Fulfilling Potential Consultation:
The views of people with learning disabilities who are carers

Participants at the consultation events
## Contents Page

<table>
<thead>
<tr>
<th>Section</th>
<th>Page no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>3</td>
</tr>
<tr>
<td>Methods</td>
<td>4</td>
</tr>
<tr>
<td>How we became carers and who we care for</td>
<td>5</td>
</tr>
<tr>
<td>What is it like to be a carer?</td>
<td>9</td>
</tr>
<tr>
<td>Getting a good life as a carer</td>
<td>12</td>
</tr>
<tr>
<td>What support do we need?</td>
<td>19</td>
</tr>
<tr>
<td>Carers with learning disabilities - what do we want?</td>
<td>24</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>26</td>
</tr>
<tr>
<td>Appendices</td>
<td>27</td>
</tr>
<tr>
<td>Appendix A - Workshop Agenda</td>
<td>27</td>
</tr>
<tr>
<td>Appendix B - Questionnaire</td>
<td>28</td>
</tr>
<tr>
<td>Appendix C - Participants Drawings</td>
<td>30</td>
</tr>
</tbody>
</table>
Carers with Learning Disabilities: Fulfilling Potential Consultation

Introduction

This consultation drew on the views and experiences of people with learning disabilities who are carers. It was facilitated by the Carers with Learning Disabilities Network in partnership with Mencap, The Princess Royal Trust for Carers, The Institute of Applied Social Studies, University of Birmingham and the Norah Fry Research Centre, University of Bristol. The events were supported by national charity Respond and local organisations, Speak Up Self Advocacy based in Rotherham, Bath and North East Somerset Carers’ Centre (BANES), Sheffield Mencap and Gateway and Bromley Mencap.

The Carers with Learning Disabilities Network was formed after carers with learning disabilities were seen as a priority by the Families Lead in the Valuing People programme. The Network includes representatives from The National Family Carer Network and the Foundation for People with Learning Disabilities and a representative from the Standing Commission on Carers. Despite the work of the network to increase identification of carers with learning disabilities, there has been very little recognition of the existence or needs of carers who have learning disabilities.

While carers with learning disabilities remain a largely hidden group research suggests that a significant number of people with learning disabilities may find themselves in caring roles for others. One major survey of people with learning disabilities estimated that of the 69% of people with learning disabilities living in private households 10% were caring for someone they lived with (Emerson et al, 2005).

Further, we believe carers with learning disabilities to be increasing in number as an unseen consequence of successful government policies in two key areas. Independent living has enabled more couples with learning disabilities to live together with approximately 6% now living with a partner. Some couples are living together in a situation of mutual caring, whilst for others there is a significant caring role for one partner due to differing abilities.

Secondly, increases in life expectancy mean that there are more older people with learning disabilities living with older and increasingly frail family carers. Approximately 33% of people with learning disabilities live at home with family carers aged 70 or over. The recently published ADASS paper ‘Caring Conversations’ highlights the needs of this group.

Recognised, valued and supported: Next Steps for the Carers Strategy’ the Coalition Government’s policy document highlighted the part carers have to play in the Big Society noting that ‘Being a carer can be both rewarding and frustrating...By caring for people in
their own time and supporting other people’s independence, carers embody the spirit of the Big Society’ (HM Government, 2010:3)

**Methods**

Using the Carers with Learning Disability network and our own contacts we invited carers with learning disabilities and their supporters from across England to participate in workshops to discuss their experiences. Two workshops were held in geographically separate areas in order to maximise the number of people who were able to attend.

In addition people within the Carers with Learning Disabilities Network were offered the opportunity to comment through a brief questionnaire (see appendix A) or by email so that those unable to participate in the workshops could give their views and opinions if they wished.

A total of 19 people (11 in Sheffield, 8 in Bristol) attended the workshops, 12 completed questionnaires (of whom 5 also attended the workshops) and a further 6 people sent information by email. The participants were primarily involved in caring for their parents but also cared for siblings, children, partners, other relatives and friends. 9 of the people who attended the events had had multiple caring roles throughout their lives. There were 7 men and 12 women at the events, and they were a diverse group ranging in age from their 20s to 60s. Gender and age characteristics are not known for those who submitted information electronically.

