



sense
for deafblind people

Fair care for the future

Why social care matters for deafblind people



“My daughter couldn’t survive without social care support.”

“It would be different if I got help. Hopefully, it would enable me to go out and communicate with more people.”

“I am fed up being worried and frightened because they threat to cut or less my hours.”

“I don’t get any social or leisure activity because without support I can’t get out of my flat.”

“I eventually got a specialist assessment after trying for five years.”

“Having the right support brought the whole family together.”

All the quotes in this report are verbatim.



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Recommendations

1

The Government's reforms of the funding and legal structure for social care must enable local authorities to commission and provide social care that allows deafblind people a reasonable quality of life.

2

The Government should ensure the new social care system both recognises, and provides for, deafblind people's social care needs. Deafblind people have particular and specialist needs around communication, mobility and access to information. Social care for deafblind people does not just mean personal care.

3

The new social care system must provide deafblind people with an adequate amount of social care, in proportion to their needs. Deafblind people need more social care than they are currently receiving.

4

The reform of the legal structure of social care must include deafblind people keeping their entitlement to a specialist assessment of their needs, carried out by a suitably trained person. Having the assessment carried out by a person who is able to recognise the impact of dual sensory loss on deafblind people's needs for care and support is essential.

5

Deafblind people should not face any unnecessary delay in obtaining a specialist assessment.

6

If this assessment shows the deafblind person has needs the local authority is obliged to meet, deafblind people should receive those services without delay.

7

If this assessment shows specialist services would be the most appropriate to a deafblind person's needs, these must be provided, rather than providing a deafblind person with mainstream services.

8

The new social care law should ensure adult social care teams assess deafblind young people at an earlier stage in the transition process. This would help make the process of transition smoother for deafblind young people, and would ensure that they received appropriate services from adult social care that meet their needs.

It would also ensure that progress and achievements made while receiving children's services were not lost, as well as allowing local authorities to commission and plan services.

9

Transition to adult services should only occur when an effective package of adult social care services is being provided.

Introduction



A growing number of voices – including those of deafblind people – are saying that the social care system is under-funded and not working.

This report describes deafblind people’s experiences of social care in England and Wales. It shows that deafblind people need the social care system to work in particular ways to meet their needs – but this often doesn’t happen.

Deafblind people already have concerns about the existing social care system – and so it is doubly important that social care reform makes sure that deafblind people’s needs are met.

The challenges faced by deafblind people

Deafblindness is a combination of sight and hearing difficulties. Each deafblind person is different, but anyone with a dual sensory loss is likely to need support with:

- communication
- accessing information
- mobility and getting around safely.

Many deafblind people have additional complex and specialist needs, which mean they can have very high support needs. People can be born deafblind, or become deafblind through illness, accident or in older age.

“A growing number of voices – including those of deafblind people – are saying that the social care system is under-funded and not working.”

The support deafblind people need

Deafblind people need a variety of social care in order to live as independently as possible.

For example:

- Individual support to enable someone to take part in daily life and activities, in their home, community or in a day service.
- Communicator-guides, who offer guiding skills, practical help and communication support – such as helping with shopping or dealing with post.
- Intervenors, who work one-to-one with deafblind individuals. For example, children are encouraged to develop new skills through co-active play and tactile stimulation; adults are helped to develop their communication and independence skills and use local community resources.
- Residential care and supported living.
- A minority of deafblind people who have more complex needs will need support with personal care.

It is vital that those who are making decisions about the future of social care understand the variety of specialist care and support that deafblind people may need.

Our survey on deafblind people’s experiences

We asked deafblind people, and the people who support them, to tell us, anonymously, about their experiences of social care. 89 people contributed through surveys and interviews. Their voices are at the core of this report.



“A large percentage of people are not getting what they need.”

What support do deafblind people receive?

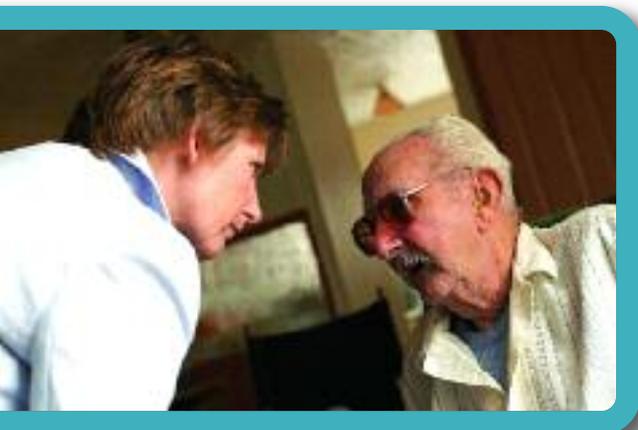
81% of the individuals (63 people) who answered this question in our survey receive social care support.

