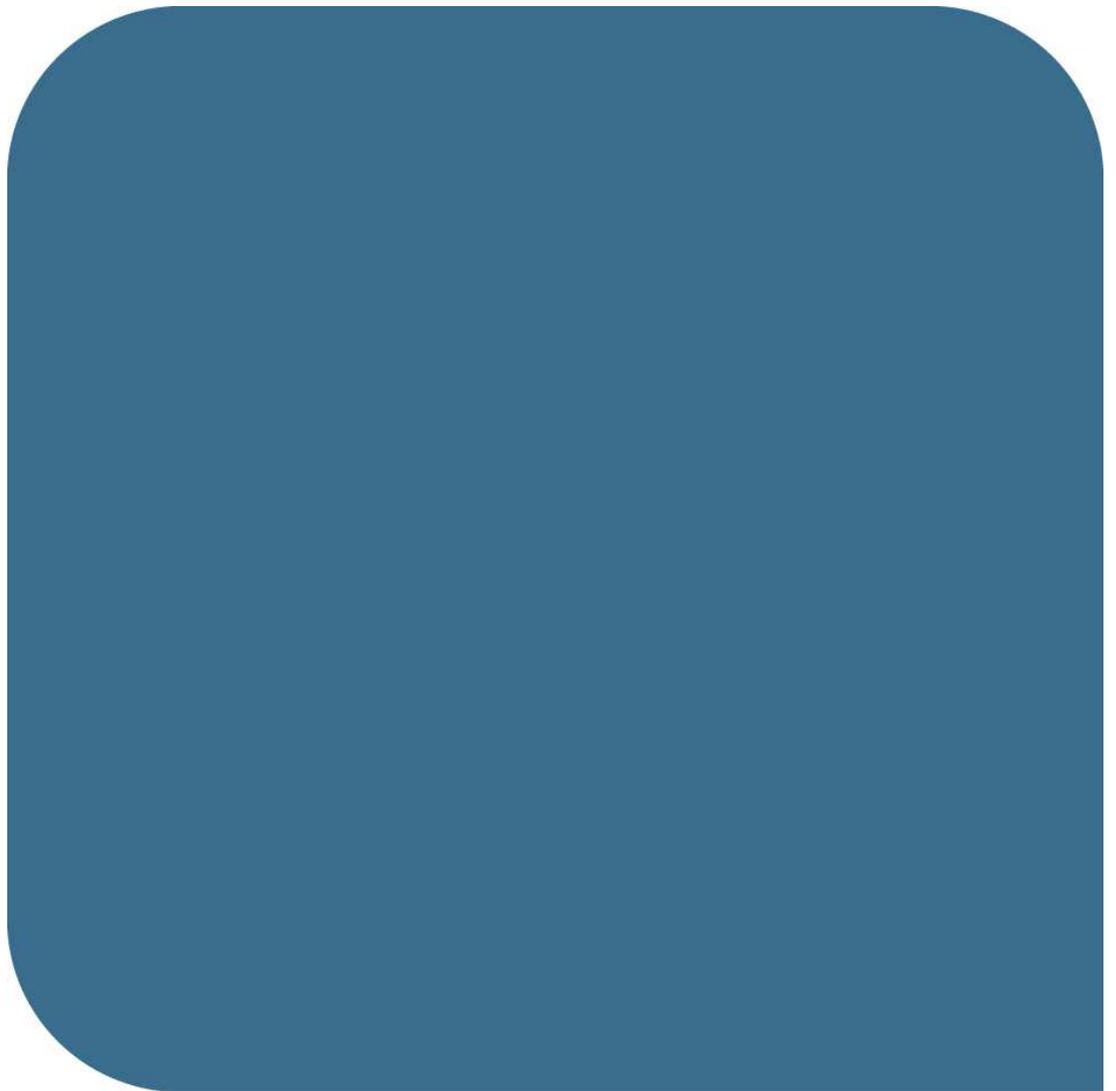


**'I'm not asking to live like the Queen.'**  
The vision of service users (or potential service users) and carers  
who are seldom heard on the future of social care for adults in  
England



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## Executive summary

### Introduction

The Social Care Institute for Excellence (SCIE) was commissioned by the Department of Health to consult on the green paper *Independence, well-being and choice: Our vision for the future of social care for adults in England* with service users (or potential service users) who are seldom heard or often described as being 'hard to reach.'

The consultation's aim and objectives were as follows:

### Aim

To consult with service users and groups that agencies find hard to reach on the proposals laid out in *Independence, well-being and choice: Our vision for the future of social care for adults in England*.

### Objectives

- To identify service users and groups that agencies find hard to reach through partnerships with key organisations.
- To provoke discussion with those that agencies find hard to reach about how social care can offer more control, more choice and high-quality support for those who use or need to use social care services.
- To enable those people that agencies find hard to reach to play an active and informed role in commenting on the green paper, and furthermore, to have a say in what services are needed to meet their needs and expectations.

The emphasis of the consultation exercise was not to pursue a rigorous research exercise, but to use outreach work to ascertain qualitative information from a range of service users (or potential service users) and carers who are seldom heard or engaged with in national policy, practice and service development initiatives such as the green paper consultation.

The following groups were included in the consultation:

- homeless people and people with chaotic lifestyles (people with multiple substance abuse and mental health problems)
- black and minority ethnic people who do not have a national or other organisation that might represent their views
- refugees and asylum seekers
- people with severe learning disabilities and/or communication impairments.

The original Department of Health specification for the consultation work included people with profound and/or sensory impairments, however the methods used to consult with this group need to be very varied and based on establishing an effective two-way communication mechanism which has to be developed over time with repeated visits and gradual discussions. Due to the short time span and the practical constraints of addressing all of the necessary access requirements, including communication mechanisms it was only possible to do a piece of small scale work with a group of people with severe learning disabilities and/or communication impairments.

Different methods were used depending on the requirements of the service users (or potential service users) and carers that were being consulted. The executive summary draws together some of the common themes and issues that cut across the four groups. It then goes on to provide the conclusions and summary of key findings to emerge from the different strands of consultation work undertaken.

## Overarching conclusions

Homeless people, people with severe learning disabilities and communication impairments, refugees and asylum seekers and black and ethnic minority service users (or potential service users) who are not represented by a national or other organisation are an extraordinarily diverse range of people. What they all have in common is that in different ways the processes they use to access and use social care services need to be improved.