The workshops were co facilitated by staff from Mencap, The Princess Royal Trust for Carers, The University of Birmingham and Norah Fry Research Centre, University of Bristol alongside people 4 members of the Carers with Learning Disabilities Network. There were 4 facilitators at each event.

The ‘Fulfilling Potential’ consultation questions were adapted and developed into a series of workshop activities to enable participants to share their views about what it was like to be a carer, what support they got to enable them to undertake their caring role and to think about what would help them to realise their ambitions and conduct their caring role more easily (see Appendix B). Throughout the day thoughts, feelings and discussions were captured by Pen Mendonca, a graphic facilitator and these illustrations are incorporated into this report.
How we became carers and who we care for

In the first activity people talked together in pairs about when they became carers and for whom they cared, questions which were also asked of those completing the questionnaires. The tables below provide a breakdown of the relationship between the carer and cared for and also demonstrate the multiple and cyclical nature of the care provided by many.

Tables 1 - 3 - Who we Care For

Key =  (P) = cared for this person in the past  (C)= cares for this person currently

Sheffield Participants

<table>
<thead>
<tr>
<th>Person Cared for</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Father</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Grandparent</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Sibling</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Partner</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Daughter</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Uncle</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Friend</td>
<td>✓ (P)</td>
</tr>
</tbody>
</table>

Bristol Participants

<table>
<thead>
<tr>
<th>Person Cared for</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Mother</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Father</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Grandparent</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Sibling</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Partner</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Daughter</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Uncle</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Friend</td>
<td>✓ (P)</td>
</tr>
<tr>
<td>Son or daughter</td>
<td>✓ (P)</td>
</tr>
</tbody>
</table>
Questionnaire Participants

<table>
<thead>
<tr>
<th>Relation</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Father</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Grandparent</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
</tr>
<tr>
<td>Sibling</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
<td>✓ (C)</td>
</tr>
</tbody>
</table>

The illnesses and disabilities of those who were being cared for were serious and included: arthritis, bipolar disorder, ADHD, cancer, dementia, epilepsy, schizophrenia, head injuries, strokes, cataracts, hip replacements and heart conditions. More significant was that in all cases the carer was involved in long term care of their loved one. One man said he had cared for his mother since he was small. Others had been caring for three to ten years.

Some people were involved in mutual caring, for example a mother with physical disabilities and a daughter with learning difficulties were caring for each other. Other people had some support in caring from other family members. However a significant number of people were involved in sole caring. Two of the people who attended were no longer caring as the person they had cared for had died. Others in the groups had been in multiple caring roles but one of the people that they cared for had since died.

Recognising themselves as carers was difficult – some of the carers were unsure whether they were carers, several participants said that they hadn’t realised that they were carers until someone had pointed it out to them whilst others noted that the person they cared for didn’t want them to be their carer.

‘caring isn’t a word I’d use, I just help her out. You’re not to be my carer she said, she wants to do things her way’

Some people told of how the person they cared for was reluctant to admit that they were being cared for by a person with a learning disability. One person commented that she was in a mutual caring relationship with her mother but only her mother received a carers’ allowance.

During the introductory session there was a discussion on some of the issues that the carers present faced in their lives, as illustrated below:
Often people became carers at times of rapid change, such as because a loved one had had a stroke, or because one parent had died and the one remaining required support. In such circumstances there was little time to plan or develop skills in caring.

‘I feel as l was forced into caring and it was something that l had no control over’

In situations where people became carers as a result of a bereavement they not only had to adjust and cope with their additional caring responsibilities, but also their feelings of, grief and loss.

‘I had to stay back and look after my dad because he couldn’t answer the phone or go to the door. My dad said you’ve got to look after your mum now. I didn’t understand what he meant at first. I was closer to my dad. When he died I got closer to my mum. My mum used to fall a lot. Every time she fell I couldn’t pick her up. I had to get help. It was difficult at times.... I enjoyed going places with my mum, but it was
difficult when my dad died. I cried a lot. When it comes up to birthdays, anniversaries it gets hard’

KEY MESSAGE

Many carers with learning disabilities become carers at a time of rapid change in their lives. People would find this easier if there was more support in place to help them to plan for such circumstances and a greater acknowledgement that ‘transitions’ can happen at any time of a person’s life.
What is it like to be a carer?

While for some, the onset of their caring role was sudden and unexpected, for others the level of the care that they were providing had gradually increased over time. All saw being a carer as an important responsibility, and a way in which they could make a positive difference and contribution to the lives of their loved ones though they also noted that it was a role which they were often not given recognition for.

