



Deafblind Direct consultation report

Deafblind people and families' experiences of direct payments

February 2008

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Executive Summary

This report presents research into the experiences of deafblind people and families in relation to direct payments. The research was carried out as part of Deafblind Direct, Sense's direct payments project.

A consultation with deafblind people and families was carried out from June to November 2007. Detailed information was gathered from deafblind people and families currently using direct payments and those who had thought about using direct payments. The research covered particular aspects of direct payments, including some of the key factors that help or hinder the uptake of direct payments among deafblind people and families. Respondents had varying experiences of direct payments, making it clear that while some thought they benefited from receiving direct payments, there are a range of challenges.

Respondents included comments on the following:

- The hourly rate of direct payments
- One-off direct payments
- Direct payments information provision
- Why individuals may choose to receive direct payments and why they may not
- The impact of direct payments on individuals' lives and attitudes towards direct payments
- Barriers hindering take up of direct payments
- Recruitment of appropriate staff
- Managing direct payments

The research also highlighted cases where it seems that the Department of Health statutory guidance documents on direct payments (2003) and the Deafblind Guidance (2001) are not being implemented correctly.

The research also looked into other relevant initiatives, including

- Self-directed care initiatives
- The Independent Living Fund (ILF)

Respondents suggested a range of actions and the report brings together recommended actions for Sense, other organisations and local and national government.

1. Introduction

1.1 Sense

Sense is the leading national charity that supports and campaigns for children and adults who are deafblind. Sense has worked with deafblind people and their families for 50 years. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. We have established services and campaigned vigorously for change where it is wanted - earning us our worldwide reputation as the leading experts in deafblindness. In addition, we support people who have sensory impairments with additional disabilities. We offer support and services to individuals with a single sensory loss and additional disabilities as sometimes Sense services or expertise can be suited to meeting the needs of such individuals.

1.2 Deafblindness

Deafblindness is a combination of both sight *and* hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people face major problems with communication, access to information and mobility. People can be born deafblind, or become deafblind through illness, accident or in older age. Deafblind people may identify themselves differently, for example as deafblind, a person with Usher syndrome,¹ a person with dual sensory loss or Deaf visually impaired. For the purposes of this report, the term 'deafblind' is used to cover respondents with dual sensory loss, as well as those with a single sensory loss and additional disability. Further information on the causes of deafblindness is found in the glossary. There are about 27,000 people in the UK who have a serious impairment of both vision *and* hearing. Some of these people are completely deaf and blind, but many have some remaining use of one or both senses. A further one in six people over the age of 60 experience some degree of combined sight and hearing problems.

1.3 Deafblind Direct

Deafblind Direct is Sense's project about direct payments. This project aims to fill a gap in information about direct payments that is available to deafblind people and families. Deafblind Direct is funded by the Department of Health.

1.4 Direct payments

Direct payments are money given to an individual by social services to buy the support that they have been assessed as needing. An individual can take this payment instead of using a service provided by social services. Direct payments

¹ See glossary

can be used to pay for a range of assessed needs, including communicator-guides, intervenors, short breaks, and equipment. The individuals who can receive direct payments are: disabled people over 16 years old, older people and carers over 16 years old, including people with parental responsibility for a disabled child.

1.5 Planned aims for Deafblind Direct

The planned aims of Deafblind Direct are:

- Producing appropriate information on direct payments in a range of formats
- Providing a direct payments advice service for deafblind people and families
- Creating a directory of communicator-guides
- Providing specialist deafblind awareness training for services that support disabled people and families to use direct payments

2. The Deafblind Direct consultation

2.1 The Deafblind Direct questionnaires and consultation events

From June to November 2007, deafblind people and families were consulted about this new project. Individuals had the opportunity to fill in paper or computer-based questionnaires, respond to questionnaires over the phone or attend consultation events. In June 2007, Questionnaire 1, a short initial survey, was sent out to all Sense members and other contacts. This asked individuals to briefly state their experience and/or knowledge of direct payments (DP) and to request longer questionnaires as appropriate.

Following on from the initial survey, individuals could request either Questionnaire 2 for people who currently use direct payments or who have used them in the past, or Questionnaire 3 for people who have thought about using direct payments but have decided not to. Following requests from respondents, Questionnaire 4 was also produced for people who said that they wanted direct payments, but who were then told this was not possible.

In October, there were two consultation events. One was aimed at British Sign Language (BSL) users who might have found it hard to access a questionnaire in English. The other was aimed at deafblind people or families.

In November, a consultation session was held at Sense Forum with a group of deafblind people and family members who are active within Sense. This consultation differed from the other events and questionnaires. The group was asked to comment on a selection of issues drawn out from the rest of the consultation.

2.2 About the people who took part in the consultation

2.2.1 Questionnaire 1

71 responses were received.

Table 2a: Responses to Questionnaire 1

Who responded?	Number (out of 71)	Percentage
Parents of deafblind people	33	46%
Deafblind people	24	34%
Individuals on behalf of a deafblind person	12	17%
Anonymous	2	3%

Table 2b: The ethnicity of respondents to Questionnaire 1

Ethnicity	Number (out of 71)	Percentage
People who identified as white	62	87%
People who identified as white other or BME ²	5	7%
People who did not give their ethnicity	4	6%

Table 2c: What were respondents' experiences and/or knowledge of direct payments?

Group	Currently use DP	Have used DP in the past	Thought about using DP, but decided not to	Decided to use DP but was told it was not possible	Do not know what DP are
Deafblind people	8	-	7	1	8
Parents	12	1	8	1	10
Individuals on behalf of a deafblind person	7	-	2	1	3
Anonymous	1	-	-	-	1
Total (out of 71)	28	2	17	3	22
Percentage	39%	3%	24%	4%	31%

In some cases respondents marked two options as they had experiences from different local authorities or had parental responsibility for more than one child.

31 individuals requested Questionnaire 2 for people who use direct payments, or who have used direct payments in the past.

22 individuals requested Questionnaire 3 for people who have thought about using direct payments, but have decided not to.

3 individuals requested for a questionnaire for people who wanted to use direct payments but were told it was not possible. This resulted in Questionnaire 4 being written.

2.2.2 Questionnaire 2

20 responses were received; all of those who replied were current direct payments users.

² Black or minority ethnic

Table 2d: Who responded to Questionnaire 2?

Who responded to Questionnaire 2?	Number (out of 20)	Percentage
Parents of deafblind people	9	45%
Deafblind people	6	30%
Individuals on behalf of a deafblind person	5	25%

Table 2e: The ethnicity of respondents to Questionnaire 2

Ethnicity	Number (out of 20)	Percentage
People who identified as white	19	95%
People who identified as white other or BME	1	5%

2.2.3 Questionnaire 3

Table 2f: Who responded to Questionnaire 3?

