

# Developing social care: service users' vision for adult support

Peter Beresford, Michael Shamash, Vic Forrest, Michael Turner  
and Fran Branfield

First published in Great Britain in July 2005  
by the Social Care Institute for Excellence

© SCIE 2005  
All rights reserved

Written by Peter Beresford, Michael Shamash, Vic Forrest, Michael Turner

Produced by The Policy Press  
Fourth Floor, Beacon House  
Queen's Road  
Bristol BS8 1QU  
tel 0117 331 4054  
fax 0117 331 4093  
tpp-info@bristol.ac.uk  
www.policypress.org.uk

**This report is available online**  
**[www.scie.org.uk](http://www.scie.org.uk)**

Social Care Institute for Excellence  
Goldings House  
2 Hay's Lane  
London SE1 2HB  
tel 020 7089 6840  
fax 020 7089 6841  
textphone 020 7089 6893  
[www.scie.org.uk](http://www.scie.org.uk)

Acknowledgements	iv
Overall summary	v
<b>Part 1: Introduction</b>	<b>1</b>
1.1 How this study was undertaken	2
1.2 Who took part?	3
<b>Part 2: Overall findings</b>	<b>5</b>
2.1 Social care: the reality now	5
2.1.1 Problems of service	5
2.1.2 Inadequate support	7
2.1.3 Problems with agency workers	7
2.1.4 A struggle for good support	7
2.1.5 Lack of reliability	8
2.1.6 Bureaucracy still a problem	9
2.1.7 Variability: lack of equity	9
2.1.8 Unequal treatment	10
2.1.9 Lack of flexibility	10
2.1.10 Departmentalism	11
2.1.11 Fears among service users	12
2.1.12 Social care workers – continuing problems	12
2.1.13 What people value about social care workers and social care	13
2.2 How to make things better	14
2.2.1 Language	14
2.2.2 Training	14
2.2.3 Making things simpler	15
2.2.2 Addressing resource issues	16
2.3 People’s vision for social care	17
2.3.1 From personal to social care	17
2.3.2 Service user’s principles for positive social care	18
2.3.2.1 Effective involvement	18
2.3.2.2 A participatory process of social care development	20
2.3.2.3 Involving service users in defining quality	21
2.3.2.4 Quality and choice	21
2.3.2.5 Prioritising equality and valuing diversity	22
2.3.2.6 A rights-based approach	23
2.3.2.7 Social model-based social care	23
2.3.2.8 Independent living	24
2.3.2.9 Developing direct payments	24

2.3.2.10	Strategically supporting more user-led activities	26
2.3.2.11	Listening to service users	26
2.3.2.12	Truly person-centred social care	27
2.3.2.13	Improving access, improving support	30
2.3.2.14	An integrated approach to social care	31
2.3.2.15	Revaluating social care	32
2.3.3	Are you being serious?	32
<b>Part 3:</b>	<b>Findings from people with learning difficulties</b>	<b>33</b>
3.1	Summary	33
3.11	The reality now	33
3.12	What makes things better	33
3.13	People's own vision for social care	33
3.2	What people with learning difficulties say	33
3.2.1	Introduction	33
3.3.2	The reality now	34
3.2.3	Social care workers now: the lack of reliability	34
3.2.4	What people value about social care workers	35
3.2.5	Valued sources of support	37
3.2.6	How to make things better	38
3.2.7	Resource issues	39
3.2.8	Issues to address for the future	40
3.2.9	People's own vision for social care	41
3.2.10	Key values for future social care	43
	<a href="#">Appendix 1: Schedule used for group discussions</a>	<a href="#">44</a>
	<a href="#">Appendix 2: Shaping Our Lives</a>	<a href="#">47</a>

## Acknowledgements

We have many people to thank for making the production of this report possible. First we want to thank Dr Stephen Ladyman, Minister for the Community, for commissioning it, and Andy Nash of the Department of Health for supporting us to do it. We want to thank Sara Lewis and Don Brand of the Social Care Institute for Excellence for all their help, support and patience in undertaking it. We want to thank everyone in Shaping Our Lives for the part they played, coordinating the work and getting it done smoothly and efficiently, particularly Jenny Willis, Eamon Andrews and Carole Williams. Also our thanks to Munir Lalani and Patricia Chamber for their contribution and Tom and Ivy Griffin, of the Shaping Our Lives National User Group, for adding their wisdom and experience. Thanks too to Sue Bott of the Shropshire Disability Consortium for facilitating a group discussion.

We want to say a big thank you to all the service user organisations who helped carry out the consultation. It would not have been possible without them. This includes: Essex Coalition of Disabled People, Southampton Centre for Independent Living, Disability Action North East, Shropshire Disability Consortium, Greater London Action on Disability, Worcestershire Association of Service Users, People First Lambeth, Bournemouth Forum, Wiltshire and Swindon Service Users' Network and Awaaz/Achi zindagi, the Hammersmith and Fulham Black User Group.

Most of all, though, we want to say thank you to the 112 service users who took part in this consultation and contributed their experience, expertise, ideas, knowledge and hard work to it. We want to offer our sincere thanks and say we will do all we can to make it possible for what they say to be listened to and acted upon.

## Overall summary

This report by Shaping Our Lives provides service users' views as part of the government consultation for developing a new vision for adult social care initiated by the Department of Health at the request of the Minister for Community, Dr Stephen Ladyman. Shaping Our Lives was commissioned to undertake this work as a national independent user-controlled organisation.

This report is based on the views of a very diverse range of social care service users – 112 in all – gathered from many different parts of the country. More than a quarter of the participants in this project were black or from minority ethnic communities. The study was almost entirely undertaken by service users and their organisations, drawing on their networks and experience at local and national levels in undertaking user-led research, evaluation and consultation. There was a remarkable degree of consistency and agreement in what different service users and service users from different parts of the country said.

The report is organised in three parts: the first sets out how the consultation was undertaken; the second contains the views of service users generally; and the third reports the views of three specific groups of people with learning difficulties to ensure that their comments have equal visibility.

This consultation was generally undertaken by people with experience of social care and who identify themselves as social care users. It was carried out using a semi-structured schedule, drafted by service users (see Appendix 1). Service users took part in 13 group discussions which were carried out during September and October 2004.

The report findings are organised according to the issues highlighted by participating service users:

- service users' views about existing social care based on their experience
- service users' suggestions for improving social care provision and practice
- service users' own ideas, proposals, values and principles for a new vision of adult social care.

All three of these offer insights into how things might be better for the future from service users' perspectives. Problems now offer important indicators about how things need to be different. But service users also show a great capacity to set out the alternatives that they believe are needed.

### Key components of service users' new vision for adult social care

Ensure:

- better funding and resourcing of social care and social care workers
- less charging for service users (which excludes some from support)
- key problems are tackled, including:
  - > poor-quality provision
  - > poor processes for accessing and maintaining services and support
  - > inadequate support

- > problems with agency staff
- > having to struggle to secure good support
- > the lack of reliability of social care
- > problems of bureaucracy
- > departmentalism
- > patchy provision and inequity
- > unequal treatment
- > inflexibility
- > poor practice
- > insecurity
- > poor-quality staff
- > lack of continuity and security
- that the bullying of service users and service users' fears of bullying in services are acknowledged and addressed.

Build on:

- examples of good practice – what service users value from workers
- a language of support rather than 'care'
- appropriate training and the capacity of user-led training to bring about cultural change
- involving 'good staff' in social care training
- making things simpler
- safe ways for service users to assess or complain about services
- efforts to address diversity and challenge racism
- good models of day services *and* employment schemes – choice, not one or the other.

### Service user principles for a new vision for adult social care

The principles that the service users identified for improved adult services include:

- policy and practice for *social* care, not just personal care
- effective user involvement
- a participatory process of social care development
- involving service users in defining quality
- offering quality and choice on service users' terms
- prioritising equality and valuing diversity
- a rights-based approach to social care
- social model-based social care
- social care which supports people to be independent by ensuring them the support to live as they want to
- social care which supports and enables service users to participate, contribute, have real choices and do things with others in the mainstream
- developing direct payments
- strategically supporting more user-led services
- listening to service users
- truly person-centred social care
- improving access, improving support
- an integrated approach to social care
- revaluing social care.

## Part 1: Introduction

"I would start from a dream and say: 'How do we achieve that dream?'. The totality of people's lives needs to be understood and appreciated. [Service users] are not a burden, so help them make a contribution.

Good support is a sign of a good society. We just want to have a normal life and be able to do the things that everybody else does and takes for granted." Service users who took part in the consultation

This report sets out what service users want from social care. It reports their vision of social care policy and services for the future, as well as reporting their views of the strengths and weaknesses of existing provision as a basis to build on. It represents the views of a substantial and diverse body of service users, and many of them have many years' experience of social care. Together, they provide a significant and unprecedented body of evidence for social care to build on to shape the future.

To the best of our knowledge this report represents the most comprehensive attempt that has so far been made to find out what service users themselves want for the future from social care policy, provision, practice and services. The report is based on the views of 112 service users in England. They constitute a very diverse group in terms of the service they use, their personal characteristics and identity, the areas they come from and the experiences they report. There is often talk of the difficulty of involving black and minority ethnic service users; more than a quarter of participants in this project were from black or minority ethnic communities. The study was almost entirely undertaken by service users and their organisations, drawing on considerable experience at local and national levels in undertaking user-led research, evaluation and consultation.

It should also be stressed that service users were keen to be involved in this consultation. Facilitators reported back that discussions were lively and enthusiastic. People had as many ideas and proposals to offer about what was needed for the future, as about what was wrong with the present. We were unable to speak to all the service users who would have liked to take part because of time and resource limitations. There was no sense of 'consultation fatigue' among participants in relation to this study. They felt that, because the consultation had been requested by the Minister for Community, Dr Stephen Ladyman, what they said "could go all the way to the top". Service users were also anxious to get feedback about what would be done with what they said.

The government is developing a new vision for adult social to match the development of new legislation for children. This vision is intended to provide the basis for future policy and provision for adult social care. The government is producing a Green Paper on adult social care as a starting point for this change. In its original consultation about this new vision, the government did not succeed in gaining the views of service users. It knew it was very important to gain these views and therefore organised a further stage of consultation to get them.