19% (15 people) receive no social care.

Support (some people receive more than one type of support)	Number of people
Communicator-guide	21
Help with personal care	20
Residential care	20
Equipment*	16
Personal assistant*	15
I don't get any social care	15
Day centre	13
Intervenor	7
Meals-on-wheels	1
Something else **	21
Not stated	5

* See glossary

** These included care from a friend or family member; cleaning and laundry; communication support; cooking; respite; Sense holiday; and transport (e.g. to a day centre or medical appointment).



Do deafblind people receive enough support?

We asked how much support deafblind people received and whether they felt this was enough.

39 people told us how many hours social care they receive each week:

Hours	Number of people
0–20	20
21–40	5
41–60	5
81–100	1
101–120	1
161+	7

We then compared the hours they receive with the hours they feel they need. No-one was getting more social care than they needed, **14** were getting exactly the hours they needed and **20** people were getting less than they felt they needed (5 did not answer).

We asked people how many more hours of support they felt they needed to meet their needs. The answers ranged from one person saying they need one more hour per week, to someone needing **135½** hours more. It might seem that only having to do without one hour of support would not be that hard to bear. It is important to understand that even an hour could make all the difference between being able to do all the things you want or need to do in a week, and not. 135½ hours more support may seem excessive, but this represents a person who is in need of full-time residential care and is not receiving it.

A large percentage of people are not getting what they need. The people who are not getting enough social care need **50%** more than they're getting – on average. The impact on those individuals is huge.



“They think that if you can survive, that’s enough... they don’t have a clue about what it means to be deafblind.”

Catherine, 50

“I was born profoundly deaf, and now I am blind as well – I have a tiny speck of vision about the size of a 5p coin. Everything I do is with communication support, and life without it isn’t worth living.

But because I look ‘normal’ and do my best to cope, social services cut my hours in half. They think that if you can survive, that’s enough, and every time I have an assessment for social care the people don’t have a clue about what it means to be deafblind – they think you can just stick ‘deaf’ and ‘blind’ together, but it’s so much more than that. Deaf people can see, blind people can hear. I can’t do either.

Social services seem to want people to be trapped in their homes and be ‘safe.’ But I’m not even safe there because I fall over things and sometimes burn myself. I wouldn’t even know if someone was at the door.

British Sign Language is my first language, but because I can’t see the signs anymore I need to feel the interpreter’s hands to understand. Without an interpreter it is completely impossible for me to

communicate with anyone at all. My eldest daughter often acts as an interpreter for me, but she is only 12 and I want her to be able to do things other girls her age do. But she often doesn’t have the chance because she has to help me with things around the house and look after her little sister, who’s now nine.

Without support I just sit at home, alone and bored all day. But when I do get support it makes me feel alive, like a human being – if I didn’t I would simply go insane, and then cost the Government more money.

Since my hours were cut I feel like I can’t be a proper mum anymore. I don’t know if my girls are happy or sad unless the communicator-guide is there to tell me. I feel social services took my family life away when they cut my support. I am terrified for the future and I am so worried about all the cuts. I am so frightened. I love my house, but I view it as a prison when I don’t have support.”

People need MORE help

Across the whole sample people need an average of **30%** more support than they are getting – which shows the under provision in the whole system.

Extra hours needed	Number of people
0–20	16
21–40	2
121–140	2

Direct payments

Some people receive a direct payment from their local council to buy their own social care.

Of the 63 people in our survey who receive some social care, **55%** (27 people) receive a direct payment to buy this, **43%** (21 people) don't receive this and **2%** (5 people) weren't sure.

Paying for care

Of the people who were receiving social care support, some deafblind people pay for their social care. **24%** (19 people) pay for their care, **6%** aren't sure (5 people), **34%** don't pay (27 people) and **36%** (29 people) didn't answer.

Starting to receive care

For a deafblind person, asking their council to assess their needs is the first step to finding out what care and support they need – and what support they will receive from social services.

The Deafblind Guidance

The Government has issued statutory guidance – “Social Care for Deafblind Children and Adults” (commonly called the “Deafblind Guidance”). This entitles deafblind people to various things, including a specialist assessment of their needs:

“Carried out by a person specifically trained to assess the needs of a deafblind person...”