Who responded to Questionnaire 3?	Number (out of 19)	Percentage
Parents of deafblind people	10	53%
Deafblind people	5	26%
Individuals on behalf of a deafblind person	3	16%
Anonymous	1	5%

Table 2g: The ethnicity of respondents to Questionnaire 3

Ethnicity	Number (out of 19)	Percentage
People who identified as white	16	84%
People who identified as white other or BME	2	11%
People who did not give their ethnicity	1	5%

2.2.4 Questionnaire 4

Out of the 3 requests that were made for this questionnaire, only one person has so far replied. So it is most appropriate to include their comments in other parts of the report.

2.2.5 Consultation events

In total, 27 people attended these 3 events. 9 deafblind people (including a deafblind parent) and 18 parents attended. 13 attendees were current direct payments users. 14 attendees did not currently use direct payments.

3. Deafblind people and families using direct payments

- 13 out of 20 respondents started to use direct payments in 2004 or later
- Individuals use direct payments to pay for a range of support needs
- Individuals are sometimes unclear about what they are entitled to spend a direct payment on
- Individuals may use direct payments for all their support needs or some of their needs
- Individuals may decide to use direct payments for some of their needs because they are the best or only way to get specific services
- The majority of deafblind respondents used direct payments for all their needs
- Family members are more likely to use direct payments for some of their needs
- There are some differences between what deafblind people and what family members use direct payments for

Table 3a: What have you used direct payments for? (Questionnaire 2)

How much are direct payments used?	Deafblind people (out of 6)	Family members (out of 14)
For all needs	5	3
For some needs	1	10
Not specified	-	1

Deafblind respondents used direct payments for the following areas:

- Guiding and communication support
- BSL relay interpreting and BSL interpreters
- Support with reading mail and accessing email
- Hospital and doctor's appointments³
- Cleaner, gardener, everyday tasks, housework, preparing meals, washing and ironing, shopping
- Human support to attend courses and go to college
- Exercise and swimming
- Socializing and leisure activities, including football matches, concerts, cinema, visiting family, celebrations, clubs
- Travel and holidays

³ Individuals should not have to use their support hours for these appointments as the Disability Discrimination Act (1995) requires service providers to make reasonable adjustment to the way in which they provide their services. Providing an interpreter at a medical appointment or information in an accessible format are examples of a reasonable adjustment. When deciding if an adjustment is reasonable, the size and nature of the service provider and the resources available to them can be taken into account.

As one respondent pointed out, staff may be asked to perform a range of tasks:

‘I use direct payments to pay for people who work with me in a variety of tasks – both simple and demanding’

Family members said that they used direct payments for the following areas:

- Intervenors, carers, communicator-guides, enablers and befrienders, babysitting
- Equipment, a computer, printer and webcam
- Guitar lessons
- Sports club membership
- Outings and ‘access to leisure’ in both the daytime and evenings, including an after-school club, McDonalds, cinema, bowling, visits to the zoo, art class
- Respite and Sense holidays

4. Direct payments hourly rates

- The hourly rate of direct payments can vary greatly between individuals
- Only some individuals are being awarded a high enough rate to recruit staff with the specialist skills to meet their needs
- The correct hourly rate varies according to local levels of appropriate staff as well as the local area and economy
- Individuals can be offered what the local authority calls a 'higher rate', but this is often not enough to recruit staff with the skills they need
- A number of respondents successfully negotiated an adequate rate to cover recruiting someone with specialist skills, as well as the costs related to employing people
- Legal advice or involving a solicitor helped some respondents to negotiate a correct rate
- Respondents were not clear on whether rates include provision for income tax, National Insurance, Statutory Sick Pay (SSP), holiday pay, training costs, staff handover and expenses

Respondents expressed concern that the rate of direct payments affected their ability to recruit staff with the right skills. The Department of Health (DH) guidance on direct payments states that the amount of direct payments:

'must be equivalent to the council's estimate of the reasonable cost of securing the provision of the service concerned... This means that the direct payment should be sufficient to enable the recipient lawfully to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service. There is no limit on the maximum or minimum amount of a direct payment either in the amount of care it is intended to purchase or on the value of the direct payment.'⁴

However, one response presents a serious problem:

'I was given only £6/hr to employ a carer for an epileptic deafblind child. When I said that wasn't enough, the manager said to reduce the number of carer hours if I wanted to pay more.'

The hourly rate should be enough to recruit specialist staff and the above suggestion should not have been made as it contradicts the DH direct payments guidance. Indeed, a maximum or fixed 'higher' rate creates difficulties for deafblind people and families.

Respondents also noted that expenses are not always part of a direct payment:

⁴ Department of Health, Direct Payments Guidance, 22

‘...if the travel and accommodation expenses for the support persons...are not part of direct payments...it has to come from my own money. It can be very expensive when you bring two people with you...’

Yet the DH direct payments guidance states that:

‘local councils should include all costs that are necessarily incurred in securing provision...such costs might include recruitment costs, National Insurance, statutory holiday pay, sick pay, maternity pay, employers’ liability insurance, public liability insurance and VAT.’⁵

The need to have two support staff is sometimes applicable to deafblind people who have specific communication needs or the need for a guide and an interpreter. Again, this is something that must be considered when local authorities are setting the rate.

‘You are not allocated anyway near the amount of hours needed e.g. hoisting – at school or children’s hospice you have to hoist with two people (legally), at home you’re expected to manage on your own.’

So, it is important that individuals know that it is possible to negotiate for an appropriate hourly rate, number of staff hours and appropriate staff ratios and how they should go about this. Respondents stated:

‘I discovered the hard way that I could negotiate an increase in [the] standard rate to pay for specialist skills e.g. BSL and deafblind awareness.’

‘[The local authority] were reluctant to pay the “going rate” but have agreed that £25.00 an hour is the sort of rate they would have to pay someone if they got someone in themselves for a communicator-guide BSL user.’

There is also a lack of clarity on how the rate of a direct payment can be changed if an individual’s needs change:

‘What happens if more money is suddenly needed... [or] if the provider has to put the fees up?’