The experience of discrimination, poverty, impairment, addiction, mental distress, poor living conditions, racism and immigration status means that social care support, community engagement and citizenship are vital ingredients for promoting independence, choice and well-being.

In the process of the consultation, participants who are seldom heard had an enormous amount to say about their lives and made many extremely useful comments about the proposals contained in the green paper.

It is difficult, perhaps even dangerous, to draw overall conclusions from such a diverse range of groups. However, that said, there do appear to be some issues that cut across all four groups.

## Basic needs not meet

Many people in the various groups are preoccupied with attempting to fulfil their basic needs. Therefore it is difficult for them to fully consider wider structural issues. This is combined with either a low awareness of what services may be available or a suspicion of statutory provision.

## Accessing community services

For many members of these diverse groups, accessing community services presents real problems. There are issues of access of various kinds including language, societal discrimination, fear as a consequence of real issues around safety, legal status, financial issues and lack of information. For some members of these groups there is a feeling that they are not part of the community. However, there was also a sense that accessing community resources could potentially be of enormous benefit.

## Perceptions of risk

For some of the people in these groups, in particular homeless people and refugees and asylum seekers, daily life circumstances can be risky, unsafe and provisional. Other people did not feel that their lives were any more risky than people's who did not require social care support. Therefore, the concept of risk – as put forward in the green paper – was not always easy to understand.

## Assessment

There were very mixed views about assessment and a fairly low understanding of the concept. The idea of self assessment was generally not well received. The idea of developing a package of care in genuine partnership with someone knowledgeable about local services was welcomed. Participants were cautious about the proposal to share information between agencies. Information about benefits, legal status and nature of difficulties (particularly mental health problems) were felt to be especially sensitive.

## Direct payments

There was a fairly low awareness of direct payments among service users (or potential service users) and carers. Many people had concerns about the organisational capacity needed to administrate a direct payment. Various access issues including financial management, knowledge of possible services, language barriers and literacy were perceived as barriers to the take up of direct payments.

## Workforce issues

Participants had a lot to say about the qualities of their ideal social care staff. These included being non-judgemental, friendly, able to listen, committed, good communicators and service user-centred and carer-centred. It was widely felt that it was essential for managers to be recruited from front-line staff. The employment of service users was seen as a particularly good idea.

## Strategic issues

On a strategic level, services provided by voluntary organisations were particularly well liked and many participants would like to see more resources directed toward the voluntary sector.

Service user and carer involvement, at both an individual as well as strategic level, was seen as a very important way of developing high quality services. However the need for feedback on findings and outcomes was strongly emphasised. The focus on preventative services was welcomed.

## Principles of the green paper

The principles contained in *Independence, well-being and choice* are broadly welcomed by the majority of participants. However, some of the proposed instruments to implement the vision will need to be worked on and adapted if the full inclusion of these marginalised groups is to be achieved.

## Conclusions from consultation with homeless people

Homeless people had a great deal to say about their lives and experiences and had many useful comments and suggestions about the proposals contained in the green paper.

Homeless people are generally excluded from using community services by a number of factors including: societal prejudice, poverty, lack of information and confidence. If these issues could be addressed, there may be many positive benefits to be gained for service users through greater use of community services.

The lifestyles of this group are inherently risky. Therefore the concept of 'risk' which is centred on taking risks may have positive outcomes.

The issues of assessment, user control and genuine partnership between service users and staff were seen as more important than self assessment. The sharing of assessments and other information held by agencies was not broadly welcomed and information should only be shared by explicit consent.

Direct payments have an extremely low profile among this group. There was a range of issues which would need to be resolved before many of the group could access direct payments or individual budgets.

The qualities required by their ideal social care worker were as follows: non-judgemental, caring, client-focused, sensitive and positive. They also valued staff who had had experience of using services. It was seen as essential that senior managers maintained ongoing contact with both service users and front-line staff.

User involvement was felt to be an essential component of developing appropriate social care services. Services provided in the voluntary sector were thought to be preferable to statutory services. Investment in preventative services was widely supported.

The principles contained in *Independence, well-being and choice* were broadly welcomed by the majority of participants. However some of the proposed instruments to implement the vision will need to be worked on and adapted if the full inclusion of homeless people is to be achieved.

## Summary of the key findings from the consultation with homeless people

### Accessing community services

- Homeless people are generally excluded from using community services by a number of factors including: societal prejudice, poverty, lack of information and confidence.
- There is anxiety that general community services may not be able to provide the levels of support necessary to accommodate the needs of some homeless people.
- If the issues identified above could be addressed, there may be many positive benefits to be gained for service users through greater use of community services.

### Emphasis on preventative services

- Service users in particular were very positive about an increased emphasis on preventative services.
- For people with experience of being on the streets this meant more access to services before problems became severe.
- Services that are open, friendly and flexible were more likely to be accessed by homeless people.
- Statutory services were perceived to be difficult to access, bureaucratic and often unhelpful.

### Perceptions of risk

- The lifestyles of this group are inherently risky. Therefore, the concept of 'risk', which is centred on taking risks, may have positive outcomes.
- There was concern that there was not enough support directed at people who were ready to move on and take jobs, go into education or into more stable housing.
- Service users were unclear about who should take the blame if things went wrong, however, there was a feeling that the green paper was shifting the burden of responsibility from statutory agencies to individuals and they were uncomfortable with this.

- Link workers were clearer that it was individual clients' responsibility to make choices and live with those decisions.

## Assessment

- The idea of self assessment for this group was not well received.
- User control and partnership between service users and staff were seen as more important than self assessment.
- The idea that assessments should be more client centred was well received.
- The ideal assessment was one carried out in genuine partnership between a service user and someone with knowledge of the local services.
- Sharing assessment between agencies was not necessarily seen as desirable for this group.
- Information contained in assessments could be of an intensely personal nature, which it may not be appropriate or necessary to share.
- Sharing assessments, which include details of service users' past criminality, history of drug use or mental health issues may limit service users' ability to access services.
- It was felt that information about peoples' support needs and their financial circumstances, especially about state benefits, should be kept separate.
- The sharing of assessments and other information held by agencies should only be shared by consent.

## Direct payments and individual budgets

- Direct payments have an extremely low profile among this group.
- There was a range of issues, which would need to be resolved before many of the group could access direct payments.
- Many participants doubted their capacity to administer a direct payment or individual budget. Several pointed out that they would not be on the streets if they were able to coordinate a package of care.
- There were fears around how flexible the system could be if needs or preferences changed.