All the participants in the workshops felt that being a carer was a very important role, and one that they were all committed to fulfilling.

‘it’s a good thing when you care, you reward the parents who bought you up’

‘I enjoy playing my part in keeping the family together’
However some indicated that they would have preferred not to be a carer if that had been possible.

‘caring was something I had no control over’

While some of the participants said they would prefer not to have a caring role others saw positive aspects to this.

‘there are some funny moments..’

‘caring can bring you closer to the person you are caring for’

‘it is good to see progress in the person you are caring for.’

Some carers commented on the fact that they felt ‘wanted’ by the person for whom they were caring. Supporting people with household jobs was seen as positive by many of the carers and particular emphasis was given by three people to the importance of pets in making life good. A sense of achievement in managing the issues associated with caring was raised by other members of the group.

Many carers with learning disabilities had learnt new skills that others didn’t know they possessed, or were capable of, when they took on their caring role:

‘I had to learn all the household skills. Before I moved in with [my partner] I lived with mum and dad and they did it all.’

‘I could bake but I never cooked a meal because mum always did it. I had to learn’.

‘it’s really good ... we work together on things. This morning we got dressed at the same time. It’s a work in progress, I’ve really enjoyed it’

Many saw being a carer as their primary role, and found it difficult, with the level of support they were giving, to think about education, getting or staying in a job, or living independently.

‘It would help to give me a break if someone else came in, but I don’t want to get out of helping her’

‘next day I went to the centre but I was shattered because I didn’t get any sleep’

It was clear from the discussions and the questionnaire responses that participants were concerned to plan for their futures and were considering what they might need to do in order to live independently. For example one participant said:
‘I am very worried about what will happen to me when Dad isn’t here anymore’

Whilst another said:

‘I am looking at flats because I want to live on my own when Dad is not here any more. He is 88 and very frail and he keeps falling off his chair’
Participants noted a range of support that would help to make a difference to their caring roles both in terms of enabling them to care more effectively but also in enabling them to have full and productive lives beyond their caring roles. Participants identified both practical and emotional support needs and this will be explored in the following section.

### KEY MESSAGE

Carers with learning disabilities need to have access to support while they are carers which will not only help them to fulfil their caring roles but which also allows them to plan for the future.

---

**Getting a good life as a carer**

### Supporting a good life

When asked for vision of what they felt they would be able to do if they were not caring, there were some clear hopes and dreams. These ranged from a paid job, travel and being able to choose where one lives to

‘I’d just be myself’

and

‘I’d be able to sit down and have a cup of tea.’

### Problems in getting a good life

Carers said a great deal about their concerns in caring. In large part these related to external issues of support and funding rather than to the caring itself. However a common theme was the feeling that they couldn’t put themselves first and the guilt attached to doing things for themselves.

Participants talked about having to give up work, college and social activities when they became carers. For some practical support, such as having someone from a carers agency come and support the person they cared for while they went out, was helpful but many still
worried about leaving their loved ones and felt guilty about this. One participant noted that
it was her responsibility to care for her mother saying

‘when I went to college she was on my mind all the time’,

At the Sheffield workshop one of the participants talked about her concerns about leaving
her daughter at school, despite this being a ‘safe’ environment:

‘I sometimes worry about [her] when I’m at work. When she was five she had a
bad fall at school, and people weren’t there. I still worry about her – I think
shall I go to work, am I being selfish. I do sometimes have to force myself to go
to work.... Even though her epilepsy doesn’t happen now I still worry. I know
they [seizures] can come back’

Lack of support

‘I would like to get more support so I can have a life on my own which caters for
both my well-being and financial needs. Also get more practical help so I won’t
drop off a cliff when the time comes. For example, have sustainable
employment so I’m not a burden on my family’

This comment showed the importance of gaining support now so that the carer could
develop a life of their own but also showed a concern about the future when they were no
longer a carer.

Lack of support included a perceived lack of support from other family members which was
raised by a number of carers at the workshops and in the questionnaires. There was a
feeling that ‘it’s left to us to do the caring’, with sometimes a sense that other family
members were judgemental rather than supportive, comments included:

‘My partner’s mum expects too much; she expects me to be always there’

‘I always have to think of others before myself’.