Some respondents were concerned that direct payments are viewed as a cheaper option for local authorities and therefore direct payments packages would not be properly funded to provide an appropriate hourly rate. This issue is extremely important; research has noted that a lack of flexibility in hourly rates results in difficulties for both current and potential direct payments users.⁶

⁵ Department of Health, Direct Payments Guidance , 23

⁶ Department of Health, Modernising Adult Social Care- what’s working, 72

5. One-off direct payments

- Only some people are offered one-off direct payments
- Some respondents knew very little or nothing about the possibility of receiving one-off direct payments
- One-off direct payments are often to pay for equipment, short breaks (respite) or holidays
- Some respondents said they felt it was easier to get a one-off payment than a regular direct payment

Respondents had a varying level of awareness of the possibility of receiving one-off direct payments. Some respondents didn't know that it was possible to receive a one-off direct payment.

As one respondent expressed, one-off direct payments can very useful and easy to manage:

'It seems that direct payments for equipment, one-off payments, or payments for specific activities or classes are simple. It becomes more complicated when employment of staff is involved.'

Deafblind people and families may benefit from receiving one-off direct payments, but in some cases a low level of awareness of them seems to prevent this.

6. Information about direct payments

- Respondents initially heard about direct payments through a variety of means
- One third of respondents heard about direct payments from their social services department or local authority
- Deafblind people and family members have had varying experiences of accessing information about direct payments
- Both deafblind people and families had both negative and positive experiences
- Information about direct payments is sometimes given to deafblind people in inaccessible formats
- Individuals are sometimes overwhelmed by both the amount of information available and conflicting advice
- Some respondents felt they often or always had to ask for information, rather than be offered it
- There are gaps in the provision of good information on some of the ‘finer points’ of using direct payments

Table 6a: ‘How did you find out about direct payments?’ (Questionnaires 2 & 3)

How did you find out about DP?	Number (out of 39)	Percentage
Social services, social worker, local authority	13	33%
Sense	7	18%
Family member or friend	5	13%
Local voluntary organization	4	10%
Usher UK	2	5%
Joint Agency Team	2	5%
Independent Living Fund (ILF)	2	3%
Review at care home	1	3%
Workshop	1	3%
Specialist health visitor	1	3%
Parent support group	1	3%

It is important to note that only one third of respondents initially heard about direct payments through social services, social workers or the local authority.

‘[I] didn’t have a problem with the social services [department] as they already knew about this and I was their first ‘deafblind’ person in the borough to use direct payments.’

‘My social worker has not told [my daughter] or myself anything about direct payments, but my friend said she wouldn’t do without it [direct payments].’

‘I did not know anything until this survey came.’

It seems that individuals’ personal networks with both national and local organisations, family members and friends are good means of them learning about direct payments. Responses included comments that if a deafblind individual is in a residential placement, contact with social services is less, so there is less chance of families hearing about direct payments. Individuals should hear about direct payments from social services teams. Indeed:

‘Wherever a person is assessed as needing social care services, a council should check whether there is a duty to make a direct payment in respect of that service.’⁷

Yet it seems that the statutory requirement to offer direct payments is not always adhered to. Many respondents mentioned that information about direct payments should be balanced and it is crucial to stick to DH direct payments guidance that ‘recipients of services should not be unfairly influenced in their choices one way or the other.’ As stressed above, individuals must be presented with a real choice between services provided by the local authority and direct payments and must feel that whatever option they choose, it will be properly resourced. If individuals are thinking of choosing direct payments, it is important to start thinking about this during the assessment process as this can have an impact on how effective and resourced the direct payments package will be.

Table 6b: ‘What did you think about the information you received on direct payments?’ (Questionnaire 2, respondents often made more than one comment)

What did you think about the information you received about direct payments?	Number (out of 20)	Percentage
Confusing/complicated/hard to understand	6	30%
Good/ Fine/informative/very helpful	6	30%
Minimal/too little/poor	4	20%
No guidance on employers’ responsibilities	3	15%
Too much	2	10%
Inaccessible	2	10%
Stressful/anxiety-creating	2	10%
Irrelevant	1	5%
No scenarios	1	5%
Vague	1	5%
Satisfactory	1	5%
I wasn’t prepared for any negative aspects	1	5%
No guidance on health and safety	1	5%
Didn’t get any	1	5%

⁷ Department of Health, Direct Payments Guidance, 4

It was felt most useful to ask people that had started to use direct payments what they thought about the information they received, as they would have also had firsthand experience of using direct payments. Although there were some positive responses about the quality of information, over 75% of comments were negative. Receiving inconsistent or contradictory information served to confuse individuals more and generate extra stress and anxiety. Some respondents received incomplete or no information.

‘It was a bit complicated at first, due to the amount of direct payments information and its policies.’

‘[Need] clearer info on what it can be used for (as opposed to what it can't).’

‘I have repeatedly requested info around risk assessment and health and safety training for employees – not forthcoming.’

It is also very important to add that although information may be good quality, cases were reported of good information being presented in an inaccessible format. One Braille user commented that ‘the information was fairly comprehensive but inaccessible.’

7. Why respondents chose direct payments

- 30% of respondents who use direct payments said they chose direct payments because of the flexibility and choice they can offer
- 25% of respondents using direct payments said that they had to choose direct payments because the local authority would not provide a service
- Some individuals feel they will get a better service through direct payments than through a local authority service or feel that the local authority service does not give them enough support
- Some individuals choose direct payments because they have identified a person they want to employ to provide support
- Other reasons why people choose direct payments include: direct payments being suggested by care managers or social workers, poor levels of service from an agency, being able to control recruitment and as an opportunity to address changed needs
- Pressures on local authorities to increase the uptake of direct payments could have an impact on individuals' choice

Table 7a: 'Why did you choose to use direct payments?'

Why did you choose to use direct payments?	Number (out of 20)	Percentage
Flexibility or choice	6	30%
No choice or other service available	5	25%
Insufficient services from LA	4	20%
Social services supported it	3	15%
To use an existing or identified person	3	15%
Poor service from an agency	1	5%
To control recruitment	1	5%
To address changed needs	1	5%

Individuals do see direct payments as a way of having more choice and flexibility in the service that they receive. The participants at Sense Forum generally agreed that direct payments do promote flexibility and choice 'in theory'. An adequate budget, recruitment difficulties, individuals' location and ability to manage direct payments were all given as barriers to this being a reality.

However the fact that over a quarter of respondents to Questionnaire 2 said they chose direct payments because they would not get any other service is of grave concern. Respondents' comments included:

'No choice. Local Authority Children with a Disability Team withdrew Homecare support for children. We used to receive 3 hours "respite" per week.'

‘So I could find my own supporters/carers and then pay them. If I had waited for social services to find me carers I would have waited ages.’

‘Because our social worker was an obstacle to me getting overnight payments. He would lose or not sign forms or not respond to our messages.’

