	10.0
Telephone interview	10	4.5
Face to face interview	9	4.1
<b>Total</b>	<b>220</b>	<b>100.0</b>

**Would you like to have feedback in**

	No. of respondents
Standard print	92
Large print	33
Braille	1
Audio tape	1
Computer disc (CD)	6
Standard print & CD	1
<b>Total</b>	<b>134</b>

**Specify other language**

	No. of respondents
Urdu	1
French	1
Punjabi	3
<b>Total</b>	<b>5</b>

**Email address**

	No. of respondents
Yes	14
Not applicable	204
Missing	2
<b>Total</b>	<b>206</b>

**IF you would like to take part in further consultations Social Services would like to have your details so that they could contact you. Can we give them your details.**

	No. of respondents
Yes	121
No	3
<b>Total</b>	<b>124</b>
Not applicable	96
Total	220