Some carers felt that it was their role to keep the family together and provide emotional
support. Others felt neglected and dismissed by other family members, comments
included:

‘I can’t get independence’,

‘I need more family support’,

‘I feel used’
There was also a feeling that they wanted to be available all the time and some people felt guilty if they weren’t always available. Carers said that they would value more and better practical and emotional support.

There was also a perceived lack of appreciation and support from services and professionals. Some people felt that they were not included in discussions about the person whom they were caring for and that their expertise was not recognised by professionals. The angry reaction to this exclusion is summed up in the comment below.

‘It has been said that people like us can’t be carers, well that’s a load of b***cks cos we’re all doing it ... we’ve proved it wrong, we’ve got loads of stories ... right now we’re proving it wrong!’

The lack of recognition of carers by professionals occurred in spite of the fact that carers were often making big decisions for family members, for example when to call an ambulance or ensure that someone received medical help.

Concerns were expressed about the level of carers’ allowance and the speed with which it was cut off when someone was admitted to hospital. One example was given when the carers’ mother was admitted with particular dietary requirements which were not met by the hospital. The carer brought meals to her mother but still had her allowance cut off after a month.

Responsibility

Some carers found the level of responsibility they had to take on was worrying. For example deciding when to ring for an ambulance or the need to be constantly with the person for whom they were caring. Sometimes the emotional aspects of caring with the responsibility attached to this were seen as problematic: for example one carer talked of needing to put her father’s needs before her husband’s. Another spoke of the jealousy between other members of the family when the carer brought presents for one or other of the people she was caring for. There was a stated need to share responsibility more with other members of the families but a sense that this was not always possible. The isolation of caring in terms of a perceived lack of family sharing the responsibility of care was a strong theme in the group.

In the Sheffield workshop some of the participants talked about end of life care. Some people mentioned going to see their loved one in palliative care. One participant spoke very strongly about how he felt it was wrong to put his mum into a home, and that he wouldn’t do that, something which was quite uncomfortable for some members of the group who'd
had to take the decision that they were no longer able to give the increasing level of support needed by their cared for person towards the end of their life.

Lack of flexibility of services

The need for a quick response when support was needed was raised a number of times. Being able to go to a wedding or have a birthday treat were named as things that carers felt often unable to do because of a lack of flexibility in services. One person commented that just to be able to go shopping and have lunch would be really good. Others found that it had been too difficult to arrange respite care or that the person they were caring for was unable to manage the different environment of a respite service. The need for practical support from someone who was trusted was raised but often this did not seem to be available.

The increasing nature of care

A number of carers commented that the amount of caring they had to do was increasing as the person for whom they cared became more vulnerable. This meant that caring became more time consuming and left less time for the carer to have a life of their own.
Issues with the person being cared for

Sometimes the person being cared for didn’t want the carer to be away or didn’t want to receive other support:

‘I would like it if Mum let the carer lady shower her on a Monday then I wouldn’t have to do it’

Some people also wanted to do other activities but weren’t allowed to:
‘I didn’t go out much. I was in most of the time with them. I didn’t sleep and it got very tiring – I used to fall asleep anywhere. I wasn’t really allowed to go out much as they didn’t want me to. I wanted to go out with friends’

Two people in the Sheffield group whose person being cared for had dementia spoke of the difficulties and conflict that arose whilst supporting them:

‘We had an argument. My mum wanted to go to the toilet on her own, but I didn’t want her to, I knew she couldn’t cope but she wouldn’t have it. I went into the front room, and she had a fall. I still feel guilty about that’.

‘When my mum got dementia I couldn’t relate to the things she was asking me. She’d ask me to go shopping for things we didn’t need. I wouldn’t want to go.’

Professionals’ attitudes and understanding

As noted above carers with learning disabilities were concerned about some professionals’ attitudes towards them – one carer commented,

‘Doctors don’t give information to us as carers’.

Information that was given was often not accessible or easy read and it was suggested that professionals could benefit from training in providing accessible information.

Pressure from others was a key issue for many of the carers in the group. One carer said that the flat she shared with her partner was inspected on a monthly basis by her landlady for cleanliness, and this put a lot of pressure on her to keep the place tidy.

Participants thought that there needed to be more awareness, particularly within mainstream services, that people with learning disabilities can be carers; professionals needed to understand that people with learning disabilities who are carers may have support needs as both a carer and as a person with learning disabilities in their own right. At the Sheffield workshop only one of the 11 participants had been registered as a carer by her GP, and this was only because she had informed them during her registration with the practice that she was a carer.