So local authorities or their staff are sometimes either unwilling or unable to provide a service. Yet, as stated in the DH direct payments guidance:

‘The council should also make clear that a person does not have to agree to a direct payment and that it would arrange services in the normal way if someone decides not to accept direct payments.’⁸

Clearly for some respondents this is not happening, yet the Deafblind Guidance⁹ states:

‘Councils need to recognise the importance of providing appropriate services to deafblind people. This may mean commissioning services that are specifically designed for deafblind people.’¹⁰

It is well-documented that many deafblind people, both children and adults are not being identified by local authorities, receiving the correct assessment or the services that they should be.¹¹ It is important to ask whether local authorities are offering direct payments as a means of escaping from their duties under social care legislation as well as the statutory Deafblind Guidance. Once individuals have consented to accept direct payments (for whatever reason, including thinking that this is the only way to actually receive any kind of service), many responsibilities are transferred to that individual, and the local authority has to a certain extent fulfilled its responsibility in providing a service. This has created a considerable amount of suspicion about direct payments; one respondent stated:

‘I think the government is exploiting vulnerable parents and calling it ‘empowering’. It is actually exhausting!’

Since 2002-03, the uptake of direct payments has been included as an indicator against which social services’ performance is rated.¹² So there is considerable emphasis on local authorities needing to increase the uptake of direct payments. This prompts concerns about whether, in some cases, direct payments are promoted to improve department ratings, rather than for the benefit of a service user.

⁸ Department of Health, Direct Payments Guidance, 14

⁹ See glossary

¹⁰ Department of Health, The Deafblind Guidance, 7

¹¹ Sense, Local Authority Survey 2006, 5-6 and Sense, Breaking Out 2007

¹² Department of Health, 2002-03, Performance Assessment Framework Indicator, A0/ C51, 114

8. Why respondents did not choose direct payments

- There is a large range of reasons why respondents had so far decided not to use direct payments
- Over half of respondents did not want the extra responsibility of direct payments
- Over half of respondents said they were happy with the current situation
- Just under half of respondents felt that there were not enough support services for direct payments users. This would undoubtedly have affected their decision not to take on the extra responsibility of direct payments
- Issues around recruitment and employment are important issues when people are deciding whether to use direct payments or not
- Respondents were split relatively evenly on whether they thought they might use direct payments or not in the future

Table 8a: 'What issues led you to decide not to use direct payments?'
(Respondents often made more than one comment)

Issue	Number (out of 19)	Percentage
I did not want to take on the extra responsibility	11	58%
I was happy with the current situation/traditional services provide what is needed	10	53%
There aren't enough support services for direct payments	9	47%
It is hard to find qualified or experienced staff	8	42%
I did not want to become an employer	8	42%
I worried about staff cover for sickness and resignation	7	37%
I think direct payments create more risk	6	32%
The council did not have enough information	5	26%
I did not feel able to manage direct payments	5	26%
I was unable to employ a relative who lives in my house	5	26%
The council has a limit on direct payments	3	16%
I prefer to rely on the council, rather than family	2	11%
The process was taking too long, so I gave up	2	11%
Negative feedback from others	2	11%
Powerless to fight social services' obstacles/negotiate	2	11%
Not understood if eligible/confusion about means-testing	2	11%
Council staff discouraged me from using direct payments	1	5%
Independent Living Fund paperwork is taxing	1	5%

Issue	Number	Percentage
More funding is needed	1	5%
The legal aspects	1	5%
Who will provide training?	1	5%
Rural location affects recruitment and activities	1	5%
The pressure on family members	1	5%
A residential service is a better means to address needs	1	5%
Mental health issues of carer	1	5%
Purchasing power of social services is stronger than individual	1	5%

Improved provision information and support services to deafblind people and families who may want to use direct payments could lead to more individuals wanting to take on direct payments. However, it is important to provide information and support that serves to reassure potential direct payments users as well as making them fully aware of what it is they would be accepting to take on as a direct payments user. Individuals highlighted specific areas where information is unclear and this can be very off-putting. Information on issues such as the law, employing people, insurance, risk and health and safety, needs to be adequate in order for people to feel they are making a fully-informed decision.

Table 8b: 'Would you want to use direct payments?'

Would you want to use DP?	Number (out of 19)	Percentage
Yes	5	26%
No	5	26%
Maybe/ not sure	4	21%
Blank	3	16%
Other	2	11%

Some respondents did not see how direct payments would add anything of a value to a deafblind person:

'With [Sense's] support, [our son] accesses all the community-based activities which are of value to him. We are quite certain this would not be possible under a direct payment system.'

'I believe they are right for some people with less complex care needs but for some I feel it would be like running a business for nothing.'

Some respondents had the perception that direct payments may not be appropriate for addressing the needs of deafblind people:

'I think they are brilliant for young people with a physical disability, to allow them to employ a P.A. [personal assistant] who fits their needs.'

9. The impact of direct payments on respondents' lives and their attitudes towards direct payments

- 65% of respondents felt that direct payments had changed things for the better
- 10% thought services through direct payments were good
- Deafblind people seem to be more certain than families that direct payments have brought improvements
- Families often identified an improved service but qualified their responses
- In some cases receiving direct payments may be better than no service at all, rather than an improvement on a service provided by the council
- Deafblind people also expressed more often that direct payments gave them 'a lot' of control over their support
- Families often thought they had 'some' or 'enough' control over their support
- Some respondents expressed concern over whether the idea of service users being in control has been distorted

Deafblind people provided more unqualified answers to the question 'Have direct payments changed things for the better, worse or are they the same?' Families often added that the responsibility of a direct payment is often a considerable downside as well as the uncertainty if staff do not deliver. In some cases a service provided through direct payments was considered better than not getting **any** service, rather than it being an improvement on a service provided by the council.

Table 9a: 'Have direct payments changed things for the better, worse or are they the same?'

Have direct payments changed things for the better, worse or are they the same?	Deafblind people (out of 6)	Family members (out of 14)	Total (out of 20)	Percentage
Better	5	8	13	65%
Good	-	2	2	10%
Same	-	2	2	10%
Other	1	1	2	10%
Worse	-	1	1	5%

'Direct payments have made mine and my son's life better.'

'Better, you can organise your own life more...'

‘When I have a worker, on balance they are better for my son as he is able to go on outings just for him. For me [mother] it is just more paperwork and very stressful when someone leaves.’

‘Direct payments have been good for evenings out and have given me a break.’

‘Worse much WORSE, I seem to spend nearly all my time organising care for my severely disabled deafblind son. If a carer is ill, there is no cover...it takes me hours to organise patchy cover. Therefore it is impossible for me to have any job or life as I have to be around constantly. Bring back properly qualified, trained and vetted homecare – they were wonderful.’