This specialist assessment is the key to getting the right care and support.

Getting a specialist assessment

66 people answered our survey question about whether or not they had had a specialist assessment of their needs as a deafblind person.

	Had a specialist assessment	Not sure if had a specialist assessment	Not had a specialist assessment
Number of people	42	5	19
Percentage	63 %	8 %	29 %

This shows that not enough deafblind people are having specialist assessments. Even when deafblind people are receiving specialist assessments there were still difficulties. Concerns raised included that some councils refused to pay for a specialist assessment, had to be pressured to do it or took a long time.

Concerns about the assessment process

There were also concerns about the quality of the process as well as the assessment itself:

“Social workers that have assessed me in the past have not been qualified to assess deafblind people.”

“I eventually got a specialist assessment after trying for five years, making numerous formal complaints and having to go to the Ombudsman to make the local authority look at one complaint.”

Of those who had not received a specialist assessment, comments included: “I have never been offered a specialist assessment. The assessment has been done by a social worker in the local children with disabilities team.”



“The more support Ellie gets now, the more she will learn to do for herself and the less she will cost the state in the future.”

Eleonore, 22

Mum, Jacky

“I remember the shock and disbelief of Ellie’s diagnosis as if it were yesterday. It felt like I was walking through a strange dream, and I had to be really brave to not break down when other mums looked into the pram knowing something wasn’t quite right.

I gave up my career to care full time for Ellie. It wasn’t until we reached crisis point when Ellie was 16 that we received proper support with direct payments and respite. Our family has always focused on Ellie with our two sons taking a back seat. We wouldn’t be able to manage without continued support from the local authority. For Ellie to lead as fulfilling a life as possible she will need a lot of social care support.

The Government should shadow Ellie for a day just to witness the amount of support one young lady needs. We’ll never give up our roles as carers for Ellie, but I’m asking the authorities to please try to give us more support. Ours is a lifetime role, and while we will not shirk our responsibility, we cannot do it alone.”

Dad, Robert

“My daughter couldn’t survive without social care support. Eleonore is 22 years old and was born with severe learning disabilities, epilepsy and hearing and sight problems. What she needs is support from a real

person, not more technology. She has a hearing aid, but what’s the point if she can’t make sense of what she hears?

Ellie has developed her own sign supported English which people close to her understand. She can find her way around, but has problems with depth perception so stairs can be very dangerous as well as sudden changes from dark to light. She needs 24 hour one-to-one support from people who really understand her, as Ellie will happily sit in her room all day if no one prompts her to do things.

The transition from children’s services to adult worked fairly well for us thanks to the local authority’s flexibility. For example, they let Ellie stay at a respite centre before moving to college so that she got used to living somewhere else.

But it wasn’t until someone from Sense told us about the Deafblind Guidance that Ellie got a specialist assessment – something the local authority is legally obliged to give her to base her care package on.

The more support Ellie gets now, the more she will learn to do for herself and the less she will cost the state in the future. I don’t have misplaced optimism when it comes to Ellie’s independence, but I want her to achieve as much as she can.”

How easy is it to get a specialist assessment?

41 people told us whether or not it was easy it was to get a specialist assessment:

	Easy to get a specialist assessment	I'm still trying to get a specialist assessment	Not easy to get a specialist assessment
Number of people	21	5	15
Percentage	51 %	12 %	37 %

Again, there were a range of concerns to do with the process:

“Very difficult – it took over 2 years of asking.”

Some people required help from multiple agencies – such as Sense and a ROVIC* to get the specialist assessment.

For many it is a battle:

“It was easy to get social services to agree to a specialist assessment but difficult to complete it – they repeatedly used delaying tactics.”

Councils have a legal responsibility to be pro-active in identifying deafblind people and assessing them – and the Deafblind Guidance gives individuals the means to challenge councils who are not fulfilling their duties.

What happens after the specialist assessment?

For deafblind people, having a specialist assessment that recognises their level of specialist needs is important.

In our survey we asked: when a council has assessed that someone has a social care need (that they were legally required to meet) were there any difficulties in getting these services? Were there difficulties in getting the council to accept the assessment itself? 53 people answered this.

	Lots of difficulties getting services	Some difficulties getting services	No difficulties getting services
Number of people	17	19	17
Percentage	32 %	36 %	32 %

Concerns expressed by deafblind people included:

“The fight and length of process, as well as the support needed to get one... we had to engage a solicitor.”

“I had to make a complaint when I was first assessed as it took them so long to take my case to panel...”