The Social Care Institute for Excellence (SCIE) asked Shaping Our Lives (see Appendix 2), an independent national user-controlled organisation, to undertake this consultation. Shaping Our Lives has produced this report which sets out what a wide range of service users offer as their vision of adult social care for the future. Shaping Our Lives hopes that the government will try very hard to listen to what service users say and make it a cornerstone of the changes that they make.

It is important to make a general point first; because of their direct experiences of social care and their personal knowledge of its strengths and weaknesses, service users and their organisations have already been working for many years – at least a quarter of a century – on developing a new vision for how it could be more helpful to people as service users. This work began with the disabled people's movement in the 1970s, but it has developed more widely since then, and many groups – including mental health service users/survivors, people with learning difficulties, older people, people living with HIV/AIDS, black and minority ethnic service users and many more – have been developing ideas and arrangements for better policy and provision that works more effectively and economically.

If we consider the key new directions that social care has taken in recent years, almost all, if not all, seem to have originated with service users. Included in this is the idea of direct payments, independent living, social models of disability and distress, ideas of self-management, peer and self-advocacy, non-medicalised services and support, user-controlled services and so on. These have all had a fundamental effect already on some people's lives and are now recognised as important developments in social care more widely. That is why it is so important for government and services to give the views and proposals of service users and their organisations value and respect. They have already shown that they have an important contribution to make.

## 1.1 How this study was undertaken

This consultation was undertaken by Shaping Our Lives, an independent national user-controlled organisation with a long track record of undertaking such work. The consultation was carried out through organising a series of 13 discussion groups across England. Discussion was based on a structured schedule with a range of open-ended questions. This schedule was initially tested and found to work well and this was the common experience during the course of the consultation. All discussions were organised and facilitated by social care service users, with one exception (see below). All participants' expenses (including service users' support and travel costs) were paid and, in accordance with general principles of good practice for participation, they were all paid a fee for contributing their experience and expertise.

While Shaping Our Lives organised the overall consultation, the discussion groups were largely organised by independent local and regional service user-controlled organisations. From experience, this has emerged as the most effective way of involving as wide a range of service users as possible. Thus Shaping Our Lives paid a management fee to these organisations and they in turn:

- contacted service users through their own extensive networks
- invited them to the discussion

- organised suitable premises for group discussions
- organised food and refreshments
- made sure that participants' access needs were met.

One local organisation employed a disabled consultant to do this; the others used their own staff. In one case an experienced local disabled woman facilitated the discussion group. Two experienced service user researchers working with Shaping Our Lives facilitated most of the others. A skilled black service user researcher facilitated a discussion with a black mental health service user group.

All organisations and discussion facilitators received the same schedule and briefing document to maximise consistency. All provided process notes setting out key issues emerging, their immediate thoughts on the discussion and a breakdown of the demographic characteristics of participants.

Shaping Our Lives wanted to ensure that a wide range of people with learning difficulties would be able to contribute to the consultation. To ensure that this was possible and that their access needs were met as fully as possible, three discussion groups were organised specifically with people with learning difficulties. Two were held in London and one in Bournemouth. The person who facilitated these discussions was not a service user himself, but was highly experienced in supporting people with learning difficulties. He liaised with two organisations of people with learning difficulties – one in Bournemouth, the other in London – to set up two of the discussions, organising the third through his own extensive networks. An emphasis was placed on enabling contributions from a wide range of people with learning difficulties, in terms of both diversity and the difficulties they experienced. To ensure that this was possible, these groups were all kept small, each consisting of five people.

The smallest group included two people; the largest 17. Most were made up of between 8 and 12 people. Group discussions lasted from between two hours and five-and-a-half hours, most taking about three hours or so. Refreshments were provided in all cases, both to signify that participants were valued and to make the occasion more pleasant and accessible. Participants were also able to have breaks when they wanted them.

With participants' agreement, discussions were tape recorded and then a short report was written on each discussion, organised according to the key issues covered in the schedule and including verbatim comments and quotations from participating service users. These short reports formed the basis of this report.

## 1.2 Who took part?

The aim in undertaking this consultation was to include as wide a range of service user perspectives as possible. In order to work within ministerial timetables, the consultation had to be undertaken with some speed. Group discussions were carried out during September and October 2004. Shaping Our Lives was initially asked to undertake six group discussions and then this number was increased to 12. In the event, 13 group discussions were undertaken. While there was some pressure on time, because of the method adopted to undertake this project – drawing on the skills, experience, networks and credibility of local and regional service user organisations

– it was possible to carry out the work effectively and sensitively without adversely affecting the participatory principles which Shaping Our Lives has sought to maintain in its work. An interim report, describing the findings from the first seven group discussions, was produced on 17 October 2004 to feed into government discussions. The final report was produced in mid-November 2004.

In total, the consultation included 112 service users. This included 65 women and 47 men. There were 31 black and minority ethnic service users and 81 white service users. The black and minority ethnic service users included Asian, African and African-Caribbean service users, service users of mixed parentage and service users with Chinese, Iranian and Middle Eastern backgrounds. In addition to the 15 people with learning difficulties who took part in the three specific discussion groups, a further seven took part as members of five other discussion groups. Participants were not asked their age; this was estimated. The sample included a wide age range. It included someone who was 18 and people in their 20s, 30s, 40s, 50s, 60s, 70s and 80s. To avoid being intrusive, participants were not asked about their sexual orientation. However, in two of the discussions issues were raised about social care in relation to sexuality which indicated that participants were involved who were gay, lesbian or bisexual. In another group one person seemed to indicate that he was gay.

We particularly wanted to include people in the consultation who tend to be marginalised, in society, in public policy and in such consultations. Because of this, we sought to include as wide a range of people as possible rather than reflect what might be actual proportions of people using particular services or particular 'kinds' of service users.

The sample included people with a wide range of physical and sensory impairments including older people, a Deaf person who used British Sign Language (BSL), someone with a facial impairment, a care leaver, mental health service users/survivors and people with learning difficulties.

Participants included parents, including parents with learning difficulties, people with experience as refugees, people with multiple impairments – including, for example, someone who was deaf and blind – people with physical impairments and learning difficulties and people with experience both of using mental health services and of physical impairments. The sample included people with diverse experiences of using social care services – such as community equipment, day services, domiciliary services, home helps, user-controlled services, residential services and services to support people who use direct payments. It also included people in touch with social workers, key workers, floating support workers, home helps and other social care workers (as well as health, housing and other workers). There were people who were self-financing users of social care, people in receipt of local authority services and recipients of direct payments. Discussions were located in London, Essex, Southampton, Wiltshire, Manchester, the North East, Shropshire, Worcester, Liverpool and Bournemouth. They included people living in both urban and rural settings.

## Part 2: Overall findings

### 2.1 Social care: the reality now

Service users presented a complex picture of social care, talking about positive experiences and frequently highlighting problems which had had adverse effects on many of them. More problems than positives were generally identified by service users. Some groups expressed strong views that social care provision had worsened in recent years. They talked about reduced support and reduced quality of support.

#### 2.1.1 Problems of service

The process of accessing social care was frequently negative for service users. The assessment process was widely seen as arbitrary and very dependent on the quality of the staff carrying out the assessment, with some staff adopting a more advocacy-based role than others.

“Bad assessments are service driven and disempower the user.”

“You have to go through all these hoops to lead a normal life.”

“One assessment and that’s it.”

“Care staff with no independence perform assessments and cause stress to service users afraid of services being withdrawn.”

Participants felt that assessment was too focused on finding the fastest solution and not necessarily the best one. They talked about people with communication impairments and those seen as having multiple or ‘severe’ impairments as being at most disadvantage with services.

“Care plans need to be done properly and people need to be involved. Some people don’t even know what a care plan is. When people are not feeling good, they need support to be involved.”

Fears were expressed that the assessment review process could result in either a withdrawal of services or the organisation of inappropriate ones. The process of accessing services was frequently criticised.

“Phone access is poor and may deter people on low incomes. There is also little continuity in the duty process.”

“The delay in [receiving] services is adding to my stress levels.”

“Life changes and increased disablement are hard enough. To access care you have to do the donkey work whilst coming to terms with major life changes.”

"Hospitalisation creates particular insecurity. Social care agencies then often don't listen to people's wishes."

Gaps in service can leave people feeling vulnerable:

"It's devastating."

"The system assumes you have friends and relatives who will drop everything to help. This is not always the case."

One service user spoke for many more when they highlighted the frequently mechanical nature of the process of social care provision:

"Last review I had was one minute over the phone. Social workers should come to your home and listen to what you have to say."

Access to services is sometimes very poor. One mental health service user reported not being able to get support even after a suicide attempt. Another person talked about how quickly services are withdrawn from mental health service users once they are judged to have recovered and how difficult it is to get them back when you need them. This led into a discussion about how lack of support could lead to people using illicit drugs and alcohol and end up with bigger problems.

One group of black mental health service users generally thought that the social care services they received were good and helpful, but the exceptions they identified highlight broader problems facing this group:

"Let's not forget how much they drug us up."

"They tell us we're going to be on these drugs for the rest of our lives."

The things they liked the least included:

"Medication – Haloperidol – being told to take the medication."

"Services being lost."

Service users routinely described services that were problematic and of poor quality:

"You have to do everything yourself. It is a nightmare trying to get a wheelchair repaired. Basically it's beyond repair, but they won't admit that."

"Had rollator delivered – had to fix the handles myself."

"There's a lack of understanding towards self-funders. Even though we are having to pay for care, we still need help to sort it out."

### 2.1.2 Inadequate support

A common theme among many service groups and users was that the support provided by social care was inadequate.

“One hour shopping and one hour’s cleaning per week is all I get.”

“Social services are a social disservice.”

“Hours [of domiciliary support] need to be much more realistic.”

One group felt there was a vacuum in service provision between what was available for young people and older people. One participant said that the only choice offered them had been between a day centre and nothing:

“[Social services]... they visit you and then forget you.”

Frequent staff turnover means that some service users were faced with the problem of repeatedly having to explain their particular circumstances.

### 2.1.3 Problems with agency workers

There was also criticism of the increasing use of agencies to provide care services. Agency staff were criticised for their variable quality.

Services are often taken out on a block contract with little choice or flexibility for service users. People felt that the primary motivation was profits for the agency. If negligence was alleged, the local authority was sometimes unwilling to take any corrective action for fear of losing the contractor. One participant said that agency staff were unwilling to work with her children. Another cited the example of someone who had to live in a nursing home during the holiday period because of staff problems.