Table 9b: ‘How much control do you have over the services you buy through direct payments?’ (Questionnaire 2)

How much control?	Deafblind people (out of 6)	Family members (out of 14)	Percentage
A lot	5	4	45%
Enough	-	4	20%
Some	1	4	25%
Little	-	1	5%
None	-	1	5%

Respondents cited recruitment difficulties, lack of choice over appropriate support and the need to involve legal practitioners as reasons why they felt the level of control they had was adversely affected.

‘It would help if I had more control over how I use my direct payment.’

‘It’s a total myth to think we have more control. Direct payments are based on laziness (on behalf of the local authority) just handing over huge amounts of money and assuming no responsibility.’

10. Barriers hindering deafblind people and families when using direct payments

- Finding qualified and experienced staff was the biggest hindrance for people wanting to use direct payments
- Other major barriers were: local authorities' lack of promotion of direct payments, worries about staff sickness and cover and the lack of support services for direct payments users
- Respondents identified a broad range of barriers and concerns

Table 10a: 'Have you encountered any of the following issues when using direct payments?' (Questionnaire 2)

Barrier	Number (out of 20)	Percentage
It's hard to find qualified or experienced staff	14	70%
The council has not promoted direct payments enough	10	50%
I worry about staff cover for sickness or resignation	10	50%
There aren't enough support services for direct payments	9	45%
I have difficulty acting as an employer	6	30%
I don't want to take on the extra responsibility (for example paperwork)	6	30%
The council has set a limit on direct payments	5	25%
I think direct payments create more risk	5	25%
Council staff don't know about direct payments	4	20%
I cannot get enough information about direct payments	4	20%
I am not supposed to employ a relative who lives in my house	4	20%
I have a problem organising CRB checks	2	10%
I don't feel confident enough to manage direct payments	2	10%

Respondents also added other barriers:

- Managing staff
- Paying Statutory Sick Pay
- Issuing P45/P60
- Carers not giving notice/carers need to be more committed
- Need for clarity on employing relatives

- No information on carers' access to services
- Need info on each local authority's procedure
- Opening a bank account on behalf of an adult
- Setting up a trust account
- Money being paid into wrong account
- Local authority insisting on print versions of bank statements (when a deafblind person receives them in Braille)
- Needing information on auditing
- Not enough hours of support
- No account of time or expense taken by families when managing direct payments
- Expected to manage with fewer staff at home rather than in other settings (for example with hoisting)
- End of year online financial returns
- Different dates or deadlines for different funding and invoicing
- Expenses or transport not being covered by direct payments
- Having to spend each week's direct payment in the same week
- Local authority set a limit on how much money should be in a direct payment account at any one time
- Needing to explain an underspend
- Being told to use unqualified staff or possibility of losing DP
- ILF want a separate account to the direct payments one, even though they both fund the same care
- Local authority are unclear what can be in an ILF account
- Transition difficult
- No training group for DP users
- Service user feedback meetings hard to attend
- Feel deserted

No respondent marked the option that the local authority said that they thought they were unable to manage direct payments. This may be a sign that assumptions are not being made about people's capacity to manage direct payments with or without appropriate support. However, given that a good number of respondents felt they were not getting enough information about the 'finer points' of direct payments, it is important to ask if social services staff should spend more time exploring management issues with potential direct payments users.

11. Recruitment of appropriate staff

- Both deafblind people and family members employ staff themselves, recruit self-employed staff and use staff from agencies
- Respondents shared many positive and negative experiences of recruitment
- The difficulty in recruiting staff can have a large impact and affect the independence of individuals

Factors that can aid recruitment

- Receiving an appropriate hourly rate
- Recruiting locally or using local contacts
- Meeting people face-to-face
- Employing family members
- Employing people who already know an individual's preferred means of communication
- Being clear on methods of managing staff and what is expected of them
- Trying to recruit staff who can interpret and guide

'It has only been worthwhile because we have had such a good carer who we didn't want to lose.'

Factors that can hinder recruitment

- Not receiving an appropriate hourly rate
- Finding qualified people with appropriate skills
- Recruiting staff who are appropriate to individuals (e.g. a similar age)
- There is currently no register of communicator-guides
- Knowing where to advertise
- Lack of clarity about being able to employ people that live with direct payments users
- Turnover of staff and staff not being able to stick to their commitments
- Staff not being aware of the kind of work they are taking on
- Issues over expenses
- Hours of work can be anti-social and vary from week to week
- CRB checks¹³ and references
- Confusion over who can provide training

'[Using direct payments is] a great option if you know someone already or are looking for bog-standard personal care at home. It's a nightmare if you need specialist support and know no-one.'

¹³ See glossary

‘My carers seem to come and go all the time; I only receive direct payments to pay for a few hours a week. So it is not enough for someone to leave an [other] employment for and a few hours don’t always appeal.’

‘Very poor support service to help one find appropriate staff and very little understanding of people’s needs’

‘An individual or individual family is not in nearly as strong a position to negotiate with a service provider as is an organisation like a social services department...’

Research has identified that issues such as staff shortages in rural areas and recruiting people to relatively low-paid occupations (especially if the rate of a direct payment has not been appropriately set) can have a significant impact on the implementation of direct payments.¹⁴

The impact of recruitment difficulties

Difficulty with recruitment can have a range of adverse effects on individuals, including:

- Individuals’ needs are not met
- Isolation
- A lack of consistency
- Negative impact on the mental health of deafblind people and family members
- A disruption of attempts to promote individuals’ independence (if for example a parent has to step in when staff are unavailable)
- Disappointment and/or distress
- Cancelling appointments
- Staff working more hours than they are paid for to cover for a lack in support

¹⁴ Department of Health, Modernising Adult Social Care – what’s working, 72

12. Managing direct payments

- 60% of respondents said they needed support to manage their direct payments
- Both deafblind people and parents may use a direct payments support service
- Both groups reported a range of support needs
- Some deafblind people also needed specific support with paperwork, including cheques, forms and making calculations as this work was often inaccessible to them
- Both groups express different levels of satisfaction at the support they receive to manage direct payments
- 50% of respondents said they were satisfied with the support they receive
- 35% said they were not happy with the support they received
- Deafblind people often use their support staff to help them manage their direct payments, especially in dealing with paperwork
- Deafblind people may use staff hours to deal with paperwork rather than supporting them with their assessed needs, they may not have been allocated extra hours for support with managing their direct payments
- If individuals think that they may need to use support staff to help them to manage direct payments, this can put them off direct payments

The DH direct payments guidance states that:

‘If a person consents, local councils are under a duty to make direct payments to anyone who appears to the council to be able to manage them (either alone or with help).’¹⁵

So support should be in place for individuals to be supported to manage their direct payments as appropriate and according to their needs and access requirements.