There were also experiences of councils trying to avoid paying for or not understanding the cost of specialist care:

“Social services wanted to use a matrix to decide on the cost of my care although it was obvious that the matrix did not recognise my needs as a deafblind person.”

There were also experiences of services simply not being provided – despite the assessment saying services were needed:

“It said there should be respite but it has never been provided.”

“Difficulties in finding services and provision to meet needs.”

There were clear benefits to an assessment though:

“We got more services following assessment.”

This shows the length of the battle – to find out that there is such a thing as an assessment, to get one, and then to get the services in place following the assessment.

“It would be different if I got help. Hopefully, it would enable me to go out, to communicate with more people.”



Ron, 72

“I wear a hearing aid in both ears. Without my hearing aids, people would have to speak right up to my ear, for me to hear. I can only hear thumps without them, and I can’t even hear the phone ring which I have next to my bed. I used to lip-read when I could see. I can’t see people, objects, but I do know when it’s day and night. Like if someone switched the light on in the room, I’d know there’s a light on. I can’t see anything apart from that.

When I lost my sight I did go through depression. I had counselling. Only in the last year to 18 months, did it hit me. You would’ve thought I’d have it at the beginning. That’s why I asked for an assessment to see if I can get out more.

My routine doesn’t hardly vary at all really. I get up in the morning, come down, make a cup of tea, do my breakfast, wash-up. Go round and tidy up. I do dusting – which is probably not necessary, but I do it every day, it’s a habit – I Hoover. That’s it. In between, I can make myself a cup of tea. Do my lunch. Then I have a sit and listen to the radio, or listen to a talking book. That is my every day.

Once a month I come to this club [Essex Day Club – Sense branch]. Tomorrow afternoon my best friend is coming to see me. He comes once a month. We go to the pub for something to eat and a drink.

I might occasionally go out on a Saturday morning to do a bit of shopping with my sister. My family – they don’t ring me up or take me out very much but maybe that’s because I live with my sister. If I were on my own I think they would help.

Otherwise, apart from that it’s all routine, I’m just at home.

It would be different if I got help. Hopefully, it would enable me to go out, hopefully to communicate with more people. But I know it wouldn’t be every day, but I’d just have to accept it when it came along. It’s not as if I can just jump into a car. I often wake up, if it’s a lovely morning, and I think gosh, there’s a forest across the way from me, I’d like to be able to walk in the forest.

I get some support from my sister. I have to ask. She’ll take me shopping or she’ll take me to the bank if I need something; she cooks me meals if she’s indoors.

If I could tell the government one thing, I’d tell them I know money’s tight, but I always feel they should think long-term, not to see things for six months or one year. They should invest in us. They would probably save money in the long-term where we’re able to get out and contribute to society instead of being told to sit indoors. We don’t expect everything to be given us on the plate. But we just need some support.

Changing needs over time

“They do not understand I am very isolated and lonely. I cannot see and hear anything.”



Transition

Deafblind/multi-sensory-impaired * (MSI) young people face particular challenges when they make the transition from children's to adult social care.

Transition should happen as part of a planned process, with the young person at its centre. Effective transition planning should include opportunities for the young person (with the support of family members, practitioners, an intervenor or advocate) to:

- explore their options about what services might be available
- understand any changes there might be to their existing services (they may lose access to specialist young people's services or tailored support)
- have time to find the right package of care and support for them
- adjust to new services.

58 people told us whether the team that provides their social care services had ever changed just because of their age. Of these people, **29%** (17 people) had experienced their service changing because of their age. **14%** (8 people) were not sure if this had happened to them.

When asked “How well did this transition work?” **33%** (10 people) felt it had worked well, **17%** (5 people) were not sure, and **50%** (15 people) felt it had not worked well.

Changing needs because of older age

We also heard from older deafblind people. One person said:

“I was told that my hours might be less because I'm

over 65. They do not understand I am very isolated and lonely. I cannot see and hear anything. I did not hear from my social worker yet but social worker said my hours are the same until next review. I am fed up being worried and frightened because they threat to cut or less my hours.” (BSL user).

Changing needs over time

We asked about when people's needs changed over time how their local authorities responded – for example, by re-assessing them and offering different, or more, help.

51 people answered this question. Only **29%** (15 people) were happy with the way their council had helped; **24%** (12 people) were not sure how the council had helped, and **47%** (24 people) were unhappy with the way the council had helped.