“The care workers are cowboys.”

“Care agencies just employ anybody – they are not interested, only want to make money.”

“Any Tom, Dick or Harry coming into the house. You don’t know who they are.”

“I get sick of the in–out business [from care agencies]. Come in, get up, go away, come back, put to bed, gone again. If you want a drink at night, tough.”

### 2.1.4 A struggle for good support

The original hope was that having choice in service suppliers would improve quality of support. However, from service users’ experience, agency care undoubtedly creates additional problems of its own:

“Agency care – I never knew who was going to turn up, or even if they were going to turn up.”

Not all the news about agencies and agency workers was bad, however:

“Using an agency that gives carers for three periods, so that there is continuity [has been a positive].”

But in this example, as in some other reports of positive support, people stressed that you had to be determined and assertive to get it, and this is not a good basis for equity.

“Any assistance you need, you have to fight for it.”

“... But you have to push to get what you want – this is an agency that is expensive, so [the local authority] may not keep their contract.”

“It’s difficult to ask if a police check has been done. You need to know who to complain to.”

“We get good support from a GP – we helped get direct payments for a carer – but we are a group that knows about things. Others don’t know.”

“Benefit appeals take too long. Got to keep ringing and pressing buttons.”

Help with equipment needs was forthcoming but it was often slow in arriving. There were also problems expressed about rehabilitation services:

“I know more about my condition than they do.”

Concerns were frequently raised that the model on which social care was based was still primarily medical:

“Professionals don’t understand the social model of disability.”

One participant who used personal assistance complained that she had to pay for a system, which should be “free, unlike any other utility”. This reflected a more widely held view agreed among many service users that social care should be free at the point of delivery. It should be needs-led and not budget-led.

### **2.1.5 Lack of reliability**

Social care intervenes in the most personal aspects of people’s lives, often at times when they are particularly vulnerable or over issues that are particularly intimate and sensitive. Yet many service users comment on how unreliable they are, despite the crucial role they often have to play. Service users cannot be sure if support will be available regularly or securely or if it will be of consistent quality.

“Attitudes of social workers vary considerably. Their attitude depends on who you get.”

“It would be nice not to have to worry about there being more cuts all the time.”

“Some workers are rare pearls, but there could be a change of staff that upsets all that.”

### 2.1.6 Bureaucracy still a problem

While welfare bureaucracy has been condemned by successive governments for at least 25 years, service users still identify it as a major problem:

“The worst problems are red tape, inflexibility and lack of understanding.”

“Too much paper goes round and round.”

“There’s too much paperwork and not enough hands on.”

The bureaucracy of social services was contrasted by one group with the accessibility of a local user-controlled service. They found this bureaucracy disempowering, with paperwork mislaid and service users’ versions of what they wanted being treated as at odds with care workers’ written interpretation.

“Not having to fill out big forms and be made to feel like beggars.”

One example given was the complicated structure of the local wheelchair service, where different types of wheelchairs were provided under different terms and conditions. Service users also saw this bureaucracy as taking money from the provision of direct services. Service users stress that services must dispense with tokenistic attitudes. It was generally agreed that the emphasis on bureaucracy must be dealt with.

### 2.1.7 Variability: lack of equity

There was also much comment about the variability in services from one council to another, and also about the inability to transfer the service previously provided. More and more local authorities use agencies to provide services and consequently ignore the importance of individual needs and individual relationships.

There was particular dissatisfaction aired at the level of service provision in one area: the North East. However, there were comments more generally about the lack of consistent services across different areas. People want consistency.

“Wheelchair service should be fairer and not dependent on where you live.”

“There is a two-tier level of care. Some can go to the football and the pub. Why can some go and not others?”

“Reviews should be standard, not at the whim of a social worker.”



## 2.1.8 Unequal treatment

The issues that service users report in this consultation are mainly common among the many different service users included in it. But while there are many common concerns, there are also different issues raised by and facing different groups. For example, mental health service users are fearful of proposed new legislation which looks set to increase controls, while not ensuring adequate support for the majority of service users.

Also, particular difficulties seem to face some groups, which relate to the way in which social care currently works (or does not work). Some groups definitely seem to be at a disadvantage, or to be given a lower priority than others. Where people cross over the categories that services use, they can expect to face particular problems. Some groups seem to face particular stigma and lack of understanding. For example:

“I have a label of multi-disability person, which means I have “lots of things wrong’ with me and they don’t know which box to put me in.”

“No social worker with Deaf people. No one can use British Sign Language (BSL).”

“It’s better [here] for hard-of-hearing people because they have a hearing therapist who acts as liaison between professionals and service users.”

“There are problems of transition, for example, moving from child to adult services and from adult to older people’s services. There are problems around having to start with a new set of staff.”

“Issues around getting workers and training are particularly difficult for deaf-blind people. There’s a lack of resources for deaf-blind people. You have to be [seen as] at risk to get support. For this meeting a PA had to come from miles away.”

“Our son has mental health needs and [needs help from] alcohol services but has not been able to get any support.”

There are still major problems with some groups having particular difficulties accessing valued services and support and some groups being more likely to be restricted to devalued and controlling services.

## 2.1.9 Lack of flexibility

Services were frequently thought to be “out of synch with people’s lifestyles”. Service users commented that too-rigid patterns of care provision deny the individual sufficient autonomy. Half the participants in one group used day centres that they thought were too segregated. In another group, service users valued day centres, but arbitrary cuts were now being made.

“[We need] quicker provision.”

Many service users do not have the support that they feel is most appropriate. There is little flexibility, for instance, in the area of carrying and lifting. There were also concerns expressed about the lack of confidentiality when working with people doing NVQs.

“Bring back old services like home help.”

### 2.1.10 Departmentalism

Mention was also made of the division between health services and social services that, for example, means that direct payments cannot be used to pay for health service provision. This penalises people with complex needs.

“Someone in a car crash could have their needs met by the health service while someone with the same needs due to disability will have services provided by social services.”

A common consequence of departmentalism continues to be lack of coordination:

“I have social workers, occupational therapists, district nurses and others and they never talk to each other. Every time a different worker comes, they ask me what’s wrong with me. I say, ‘Haven’t the other people told you?’ and they say, ‘We don’t do that.’ A friend suggested I throw a Christmas party for them all, get them all here and make them talk to each other.”

“The division of services is driving people mad.”

Services are impairment-specific so different groups will have differing services despite often having needs in common. Departmentalism makes life difficult for service users in many ways.

At the same time, many service users are worried about the impact of ‘integration’ between health and social care services as it is actually taking place. While some felt that it might be “OK” in the long term, there are big fears that new problems are being created, relating to user involvement and funding for service user organisations.

“If there is one group of workers who have less understanding of our needs than social care workers, it’s health workers.”

There are also concerns that integration is resulting in a return to medical interpretations of disabled people and other service users, which many service users have found very unhelpful.

“Social care works from the social model of disability – health services use the medical model.”

“We have to educate the health side on the social model [of disability].”

At the same time, service users report the problems that come from the operation of boundaries and barriers between services and policy areas and argue for change:

“[There needs to be] more confidentiality between the professions.”

“[There is continuing] poor communication between services.”

“[There need to be] better systems so you don’t have to keep repeating things to different people in different parts of the service.”

### **2.1.11 Fears among service users**

“People are scared at having services withdrawn if they are seen to be stroppy.”

There are real fears among service users that they may be returned to care homes and hospitals. That fear undermines the will to assert themselves and breeds a culture of gratitude. Personal assistance services need to be regulated to ensure that disabled people are not left unsupported. This is a real fear and reality for people.

Participants in the consultation also remarked about the high levels of guilt and the lack of self-confidence which many service users have in requesting and obtaining service provision. There is little understanding shown towards disabled people’s negative feelings when asking for services.

“The culture of gratitude and dependency is everywhere.”

“People should not always [have to] feel grateful.”

While participants felt that service users should be able to be confident to express their needs and to assert their identity, there was a common view that social care created barriers in the way of this. Because of this, participants in several groups highlighted the importance of service users becoming more assertive.

“Disabled people should be confident to express their needs and to assert their identity.”

“People should assert themselves more and stop assuming.”

### **2.1.12 Social care workers – continuing problems**

Much comment was made about the quality of care workers. Although good examples were cited, there was a more general view that, because of the low pay that care workers receive, the standard of workers is often low and they are sometimes rude to service users.

People in one group made explicit comments about a lack of sympathy they felt among some social care staff:

“They look at you as though you are stupid.”

“Workers can be patronising.”

“We should be treated on equal terms, not talked down to.”

Other people talked about the demeaning and disempowering way in which they were sometimes treated by workers. This was one of the most disliked aspects of social care for some service users:

“The people who come to you just see you as a number. They’ve got 12 to 14 people to see in the morning so it’s [like] you’re on a conveyer belt. People do not get quality of life. They lose their privacy and their dignity.”

“I feel like I could die and it wouldn’t matter. The people don’t know you. They don’t care about you.”

“They [social workers] think they should be in control. That’s got to change. They should have a more hands-on attitude, give you help to find appropriate [support]. They are too keen to hand you over to someone else.”

In one group, a lesbian participant had found it difficult to get social care workers who were sympathetic towards her sexuality, and as a result, she felt that she would be much happier with a lesbian carer.

### 2.1.13 What people value about social care workers and social care

In one discussion group, participants said that they felt many care workers were good and did an invaluable job for little financial reward.

“Bad ones stick out like a sore thumb.”

Workers who adopted a more enabling role were appreciated. Having a line manager from a particular service working with you also helped in accessing it. In one group, the view was that the quality of social workers was improving and the system was getting better. One person noted that the wheelchair repair system was being reorganised within their authority on a priority basis and not on a “certain region, certain day” structure. One mental health service user made very favourable comments about the mixed housing project that he lived in. The range of people there meant that he did not feel that he was living in a ghetto or becoming institutionalised. Another service user, in another group, highlighted the disproportionately positive effect a valued social care worker can have on service users’ lives:

“The most constructive thing I’ve had with social care is through this centre and having the same key worker – continuity.”

## 2.2 How to make things better

### 2.2.1 Language

Language needs to change. Many participants dislike the term 'care'. There was a wide sense of discomfort with the use of the word. With a change in emphasis to a more service user-centred approach, they felt that a change must come in language, with the word changing from 'care' to 'personal assistance'. 'Care' was felt to be a passive and unhelpful term.