Table 12a: ‘What support have you had to manage your direct payments?’ (Questionnaire 2)

What support?	Number (out of 20)	Percentage
Paperwork/forms/quarterly or half-yearly paperwork	7	35%
Payroll	2	10%
Cheques	2	10%
Day to day planning/how to spend money	2	10%
Timesheets	1	5%
Tax	1	5%

¹⁵ Department of Health, Direct Payments Guidance, 14

What support?	Number (out of 20)	Percentage
NI	1	5%
Visits	1	5%
Financial monitoring sheet	1	5%
Advertising for recruitment	1	5%
Initial set up	1	5%

Respondents who said they were happy with the support they receive also added additional comments:

- Confident of own skills
- Queries answered
- Only needed support for initial set up
- The support service fills in the gaps when social services fail
- Simple to manage DP for equipment or a fixed activity
- Happy with using an on-line direct payments bank account to make payments

Respondents who said they were not happy with the support they received also added additional comments:

- More recruitment support needed
- Have to check or query what I am told
- Always have to ask for information rather than be given it
- Need more support for administration
- Need more support with financial forms
- Need guidelines on Health and Safety
- More support needed
- Left with booklet to read later
- Too slow
- Changeover was poor
- Access to local authority risk assessments
- Lack of support to write risk assessments

Respondents also noted:

‘The administration is quite demanding and financial returns are difficult.’

‘[I] would prefer an agency to take the strain. My son now receives intervenor services via Sense and it is such a relief!’

‘After one year, we were audited by social services who finally explained how we should have been dealing with the direct payment.’

‘Less capable parents would be inclined to give up and do without respite.’

Support to manage direct payments: An example of good practice by a local direct payments support service

A deafblind person who is a Braille user employs several staff through direct payments. He receives payroll support from the local direct payments support service. At the end of the month, he emails the support service with details of the hours that his staff have worked. The support service work out any deductions from pay (such as National Insurance and tax) and email him to tell him how much he should pay the staff via cheque. They then send him pay slips to be given to staff. The envelope that the payslips are sent in has two staples in the corner so that he knows who the letter is from. The payslips themselves are labelled in Braille so that he knows which staff to give them to. The support service also tells him how much he needs to pay each quarter in National Insurance and tax. The service also fills in quarterly Inland Revenue paperwork. At the end of the year, the support service sends relevant information to the local authority, so that they are aware of how the direct payments are being spent. The support service also uses Tynetalk to communicate with him.¹⁶

This individual has taken on only some of the responsibilities of employing people, the support service have taken on what he wants support with. Control still remains with the individual and confidentiality is maintained by using accessible labelling. These accessible systems were suggested by the direct payments user and the support service has adjusted its service to meet this individual's preferred means of communication.

¹⁶ Tynetalk is the national telephone relay service for people with communication difficulties. The service is managed by RNID (The Royal National Institute for Deaf people) and funded by BT.

13. Self-directed care initiatives

- Direct payments are part of government's commitment to self-directed care or self-directed support
- New initiatives, such as individual budgets and In Control are already having an impact on individuals' assessments and services in some local authority areas
- Direct payments are involved in both of these initiatives
- During consultation, participants wanted to discuss different self-directed care initiatives
- Some participants said that Sense should provide some information on other self-directed care initiatives

14. The Independent Living Fund (ILF)

- Some respondents used both direct payments and the Independent Living Fund (ILF)
- It can sometimes be difficult for people to manage the two funding streams as well as benefits and other income
- If people have already had negative experiences using ILF funding, they may not be keen to take on direct payments too

Direct payments funding comes from the local authority, whereas ILF funding comes from central government. Respondents did report difficulty with both deadlines and bank accounts when managing these two funding provisions. Respondents said that it could be hard to manage timings for both funds – money is sent to accounts at different times in the month and payments are spread differently throughout the year. This can make it hard to budget for spending, to ensure invoices for services can be paid and to make sure the bank account stays in credit. Respondents said there was confusion over whether the same bank account could be used for both direct payments and ILF money.

One respondent highlighted how a negative experience with ILF funding had deterred her from accepting direct payments too:

'I found it very difficult to recruit suitable staff to work with my son using ILF.'

15. Respondents' suggestions for actions

This section presents the comments from individual respondents, comments are direct quotations. Respondents were asked what could help improve individual experiences of direct payments and accessing information on direct payments. People identified the following as important issues in trying to make direct payments work better for deafblind people and families. Their comments are split into general ideas and ideas for Sense. The comments are wide ranging and in some cases demonstrate a potential tension between wanting control and independence as well as appropriate support from organisations.

15.1 General

- 'It is important that there should be various ways available to support the learning disabled not just the reliance on one system'
- 'A change in attitude of the population'

Local authorities/ Social services

- 'Making the system of implementation of direct payments standard across all local authorities'
- 'There needs to be information from the council regarding the direct payments arrangement and what qualifies you to be able to use the system'
- 'At every deafblind assessment, direct payments should be explained in detail'
- 'More robust systems in local authorities to prevent errors'
- 'More funding to be made available'
- 'More local services to tap into and more money for these services'
- 'To be given extra money and/or support for administration or agency fees'
- 'Being given enough money to purchase services from an agency and not directly responsible for being an employer'
- 'Allow for individuals' changing needs'
- 'Provide a better appeals service'

Information

- 'A forum with comments from people who use direct payments'
- 'To hear about other people's successes and disappointments to be able to go about correct assessment'
- 'Being more informed about what to do in difficult situations so that direct payments users do not upset staff'
- 'Accessible paperwork'

Recruitment

- 'A register of available carers, communicator-guide contacts'
- 'More communicator-guides'
- 'Being able to find suitably qualified staff and not having to worry about hiring and firing and finding staff'
- 'Employing family members'

Managing direct payments

- 'More hand-holding? (not sure but the process seemed daunting and would put some off)'
- 'Somebody to tell you how to get [direct payments], what you would be entitled to and whether it would benefit you'

15.2 Sense

Brokerage

- 'Need to be able to lobby social services'
- 'Help in negotiating level of payment (e.g. manager saying to reduce hours to cover hourly wage)'
- 'Support for individuals to get reassessed'
- 'Negotiating with JAT [Joint Agency Team]¹⁷ to provide an intervenor service'