Money

Money was an issue which arose in a number of different contexts for carers. Some did not receive a carers allowance and did not know that they may be eligible. Some people in a mutual caring relationship with a parent found that their parent received a carers allowance
but they did not. Some people felt that the carers’ allowance was not enough and the amount given did not reflect the amount of work, which sometimes involved being on call 24 hours a day 7 days a week. Carers felt too that the allowance should reflect the value given to this work by the community. One man had worked out that while he was paid £10,000 per annum, his care for three members of his family had saved the Government £40,000. One carer who had a personal budget had wanted to use it to purchase a van which would have made transport much easier for him and his family. He was told he could not do this although transport was recognised as a serious issue for his family.

**Stress, worrying and health**

Some carers had sole responsibility for the person or persons for whom they were caring. This and the demands of the caring role itself were sources of stress and worry. One person commented: *When I am not at home I worry about mum and dad.* Others talked of the tiring nature of caring. One person’s husband was unable to leave his bedroom for meals and so his wife took meals upstairs to him. One person with primary responsibility for caring for three members of his family worried about what would happen if he became ill. For some carers who did not themselves have good health, there was a constant tension between their own needs and those of the people for whom they were caring. The need to ‘look after ourselves’ was said often as was the comment ‘I am needed most of the time’. There was clearly little time available for these carers to take time out or to care for themselves, which coupled with a lack of awareness (as indicated above) amongst health professionals of the caring roles that people with learning disabilities are adopting, could lead to increasing health problems and crisis.

Practically participants noted what a difference it made when they had been able to access carers’ assessments or when the person they were caring for had access to self directed support. These things led to more practical support being available such as a paid carer to stay with the person they cared for while they went out. For some people access to simple technology, such as a mobile phone, helped them to feel safer about leaving their loved ones. Others suggested that they wanted help with other household chores, such as cleaning and gardening.

Emotionally people valued having friends and other carers to talk to though for many this had come via specialist rather than mainstream services which tended not to recognise people with learning disabilities as carers; so having friends and advocates made a real difference to people.
What support do we need?

For many people with learning disabilities who are carers the issue was that they are not recognised as carers and, because of assumptions about their ability to understand, they are not always included in discussions and decisions about the person they are caring for. Participants in the consultation felt that they would be better able to manage and plan their lives if they were included in decisions and had their skills and their role acknowledged. This meant that both professionals and sometimes families needed to be less protective.

‘If my sister wasn’t here I would have had to do the shopping for mum on my own – mum gets anxious about me doing it’

‘Knowing from the experts what was wrong with my mum and uncle – what it [dementia] meant’

Recognition and respect

Knowing they were carers and being recognised as a carer by other people and by services was seen as very important. Carers said that they were seen differently when they were caring or working. ‘People think we can’t do things’. Awareness raising and better information on carers with learning disabilities would help others to understand the particular issues this group faces. It was important for participants to not only be listened to but also to be believed and have their views respected.

People felt that they needed to get their needs assessed and support services in place more quickly. This would be more effective if different services worked more closely together. Support needs to be timely and needs to be built on a relationship of trust and respect.

The participants and respondents from the questionnaire also found that at times, their cared for person could be a barrier to them getting the support they needed.

KEY MESSAGE

Carers with learning disabilities need to be supported to access services which give them more choice and control over their lives, both as carers and as individuals. They are being held back by assumptions made by professionals that they cannot be carers and that they don’t have the ability to do so. The lack of awareness that people with learning disabilities can be carers means that it can be hard for them to get the right support.
I would like to go out a bit more. I have just got a girlfriend and haven’t told Mum about it in case she doesn’t want me to see her. Mum is scared about being on her own for too long.

‘I wasn’t really allowed to go out much as they didn’t want me to’.

‘They organised a lady to come in and shower Mum every Monday but she won’t let them do it’.

When situations like this arose, they were difficult for the carer to manage. Having someone to support them in negotiating difficult issues with the person they were caring for is important.

For some people with learning disabilities having a role as a carer, and having this acknowledged, has changed the way they are seen by individuals as it provides them with respect and acknowledges their ability to be responsible and to give something back.