- Making payments directly into service users' bank accounts was not a viable option. For many people, access to more funds either provided the temptation to spend the money inappropriately and/or opened the individual up to potential exploitation.
- Very few of the participants in the consultation had bank accounts and are, largely, completely outside of the financial mainstream. Literacy and numeracy are low among this group. Therefore additional support and training would need to be available to people if they took up direct payments.
- However, direct payments and individual budgets did open up some positive opportunities.
- If direct payments or individual budgets could be portable across borough boundaries this could be especially helpful for this group who may move area often.
- Portability may also offer the choice of a greater range of services even if the service user is staying in one place.
- The concept of working out a package of care in partnership with a professional was well received.
- Several solutions to the difficulties with bank accounts were put forward including the budget being held by an independent agency on the service users' behalf.
- There was uncertainty about the long-term implications of direct payments and individual budgets, in particular around the possible reduction of direct access to services.
- Direct payments may be more appropriate for members of this group once an individual has achieved a measure of stability in his or her life.

### Workforce issues

- The qualities required by social care workers were as follows: non-judgemental, caring, client-focused, sensitive and positive.
- Many service users felt that people who had experience of using services would bring these qualities to the work.
- It was essential that senior managers maintained ongoing contact with both service users and front-line staff.
- Senior managers should both inspire staff and users as well as provide clear lines of accountability.

- More money, better conditions, more resources, more opportunities to work with users in empowering ways and greater involvement on a strategic level were seen as the ingredients that would attract more people to work and stay in the social care field.

## Strategic issues

- User involvement was felt to be an essential component of ensuring the development of appropriate social care services.
- Statutory sector agencies were perceived to be less likely than the voluntary sector organisations to consult with service users effectively.
- Services provided in the voluntary sector were thought to be preferable to statutory services. There was a deep-seated distrust of social services.
- Investment in preventative services was widely supported.
- Services which promoted emotional well-being were widely supported.

## Conclusions from consultation with black and minority ethnic service users (or potential service users) and carers not represented by national or other organisations

The consultation exercise demonstrated (without a doubt) that black and minority ethnic service users (or potential service users) are not an homogenous group. The views and perspectives they bring are as rich and diverse as the communities they belong to.

It is impossible to draw out a consensual view on the green paper amongst black and minority ethnic service users (or potential service users) and carers although most participants agreed that eligibility criteria and gate keeping mechanisms made the current process of accessing social care services extremely difficult. Service users particularly wanted to drive home the message that home/personal care services were riddled with problems and were failing to meet their needs.

The principles of self-definition of need (with appropriate support), choice, direct payments and individual budgets (with appropriate support), participation in the community, focus on preventative services and provision of voluntary sector services were of great interest to people, although there was a degree of scepticism about how they may be implemented in practice.

Equally, there were clear ideas about how support and training for carers could be improved and workforce issues such as recruitment, social work training, promotion of front-line staff to management roles, and information sharing and communication should be addressed and improved.

Arguably, many of the issues raised are relevant to other indigenous groups of service users and carers. This may well be true, but the experience of racism, discrimination, poverty, language barriers, lack of culturally appropriate resources and limited choices severely exacerbates the difficulties faced by black and minority ethnic service users (or potential service users) and carers.

The green paper's proposals for promoting choice, independence and well-being could go a long way to providing appropriate individually tailored solutions for black and minority ethnic service users (or potential service users) and carers. The challenge for policy makers and practitioners is to hear what black and minority ethnic service users (or potential service users) and carers have said, focus on the practicalities of implementing the key proposals and ensure that this consultation is the beginning of an ongoing dialogue.

## Summary of key findings from the consultation with black and minority ethnic service users (or potential service users) and carers not represented by national or other organisations

### Knowledge about social services

- Most of the Chinese elders and older Somali women had not heard of or been in contact with social services.
- Information about entitlements to services and the process of applying for them came from voluntary sector groups.

### Knowledge of green paper

- None of the black and minority ethnic service users (or potential service users) and carers interviewed were aware of the existence of the green paper or the proposals contained within it.
- Feedback on what came out of the green paper consultation was very important to people.

### Experience of accessing services

- There was a lack of knowledge about how to access services.
- People believed that if you (or a family member) know how the system works and how to present your needs then you have a distinct advantage.
- The interpretation of eligibility criteria meant services could not be received until you were in crisis or in major difficulties.
- None of the carers had had a carer's assessment.

### Self assessments

- Practical difficulties (e.g. language and literacy) of self assessments have to be ironed out before it can become a viable option.
- There were concerns about whether professionals would accept self-defined needs.
- Support is needed from the voluntary sector to complete self assessments.

## Complex assessments

- There was a lack of clarity about what constitutes complex needs.
- There was concern about whether or not there would be an entitlement to a social worker.

## Information sharing

- People were frustrated about having to provide the same information to a number of agencies.
- Principles of information sharing were welcomed but with some caveats.
- Practicalities around confidentiality and access to people's personal information raised concerns.

## Experience of using services

- Carers had very limited experience of using services – their main sources of support were carers groups.
- A great deal of dissatisfaction with home/personal care agencies was expressed. This dominated discussions with service users.

## Direct payments

- In response to difficulties with care agencies, three service users had started using direct payments.
- There was some interest expressed by elders in using direct payments but carers were sceptical about them.
- Concerns were raised about the practical difficulties of managing a direct payment, including bureaucracy and accounting arrangements.

## Independent living and risk taking

- Service users valued independent living and they did not perceive themselves at any more risk than people who did not have social care needs.
- Direct payments were seen as an important way of having control.

## Residential care

- There was an overwhelming consensus amongst Chinese elders that residential care was their preferred option for future care.

## Preventative services

- There was a belief that preventative services would have prevented deterioration.
- There was a strong perception that services were only available for people in the most desperate situations.
- People thought a more proactive approach to reaching black and minority ethnic elders should be taken.
- Accessible information, lunch clubs and other support groups were considered essential for reducing isolation and promoting well-being.

## Training and support for carers

- Arrangements must be made for supporting carers in employment.
- Carers stressed the importance of being able to have a break from their role as a carer.
- Training on lifting techniques, managing dementia and stress management were wanted.