Campaigning

- 'Campaign to increase awareness'
- 'Educating local authorities and others about the needs of deafblind people such as the need for specialist support and the need for accessible paperwork'
- 'Sense need to ensure that all councils provide information on direct payments to deafblind people on their register and ensure uniformity in who qualifies for direct payments'
- 'Campaigning for the rights of Usher/Deafblind people for their choice how to use direct payment – not control by the council's decision'
- 'Campaign to get more information about Direct Payments in accessible formats e.g. Braille'¹⁸

¹⁷ See glossary

¹⁸ See footnote 3, page 8

Advice

- 'Acting as a confidential sounding board for carers of a deafblind person'
- 'To have somebody come and visit you and advise you'

Information

- 'The basics of what direct payments are, what they can be used for, who can use them, what individuals are entitled to ask for'
- 'Explain the advantages and pitfalls of using direct payments'
- 'Tips on how to negotiate for a higher rate'
- 'The assessment process'
- 'The quantity of paperwork involved'
- 'Info on Health and Safety, risk assessments, insurance, employing people (including payroll, tax, National insurance, CRBs, sickness and holiday pay), bank accounts'
- 'Provision of training'
- '[Usher people] not being able to fully understand the nature of direct payments because some people with Usher prefer to use BSL and there is a lack of appropriate information in BSL'
- 'Signposting to good external information'
- 'Look at the general issue of self-directed care and how it related to direct payments'

Recruitment

- 'Provide a way of assessing new staff prior to engagement'
- 'Create a directory of communicator-guides'
- 'Ideas on sources to find workers'
- 'Run assertiveness courses for employers'

Services

- 'Offer extra intervenor hours [by training or recruitment]'
- 'Offer extra holidays'
- 'Offer management support for direct payments users'
- 'Become the indirect employer'
- 'Have somebody come and visit and advise you'
- 'Sense, as a joined up service, could assist the local authority in finding intervenors, companions, for example to do the paperwork, become the direct employer'
- 'Sense to approach social services or council on my behalf, but to keep me informed about any payments and the process'
- 'Setting up an agency of communicator-guides'

16. Recommended actions following the consultation

- Many actions will be carried out as part of Deafblind Direct, some work will need to take place in other parts of Sense
- Actions taken in other parts of Sense will be especially important in creating internal capacity for when Deafblind Direct funding ends in 2010
- There are also recommended actions for the Department of Health, local authorities, direct payments support services, CSCI and the individual budgets pilots

16.1 Deafblind Direct

16.1.1 Deafblind Direct information and advice service

- Use and refer to good examples of advice mentioned by respondents
- Avoid the mistakes of poor quality advice mentioned by respondents
- Aim to fill the gap in information provision (receiving a higher rate, recruitment, training, issues related to the Deafblind Guidance, accessible information, managing direct payments)
- Guide people as best as possible to the information they need so diminishing stress and confusion
- Cover the issues that are specific to deafblind people and families, particularly with regards to their needs and recruiting people with specific skills
- Disseminate examples of good practice to relevant external organisations, including local authorities

16.1.2 The Deafblind Direct Directory (the register of communicator-guides)

- The directory will be set up in a way that is accessible on-line
- Although primarily internet-based, the directory must be accessible to all
- The directory should be accompanied by information that supports individuals in recruiting staff and recognising their own responsibilities and the responsibilities of staff they recruit
- Individuals who receive direct payments use a broad range of staff with a variety of skills, qualifications and experience, so it seems better to include a range of individuals on the register, not just communicator-guides
- It will be important to clearly indicate the skills of each individual who is included on the register

16.1.3 Working with local direct payments support services

- Advice and training given to support services will cover the issues identified by respondents (receiving a higher rate, recruitment, training, issues related to the Deafblind Guidance, accessible information, managing direct payments)
- Disseminate Sense materials to these services prior to training

16.2 Sense - Community Support and Information division (CSI)

- Increase knowledge and awareness of direct payments within CSI

16.3 Sense – Children and Adults Services (CAS)

- Investigate the impact of direct payments on Sense services
- Investigate whether Sense can provide services to people using direct payments on a broader scale
- Build the capacity of outreach teams and regional staff to be able to offer advice on direct payments

16.3 Sense – national

- Ensure that direct payments and other self-directed care initiatives are taken into account across Sense

16.4 Department of Health

- Take account of and act on the specific challenges faced by deafblind people and families in relation to direct payments

16.5 Local authorities

- Individuals should be offered direct payments both in accordance with both the DH direct payments guidance and the Deafblind Guidance
- Individuals must be presented with a real choice over whether to accept a direct payment or receive a service provided by the local authority
- Rates offered to individuals should take account of the higher costs of appropriate support from qualified staff as well as other recruitment difficulties
- Information should be given in individuals' preferred formats
- Local authorities should recognise that managing direct payments can be onerous
- The needs of individuals managing direct payments should be taken into account in their direct payments packages
- Deafblind people wishing to manage their direct payments themselves should be supported to do so

- Appropriate support, such as extra hours of support, should be provided in order to support individuals to manage direct payments in addition to direct payments to cover assessed support needs

16.6 Local support services for direct payments users

- To seek advice and guidance from Sense regarding the needs of deafblind people and families who are interested in or using direct payments
- To take up the specialist training that will be offered by Sense in 2009/2010
- Individuals should receive information from these services in their preferred format

16.7 Commission for Social Care Inspection (CSCI)

- Take account of and act on the specific challenges faced by deafblind people and families in relation to direct payments
- Ensure that the DH guidance on direct payments and the Deafblind Guidance and correctly implemented
- Ensure that local authority targets for increased numbers of direct payments users are reached without disadvantaging service users and in accordance with the DH guidance on direct payments and the Deafblind Guidance

16.8 Individual budgets pilots and other self-directed care initiatives

- To identify the elements of this report that could apply to the implementation of individual budgets and other self-directed care initiatives

17. Conclusions

- There are a range of factors that can help or hinder the uptake of direct payments by deafblind people and families
- Information provision and recruitment are key issues in hindering or helping people to take up direct payments
- Direct payments can have a positive impact on the lives of deafblind people and families
- Local authorities should offer deafblind people and family members a real choice between services and direct payments
- Sense can play an important role in supporting deafblind people and families who want advice about direct payments and who want to recruit staff through direct payments
- Sense can work with local authorities and other organisations to foster best practice in supporting deafblind people and families who want advice about direct payments
- National and local government bodies play a crucial role in the successful uptake of direct payments by deafblind people and families, but should take account of the specific challenges faced by these individuals.

18. Glossary (A-Z)

Acquired deafblindness

If someone loses their sight and hearing, this is called acquired deafblindness. This may be due to an accident, illness or as a result of ageing. There are many causes of acquired deafblindness and there are increasing numbers of older people with failing sight and hearing.