"'Care' is what people who love you do."

One participant stated that the use of the word 'care' had actually made them think twice about taking part in the consultation. The language, it was argued, is tied to negative understandings.

"The government treats us as scroungers."

Yet service users felt that the opposite to this was the case, with them being the experts, for example, on disability and saying that this needs to be acknowledged.

"We are hidden away [from society]."

### 2.2.2 Training

Training was seen as an important route to positive change. Many service users had given a lot of thought to training. There was considerable debate on this issue in some groups – what the most appropriate training was, whether it was better to have someone without training so that they did not have any preconceived (negative) ideas, or whether the problem with training was that it was often the wrong kind of training.

"Training doesn't necessarily mean they are good."

"Qualifications are sometimes not much good. Relevant training is needed."

"I get good workers who are not trained. Trained workers think they know it all and boss you around."

- Training should be provided to ensure that social care workers have the requisite knowledge and skills.
- Social care needs to be more actively promoted as an academic and professional pathway.
- Service workers need to be encouraged to be more open to differing needs and to use their own initiative.
- Care workers should learn to listen to service users.
- Courses for personal assistants are still often organised on a medical model with tasks such as shopping being done for service users instead of adopting a more

participatory approach. Training should ensure that workers treat the disabled person in a more individual manner.

- User involvement in training and user-led training are seen as key to such a shift in culture.

“[We] need more user input into the training and the skills required.”

“Carers should not infantilise the disabled person.”

“Workers should have honesty, truthfulness and politeness which in turn should be returned.”

“I would like assistants to do whatever they [the disabled person] want, as they want it done, when it needs to be done. It should be the disabled person who sets the agenda with disability equality training (DET) obligatory for staff.”

“We don’t want to be seen as “tick boxes”.”

“Listening skills are important, to think outside the box. People should be open to new ways of working and new ideas.”

### 2.2.3 Making things simpler

Members of one group felt that the level of complexity needed to engage social care services was still a deterrent.

“It’s too stressful. A real barrier. I just want to be left alone to get on with it.”

“[We need] an easy-access complaints procedure.”

“We need easier-to-use services.”

“‘One-stop shop’ should be the principle for services.”

People also felt that there should be a greater awareness of the choices available to disabled care service users. There needs to be joined-up thinking. The range of benefits is far too complicated and diffuse and is ultimately inefficient.

“It gets people into trouble, can lead to financial mismanagement and is open to abuse.”

Instead of an array of advice workers, perhaps the answer would be a simplified benefits system. The benefit trap can exacerbate the person’s ill health and self-image.

“Health improvement is penalised in terms of benefit receipt that encourages a state of learnt dependency.”

## 2.2.4 Addressing resource issues

While service users know that policy makers and politicians do not like hearing about resource problems, they felt that the support they received was often badly affected by them. The 'm' word – money (and the lack of it) – kept cropping up. There was a feeling that, as social care funding was not ring-fenced, at times of local government budgetary problems it was absorbed by other demands.

“More money [needed] for social services. They have been cut back for many years.”

“There is an urgent need to increase resources to social care.”

“Social care’s lack of priority means it is financed through non-ring-fenced budgets resulting in permanent insecurity and an uncreative approach to service delivery.”

As one group put it, service users are denied services on grounds of cost, rather than these being provided on the basis of need.

“We feel patronised by this.”

“There is scant attempt to measure unmet need, and service levels often become totally unrealistic.”

Another expression of this, which has already been touched on, was the view that care workers were poorly paid and this was obviously a major disincentive to carrying out this role or to doing it well. Low wages topped up by benefits devalues the role of the care worker and the esteem in which they are held. There was a commonly held view that services placed too many demands on care workers. Service users showed a considerable understanding of the difficulties and pressures social care workers face:

“In a job which requires 10 people, they have three people to do it.”

“They could employ more workers and not overload the ones they have – and pay them more. There should also be room for workers to deal with stress.”

“Often the principles are good, but staff are overburdened and burn out.”

“There should be enough social workers to go round and they should pay them more if they need to be paid more to recruit.”

“We want them to stay on the job.”

“Staff continuity.”

There was a strong sense among a significant number of the service users who participated that none of the problems of staffing would change as long as people were paid relatively little and the work had low status.

Another consequence of under-funding which service users identified was having to pay for services. This was felt to create major barriers in the way of people being able to get the support they needed and to live independently and as full and equal members of society.

“We need a fairer system – get away from means testing.”

“Community care charges: cannot pay them.”

One group expressed a particularly strong view that the more service users had to contribute financially, the less social care was available to help and that this was not fair.

Ultimately, it was strongly felt by most service users that any real changes towards a new vision for adult social care would need to be properly resourced if they were to be realised.

## 2.3 People’s vision for social care

Service users had strong, well-thought-out ideas about what social care should look like in the future. They had no difficulty at all in offering proposals for alternatives. They were as able to offer new ideas as they were to comment on existing policy and practice.

People had clear ideas about what they thought social care should mean for the future.

- “It is getting assistance from the community as opposed to family and friends.”
- “It enables people to live more fulfilling lives and to be independent in society.”
- “Assistance to lead your life in the way that you choose.”
- “Social care should transcend disability and include education, training and support ... [People’s] aspirations are greater than services.”
- “Whatever help is needed is provided in an understanding manner.”
- “[It’s about] choice and control.”

### 2.3.1 From personal to social care

One group drew an explicit distinction between ‘personal’ and ‘social’ care. This could be seen to underpin the thinking of many service users. By this they meant personal care being basic support, while social care was having the support to be part of your community, part of society:

“... it’s the need for continuing support – not medical need.”

All this is what service users undoubtedly want social care to mean, but for many it still offers little more than (limited) personal care.

“Currently it is like house arrest.”



"[Addressing diversity] takes understanding, resources and flexibility. At the moment services are stuck in the rut of just delivering personal care."

"I have got to stay in the house. I should be able to get out and lead a normal life."

"I've got to fight to be able to go to church!"

Service users see real social care as meaning something very different:

"It means you can be part of the community. Means you don't have to live in a hospital."

"[It's] not just personal care. It's help with social life and so on."

"Care statements need to look at people's whole lives."

"[It] means having communication support which means having equal access."

"Social care is about providing a level playing field with those around you, to give opportunities for interaction."

"Less bureaucracy, more understanding and treating users as people, part of the community; services that help people be part of the community, not just personal care."

"More flexible services, for example, more help for older people with decorating and cleaning so that they can stay in their own homes and be independent."

It is clearly important to service users that all that has long been known about what is needed to provide good social care services and support is acted on. Otherwise any new vision will be built on sand.

However, service users also offer a broader vision of new principles, values and practices for the future

### **2.3.2 Service users' principles for positive social care**

Taken together, service users' comments add up to a set of core principles and values for positive social care.

#### **2.3.2.1 Effective involvement**

User involvement is beginning to be implemented. It is required in many aspects of social care. However, it still faces many problems: service users in the consultation raised problems of tokenism. The fundamental change user involvement signifies is not coming easily.

"User involvement is very difficult. You can't get your say because there are so many professionals [in the way]."

Service users say that user involvement in social care should not just be a passive process of feedback but should be a continual and ongoing activity.

“It should not be simply a rubber-stamping process.”

“If you want genuine involvement for people, you have to be prepared to pay for it.”

“We need more opportunities to talk in a focus group like this.”

One group thought that effective user involvement would be a way of ensuring that diversity was acknowledged and the differing needs of different service users and service user groups addressed. User involvement has to engage a much wider range of service users. Funding has to be provided to ensure that these ambitions become a reality.

Many service users felt that user involvement should extend to greater employment of service users in social care. Their direct experience and ‘experiential knowledge’ should be seen as strengths to be built on that are valued by other service users, and opportunities for them in social care employment should be widened.

“[We need to see] more service users working in service provision.”

Effective service user involvement was widely seen as the only way in which accountability could be ensured in social care.

“[We] want to know more about where the money is spent.”

“User involvement is the only way to get accountability.”

“Users and the public have to have more say.”

“There needs to be some kind of monitoring panel to look at the way people are doing their social work.”

“You need monitoring to ensure you are getting the help you need.”

“We need more advocacy.”

“There needs to be more of a dialogue and discussion between social care professionals and users of services and not have things forced on you.”

Another suggestion made to achieve this was the establishment of ‘scrutiny panels’ with the majority of those on them being service users.

Another group talked about accountability arising from their needs being listened to and being based around a notion of trust. They felt that involvement from service users should be at every stage, from the suggestion that they use a service to its inception and delivery. It should not be tokenistic, but a real process of consultation.

There also needs to be fuller participation by service users within the political process. At a local level, scrutiny panels should be established using the skills and experience of disabled people.

“All services should be open to service users’ input. This would mark a major cultural shift.”

It was felt that, for all this to work, ultimately there should be a greater level of involvement by service users at a policy level within central government.

“There need to be more disabled people doing jobs of responsibility because they will understand what it is like to be a disabled person.”

“Dynamic contracts are needed to employ disabled people at a [higher] project level.”

“We need to widen the participatory net.”

For most service users in the consultation, however, the key route to achieving effective user involvement is the adequate resourcing of local user-controlled service user organisations. They feel that government needs to recognise that service users have a key role to play in making broad-based user involvement a reality, but they need support and resourcing to make this possible. One group highlighted the broader concerns that service users now feel about funding and the future of service user organisations.

“We can’t get the money to do the job they want us to do. They give less money and they want more work. Accountability? I don’t think social services or the health trusts have a clue about accountability.”

There was some discussion about where funding should come from to maintain an adequate infrastructure of local service user-controlled organisations. Some people felt it should come from central government, others from local authorities/health trusts. There was agreement that such funding was essential for effective user involvement.

### **2.3.2.2 A participatory process of social care development**

User involvement is not just seen by service users as an important element in social care provision and practice, but also as a cornerstone of developing social care and moving to a new vision for adult social care. The process will work best if it starts and continues in a participatory way.

“However care services are developed, there must be an engagement with service users in a consultative role.”

“Social care needs to be more inclusive of us.”

“We are the experts on disability.”

“Social care needs to be developed in an inclusive manner.”

“[We] need a national advisory committee of service users.”

### 2.3.2.3 Involving service users in defining quality

While service users recognise the importance of existing policy discussions about improving the quality of social care, for this to have real meaning many feel service users feel they themselves need to be centrally involved.