## Barriers to using community-based resources

- Lack of accessibility, poor transport and the public environment presented considerable difficulties for service users (or potential service users) and carers.
- Cost was a deterrent to people attending community-based services.

## Aspirations

- Carers wanted to have a more fulfilling lifestyle.
- Service users felt penalised for doing voluntary work and there was a wider belief that paid employment was not an option because of support needs.

- Low expectations and lack of recognition of the skills of service users were thought to be prevailing attitudes.

## Workforce issues

- People acknowledged the pressure social workers are under.
- Qualities people wanted in a social worker included good communication, respect, improved attitudes, courtesy, empathy and the ability to follow up.

## Recruitment

- Recruitment of managers from the front-line would improve knowledge of people's needs and services required.
- Recruitment of social workers from abroad and their knowledge of processes and systems in England were identified as areas of concern.

## Social work training

- People emphasised the importance of information sharing and communication, particularly when talking to service users (or potential service users) and carers.
- Service users and carers wanted social workers to have a better knowledge of the policies, procedures and the systems within which social care is provided.

## Strategic issues

- Improved access to services was wanted.
- People were cynical about how social services manage their budgets.
- Security of funding and support for the development of voluntary sector were considered essential.
- Recognition and support of the vital role the voluntary sector plays through various support groups and activities in overcoming language barriers, offering mutual support, reducing isolation, offering advice and information and developing directly provided services (meals on wheels, home care) was needed.

## Conclusions from consultation with refugees and asylum seekers

The overwhelming issue to emerge from the refugee and asylum seekers consulted was that their starting position for accessing services was very different. A major concern for this group was that some of their basic human needs such as food, appropriate accommodation, social contact, transport and so on were not being met. Immigration, social policy and political discourse about refugees and asylum seekers had a profoundly detrimental effect on people's options for having their social care needs met.

The principles of independence, well-being and choice were very applicable to service users (or potential service users) and carers from refugee and asylum seeker communities. However, the reality of their lives often meant it was very difficult to envisage how self assessments, direct payments and individual budgets, independent living and opportunities to take risks and have someone who was concerned about the risks taken, was very far removed from what refugees and asylum seekers understood and experienced.

Networks and support groups for refugees and asylum seekers were a vital source of support, advice and information. However the people consulted said that it was very important that some of these were targeted at service users (or potential service users) and carers so that they did not have to worry about stigma associated with disability, mental distress or requiring social care support.

Refugees and asylum seekers may not have used the language embodied in the green paper, but they were clear about the type of assistance that would help to promote respect, dignity, safety, choice and control. The ideas put forward have implications for policy and practice. Perhaps one of the greatest challenges posed is for the Department of Health and the Home Office to work collaboratively to improve support and access to social care.

## Summary of key findings from consultation with refugees and asylum seekers

### Needs of refugees and asylum seekers

- The experience of trauma and fleeing their country of origin had a profound effect on the mental health of the refugees and asylum seekers interviewed.
- For some of the asylum seekers, the living conditions and circumstances they found themselves in exacerbated their problems. Boredom presented a major problem.

### Barriers to accessing social care services

- People didn't know how to access social care services.
- People were confused about what social care services could provide.
- Refugees and asylum seekers' social care needs were rarely acknowledged by local authorities.
- Different approaches were taken when responding to refugee and asylum seekers.
- Restrictions on entitlement to social care services for asylum seekers meant that they had to cope without social care support.
- People believed that they shouldn't rely on the state for support.

### Advice and information

- General Practitioners and other medical staff were important sources of advice and information.
- Refugee and asylum seeker networks were people's preferred routes for receiving advice and information.

### Sources of support

- Family members, including children, provided informal care and were a major source of support.
- Some refugee and asylum seekers were isolated and lacked support because they had no family or friendship networks.

- The Refugee and Asylum Seeker Social Support Group in East Suffolk (MIND and Community Refugee team project) provided an invaluable service to local refugees and asylum seekers with mental health problems.

## Self assessment

- The notion of completing a self assessment was very difficult to understand.
- The best people to identify needs were the refugee and asylum seeker networks people associated with.
- Professionals need to reach out to refugee and asylum seekers.

## Information sharing between organisations

- Opinions were divided about whether it would be helpful for organisations to share information.
- One third of refugees and asylum seekers thought it would be appropriate to share information.
- Confidentiality was seen as crucial.
- People were concerned about the potential impact on immigration status and support received if information is shared.

## Risk taking

- The idea that people might worry if refugee and asylum seekers who needed social care took risks was considered to be quite strange.
- Basic things like being able to wear traditional Muslim clothes were considered a risk.
- The risks people wanted to take were more linked to restrictions placed on them by their immigration status rather than limitations because of social care needs.

## Direct payments

- People struggled with the concept of direct payments for social care needs.
- Priorities for spending direct payments were based on basic needs such as food, transport, housing and so on.

- Views on who would be best to assist with managing a direct payment varied from wanting social workers to help, to thinking no assistance would be needed.

### Use of community-based resources

- Religious establishments were used both as a place of worship and support.
- The ability to use local amenities was limited because of language barriers, limited financial resources and feeling unsafe.

### Aspirations and interests

- There was a great deal of interest in using local resources like educational facilities, sports activities, parks and libraries.
- The opportunity to do voluntary work or to take up paid employment was important but often difficult for people.

### Workforce issues

- Various suggestions were made to improve social work training including addressing attitudes, importance of value and care, learning to really listen and changing behaviour.
- The need for a true commitment to the role of social worker was highlighted.

### Consultation in policy and service development

- Consultation in the development of policy and practice was not something the refugees and asylum seekers had done before.
- They strongly believed that professionals were not interested in the views of refugees and asylum seekers.
- Different methods of consultation were preferred – some thought group discussions were better, and others wanted face-to-face meetings.

### Priorities for service development

- For some people it was difficult to envisage having a role in service development.
- People requested a wider range of activities to do throughout the whole week.

- Secure funding and capacity building for support groups and the wider voluntary sector was identified as an issue.

### Knowledge of green paper

- None of the refugees and asylum seekers was aware of the existence of or proposals in the green paper.
- A volunteer raised concern about difficulties of being cost neutral. They argued that reorganising and restructuring services costs money in redeployment, training and redundancy payments. However, 'the concept of the green paper is a good one...'

## Conclusions from consultation with people with severe learning disabilities and/or communication impairments

All the service users with severe learning disabilities, including those with communication impairments, had a lot to say about the choices they like to make, what they enjoyed doing and participation in decision making. Many (but not all) needed support to exercise choice, try new things (take risks) and use local amenities.