Decisions and practical support

Carers reported having to make difficult decisions in relation to the person they cared for, sometimes under pressure. For example one woman had two weeks to find a nursing home for her mother. Under these circumstances the need for practical support was high. Other carers stressed the importance of someone being readily available with practical support. For example one carer said that telecare was a ‘lifeline’.

Employment.

Some carers managed to sustain part time work while caring but they were in the minority. Some had given up either employment or attendance at college to care for family members. Employment was strongly valued by the group. One person said

‘I would like to go back to work’.

Work was particularly valued because it gave opportunities to socialise, and make friends. Losing employment was seen as isolating by some people in the group. Another commented on the effort of trying to keep contact with work colleagues and friends after leaving work. For at least one person

‘work can keep myself sane’.

However while work was valued it was also seen as something that was often too difficult to sustain with a caring role. There was agreement that it was difficult to manage work and
caring and in some cases people had left work because they had not received any support from their employers to work whilst also fulfilling their caring responsibilities:

‘the manager said he didn’t want to know my problems’

‘the managers say they’ll help to sort your problems out but they don’t, they sweep it under the carpet.’

In addition people expressed concerns about the effects of working on carers benefits.

Interests and Hobbies

The importance of having a life of one’s own outside of caring was strongly recognised by the group but they also felt this was very difficult. People showed a strong interest in many different activities, for example, gym, singing, getting computer skills, developing artistic talent. However they needed time to be able to pursue these interests and flexible cover to support them when they were away. The difficulties of pursuing interests or hobbies consistently was raised, carers needed to be on call and could not always go to activities. Even going to bingo was seen as impossible for one person because there was no-one to take her place as a carer.

The need to be able to have a holiday was discussed by the group. One person said they had not had a holiday for 8 years and another commented that it had been a long time.

Social Life

The need for a social life, a life of one’s own was seen as important but difficult to attain. One person commented that she was too scared to go far away in case something happens. This limited her ability to develop a social life of her own. Having something ‘just for ourselves’ seemed a reasonable but difficult goal. Some carers talked about their loss of confidence socially as their world became smaller in the caring role. The need for a friend to ‘boost my confidence’ was stated by one person. Some carers also felt that their limited freedom meant that they became more and more involved in caring and that having more freedom would mean that they would have to ‘let go’ some of the sense of responsibility that they had.

One woman reflected on her life now compared to when she was a carer. She said:

now mum’s passed away I can do more, like going to London’
The discussions by participants revealed the heavy sense of responsibility that people carried, willingly but also with a recognition of the cost of caring in terms of their own health and lives. The need for more flexible and accessible support was strongly worded.

Being Involved

Being involved in groups, in advocacy or in their communities were seen as important supports by participants at the workshops. Two of the participants from the Sheffield workshop attended their local Learning Disability Partnership Board and spoke up on behalf of people with learning disabilities and carers with learning disabilities.

One of the participants from the Sheffield workshop had cared for both his mum and uncle with dementia. They had both passed away and he was now the regular and only visitor of his friend in a local nursing home. He acted as an advocate on his behalf, speaking up to support his care.

One of the respondents from the questionnaire talked about the strong support she had had from her local church and community, being part of that community was very important for her and her mum:

‘The people at my church let me make tea and coffee every Sunday and they are very kind and they talk to me and one of them takes Mum and I to Pole Hill Garden Centre’

Another participant at the Sheffield event talked about being offered the opportunity to volunteer at a project that had made a difference for her:

‘I was referred to a youth club in Maltby for young adults with autism for 2 hours each week. That made all the difference. I’m too old now for the club but they are talking to me about being a volunteer’
Increasing awareness

Carers with learning disabilities said they need to be listened to:

‘The Government should take more notice of carers with learning disabilities’,

‘we need to be in the media’,

‘Hear what we need and do something’.

This also applied locally to service providers, who sometimes ignored carers with learning disabilities or didn’t recognise them as carers:

‘My partner’s in hospital and I’m not listened to or told what’s happening’.

**KEY MESSAGE**

Carers with learning disabilities need both practical and emotional support to help them to care well and have a fulfilled and independent life. Greater respect and attention needs to be paid to the views of carers who have a learning disability.
Carers with learning disabilities – what do we want?

Carers in Bristol produced some drawings reflecting their aspirations and needs (see Appendix C). Both workshops involved a plenary session at the end of the day the list below summarises the things that people with learning disabilities want to help them live fulfilled lives.