“We need a watchdog body with service users and professionals – people with teeth.”

“Social care workers need to have a level of competence. But there’s a lot of training in doing the wrong things. Users should set the standards.”

“Users should be judges of quality.”

Service users have already seen the weaknesses of traditional approaches to quality improvement through bureaucratic regulation.

“Over-regulation, for example: the Care Standards Commission and National Care Standards have made things worse.”

At the same time, service users recognise that there are obstacles in the way of service users becoming more central in the definition of quality.

“Users must define what quality is, but the service providers find this very difficult to accept. They are worried about losing their power.”

### 2.3.2.4 Quality and choice

What has become known as the ‘choice agenda’ has become important in public policies such as health and social care. For some time, governments have emphasised the importance of service users having a choice in the service they receive. In social care, this has tended to mean a choice of service suppliers, but with service users encountering difficulties with all sectors of service suppliers – state, voluntary and private – this may not offer any meaningful solution. Service users talk about choice in terms of the kinds of services and support they can actually access and the control they have over them. For example:

“We need more choice of equipment, better equipment.”

“Respite care – we do not want more facilities. What we want is to be able to pay care on holiday, even if we pay half.”

For the small minority who currently access them, direct payments are seen as a key route to such choice – as service users define it.

### 2.3.2.5 Prioritising equality and valuing diversity

There was a widespread feeling that principles of equality and equity should be at the core of service provision. A culturally sensitive service needs to take into account different beliefs and backgrounds. Over and over again, service users stressed equality.

“We are all equals. We still have free will.”

“Social care needs to be based on a clear principle of equality as [service users] are often the victims of both discrimination and poverty.”

“People should be on the same level. Not them up there and us down here.”

“Equal but individual.”

“We want to be treated as equals.”

“Everyone should be treated equally.”

“Too many people take no notice of the Disability Discrimination Act especially when it comes to communication.”

“Humanity should have priority over the ‘same culture’.”

“Diversity is the norm; normality is a myth.”

Service providers need to be non-judgemental. Social care service users generally feel that awareness of and respect for difference is essential. Some progress has been made around issues of diversity, including ‘race’ equality, but there is still clearly a long way to go. It is important for service users that social care services and workers can relate to them and their backgrounds:

“What I like about social care is that my key worker, my housing officer, is from my background, because once upon a time, you couldn’t really get that.”

“The workers need to have these situations in their backgrounds – for example, black people working with black people and down the list. Culturally sensitive people.”

“Make the workforce reflective of the society that it serves. Social care needs to have people that are more open minded and able to accept the differences.”

“We need more black social workers.”

“Class is still an issue. There is still a view of social work being middle class.”

“We shouldn’t forget that 80 per cent of people on the [psychiatric] wards [in London] are black people and lots of those are black males.”

There are evidently problems in some localities in prioritising equality issues and acknowledging diversity. There is a strong sense among service users that more needs to be done to engage with people from different groupings. One organisation that had received funding to enable people from black and minority ethnic communities to access direct payments felt that this was a key step forward.

One service user involved in work with a refugee community highlighted key issues for them:

- Language is an important issue
- They generally do not have community support
- Some people may need mental health services as a result of their experiences, such as torture.

“We need to have services that meet these needs.”

### 2.3.2.6 A rights-based approach

Service users spoke much less about ‘needs’ than ‘rights’. There was a strong sense that, as well as having responsibilities (which were often not recognised), social care service users also had rights and entitlements – which were often confused with obligations (particularly in the case of paid employment).

“People should have rights. People pay in taxes and don’t get support.”

“New mental health legislation will not help.”

A service user in one group argued that no services were being provided from a rights-based perspective.

### 2.3.2.7 Social model-based social care

What defines the strengths of social care for service users is the idea of a social model.

“Social care should be based on the social model informing policies, practice and procedures.”

“Services should be available on a 24-hour basis and premised around a concept of non-exploitation centred on the social model of disability.”

The emphasis has to move away from costs to “maximising the skills, talents and lifestyle of the disabled person”. Capability is penalised in that the more independent a person is, the less support they are assumed to need. In fact, they may still need support, but they can contribute more. This is the basis of social models of disability and distress.

The social model should be at the centre of future service planning. This should start from assessment.

“The assessment should deal with more complex issues such as intellectual stimulation and physical exercise.”

“We have to educate the health side on the social model.”

One suggestion was for a social model-based assessment team. This had operated helpfully in one area, but was subsequently disbanded. Current assessment forms in this area include a social model element and this is valued. The means of carrying out assessments needs to be more

“... consistent, cohesive and comprehensive.”

### **2.3.2.8 Independent living**

The corollary of the social model is what disabled people have called ‘independent living’ – ensuring the support to make it possible for disabled people to live their lives to the full alongside other people. The independent living movement, developed by disabled people, has a long history and has been influential for many disabled people. It has provided a vision of how things can change to include them in the mainstream. Participants in the consultation highlighted its importance.

“Social care means independence.”

It was not only disabled people who talked in these terms in the group discussions. Across different groups of social care service users, providing appropriate, adequate and secure support was seen as central to the role of social care. Thus it could support people to live their own lives, to live their lives as fully as possible, and to be part of society.

“Autonomy, choice and respect.”

The term ‘quality of life’ came up regularly in discussions about people having the support they needed to live their lives as far as possible as they wanted to. The term tended to be used to mean quality of life as defined by service users themselves.

### **2.3.2.9 Developing direct payments**

Direct payments are seen by many service users as one of the essentially positive elements of any new vision for social care and a key route to ‘independent living’. Where comments about mainstream social care were generally negative, those about direct payments (for those who were able to have them) were almost invariably positive.

“It’s given me my life back. Now I control who’s helping me and when they come in. It’s also given me a social life and I can do things that I want to do.”

“I have had my own personal assistants for 10 years. You get a better standard of care.”

“When you employ your own personal assistants, you have more say and know what you are going to get, when.”

“Having direct payments for communication workers has meant having a better social life, getting out. All this has boosted [my] self-esteem.”

“With a direct payment I can use hours for shopping which I couldn’t before. This is a great improvement.”

“Having a good personal assistant stops you feeling isolated.”

“The move should be to self-assessment and direct payments.”

But as one group specifically complained, there are still major difficulties in accessing direct payments:

“They need to be more widely available.”

“Everyone should have the opportunity to have direct payments.”

“More direct payments for mental health service users.”

“I waited two years to get direct payments.”

“There was a long wait to get assessment.”

“Things are very good when they are done, but you have all the hassle of getting them, so it’s the bit in between that is so nerve-racking. But when they put all the bits together, it all ends well!”

There are still big problems for service users getting well-trained personal assistants:

“Staff are not trained properly. There are problems with agency staff.”

“There are problems of getting PAs [personal assistants] trained when you are on direct payments. Who supports you while they are being trained? Who pays? We need funding for training for PAs for people on direct payments, including costs of cover for the service users.”

A greater promotion of direct payments was regarded as essential.

“The minister needs to put his money where his mouth is.”

Direct payments need to be made more manageable and more user-friendly. One way of doing this is by reinforcing the infrastructure of support from user-controlled organisations. Such a model, rather than a consumerist model of people purchasing services on their own, seems much more likely to offer an inclusive and high-quality service.



Another way forward is to avoid the inequalities and problems of portage that arise from direct payments being based in individual authorities and as yet not extending to the healthcare system. For direct payments to work, they seem to need an effective system of local user-controlled organisations to offer this support reliably.

#### **2.3.2.10 Strategically supporting more user-led services**

In one area, services had been set up under the control of the local disabled people's organisation. Service users said this made it possible for different groups of disabled people to escape from

“... the attitudes of condescending staff.”

Such user-led services are valued. Where there was a local user-controlled centre for independent living, it was strongly supported and service users valued the peer support it offered. More autonomous services on a small scale, controlled by local service users and their user-led organisations, are seen as offering a solution to present inflexibility. Service users spoke about more services based in the community and delivered by service users as members of the community:

“Things I've liked most? The local centre for independent living's service to help with being an employer [as a recipient of direct payments].”

“The peer support from the local centre for independent living is invaluable.”

“The best people to help us is us.”

“We want a genuine opportunity to manage the services.”

Services, it is felt, should start from the baseline of listening to what service users wanted. A multiplicity of services could be provided like this. Independence is the ultimate goal. More user-controlled independent living centres should be established and supported to make this possible on a much wider and more routine basis for service users.

#### **2.3.2.11 Listening to service users**

If one word sums up most what service users want from social care, it is 'listening'. Almost all the discussion groups highlighted the importance of social care workers listening to service users. Several identified this as the key or a key issue for social care practice and provision, making the difference between positive and negative experiences of social care. Listening to and respecting service users was seen as a crucial theme for good social care. For example, one person spoke about a locum psychiatrist, another about a social worker who listened and was helpful:

“Very nice, not like other social workers. She did everything she could.”

Service users referred to the need for social care workers to have 'communication and relationship skills' so that they can work with service users to identify problems and find solutions together.

“They need to listen more to people and take note of what is being said to them. One of the faults tends to be that people in authority just use that authority and do not get involved with the people they are supposed to be helping.”

“I’d like the social worker to listen to what my needs are so that they can work with you rather than telling you what to do.”

“They need to listen to our voices and our experiences.”

“They need to listen, listen, listen and not patronise us.”

“Listening skills are essential. [Workers] must listen to users.”

Listening is seen as important at all levels, from frontline staff to politicians. Listening and understanding – ‘active listening’ – was regarded as a prerequisite for social care workers.

“We want people and politicians to listen. We have to keep pushing for improvements.”

Listening to service users was seen as crucial for improving social care policy, practice and provision. It was related by service users to other core human qualities which they value: the capacity of workers to show kindness, common sense and respect. Service users in this consultation, as in other earlier exercises, consistently highlight and prioritise these.

### 2.3.2.12 Truly person-centred social care

Because of a reliance on individual and medical models, social care service users tend to be seen as a cost, and not a productive benefit, to society. Due to the broader exclusions of society, there is often still little alternative for some service users than being on benefits. As a result, as one group stated, service users tend to be seen as economically inactive and dependent. The benefit and social care provision systems need to improve if they are to support service users’ aspirations.

