

## **Disabled People's Life Chances – Feedback from Three Disabled People from Bristol**

Comments on the document were gathered during two meetings with four disabled people in August and September 2004.

### **General views about the document**

Generally the document was welcome but there was also a great deal of cynicism about commitment (whether this is on the part of Government and services/organisations) to change and improve disabled people's life chances. This cynicism is based on past bad experience of things being given and then taken away again.

One disabled person commented 'I don't get the quality of life I need to have'. But this person also commented that 'things have changed since I was growing up- there was not so much help during the past'.

Although there were examples of change over the years the disabled people giving feedback felt:

- They are still not listened to
- They experience social isolation
- The level of support and personal care they need is difficult to arrange, co-ordinate and maintain
- Non disabled people hold negative attitudes about and prejudice against disabled people
- The frustration and stress they experience can affect their mental and physical health
- It is becoming more and more difficult to rely on the support of family and friends as they have their own lives and might not be living close by

More specific comments arising from discussion of the document are outlined below:

### **Money**

Disabled people have less money and more to do with it. Non disabled people don't need to buy Personal Assistants. One service users said 'You often have to go 'cap in hand', I hate that'.

'I need to know more about benefits and how to work and get help to pay for care/ housing.'

### **Direct Payments**

One person said about direct payments - 'It is very complicated and I don't have the confidence to do it'. Other disabled people said they didn't know anything about it and needed it to be explained and then repeated so people can understand more about it.

## **Transport**

The lack of accessible, affordable and available transport is a serious issue.

“Transport is the biggest problem”. Accessibility is an issue. For example taxi drivers not helping people to get out – lack of awareness of disability. An example was given of a taxi driver saying “If I touch you, you can do me for harassment” and on this basis wouldn’t help the passenger to do up the seat belt. “More than my jobs worth”.

“ I can’t get on the bus. Have a very long walk to get a bus”. “ Cost of taxis is very expensive”. Money is an issue for transport. “Transport is the biggest issue of all”.

Roads / pavements - cobbles /raised surfaces create huge problems for wheel chair users “really shake your innards”. Obviously designed by someone who doesn’t use a pram or a wheel chair.

There is a need for lower curbs – it’s not safe going on the road but what can you do. There is an issue of overhanging branches / hedges. “Police say not to go on the road, but how else can I do it”. “Only way I can ever get out”.

‘I don’t go out on my own, I can’t see the edge of the pavement, it’s dangerous. The curbs need to be painted red or yellow or a colour that is easy to see.’

Taxi’s – If you don’t know the taxi driver and they don’t know you, it can be confusing. I’m lucky I only use one man.

## **Employment and College**

Work – “I’d love to go to work” I’d dearly love to go”. “Is there anything out there to make me feel less useless.” One woman who is over 65 years asked “Is assistance age related”.

Going to college creates difficulties as you have to be there at a set time. Fluctuating health is an issue about being there for all the course or when you’re at work. “If you need to have time out from work/ college, will they accept that?” Also time off for hospital appointments. Need flexible working hours and support employers to cope with absences. “need to cope with flare ups”

Also need to cope with issues of speed – being compared to able bodied people is difficult. She explained that she cannot work as fast as non-disabled people and would like to work from home.

People think you're thick but if you've got the right equipment you're okay. When I was last at college some time we had to rely on the teacher because the P. A. didn't turn up. P.A ratio was 1:6, but you we lucky if you got two. There should be some one to help you to get about I colleges, they think that if you are in a wheelchair you can manage. I'd like to take my own staff to college.

### **Housing**

"I lived in a home from when I was 16 years- it took me 15 years to get out. I live on my own now and take charge of my life. In the home you get-up at a certain time and go to bed at a certain time. It's much better now."

Housing "can't fault them on that".

### **Harassment**

I've been harassed but not attacked but I know people who have been attacked

Disabled people can discriminate themselves. A major barrier is people's attitude and prejudice. Mainly from older rather than younger people. "they need educating".

"That world out there don't care about you". "You're a second class citizen in that world".

Another said : " You're a nuisance " and that they had had comments from people that " you've got no right to be in here"

### **Minimum Standards**

Not sure about minimum standards. "Why minimum standards?" " I would want to know more about how it works". Would this be open to different interpretation of standards.

### **Social isolation**

One woman gave an example of some one who doesn't go out at all apart from going to the day centre. She hadn't been out independently for over 18 months. There are people who are forgotten.

"Couldn't the money be used to take people out and be there to give her a bit more".

### **Parenting**

Being a disabled parent " I felt cheated, couldn't cuddle them or play football. I relied heavily on family and friends for support. Families don't have time now, not as close".

“My daughter provides care 7 days a week in addition to her own full time job and family commitments. She is not able to claim anything for herself “

The comments showed lack of knowledge about carers assessments and direct payments.

### **Health Service**

“You don’t get half the care you used to”. This comment was from someone who had been having help from the age of 28 to 66. “Doctors and nurses don’t listen to the patient”. She gave an example of when views and comments were disregarded. She then went on to say there was “better treatment in NHS hospitals than private”.

Stress of lives is affecting health. There are feelings of frustration. People are talking of feeling suicidal. Stress affects mental and physical health. Change is difficult for disabled people for example the changes with the day centres - people threatening that they’re “going to do it”.

### **Paid Support**

“You need the right kind of people to do the jobs in the homes”

Home care – issues raised about what staff will or won’t do. For example won’t move ornaments when dusting or move furniture or put up curtains.

Complaining about services can lead to a backlash or hassle from staff.

It takes time to get to know support workers. One woman said it took 5 years before she felt confident that her Personal Assistant understood her. If there is a change in her support worker she likes an experienced worker to link up with a new one for a time until the new worker understands her routine, communication needs etc. This takes the pressure off her.

(End of text 8/9/04)