1. Respect for carers with learning difficulties. In particular recognition of carers’ expertise and intelligence ‘don’t under estimate us’.

2. Appropriate and timely support to carers when it is needed. Such support needs to be easy to access.

3. There needs to be information about caring and carers’ rights which is easy to access. This should include: easy to read information, possible home visits, use of DVDs. ‘Until you’re questioned about it you don’t realise you’re doing it’.

4. Carers should be paid an amount that values the work that they do. ‘it’s something you can’t walk away from... it is a big responsibility’.

5. Information should be available which lets carers know what benefits they are entitled to.

6. Carers should be able to earn more through work before their carers’ allowance is reduced.

7. The carers’ profile should be raised through national advertising campaigns. ‘It’s not any different being a carer with a learning disability but it needs to be more highlighted’.

8. Professionals need to be trained to listen to carers and to recognise their expertise. ‘Sometimes it’s harder to make people listen, to see us as carers’.

9. Carers with learning difficulties want opportunities to ask politicians hard questions eg through question time.

10. There need to be more opportunities for carers with learning difficulties to come together.

11. The respite allowance for carers should be restored.

12. Carers with learning difficulties feel that they are excluded by the Government. They want to be included in planning and policy.

13. Carers think that there should be national research to find out what the needs and experiences of carers are so that they can have a stronger voice.
Participants at Bristol, producing drawings that reflect their lives, and in Sheffield discussing the consultation.
Acknowledgements

Authors:

Cath Baker, The Princess Royal Trust for Carers and Crossroads Care
Professor Kelley Johnson, The Norah Fry Institute, The University of Bristol
Lucy Virgo, Mencap
Dr Nicki Ward, The University of Birmingham

Graphics:

Pen Mendonca

The authors would like to thank all the carers and their supporters who participated in the consultation.
Appendix A

Questionnaire for carers with learning disabilities

Fulfilling Potential
Focus on Carers who have a Learning Disability

Please help us to find out more about carers with learning disabilities by filling in the questionnaire below.
You might need some help to think about your answers – that’s OK.
You don’t have to answer every question – just answer the ones you can.

1. Who do you care for?

2. Why do they need a carer?

3. How did you become a carer?

4. How does being a carer change your life?
5. How do you feel about being a carer?

6. What help do you get?

7. What help would you have liked?

8. Is there anything else you would like to tell us?

Thank you for completing some or all of these questions. Please email them to either cbaker@carers.org or lucy.virgo@mencap.org.uk by Monday 27 February 2012.

If you would like a copy of the feedback to the Fulfilling Potential consultation from carers with learning disabilities, please let us know and we will email it to you.

Illustrations from the Valuing People clipart collection. Tel 0800 0430 980, www.inspiredservices.org.uk.
Appendix B

Programme for the day (Bristol event)

**Agenda**

**Thinking About Me: Focus on Carers who have a Learning Disability**

2 March 2012, to be held at:

David Hiatt Baker Conference Centre
The Vassall Centre, Gill Avenue, Fishponds, Bristol, BS16 2 QQ

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.30 – 11.00</td>
<td>Arrival. Coffee. Welcome</td>
</tr>
<tr>
<td>11.00 – 11.15</td>
<td>Introductions</td>
</tr>
<tr>
<td>11.15 – 12.15</td>
<td>Getting to Know Each Other: Who I care for and how I became a carer</td>
</tr>
<tr>
<td>12.00 - 12.30</td>
<td>What being a carer means to me</td>
</tr>
<tr>
<td>12.30 - 1.30</td>
<td>Lunch</td>
</tr>
<tr>
<td>1.30 - 2.15</td>
<td>What being a carer means to me: Small groups</td>
</tr>
<tr>
<td>2.15 – 3.15</td>
<td>Feedback from small groups: Developing action plan</td>
</tr>
</tbody>
</table>
Appendix C

Drawings by carers with learning disabilities

![Image of a drawing with the text: “It’s important to do things for myself for fun!” with icons for yoga, cinema, singing, and dancing.]

![Image of a drawing with the text: “Both to be happy to goether. No matter what they got wrong and someone to see too help you and All.”]
Liz

Mum wearing dad's medals (Navy Nurse)

Member of the British Legion

Helps out with the poppy appeal

Christophe

dad's car keys

30
50

[Sketch of car keys, 30 and 50 markers, and a man carrying shopping bags]