There has to be a shift at all levels from damaging stereotypes to a focus on the person. There is a strong feeling among service users that individuals need to be listened to. It is their needs, not those of budgets and bureaucracies, which should be prioritised.

“They should work around the person and their carers and not the other way round which is what happens a lot of the time. People should be at the centre and be treated individually. I waited 10 years to get a really decent social worker and what was good about her was that she was the first one to say to me, ‘We are going to sit down and do the care plan and I want you to be involved’.”

“Treat people as one [unique individual] and have respect for each person.”

“Social care workers should be able to fine-tune each care package to that person’s needs.”

One service user in the consultation talked about how she had worked out her own service-level agreement with the local authority and was very satisfied with the services that she had received.

“Whatever care is needed [should be] provided in an understanding manner.”

“We need more information, more openness – less force.”

“There [has to be] room for examining human growth and potential.”

As one group put it:

“What’s needed is a more affirmative approach to social care. Social care does need to engage with the issue of resources, but balance that against a sense of autonomy for the service user. Care workers need to be person-centred.”

Two service users highlighted the distinction services draw between basic ‘needs’ and ‘wants’ and challenged conventional thinking about this.

“You need to look at desires as well as basic needs – more pleasure as well as care.”

“You have to say, ‘I need ...’ to get anything, not ‘I would like ...’, or else you end up getting nothing.”

For most service users who took part in the consultation, these issues mean that the nature of service provision needs to be defined by the service users themselves. Greater flexibility needs to be incorporated into service planning (locally and nationally) to make this possible. People should be able to access appropriate support as soon as they need it.

“There should be more emphasis on prevention and early support rather than waiting until people have a crisis.”

One suggestion was that clear guidelines for what can and what cannot be provided should be laid down. This could be the basis for a much more equitable and uniform provision. Other suggestions to support greater flexibility included revisiting local authority budgets and lower rates of taxation for personal assistants where they are currently taxed as small businesses.

Service users also highlight a broader framework for social care which takes account of people’s lives holistically – for example, addressing issues of sexuality and other aspects of people’s overall life and experience. A view that was commonly repeated was that social care needed to adopt an holistic approach if service users are to be able to play a full part in society.

“Holistic services – a less medical approach.”

“[You] need to look at the whole person.”

“We don’t so much need their help. We need them to help us help ourselves.”

Relationships with other services are also seen as an inherent part of the overall social care brief. This not only includes health and housing, but also education, training, recreation and relational services.

A theme of the consultation with service users was that what was needed from social care was flexibility to respond to the individual requirements of each unique individual service user. This needs to work for all service users, regardless of the categories that social care have traditionally put them in. However, what often happened instead was patchy provision which did not respond equitably or appropriately to each person’s particular wants and needs and which sometimes clearly disadvantaged particular groups of service users.

Sensitivity allied to continuity was the major wish for a renewed social care. This sensitivity could manifest itself in choices that acknowledge cultural preferences, such as halal food. Nor should money be wasted on short-term provision that may not be of the service user’s choosing. There needs to be more information and better communication. Staff should respond to correspondence. As one woman said about a promised letter from social services:

“It went to Timbuktu and didn’t come to my house.”

Service users in one group expressed concern about the way that social workers and other social care staff were preoccupied with ‘negative risk’ and seemed concerned to ‘watch their backs’ rather than take account of the rights and needs of the individual.

“Risk is part of life.”

“They need to accept that they are there to help us. There should be less concern about risk.”

There should be greater willingness to listen to people, and services should be flexible in their responses to people’s requests. The qualities and skills that service users emphasise and value in social care workers are basic and have now been repeatedly highlighted by many service users:

“They should have knowledge of the background of the people they work with.”

“Developing trust is essential. If you don’t like their personality, none of those skills [they may have] are going to work.”

“They need to be good all-rounders.”

“They need to be more supportive – help people work out solutions.”

“[They need] a good sense of humour!”

“Respect is the major thing in the provision of sensitive social care.”

“... An understanding and caring attitude, a bit more of their time, more information of what you’re entitled to.”

“They should be able to help with form filling in and housing.”

“What they are entering is the caring profession and they should be very tolerant and patient.”

“More gentle and less forceful.”

“Local, honest and reliable [staff].”

“We should be able to set the agenda.”

“Compassion.”

Service users have to be able to respect service workers just as service workers should respect service users.

At the same time, service users highlight that workers need relevant skills.

“Staff who work with Deaf people need to have BSL [British Sign Language] skills at least to Stage 2.”

“They should be skilled in recognizing [mental distress].”

The issues of sensitivity, which service users refer to, make clear that social care and social care workers are faced with complex challenges if they are to play a truly supportive and helpful role. For example, in one group of mental health service users, participants highlighted the changing role that they found helpful from workers. When they were ‘well’, they wanted workers to be there, but more in the background. It meant support they could fall back on – if they needed to. They talked about the need for a ‘unique’ approach which recognised that everybody was different and might want different things from social care. Thus in the group, one participant felt that they were not getting enough support, another that social care was sometimes “interfering”. Social care workers were seen as important and greatly able to help, especially after an episode in hospital, but they could feel intrusive when someone felt “back on their feet”, if they did not match their role with changing needs and preferences.

### **2.3.2.13 Improving access, improving support**

Concern was expressed that service users frequently have little idea as to what is available and are not in a position to have an overview or make creative choices. There should be better information about what services are available and, it was suggested, these should be publicised more widely on television, radio and the Internet.

“We need information.”

“[We need] better access – a 24-hour helpline to get services.”

“Being able to reach workers by phone, better communication and better information about services and what help is available.”

“They ask us what we want, but we don’t know what we can ask for.”

There was vociferous agreement about the complexity of living independently as a disabled person or other social care service user. In practice, there is often a lack of transparency in the process. For example, disability living allowance forms are ‘endless’ and complex. Housing is a particular problem because there is still far too much housing which does not meet the needs of disabled people. The Disabled Facilities Grant that funds home adaptations takes a long time to access. A named, designated worker was identified as a ‘boon’ in helping people negotiate the service system.

#### 2.3.2.14 An integrated approach to social care

When talking about what social care meant to them and what they thought it should mean, service users frequently emphasised that it needed to be considered in relation to people’s lives and the society they lived in more broadly. As readers may recall, they drew a distinction between ‘personal’ and ‘social’ care and saw social care as crucially about service users and their lives in their full, social context. Social care for service users needs to make it possible for people to be full and equal members of society. Participants made this explicit in many of their comments and there are clear implications here for social care for the future. It means new approaches to support, new links with other services, new relationships with the wider community.

“We need to break down barriers, build bridges.”

“As single parents we need help with childcare so we can go back into education. We need a crèche available in the evening. We need support.”

“Social care needs to link in with other services like leisure services and education to support people to do the activities they want to.”

“The home nursing team was a big thing – care in the community in action.”

“We need a good support network.”

“Preventative measures.”

“Crisis houses [for mental health service users] – alternative to hospital.”

“[Accessible] transport.”

“Less stigma [against mental health service users]. Show us on television leading normal lives.”

As some service users said, if issues like access and transport are addressed more effectively, then there will be fewer barriers facing service users, and people are less likely to need support from social care.

### 2.3.2.15 Revaluing social care

Service users feel that social care is still the poor relation of the National Health Service. It has disproportionately fewer resources, less status, poorer conditions and less priority.

“Social care does not seem to be valued. It’s seen as a luxury and people begrudge having to pay taxes.”

“Health care and social care are important in their different ways. Both should be equal, but they are not seen like that by politicians.”

“They [politicians and policy makers] should have pride in the job.”

Social care needs to be given a much higher profile and greater kudos to ensure that the work is seen as valuable. Likewise the design of services, practice and equipment needs to improve to enhance the self-image of service users. What service users value in staff and services must be incorporated much more clearly as a basis for setting standards, measuring quality and rewarding staff.

### 2.3.3 Are you being serious?

Service users also had messages of their own for ministers and government. They are anxious that real notice will be taken of what they have to say. For example:

“Is [the minister] going to provide any more social workers?”

“Is he going to recruit more from the ethnic backgrounds?”

“Take parents with mental health issues into consideration.”

“There needs to be more openness.”

“Why are they cutting incapacity benefit?”

## Part 3: Findings from people with learning difficulties

### 3.1 Summary

This part of the report sets out the views of three groups of people with learning difficulties in response to the government's consultation on a new vision for adult social care. Participants highlighted a wide range of problems they experience with existing social care provision and practice. They also emphasise the importance of workers and services based on positive human values as central to the provision of good social care. They identify a number of principles and qualities for good social care. They also highlight a number of strategies for achieving them. Central to what people with learning difficulties say, as to how to achieve a new vision of adult social care as well as what it will look like, is the principle of more equal and respectful working with service users and the more effective involvement of the latter in policy, practice, services and training.

#### 3.1.1 The reality now

- Lack of reliability with social care workers.
- Services which are controlling, which people with learning difficulties have difficulty challenging.

#### 3.1.2 What makes things better

- Good workers who are respectful, listen and support people to be more independent.
- Being valued for who you are.
- Suitable training to improve staff.
- Enough money for services and support for people with learning difficulties.
- Service users monitoring and inspecting services.
- Choice in services and support.
- Opportunities for real training and jobs for people with learning difficulties.

#### 3.1.3 People's own vision for social care

- Getting the support and help you want.
- Real chances and choices to get direct payments.
- Being able to be part of the community.
- Supporting people to live independently – to live the life you want to.
- To have the same choices as other people.
- To be treated as equals, to have rights.

### 3.2 What people with learning difficulties say

#### 3.2.1 Introduction

An experienced supporter facilitated these three group discussions as well as offering participants support in advance. A total of 15 people with learning difficulties from



different areas took part in the discussion. They were made up of seven men and eight women between the ages of 18 and mid-50s, of whom seven identified themselves as black British, one as Iranian and seven as white British. One person indicated that he was gay, although there may have been more.

### 3.2.2 The reality now

To improve things for the future, there has to be a proper understanding of the problems there are now, as service users see them.

- Service users and service providers have different views on 'good' services.
- It is difficult for people with learning difficulties to challenge services.
- Service users want to control their own lives, but social care services try to control service users' lives.
- People find it difficult to get the support they want from social care services.
- Social care can be controlling and intrusive instead of supportive and positive.

"We are here and social care is over there – who is making the decisions? They are saying totally different things than what we are."