Changing services, but no change in needs

50 people answered a question which asked whether their local council had ever told them that their social care had to change, although their needs hadn't altered – for example, because the local authority couldn't afford to provide them with a service anymore. **30%** (15 people) said yes, **4%** (2 people) weren't sure and **66%** (33 people) said no.



“Her mother had to keep chasing social services and the stress meant that she developed depression and needed anti depressants.”



Nadira*, 21

Nadira lives with her parents, older brother and two younger sisters. She was born prematurely and her mother was told that she would have special needs, which was a real shock to her. Nadira was in and out of hospital for several months. She has physical disabilities, which mean she needs physiotherapy and has to do daily exercises. She also has a learning disability, hearing loss and recently had cataracts treated. She needs constant one-to-one support.

Nadira now attends a day service five days per week. She is very sociable, so this gives her the chance to spend time with people. It also gives her access to the equipment she needs, and more freedom and independence. She loves musical toys, lights, arts and crafts and uses a touch screen computer.

When Nadira left school, her mother felt the transition to adult care was very difficult. Planning only began a year before Nadira left school, so for a time she was at home without any support. Nadira developed behaviour problems, and her mother couldn't cope with looking after her and her nine year old sister. Her mother had to

keep chasing social services, and the stress meant that she developed depression and needed anti depressants. She also has problems with her back and wrists from pushing Nadira's wheelchair.

Nadira's mother had some advice from the local Mencap organisation and was told about the Sense day centre. When she visited the centre she knew it was right for Nadira. It is bright, has equipment, more space so that doing exercise is easier and it helps Nadira to learn. Now that her cataracts have been treated Nadira is learning Makaton which will help her to communicate.

The family noticed a big change in Nadira as soon as the service started. "Seeing her happy makes me happy," her mother says. "Having the right support brought the whole family together. But now I have to get over the stress of that time. It would have been better if planning for transition had started much earlier so that there was no gap in service between school and adult services. I also needed more information."

* name changed

What do you do with the social care?

	What does the social care you get help you to do? (number of people who answered)	What would you do if you had more (or any) hours of social care provided? (number of people who answered)
Socialising	18	22
Shopping	13	1
Exercise	11	10
Day centres	9	1
Personal care	9	1
Personal tasks	7	5
Health	6	0
Cleaning	5	1
Work/training/volunteering/education	5	5
Significant life events	1	0
Didn't state	32	44

Some of this help is very clearly unsustainable. For example, help provided by parents who themselves are growing older:

“My elderly parents provide support.”

Also, younger adults may spend more time with their parents than other younger adults:

“My mum and dad help me. But they are getting older and don't always want to do the things that I want to do, like be with other younger people.”

This puts deafblind people at risk if this support were to break down – as well as placing a heavy load on deafblind people's families :

“Years of caring is killing them [my family].”

We also heard of severe isolation:

“Spend many hours alone, family at a distance.”

“I don't get any social or leisure activity because without support I can't get out of my flat.”

“I'm in on my own all week.”

We know of the health risks of loneliness, which must affect deafblind people more too:

“Researchers rate loneliness as a similar health risk as lifelong smoking, with links between a lack of social interaction and the onset of degenerative diseases such as Alzheimer's; an illness which costs the NHS an estimated £20 billion a year. Loneliness has also been linked in medical research to heart disease and depression.”

The Campaign to End Loneliness.

The impact of not receiving adequate social care

We asked how people manage if they don't get any, or not enough, social care.

	I pay for services myself	I manage without	Someone else helps me (family, friends, civil partner, partner or spouse)
Number of people	8	15	40
Percentage	13 %	24 %	63 %



Coping without social care

“My wife helps me, is my carer. She’s very very good but she needs breaks. People – we have ‘low’ days!”



The other issues identified in the survey were how hard it is to get food, cook healthily, open post, or simply get out for a walk without support. Some deafblind people have few family members or friends and have no money to pay for more support:

“I have no family. I have only one friend. I cannot manage to pay extra. My savings are very low.”

– or simply do not have any family or friends:

“Life is an all consuming quicksand.”

We also heard how precarious some people’s lives are:

“Rely on neighbours... being kind to me. I get by by the skin of my teeth.”

“Family when available step in or I have to manage by myself. But this means I... get very depressed.”

Not getting any (or enough) social care

We asked if deafblind people had ever had any problems because they had not had any (or enough) social care.