Accessible communication methods, support and investment of time would enable even those who may be considered to have profound and complex needs to be central to the decisions made about their lives.

In many ways it could be argued that those who lived in a residential provision had a better quality of life with much wider opportunities and very active lives. This raises questions about how sufficient support can be provided to those living with families, with supported living arrangements and living independently so that they can enjoy a similar quality of life.

The consultation did not yield answers to the specific ideas and proposals embodied in the green paper. Nevertheless, a lot of the views expressed by both service users and staff strike a chord with the themes in the green paper. The challenge remains how the philosophy of independence, well-being and choice can be put in place to improve the lives of people with severe learning disabilities and/or communication impairments.

## Summary of key findings from consultation with people with severe learning disabilities and/or communication impairments

### Exercising choice

- All of the service users had a clear idea of what they liked doing and the choices they like to make.
- Being able to go out, particularly shopping, was very important to all the service users.
- Choice within the residential service was promoted in a range of ways from deciding on activities, to choosing whether or not to clean your bedroom.
- Making resources accessible enough (including using multimedia) for the individual was crucial in promoting choice.

### Decision making

- There were a number of different ways the residents were involved in decision-making, from using communication symbols to having their own bank account.
- One woman talked about wanting to be able to make more decisions for herself.

### Advocacy, independence and choice

- The concept of exercising choice and having independence is just as important in a residential setting as anywhere else.
- For people with severe learning difficulties and/or communication impairments, support from advocacy services and self-advocacy training is vital.

### Independent living and risk management

- Risk taking was a big issue for the women with severe learning disabilities.
- Staff in the residential service balanced the need for independence and risk management with a very practical approach.

## Independence and risks (chances) service users wanted to be able to take

- For some service users, the idea of doing or trying new things needed to be introduced and tried out in an experiential way.
- A desire to increase independence was expressed, although the language of independent living was not used.

## Person-centred planning

- Some service users had heard of person-centred planning and thought that they had been part of the process.
- Staff at the residential service used a variety of approaches to enable residents to take part in person-centred planning including use of multimedia and involving people who know the resident well.

## Community resources and participation

- Going out and using local amenities were top of the agenda for all the service users.
- Service users living at home were very dependent on family members to enable them to get out and be part of community activities.
- Service users who lived in the residential service had a much more active lifestyle and were very engaged in using facilities in the local community. They also retained a lot of contact with family members.
- Changes in funding regimes for support groups and the arrangements for offering college courses had a detrimental impact on the opportunities available to service users.

## Sample

The data presented here is an analysis of all participants across the four different groups consulted. Further information about each specific group can be found in the relevant chapter and a more detailed version is included in the appendices.

A total of 117 people were interviewed, 97 submitted a consultation monitoring form (see appendices for a copy). The 20 who did not submit monitoring forms were from a Somali older women's health advocacy group and Chinese elders who were at a voluntary sector lunch club.

Sixty-two of the interviewees were female and 35 were male. Seventy-six were from black and minority ethnic communities, four were aged between 18 and 25, 10 between 26 and 35, 50 between 36, and 55 and 35 were over the age of 65.

Twenty-four out of the 97 who submitted monitoring forms described themselves as carers and a further eight regarded themselves both as service users and carers. Fifteen of the carers were over the age of 65, two were between 55 and 65, six were between 46 and 55, and one was between 36 and 45.

## Service use

Sixty-four people of the total sample used social care services. Some of the of the interviewees over the age of 65 (particularly from the Chinese and Somali communities) did not currently use social care but were potential users of older people's services. Fourteen used day services, 10 used home care agencies, 22 had a social worker, 12 lived in residential accommodation and three had supported living arrangements. Three received direct payments.

## Client group

Twenty-five of those interviewed had mental health problems and 40 had physical or sensory impairments. Nine of the total sample had a learning disability. Four of those interviewed were people with severe learning disabilities and/or communication impairments. Seventeen had more than one of the aforementioned impairments. Sixteen had experienced homelessness, 10 had drug or alcohol problems and one person had early onset dementia.

## Immigration status

Twenty-three of the interviewees were refugees and asylum seekers. A very small minority were migrants or refugees who had been granted British citizenship. Most of

the asylum seekers were using or had used services related to their immigration status such as the National Asylum Support Service and/or a specialist resource such as the Refugee and Asylum Seeker Social Support Group (a collaborative project between the Suffolk Community Refugee Team and East Suffolk MIND).

## Method

The central issue in terms of consulting with seldom heard service users (or potential service users) and carers who may require or use social care services was reaching them through networks or contacts that already existed. Existing networks and contacts were used partly because it was hoped there would already be some form of relationship with an element of trust, and because the practical difficulties of reaching service users (or potential service users) and carers within a short period of time were enormous.

A strong emphasis was placed on reassuring potential participants about confidentiality and the fact there would not be negative repercussions as a result of their participation, particularly in relation to their immigration status or any support received. Nevertheless, there was a considerable degree of fear and reluctance to be involved on the part of some.

A combination of face-to-face interviews, focus groups and observation (particularly with people with severe learning difficulties and/or communication impairments) were undertaken. Two of the focus groups were held in community languages and three of the interviews with refugees and asylum seekers were conducted with an appropriate interpreter.

The methodology used to focus the discussions was based on a semi-structured talk protocol which covered the key areas that were relevant to the group of service users (or potential service users) and carers in question. The protocol was designed around the Department of Health consultation themes and work done by the Valuing People team to develop materials to use in green paper consultations with people with learning disabilities. The protocol does not attempt to address every aspect of the proposals contained in the green paper. Much of the success of this green paper consultation depended on the ability of the facilitator to work from a point that service users (or potential service users) and carers could relate with. Often this was a long way from the ideas and proposals contained in the green paper.

A note taker recorded the discussions. Tape recordings were made with the consent of service users (or potential service users) and carers. The notes and tape were transcribed to give as accurate a record as possible of the interviews and focus groups.

The majority of the data analysis was undertaken by manually identifying key issues and themes to emerge, and then grouping the views and opinions expressed.

A qualitative data analysis software programme ATLAS.ti was employed for the analysis of the data obtained from consultation with homeless and/or mental health and substance misuse problems. This material was analysed using a simple form of

grounded theory. This allowed the content and detail of themes to emerge from the data. Similar statements were grouped together to form themes.