One woman who is of mixed parentage felt she did not get any help from her social workers when she was getting racist verbal abuse from a neighbour. As a result, both she and her husband had to move home.

Social care can help:

"It's good to have people like social services and it can help but it's like them and us who are trying to control our lives."

But when you need help:

"When it comes to say what you want, they get weak. They get so weak when we tell them what's going on, their levels go right down. We are the ones telling them what to do and they get so low down."

Experience of a social worker and social care:

"[She was] ... a nightmare, she put me in a residential home, her decision, she put me there. She made it all for me, she said I was severely disabled. It was the wrong place for me."

"Service providers and staff are shocked that we are allowed to speak up. They should help us. Staff don't always want to change or want us to be independent."

### 3.2.3 Social care workers now: the lack of reliability

- The behaviour of individual workers can lead to either good or bad social care.
- Some social care workers are abusive or hurtful.
- Some social care workers are disrespectful, rude and/or frightening.

- It is important to treat service users with respect.
- Service users want all social care workers to be reliable and caring.

One person had this to say about her social worker: "It's bad." Her social worker does not tell her what time she is coming – or if she does, she is late for appointments. She also said the social worker wants to know things that are not her business. She said the social worker is "... bossy and getting annoyed with us". She also said the social worker is "scary" and "two-faced" and that she would be nervous about trying to get the social worker changed.

Other people said:

"They treat you badly and talk behind your back. They treat you like you are dirt and they don't give you a chance to do things."

"Or a chance to say anything."

"Bad [staff] think you are stupid and can't do things. They don't understand you."

"My support worker is basically an arsehole. He-sometimes-on Friday and Saturday, he makes fun of me and calls me names because I dress up as a woman.... Sometimes I cry."

"I've had bad experience. They used to hit you across the head [in one residential home for mental health service users]."

### 3.2.4 What people value about social care workers

- Service users really value good, supportive, respectful workers.
- Advocates and self-advocacy workers are valued by service users.
- Service users value good supportive services.

One way in which people with learning difficulties highlight what they value in social care and social care workers is by talking about what they did not like from their present experience. The basics are still not necessarily happening:

"[They should] treat you with respect, more independence, listen to us."

"[Social care workers] should behave themselves, come when you need help and not be bossy."

"Workers should be there when we need them and keep appointments when we want them."

"Workers should be helpful and polite."

"I'd like them to treat us better and understand us better in the future and be nice to us."

"[They should] understand what people are saying to them ... and be kind and give support ..."

"... when you need it."

"[Workers] should not treat people like children."

People with learning difficulties also highlight what they want social care and social care workers to offer by talking about positive experiences as a model for their hopes for the future.

One person liked the work experience they did in a shop for the following reasons:

"I got support, I enjoy working with support and a key worker. [The key worker was good because they were] very supportive, helping with forms and supporting me with going to different places and hearing about benefits."

"God bless our support workers [advocates and self-advocacy workers]. You just go to social work for problems."

One woman talked about a group for black people with learning difficulties that she was part of. She said it helped her a lot for the following reasons:

"[It's about] people getting together, it's a lifeline, need to get into certain groups that give you hope, need to get into a group where you are comfortable because you need that or you crack up.... The majority are all white. They don't know about us. [They] can't reach where we are."

She said People First, a user-controlled organisation of people with learning difficulties, helped her too. She also said:

"... [getting] counselling for the first time, it was really nice."

Also highly valued were:

"Free holidays ... where you want to go."

"Having bus passes."

Not everyone could think of something they liked about social care. When one man was asked by his supporter if there was anything he liked about social care, he answered, "Not really."

Several people mentioned social care workers whom they valued. Good workers, as service users define them, can make a big difference and that is why they are so important. One person, speaking about her own much-valued social worker, said this:

"Social worker ... sorts everything out when you have problems."

Some people talked about how they liked one particular work-training scheme because the manager was good and they liked her.

Another woman had just got her own flat with her husband. She was very pleased with the support she was getting from the social care worker who lived in a flat downstairs from her. She said:

“She is nice. We can go round to her flat if we have a problem.”

### 3.2.5 Valued sources of support

- Good workers need to have good social skills and value people; they need to be there for people.
- Good workers need to support service users to get their rights met.
- People with learning difficulties want to be seen and accepted for who they are.
- People with learning difficulties give each other important support.

This is how one person expressed how good social care workers should behave:

“They have to be radical, have to be real and get to the point, don’t take no rubbish.”

People emphasised how, to be good workers, social care workers had to have positive human qualities as well as skills.

Thus one man said he had never had a ‘good’ social care worker. However, he said a good social care worker should be:

“Nice, funny ... someone I can talk to.”

“... and a good friend.”

Other people said:

“Support worker needs to know the rights of the person with learning difficulties. [Good support workers] gave them [people with learning difficulties] their rights as human beings.”

“[Good support workers] ... let you know who you are and see you [as] ... a friend Not what they are paid to do, someone who knows a person well.”

“We need people around us who want us for ourselves.”

“Make sure the person’s got a good attitude, sense of humour, good eye contact.”

This man said the worker should think about what the person with learning difficulties would like to do. He also said a good support worker should have good listening skills and be good at helping people and sorting things out.

Someone mentioned that a good support worker should have patience.

“Support you to do what you want to do.”

“[Good support workers] don’t take over.”

“[A good worker is] understanding – they understand, listen, [are] kind, respectful, help us with problems.”

One woman said that good support workers need experience. When asked what she meant by experience, she said: “... Done work for a long time with people with learning difficulties.” She said workers should “go to college to get different skills for working with people with learning difficulties”. Someone said that workers “need to know how to work with people like us.”

Some people talked about how it was not only paid workers who supported people with learning difficulties and that people with learning difficulties supported each other. This is an important point for people.

One person talked about how he had supported someone else in the group when she was going through “hell”. He said that he was now a “mentor”. He told us how important mentoring is and he said the following:

“People who are very close and [have] been there all the way through help a person find a true identity for themselves. [They] look at the person inside you. [It] helps you carry on.”

### 3.2.6 How to make things better

- It is important that there is proper training for disrespectful staff.
- Service users should be supported to train staff and inspect services.
- “Good” staff could be involved in training staff.
- Service users want safe ways to assess or complain about social care workers.

Several people suggested that service users train staff.

“I don’t think social services respect the identity of the person and feel they don’t fit into the community because of how that person is. They need training on how to talk to people, respecting that person without offending them. They need to think about how they are in themselves.”

Somebody said that they would like staff that they had picked to work with other staff to train them so that their attitudes towards service users can change.

“[It is] important to look after yourself as a black person, making sure some people aren’t racist against you.”

“People should be trained to understand. Maybe people who have different needs should do the training.”

What service users want and value should be what social care workers' performance, success, assessments and promotions are based on. One person talked about the 'tick list' that some services have and the reports that services write to say that 'this department has done very well'. He said they are not checking on how people behave themselves and, as he put it, "how people respect other people". He said people do not look 'base downwards'. He said people are concerned with "performance, money, careers". He said that services should be "working to us [service users]."

"Inspectors – service users would do inspection."

Someone else said that people with learning difficulties could have the assessment forms that they used to say what they are getting from the services and how they feel about their services. She also said that social care workers should be accountable to people with learning difficulties. She talked about how people with learning difficulties are often graded by people without learning difficulties and she said people with learning difficulties could grade social care workers.

Another person said that workers should wear name badges so that you know who they are. People with learning difficulties should be able to feed back their views about social care services and workers anonymously. It would help to go out with social workers and see how they work. People with learning difficulties could keep a timetable if social care workers were late.

### 3.2.7 Resource issues

The wide range of people with learning difficulties who took part in the consultation felt:

- Not enough money is put into services for people with learning difficulties.
- Lack of funding can lead to badly paid, poor-quality workers.
- Service users doing work experience/training do not get enough money.
- Service users in work experience/training should get at least a minimum wage.

"[There are) lots of cuts for ... disabled people ... lots of discrimination."

"They are short-staffed so they fling people with no skills into jobs. Everything is money."

"[Work training schemes]: What they give you is peanuts money. They pretend you have got a real job, but it's not. The government say you must do this, you must do that, but only for a year, then back on the scrap heap. [They] need to think about what you want to do with your life."

"People with learning difficulties should get paid. If it wasn't for people with learning difficulties, [people who work in services for people with learning difficulties] wouldn't get their mortgage money paid."

### 3.2.8 Issues to address for the future

- Service users see a need for social care projects (for example, day centres, colleges).
- People have chances to meet their friends in social care projects.
- Racism in social care projects is a problem to be challenged.
- There are not enough interesting things to do in day centres and colleges.
- Choice is important.
- There is a need for more workers to support people in proper jobs.
- Some service users want to work supporting other people.

Good day services are valued. Someone said this about a day centre:

"A lot of my friends used to go to [name of day centre] to meet friends because they were fed up with seeing families and carers 24/7. That was really positive because they could go to [name of day centre]."

Another woman liked the catering work training they had done because it was friendly.

"I can make friends and have/join in conversation."

She also liked doing gardening. She said she liked "soil in pots, flowers, gardening'.

But people's experience of social and educational services is frequently negative. A man said he did not like a social services day centre he went to.

"... I didn't like it that much because it was like, felt bored and really terrible, racist names, they call you golliwog.... The staff didn't want to know ... I lost my temper ... I didn't get any help at all ... so angry and helpless, I didn't go back there. I felt let down by the staff."

Another person said:

"College, bloody boring, still going."

Several people said that there was not much to do at their day centre and that they would like to go out on more trips in the summer. Another person said that college closes for too long over the summer and there is not much else happening. The people in one group talked about an old day centre that was on an industrial estate. People thought it was wrong that it was on an industrial estate away from the shops and people. One person said that the best thing that they ever did was to close this day centre down.

One woman said that people want the chance to work but some people will always want day centres. She said: "We want choices". She also said that, instead of going to college for "years and years", people with learning difficulties want to be supported to work.

Someone talked about how she wanted to help people using services and how she was stopped from giving help:

“We can help them. I used to work ... [in a home for elderly people]. They let me help with some other people and some didn’t give us a chance to do it.”

Someone else said they wanted to move on and do other things like helping people to speak up and raising funds for charity. Another person wanted to have a job, supporting disabled people to get their shopping. One person wanted to help people who were affected by the war in Iraq. Someone else said she would like to raise money for people in Africa. People would need the right support in order to do the supportive work they want to do in the future, to make a contribution of their own.