	Lots of problems	Some problems	No problems
Number of people	18	20	13
Percentage	35 %	40 %	25 %

The real impact on people’s lives

75% had lots or some problems. Deafblind people told us how bad things can get with no social care:

“When I got no social care, my mental health got bad, I was very stressed and suffering from depression. I came very close to losing my job on more than one occasion. I got very close to suicide on more than one occasion. I have gone without prescriptions on a fairly regular basis. I have had to cancel hospital appointments because I couldn’t get there. My relationship with my family has always been difficult but it’s worse now because I can’t go to see them much and when I do see them we can’t communicate but they don’t understand and think it’s my attitude problem!”

We also heard of the impact on carers:

“My wife helps me, is my carer. She’s very very good but she needs breaks. People – we have ‘low’ days!”

We also heard about times when deafblind people and their families didn’t need very much help, or for very long, but this was hard to get, or was promised, but did not happen:

“My wife was recently discharged from hospital and we didn’t get extra help. We asked for it and we were told we’d get it. I couldn’t clean as I can’t see. We just needed a cleaner for six weeks and this didn’t happen. We did try to get help but couldn’t because agencies said it was not a permanent contract and so they didn’t want it. They made excuses. It is disheartening, I feel saddened.”

Choice and control

The issue of choice and control – a key part of personalised social care – is simply not working for some people:

“I just have to wait. I suppose if it was an emergency they might help. You can’t choose when you get the hours. We didn’t arrange it so we get no say.”

and whether down to cuts – or eligibility thresholds, social care is simply not working:

“They keep saying they cannot give me extra hours.”

We heard of isolation, leading to depression, and being unable to do anything to alleviate this:

“I’m not getting out as much as I’d like to. I have got depression and I feel isolated. I’m beginning to accept it. I had counselling due to depression but they can’t change my situation. It’s down to me, but it’s hard if no one is around to take me on a walk, I just want to get out somewhere and get some fresh air. I used to take anti depressants.”

and

“I am so isolated. I have missed out on a lot of information. It makes me depressed and ill.”

“I have had times when for a long period there was not enough social care. I have suffered emotional and physical problems which has caused difficulties...”

The financial impact of poor social care

It is clear that not meeting deafblind people’s social care needs adequately will inevitably lead to increased costs. For example, all of the following will bring extra costs for the NHS, if someone:

- stops taking their medicine because they can’t access the information about it, or get out to a pharmacist to collect a prescription
- misses their appointments with their GP or consultant
- needs in-patient or out-patient psychiatric care
- has poor nutrition leading to malnutrition or obesity

- cannot take exercise – which is linked to increased falls, obesity and poor mental health.

If someone needs crisis social care from a local authority this will be expensive to provide. And if carers have to stop working to care for a deafblind person they will be claiming benefits rather than paying tax.



“I had counselling due to depression but they can’t change my situation.”





“I don’t think I could carry on living if my support was taken away from me.”

Shane, 24

“I’m profoundly deaf in both ears and struggle when there’s a lot of background sound. I have a bit of sight in my right eye but everything I see is slightly blurred and sometimes very difficult to make out. I was born blind in my left eye. I’ve been told my sight and hearing will get worse. I also have diabetes – all of this is caused by the condition Wolfram syndrome.

I had no support till about five years ago. I didn’t know how to get it, nobody helped me, not even my GP, and I had no contact from the local authority (LA). I found out about Sense from a random internet search, and they told me about the support that might be available. I’ve now got a communicator-guide for 15 hours a week (plus additional mileage so that we can get out and about). Among other things, they make important phone calls and read through my post so I don’t miss any bills.

It is very important that I have support to get out of the house. I really need my communicator-guide to take me out to do some food shopping, or attend things I am interested in – otherwise I feel very isolated and depressed. Without support I’m a prisoner stuck at home, depressed all the time and doing nothing. I don’t think I could carry on living if my support was taken away from me.

I get Disability Living Allowance, and Incapacity Benefit, which I struggle to live on - particularly as there are additional costs associated with my complex medical condition. I don’t have any savings and would

really like to purchase some equipment which would allow me to read anything in print independently. A lot of other electronic equipment I rely on is starting to break and I would really like to replace them but I don’t think I will be able to.

Also, my LA is now charging me for the support they provide. I understand that an LA may want somebody who can afford to make a contribution towards their care, but I cannot afford to pay over £250 a month which was what they were asking me to pay. With the help of a solicitor this has been reduced, but I don’t feel I can afford to pay anything and I will certainly be unable to save for or buy the additional equipment I need. This really worries me.