A combination of direct quotations from service users (or potential service users) and carers, with commentary from the facilitator has been used to describe people's concerns within the themes and issues raised. The quotations chosen are the ones that best demonstrate a point and/or illustrate the theme described.

## Introduction

The Social Care Institute for Excellence (SCIE) was commissioned by the Department of Health to consult on the green paper *Independence, well-being and choice: Our vision for future of social care for adults in England* with service users (or potential service users) who are seldom heard of often described as ‘hard to reach.’

The following groups were included in the consultation:

- homeless people and people with chaotic lifestyles (people with multiple substance abuse and mental health problems)
- black and minority ethnic people who do not have a national or other organisation that might represent their views.
- refugees and asylum seekers
- people with severe learning disabilities and/or communication impairments.

The original Department of Health specification for the consultation work included people with profound and/or sensory impairments, however the methods used to consult with this group need to be very varied and based on establishing an effective two-way communication mechanism which has to be developed over time with repeated visits and gradual discussions. Due to the short time span and the practical constraints of addressing all of the necessary access requirements, including communication mechanisms it was only possible to do a piece of small scale work with a group of people with severe learning disabilities and/or communication impairments.

Different methods were used to approach the groups and consequently their views are represented in separate chapters. However, the final conclusions attempt to draw together some common themes that cut across the four groups.

Each section opens by describing the consultation methodology and participant sample. A summary of the key findings can be found at the beginning of each chapter. The body of each section consists of direct quotes from service users and carers and some explanatory commentary. A short conclusion closes each section. The four conclusions and common themes across the different constituencies are pulled together to provide an executive summary of the whole report. An introductory leaflet, focus groups protocols, a consultation questionnaire and the monitoring form are included in appendices.

## Aim

To consult with service users and groups that agencies find hard to reach on the proposals laid out in *Independence, well-being and choice: Our vision for the future of social care for adults in England*.

## Objectives

- To identify service users and groups that agencies find hard to reach through partnerships with key organisations.
- To provoke discussion with those that agencies find hard to reach about how social care can offer more control, more choice and high-quality support for those who use or need to use social care services.
- To enable those people that agencies find hard to reach to play an active and informed role in commenting on the green paper, and furthermore, to have a say in what services are needed to meet their needs and expectations.

The emphasis of the consultation exercise was not to pursue a rigorous research exercise, but to use outreach work to ascertain qualitative information from a range of service users (or potential service users) and carers who are seldom heard or engaged with in national policy, practice and service development initiatives such as the green paper consultation.

## Note on terminology

A full list of the terminology used throughout the report is contained in Appendix 1: Glossary of terms.

## Chapter 1: Homeless people and people with chaotic lifestyles (people with multiple substance abuse and mental health problems)

Facilitated, analysed and written by Pete Fleischmann, Principal Advisor on Participation, Social Care Institute for Excellence.

## Summary of the key findings

### Accessing community services

- Homeless people are generally excluded from using community services by a number of factors including: societal prejudice, poverty, lack of information and confidence.
- There is anxiety that general community services may not be able to provide the levels of support necessary to accommodate the needs of some homeless people.
- If the issues identified above could be addressed, there may be many positive benefits to be gained for service users through greater use of community services.

### Emphasis on preventative services

- Service users in particular were very positive about an increased emphasis on preventative services.
- For people with experience of being on the streets this meant more access to services before problems became severe.
- Services that are open, friendly and flexible were more likely to be accessed by homeless people.
- Statutory services were perceived to be difficult to access, bureaucratic and often unhelpful.

### Perceptions of risk

- The lifestyles of this group are inherently risky. Therefore, the concept of 'risk', which is centred on taking risks, may have positive outcomes.
- There was concern that there was not enough support directed at people who were ready to move on and take jobs, go into education or into more stable housing.
- Service users were unclear about who should take the blame if things went wrong, however, there was a feeling that the green paper was shifting the burden of responsibility from statutory agencies to individuals and they were uncomfortable with this.
- Link workers were clearer that it was individual clients' responsibility to make choices and live with those decisions.

## Assessment

- The idea of self-assessment for this group was not well received.
- User control and partnership between service users and staff were seen as more important than self-assessment.
- The idea that assessments should be more client centred was well received.
- The ideal assessment was one carried out in genuine partnership between a service user and someone with knowledge of the local services.
- Sharing assessment between agencies was not necessarily seen as desirable for this group.
- Information contained in assessments could be of an intensely personal nature, which it may not be appropriate or necessary to share.
- Sharing assessments, which include details of service users' past criminality, history of drug use or mental health issues may limit service users' ability to access services.
- It was felt that information about peoples' support needs and their financial circumstances, especially about state benefits, should be kept separate.
- The sharing of assessments and other information held by agencies should only be shared by consent.

## Direct payments and individual budgets

- Direct payments have an extremely low profile among this group.
- There was a range of issues, which would need to be resolved before many of the group could access direct payments.
- Many participants doubted their capacity to administer a direct payment or individual budget. Several pointed out that they would not be on the streets if they were able to coordinate a package of care.
- There were fears around how flexible the system could be if needs or preferences changed.
- Making payments directly into service users' bank accounts was not a viable option. For many people, access to more funds either provided the temptation to spend the money inappropriately and/or opened the individual up to potential exploitation.

- Very few of the participants in the consultation had bank accounts and are, largely, completely outside of the financial mainstream. Literacy and numeracy are low among this group. Therefore additional support and training would need to be available to people if they took up direct payments.
- However, direct payments and individual budgets did open up some positive opportunities.
- If direct payments or individual budgets could be portable across borough boundaries this could be especially helpful for this group who may move area often.
- Portability may also offer the choice of a greater range of services even if the service user is staying in one place.
- The concept of working out a package of care in partnership with a professional was well received.
- Several solutions to the difficulties with bank accounts were put forward including the budget being held by an independent agency on the service users' behalf.
- There was uncertainty about the long-term implications of direct payments and individual budgets, in particular around the possible reduction of direct access to services.
- Direct payments may be more appropriate for members of this group once an individual has achieved a measure of stability in his or her life.