### 3.2.9 People’s own vision for social care

- Good social care is about being able to offer what service users want.
- There is still a lack of choice around what social care is on offer and that has to change.
- Not enough people with learning difficulties are getting direct payments. This must change.

One person said that good services are those that give the individual what they want.

“When there is a crisis in our lives, [we] always have to wait. It would be good if I had a social worker, not just a duty social worker, so [I] wouldn’t have to repeat myself again.”

“... If they don’t listen to you, you are on your own again. They should know a person’s feelings. [If] they don’t respect your feelings how are they going to make sure you get the right help?’

Another man said they wanted to move out of their council flat because there is a lot of crime in the area, and as he put it, “People don’t clean up after themselves”. He wants support to find another place to live but is not getting it. He talked about how his support worker did not listen to what he wanted. He also said that lots of people with learning difficulties would like direct payments, and that people, as he put it, are: “... fighting and fighting and not getting anywhere there with getting direct payments.” He said he would like to choose his own support worker.

Another person in a different group said that direct payments might help because you can choose staff and get up when you like and go to bed when you like and have more choice and control.

Talking about social care services one participant said:

“They don’t take people with hidden disabilities into account. I’ve got autism. Sometimes I feel they don’t do a lot, not enough support. Sometimes they don’t listen to you. They seem to think carers know what’s best for you ...’



“... but we know what’s best for us because it’s our life.”

- Service users want support to get out and live as part of the community.
- People want enough support to join in social and leisure activities.
- People want to get out more, especially in the evening, safely, and with support.
- Social care should take bullying seriously and do something about it.

In all the groups, people said that people with learning difficulties do not get enough support to get out in the day and in the evening, and that people should be given support to do what they enjoy. One man said there should be more chances for people with learning difficulties to play sports. He also wanted support to go to museums and pubs. He said he liked old houses and antiques.

Another person said that they would like more new staff to take people out and about more and that he would like to go to safari parks and historical places.

One person said they would like to have escorts on public buses so people cannot bully them. Someone else said that it would be good if it was made easier to report bullying and if people took bullying seriously. She also said that workers should listen more to what people with learning difficulties want to do and help people to do it, and not make excuses about why people cannot do things.

Another person said she would like a support worker to go on public buses with her. This woman had suffered racist abuse in the past. She was a woman who was afraid of being attacked on the bus. She also said she wanted help with getting a social group together and that she wanted workers to listen to what people with learning difficulties want and then provide the support that they are asking for.

Another person felt unsafe going out at night and wanted support in the evenings to get out and about. Someone else said they needed support to get out and about. Another woman said she wanted help to go out in the community and that she needed help with buses and help to meet people.

“[We need] help with finding places and I want to go to more clubs in the evening.”

“We’ve got to mingle, mix in.”

People talked about how some people need support to read a menu in a restaurant.

“[I want someone to support me, to] ... take me out anywhere I want.”

“I would like to go to clubs and dance, do sports or swimming or tennis – you need people to help you do that.... [If I had a support worker] they would show me where to go, then I could do it on my own, help me find the place.”

Someone else talked about how they would like a support worker, and she said she would like them to use pictures and tapes to support her.

### 3.2.10 Key values for future social care

- Social care should support service users to be independent.
- Being independent does not mean being unsupported.
- Supporting independence is supporting the person to be themselves.
- People want to be supported to live the lives they want to lead.
- Service users want the choices that people without learning difficulties have.

People highlighted the values they thought should underpin any new approach to social care and social care practice. One person said social care should be based on “understanding what independence is”.

Another woman said that in the future they wanted support to be more independent. When asked “What is independence for you?”, she said: “A chance to be me”. Another person said:

“Being independent means looking after yourself and getting support if you need it.”

“[Social care should be based on] being good to the service users and giving them a chance to make a life for themselves. Giving them decisions and letting them make choices about themselves. Making choices for themselves.”

Somebody else said social care should be based on helping people to get over what is getting in the way of people with learning difficulties living independently. She said it should be about getting the support to live an ordinary everyday life and that people with learning difficulties should have equal rights with everyone else. She said that people with learning difficulties have been given that right by the White Paper Valuing People, but it is not happening:

“We have to alter the minds of people in charge by becoming trainers.”

“We have the same human rights and equal rights. Leave us alone and treat us who we are, our identity, they should respect us and treat us the same as everyone else ... treat us with equal respect.”

“We are allowed to make mistakes, want a job, want relationships, want what you got, but [we need] the support to get there, want a normal life but the support to get there.”

“Respect us, treat us like equals.”

Summing up a general feeling among participants, one woman said this about what she wants in the future from social care services:

“For me, before you [social care services] make a decision consult us first. Help us to understand what you are doing in making a change. Really consult support workers [advocates and self-advocacy support workers].... Involve us from the beginning.”

# Appendix 1: Schedule used for group discussions

## Introduction

The government says it wants there to be a new vision for adult social care. It wants to hear what service users have to say about this.

Shaping Our Lives would greatly value your involvement, views and ideas as a basis for trying to make real change in government social care policy and practice. We are an independent user-controlled organisation. We are made up of a wide range of health and social care service users. We have been asked by the Department of Health to organise consultations with a wide range of social care service users so that they can have their say in a Green Paper which the government is producing on the future of social care. We want to make sure that the voice of service users is effectively included in the development of future government policy.

The Minister responsible for social care, Stephen Ladyman, says he wants there to be a 'new vision for adult social care'. He realises there need to be changes and improvements. He has already asked people what they want to see. So far, very few service users have been involved. Only a few service users took part in the first stage of consultation which took place, so the Minister has now extended the deadline until the end of October. We now have this chance to include the views of more people who use services.

Shaping Our Lives is now organising a series of discussion groups in different parts of the country to try and change this. While we are being paid by the Department of Health to do this, we as service users have worked out what questions to ask and we will be writing the report on what service users say. We hope this will be a real chance for service users to express their views so that these can be properly heard, listened to and, we hope, acted on.

## Social care

Social care includes a wide range of social services provided by local authority social services, voluntary organisations and for-profit organisations. It includes residential and domiciliary services, daycare and time services, social workers and social care workers. It does not include medical services, nursing homes or services generally provided by hospitals and health organisations.

## Shaping Our Lives

Shaping Our Lives is an independent user-controlled national service user organisation. We were established in 1996. We have a national user group. We work to increase the effective involvement of service users and improve the quality of support that service users receive. We are made up of and work with a wide range of service users including people with physical and sensory impairments, Deaf people, people with learning difficulties, older people, mental health service users/survivors, people who use palliative care services, people who have had alcohol- and drug-related problems,

and looked-after young people. We are developing a national user network and we have links with local service users and service user organisations, as well as working for change centrally.

## The terms of service user involvement

We hope you will want to be involved. We have tried to work out a safe and positive basis for your involvement. This includes:

- We will do all we can to make sure that what you say is kept confidential and anonymous. We will not use any names or link any comments with any individuals. We will make sure that you cannot be identified as an individual from anything you say.
- Each participant will be paid £150 for taking part and contributing (unless they do not wish to be paid). This payment will be made in such a way as to avoid any conflict with people's rights and responsibilities if they receive benefits.
- All people's costs will be met. This includes travel and related costs, costs for personal assistance if required, or to cover child care or the provision of support for anyone else. Receipts and tickets will be required for payment to be made. We will seek to make such payments as quickly as possible in the way most suitable for each individual.
- We will work to carry out group discussions in such a way that all participants' access requirements are met fully and sensitively.
- Shaping Our Lives has developed a series of 'ground rules' for our meetings and activities to make sure that everyone can contribute as fully and equally as possible. We will be using these as a basis for holding these group discussions.
- We also hope to keep people who participate in this consultation in touch with its findings and what comes out of it.

If you need any additional information, then please get in touch with: [contact details provided].

## Group discussions

### Questions for service users

1. What does social care mean to you?
2. What social care services have you used?
3. What do you think of the social care (services) that you have experienced/received? (ie good/bad, helpful/unhelpful)
4. What have been the things you have liked most about the social care (services) you have received?
5. What have been the things you have liked least about the social care (services) you have received?
6. What do you most want for the future from social care services?
7. What do you most want for the future from social care workers generally?
8. What do you most want from social care workers in terms of:
  - a) What qualities do you think it is important for them to have?
  - b) What skills do you think it is important for them to have?

9. What principles and values do you think social care needs to be based on?
10. What do you feel, if anything, needs to change for social care to safeguard and meet your rights and needs as fully as possible in the future?
11. What could social care do to help you participate more fully in society?
12. What would social care need to offer to help you to live your life as you want to in society?
13. What does social care need to do to meet the rights and needs of each individual, according to their 'race', gender, class, culture, age, sexuality and other forms of difference?
14. How do you think we can make sure that social care provides a good-quality service for people who use it?
15. How can we make sure that social care is really accountable to service users and provides the kind of support they want and need?
16. Are there any other key issues which you would like to add?
17. Would you like us to pass on any particular questions or points to the minister?

Thanks. We will keep you in touch with what comes out of this consultation.

### Process notes

Could group facilitators please write up process notes from each group discussion which they hold as soon as possible after it takes place? This is to get a general feel of each discussion and to have 'demographic' details of the people who take part.

Please include the following in these process notes:

- the date of the discussion and how long it lasted
- details of how many service users take part
- the gender, ethnicity, approximate ages and (if identified by participants) the sexuality of participants
- the 'impairments' of participants (eg mental health service user, person with learning difficulties, older person, Deaf person, etc)
- a brief description of the discussion – ie where it took place, what it felt like, the mood of participants, etc
- what you saw as key issues emerging from the group discussion.

## Appendix 2: Shaping Our Lives

Shaping Our Lives is a national user-controlled organisation which is funded by the Department of Health. We were established in 1996. We have a track record of undertaking user-controlled and emancipatory research and development work, as well as working to improve the support service users receive and increase their say and involvement in their lives at local and national levels.

We include and work across a wide range of service user groups, including older people, people with learning difficulties, people with physical and/or sensory impairments, people living with HIV/AIDS, mental health service users/survivors and looked-after young people. We are currently working also to involve people with life-limiting illnesses and conditions who are eligible for palliative care services and children and young people who are recipients of health and social care services. We place an emphasis on working in an inclusive and accessible way, to support as wide involvement as possible.