Causes of deafblindness

There are many causes of deafblindness. These include premature birth, birth trauma and rubella during pregnancy, which can cause babies to be born deafblind. Some genetic conditions result in deafblindness. Any of us can become deafblind at any time through illness, accident or as we grow older. People who are born deafblind often have additional disabilities, including learning and physical disabilities. Also see: acquired deafblindness, congenital deafblindness and Usher syndrome.

CHARGE

People affected by CHARGE syndrome often have to cope with a wide range of physical difficulties in addition to sight and hearing loss. Sense has experience of helping people with CHARGE, their families, carers, and other professionals who may be involved.

Communicator-guides (Comm. guides)

Communicator-guides assist people with acquired deafblindness in daily living; they are human facilitators enabling two-way communication with other people, access to information and a means of traveling and moving about in different locations. They will visit the deafblind person at home, read correspondence, assist with bills, forms and telephone calls; accompany the deafblind person as a guide and interpreter on activities including shopping, visits to friends, clubs, doctors appointments and a whole range of other business, recreational and leisure activities. Communicator-guides do not direct the deafblind person or directly meet developmental needs. They are not simply a deafblind version of 'personal assistants'. Nor are they a universal all in one service encompassing social work, rehabilitation and home care.

Congenital deafblindness

When someone is born with combined sight and hearing difficulties this is called congenital deafblindness. Examples of this include conditions such as congenital rubella syndrome or CHARGE. People with congenital deafblindness sometimes

have additional disabilities – including physical and learning disabilities - and health problems. The problems and challenges facing people with congenital deafblindness can seem daunting. But with the right support, they can achieve a huge amount, and make their own choices about how they want to live their lives.

Criminal Records Bureau (CRB) checks

A CRB check will tell you whether a person has any listed previous convictions for criminal offences in England and Wales. CRB checks are one way of deciding whether individuals are suitable for employment.

Deafblind Guidance, The

The Department of Health issued *Social Care for Deafblind Children and Adults* (LAC 2001(8)) in March 2001 under the Section 7(1) of the Local Authority Social Services Act 1970. This statutory (compulsory) guidance is issued by the Department of Health. It gives new rights to deafblind people and places new duties on local authorities. The guidance applies to children, adults and older people who have a combined sight and hearing loss that means they have major problems in everyday life, with communication, access to information and mobility. The guidance states that local authorities should identify, contact and keep a record of deafblind people that live in their area; they should also have a senior manager who is responsible for services for deafblind people. The guidance also states that a deafblind person should be assessed by a suitably qualified person and should receive specialist services, including one-to-one support as appropriate. Under the guidance, deafblind people should also receive information and services in a way that is accessible to them.

Direct Payments Guidance: Community Care, Services for Carers and Children's Services (Direct Payments) Guidance 2003 Department of Health

The aim of this statutory (compulsory) guidance is to help local councils in making direct payments. It also provides guidance on how local councils might manage and administer direct payments.

In Control

In Control is for individuals who want control over their support. In control provide tools and information that are aimed at helping individuals to assess their own needs and receive and manage an individual budget and take control of their own support.

Individual budgets

Individual budgets are currently being piloted in 13 local authority areas. They aim to further develop some aspects of direct payments. The main idea behind individual budgets is to put individuals in control of deciding what support or services they get and aware of the total amount of money they have been allocated for support. The individual budget pilots include more than social care funding. Individual budgets should place individuals at the centre of the planning process, and recognise that they are best placed to understand their own needs and how to meet them. Individual budgets should be flexible enough to allow individuals to receive services provided by the local authority and/or a range of options for creating more personalised support, including using direct payments.

Intervenors

An intervenor is a specialist learning support assistant who works on a one-to-one basis with a deafblind child or young person to enable effective communication, the receipt of clear information and to enable the child to gain greater access to the environment.

As babies and children grow, most of their learning is incidental as a result of being able to observe and hear. A child who is deafblind only learns through the direct tactile intervention of another person. Their progress may be delayed and they face huge problems developing an understanding of the world and in developing language. The role of the intervenor is to provide opportunities and motivation for social interaction and help to interpret the environment and communication from others. It is often vital that the support of an intervenor that a deafblind child or young person receives in education is carried over into everyday, home life to maximize the opportunities to learn and interact with others and the world. This is the job of the community-based intervenor.

Joint Agency Teams

Joint agency teams have been set up to provide a more efficient service. Professionals from health and social care services and any other appropriate professionals are included in joint assessment and service provision.

Sense holidays

Sense holidays give deafblind people the chance to get away from it all, taste new experiences, make new friends, and have lots of fun! They also give families a much-needed break. In 2007, Sense organised holidays for approximately 140 deafblind people with about 200 people supporting the holiday-makers. The Sense holidays team contact social services departments to ask them for a contribution towards the costs of holidays. In 2007, five such contributions were paid through direct payments.

Sense outreach work

Our outreach services around the UK are targeted at deafblind people who are living in their own homes – many of whom feel trapped and isolated. Sense staff help them to obtain the information, services and support they need. This might involve advice and support to families, intervenor services or communicator-guide schemes.

Sense services

At Sense, we take pride in offering high quality, specialist services built around the individual needs and wishes of each deafblind person we support. Our services include sustainable help for families, day services where deafblind people can build confidence and learn new skills, and houses and flats in the community – where people are supported to live as independently as possible. Our communicator-guides offer a vital lifeline to deafblind people living in their own homes. And we provide specialist advice, for example on education options and assistive technology. Many Sense services are provided on contract to local authorities.

Sense training and consultancy

Sense specialists train local authority and health staff, raising awareness of the needs of deafblind people and how those needs can be met. This might involve making service providers aware of their responsibilities – for example the government's guidance to local authorities on social care services for deafblind children and adults – and helping them to fulfil them.

Usher syndrome

Usher syndrome is a major cause of deafblindness in adults which affects 3-6% of the people in the UK who were born deaf or partially hearing. People with Usher have a genetic condition which means they are born deaf or hard of hearing and then gradually start to lose their sight. The sight loss often begins in late childhood and is caused by an eye condition known as Retinitis Pigmentosa (RP), a disease of the retina. Over time vision gradually deteriorates until tunnel vision develops. Many people do not realise they have Usher until they begin to have problems with their sight. They will have grown up as deaf or partially hearing, and coming to terms with losing their sight as well can be very hard. Sense provides advice, information and support to people living with Usher. This includes groups run by people with Usher themselves. We are also involved in research into the genes that cause Usher syndrome.

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