Social care means the world to me because it gives me independence. I would like to do more and tried to attend college, but they failed to provide me with the additional support they promised so I couldn’t continue. I am now looking at home learning, but would prefer to get out and meet other students.

It can be very frightening going out on my own and also dangerous. I also have to fight for everything I need, which only adds to the stress I already face on a daily basis because of my condition.

I think the current system is really rubbish for deafblind people. The Government wants us to be independent, but don’t they realise that for this to truly happen we need proper support.”

Going out alone

When we asked deafblind people if it was hard to feel safe to go out alone without someone to guide or assist them we received 65 replies. Unsurprisingly, 60 people told us it did all or some of the time, and only **8%** (5 people) said it never caused problems.

Does your deafblindness make it hard to feel safe to go out alone?

	Yes	Sometimes	No
Number of people	52	8	5
Percentage	80%	12%	8%

Many people said they felt **“very unsafe”** and **“I never go out alone.”**

In addition we heard how deafblind people are rarely or seldom able to go out alone:

“Are you joking? I can only go out once in a blue moon... you wouldn't want to hear anymore!”

“I never go out alone. Always have to have guide. Taxi driver on Saturdays knows what time to collect me and helps me in and out the taxi.”

“Even with my guide dog it is unsafe. I have too many close calls with my dog.”

“I can go out with a long cane. I used to have a guide dog. It doesn't seem so safe as it used to.”

“I can only go out once in a blue moon.”



Have you had mobility training?

	Yes	No	Not sure
Number of people	35	26	5
Percentage	53%	39%	8%

Mobility training is a simple, effective intervention, yet it had not been experienced by everyone, or where it had, people had then not had any more when their needs worsened:

“19 yrs ago when my sight was nowhere near as bad.”

Sometimes training had been inadequate or of limited use.

“I've had mobility training at various times in my life. Since being deafblind, I have had two lots, both appalling. The first was a rehab worker who couldn't communicate with me and literally pushed me along, goodness knows where we went! The second was a rehab worker who booked an interpreter and made me do the route from my flat to the train station, which I had been doing everyday for the past two months, so a total waste of time. If I hadn't already learned the skills as a hearing-blind person, and then worked by myself to adapt mobility skills and to create ways of communicating with strangers, I would never have got anywhere with the mobility training I had after being deafblind.”

“14 years ago around where I lived I had white cane training. After I had it I walked up my road to see my relative every week. But when she died I stopped going out.”

Some people had been victims of confidence tricksters or unprofessional care workers, as well as possible hate crime. Some people also felt unsafe inside their own home, and so they did not have anywhere they felt safe.

“With enough support, life can be fulfilling and productive for deafblind people – but this is not experienced by enough people.”



WALK WITH ME
TALK WITH ME

Conclusion

Lack of adequate social care has a direct impact on the life of a deafblind person, including:

- Feeling exceptionally lonely and bored – which can lead to mental health problems
- Not being able to take exercise and keep fit
- Being unable to get to the doctor, dentist or hospital
- Missing out on seeing friends and family
- Being unable to go shopping and buy healthy food
- Finding themselves effectively excluded from civic and community life
- Not being able to get out to vote.

Not only does this impact on deafblind people and their families, it often brings increased costs to the economy, the benefits system, local authorities and the NHS in the short- or long-term.

Overall, our survey shows that this lack of support is experienced by too many deafblind people. Most people who answered our survey were either not getting enough support, or weren't getting any.

Although some deafblind people had had a specialist assessment, over a third had either not had one, or weren't sure. Only half of those that had had an assessment found it easy to get one, the other half had either found it hard, or were still waiting. Over two thirds had lots, or some, difficulties getting the council to provide services following the assessment.

When deafblind people's needs got worse, nearly half felt the local authority had not helped at all. Three quarters of people had lots, or some, problems because they had no, or not enough, social care. Some paid for extra support (some could not afford to do so), most either managed without or relied on family and friends to help.

Deafblind young people going through the transition to adult services had a difficult time, with a lack of planning, poor assessments and inadequate services post-transition. Half of people who answered felt the process had not gone well.

Those who had support that is working for them now had had to either wait for it, or to fight to get it. They were also anxious that this support will stop, break down or cost them more in the future. Another issue was the lack of choice. Even those who had some, functioning, support, couldn't choose when they had support, meaning many people had to make unreasonable choices about doing one thing over another.

Social care should provide everyone who needs it with a reasonable quality of life. Deafblind people do not want excessive amounts of social care – they simply need functioning support that enables them to have some quality of life.

The people who took part

67% had other health conditions (65 people).