### Workforce issues

- The qualities required by social care workers were as follows: non-judgemental, caring, client-focused, sensitive and positive.
- Many service users felt that people who had experience of using services would bring these qualities to the work.
- It was essential that senior managers maintained ongoing contact with both service users and front-line staff.
- Senior managers should both inspire staff and service users as well as provide clear lines of accountability.
- More money, better conditions, more resources, more opportunities to work with service users in empowering ways and greater involvement on a strategic level were seen as the ingredients that would attract more people to work and stay in the social care field.

## Strategic issues

- User involvement was felt to be an essential component of ensuring the development of appropriate social care services.
- Statutory sector agencies were perceived to be less likely than the voluntary sector organisations to consult with service users effectively.
- Services provided in the voluntary sector were thought to be preferable to statutory services. There was a deep-seated distrust of social services.
- Investment in preventative services was widely supported.
- Services which promoted emotional well-being were widely supported.

## Sample

Sixteen people were interviewed in total. Seven service users were interviewed at St. Anne's<sup>1</sup>, three Revolving Doors clients were interviewed in London, three Revolving Doors Agency<sup>2</sup> clients were interviewed in South Buckinghamshire and three Revolving Doors Agency workers were also interviewed.

### Revolving Doors Agency workers

<b>Age</b>	
18 – 25	2
26 – 35	1
<b>Gender</b>	
Male	1
Female	2
<b>Ethnic origin</b>	
Black Caribbean	
Mixed	1
Bengali	1
Number of people spoken to	3

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<sup>1</sup> <http://www.st-annes.org.uk/homeless.html>

<sup>2</sup> <http://www.revolving-doors.co.uk/>

## Service users

Demographics	St Anne's	RDA London	RDA S.Bucks	Totals
<b>Age</b>				
26 – 35	2			2
36 – 45	4	1	1	6
46 – 55	1	2	2	5
<b>Gender</b>				
Male	4	3	2	9
Female	3		1	4
<b>User</b>	7	3	3	13
<b>Ethnic origin</b>				
Black Caribbean				0
Black other / Black British			1	1
White British	7	3	2	12
<b>Client group</b>				
Physical disability	1			1
Mental health problems	4	2	3	9
Experience of homelessness	7	3	1	11
Drug or alcohol problem	5	1	3	9
Number of forms submitted	7	3	3	

## Method

Each group was facilitated according to an area of talk protocol drawn up by SCIE following discussions and consultations with the User Involvement Coordinator and User Involvement Trainee at Revolving Doors Agency and with an Area Manager at St. Anne's. The protocol also draws on the work done by the Valuing People team to develop materials for use in consultations with people with learning disabilities (a copy is included in Appendix 3B). The protocol does not attempt to address every aspect of the proposals contained in the green paper. Rather the specific areas which are of concern to homeless people and people with chaotic lifestyles were identified and the protocol was designed around these.

Each group opened with the facilitator giving a summary of the main changes proposed in the green paper. The groups then covered the themes in the protocol. However, the protocol was not rigidly adhered to and the discussion was allowed to develop.

The groups were taped with participants' consent and handwritten notes were also taken. The notes and tapes were transcribed to give as accurate record as possible of the groups. A qualitative data analysis software programme – ATLAS.ti – was employed for the analysis of the data. The material was analysed using a simple form of grounded theory. This allowed the content and detail of themes to emerge from the data. Similar statements were grouped together to form themes. A combination of direct quotes from homeless people and commentary are used to describe homeless peoples' concerns within these themes. The quotes chosen are the ones that best illustrate the theme described.

The work was carried out in collaboration with:

- St Anne's<sup>3</sup>, which provides a range of services for people who have experienced homelessness, mental health problems, problems with substance misuse or who have a learning disability throughout Yorkshire and the North East of England.
- Revolving Doors Agency<sup>4</sup>, the UK's only charity dedicated to improving the lives of people who are caught up in a cycle of crisis, crime, substance misuse and mental ill health.

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<sup>3</sup> <http://www.st-annes.org.uk/homeless.html>

<sup>4</sup> <http://www.revolving-doors.co.uk/>

## Findings

The analysis of the data identified seven themes:

- accessing community services
- perceptions of risk
- preventative services
- assessment
- direct payments and personalised budgets
- workforce issues
- strategic issues.

It is interesting to note that the direct payments and individual budgets theme attracted the most comments, followed by workforce issues.

The following account of each theme covers the views of service users from South Buckinghamshire, London and Leeds. This is then followed by the views of Revolving Doors Agency link workers.

### Service users' views of accessing community services

Generally participants were not very positive about the chances of themselves and their peers making more use of services already in the community.

One reason why homeless people don't generally use community services is financial:

'I'd like to go swimming with my friend but I can't afford it.'

There is also a cluster of issues around the societal stigma and institutionalisation:

'Overall I think they're trying to pass the buck. I feel more comfortable using the day centres. My point of view is it is a matter of safety whether it's going to the swimming pool or sports centre or whatever. There is still the same 'yobbery.' Whereas at a day centre, normally most people that go regularly have got to know each other and staff there already know you there and so you feel more comfortable.'

'The general public would not accept this [homeless people using community services]. There is too much stigma. The public thinks we are scum – they have no sympathy. The government needs to do more to present a positive image of people who have been on the streets.'

There was also concern that general community services would not be able to provide people with appropriate support should they require specific assistance:

'If someone with a mental illness goes into a golf club they don't know about his history. What happens if they get upset for any reason and they don't get support?'

'As I said – not just myself – this could be anybody. I have my own issues, my own history. I go in a place they don't know what I am like, are they expecting someone like me? Do they realise someone who is coming in to use that service is coming from, say, a substance abuse team, or has mental health issues? Let's say care in the community is going a bit too far.'

## Revolving Doors Agency link workers' views of accessing community services

Link workers felt that their clients were excluded from the wider community and saw a role for education to address stigmatising attitudes:

'They [clients] are not seen as part of the community and they are excluded because of who they are. Services are not accessible to our client group.'

'If an old drunk sits next to you, people will generally want to move away and will not want to talk as they do not understand or are frightened of them. This is the same with our client group with general everyday services. People are frightened of them as they do not understand them. How do you educate everyone? It's a pretty big task.'

'The policies in certain leisure centres are inaccessible to clients that use drugs. The posters in leisure centres that say it is illegal to use drugs and drug users will be prosecuted – this would frighten half the people off. They do not want to be seen in an institution where it says this as they wouldn't have the confidence to integrate in these services.'