54% of people filled the survey in themselves.

46% filled it in on behalf of a deafblind person.

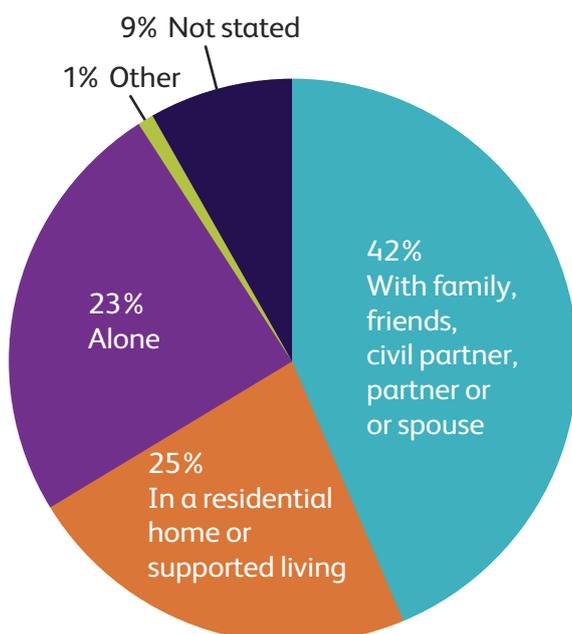
Their ages

	18-25	26-40	41-64	65-79	80+
Number of people	10	18	28	13	5
Percentage	12%	21%	32%	15%	6%

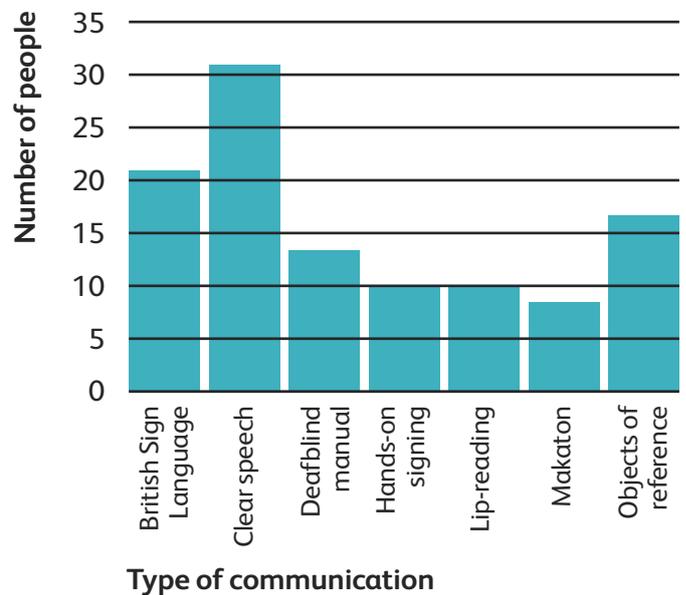
The age they became deafblind

	0-17	18-25	26-40	41-64	65-79	80+
Number of people	40	5	15	8	3	1
Percentage	56%	7%	21%	11%	4%	1%

How they live



Method of communication used



Glossary

Equipment

Equipment helps a disabled person live more independently, and helps with things like the tasks of daily life, health care or mobility. Equipment may be provided by a local authority (or an organisation they have commissioned to provide this), or purchased from a private company or voluntary sector organisation. Equipment could be low-tech, things like a long cane, a wheelchair, or a magnifier; or high-tech, things like a computer with a braille display or a CCTV for reading.

Multi-sensory-impaired (MSI)

An impairment of both sight and hearing – and sometimes other senses too. A small number are completely deaf and blind, but most have some residual sight and/or hearing. Many have additional challenges, such as medical conditions or other physical impairments. In addition, many have impairments of the other senses – for example problems with balance, taste or smell. Awareness of pressure, temperature and pain may also be affected.

Personal Assistant

The role of a Personal Assistant (PA) is to provide personal assistance to Personal Assistance Users (PA User) to enable her or him to live independently.

ROVIC

Rehabilitation Officer for Visually Impaired Children

Is social care working for deafblind people?

A growing number of voices – including those of deafblind people – are saying that the social care system is under-funded and not working.

This report is based upon a survey of deafblind

people's experiences of social care in England and Wales. It shows that deafblind people need the social care system to work in particular ways to meet their needs – but that this often doesn't happen.

Other formats

If you would like a copy of this booklet in another format – such as braille, audio tape or large print – please contact us.

About Sense

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have a single sensory impairment with additional needs.

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