Similarly to the service users, the link workers also had concerns that general services in the community may not be able to cope with the needs of homeless people:

'I think there is something about getting people into stuff that they might not be able to deal with. If somebody, for example someone with mental health needs, wanted to get involved in some kind of community service that isn't set up to meet their mental health needs and they feel it would benefit them, without support they can feel really out of their depth. They might be surrounded by people that do not understand what's going on, they might have an episode of some kind and no one is able to deal with the situation – and that's really negative.'

Even within the various services aimed at this group there are distinctions and prejudices:

'A client I met today said, "Oh I don't want to go to those services because they are all crack addicts and I'm only a drinker." It is the perceptions that people have of different services as well. It is very difficult.'

However, it was felt by link workers that there were great benefits for clients if community services could be made more accessible for their clients.

'There are probably lots of things people would use if they knew about them but service users do not know about what immediate services are there for them to use, which is why we have to help them explore these options. If somebody was there to help them look at, and take a step outside from, what they are used to and what they know about and explore other options I think there are loads of things that people could do. But then again it's about being open to the service and having the finances to do it.'

An additional issue highlighted by link workers was the needs of ethnic minority clients who may not wish to use community services.

'Where I am coming from as a specialist worker [for the Bangladeshi community] is not only in terms of the general community but also within a specific ethnic minority community – the dynamics of that, the family, the culture, and the religion. Would a service user from the Bangladeshi community go and integrate into mainstream services and [thereby] accepting the fact that they are different, they are sort of out casting themselves away from their own community.'

## Service users' views on the emphasis on preventative services

Many services users in this consultation were concerned that it was only possible to get help once they had become caught up in the criminal justice and or mental health

systems or were on the point of being made homeless. Therefore they were very supportive of the new emphasis on preventative services.

'I only got help once I got into trouble. That's not right.'

'Its not until I work myself up – that's the only time sometimes people listen.'

'There's a lot of problems that could be solved early on but its only till it gets really bad that anyone pays attention – and then its too late.'

'There is not enough support in the early stages to stop you getting on the streets with a habit. I didn't know which services to get help from.'

However, some participants found social care staff and in particular social workers unapproachable.

'Most people can't really talk to strangers and social workers. They would be better off talking to a close friend or family.'

'The attitude in social services is hard and they have the attitude that we don't care. There needs to be tender loving care.'

'I feel volunteers and workers need to have more work and training around housing issues as often they do not know or understand how much anxiety there is involved about landing on the streets. There is no sense that they understand or know your problem. I said that I was going on the street and was feeling very anxious about this but I'm not sure they realised, as there was no response to the problem. It doesn't send confidence and made me feel like just another statistic.'

'It's about assisting these charities who often seem to be not the last but the first point of call.'

**Please note:** SCIE does not have the views of the Revolving Doors link workers on preventative services.

## Service users views' of perceptions of risk

Many participants' lifestyles were inherently risky.

'Much of my life at the moment feels risky – I am currently living in a derelict house which can be and has been broken into, both when I was out and when I was asleep.'

Other participants' concepts of risk, rather than being about their current life style as above, were around the dangers of moving on from their current situation.

'What happens if someone that has mental health problems takes a job and has a panic attack and everything goes wrong and that person lose[s] their job.'

Participants wanted to speak to somebody who 'was clued up' and neutral about decisions. However, views differed about who should take responsibility if things go wrong.

'At the given time, if someone has kicked off and there's been an accident or there's been a fight or whatever it may be, it's about whether social services recommended that person or is she or she responsible for their own actions on that particular day.'

'The individual [worker] should be made accountable otherwise it is about passing the buck down to us [clients] as individuals.'

## Revolving Doors Agency link workers' views

Link workers echoed service user views that it was moving on from their current circumstances that represented a risk for many clients.

'For some of our clients even the most simple things could be taking risks for them, such as accessing a service, attending a user group, things that other people may take for granted.'

In this context, link workers viewed some risk taking positively.

'I think risk taking is a good thing, though it seems more relevant in the supported housing context in a way. But for our context because we are a voluntary organisation our clients do not have to engage with us and we set a more of a structural framework for service users.'

Link workers actively work with clients to help them make choices.

'I think we work on the basis that we give people the information to make a choice of their own. If something goes wrong, then they've made that choice and that's something that they've chosen to do and we will then support them to help them get over that. I think you're right that, as a charity, we do not have that much responsibility for what we are expected to do.'

'That's there entitlement at end of day if they make that choice. It's up to the client whether they want to take that risk or not – we don't take that risk for them in that sense. We give options and leave the choice in their hands.'

## Service users' views on assessment

Participants felt that the assessment of needs could be unfair and arbitrary.

'[You are assessed] for if you can go to the toilet, dress yourself and cook for yourself. But not for the fact that you're brain is not in the right place.'

'People with genuine disabilities that tell the truth do not get any help and there seems to be other people with no problems at all that get lots of support and money.'

'I've actually felt suicidal in the past and my case is genuine and I couldn't get help.'

'Homelessness is bad. It breaks your life down into boxes. You might get help, you might not.'

Others felt that assessments were too long and detailed.

'There is too much why's and where's – it should focus on the present and not on the past.'

Others felt that assessments were too superficial and that a person's needs may only become clear over time.

'When they talk about assessment, I think a lot of the times they get it wrong, as it could be a deep-rooted problem. The person who's assessing you could think they've got it right but things aren't always like that you know. Sometimes when you have counseling it all comes out and you find out you need more guidance and that's going to cost more money.'

## Service users' views on self-assessment

Some participants treated the concept of self-assessment with some derision:

'How are people with severe drug issues going to be able to assess themselves?'

'It is ridiculous that they can assess themselves.'

Others felt that it would be difficult to assess their own needs.

'I'm not good at expressing myself unless I'm asked questions.'

Others felt that self-assessment was a good idea in principle but the reality was that help was needed and professional judgment was required.

'People like their independence, but then they admit defeat and then prefer the support.'

'I would have thought after meeting with a professional they would be able to tell you how much you could possibly be entitled to and which direction to go.'

The ideal situation put forward by many participants was an assessment with a professional or an advocate but in a partnership, which offered the client a measure of control.

'Certainly self-assessment is all very well but you need somebody in the professional world to give you assistance on how to actually assess yourself.'

'Basically, you need someone to help you to self-assess. It's nothing contradictory. It's like me coming to you and saying, "I've got this, this and this. How do I put this down?" And it's like you saying, "Well right. In technical terms it's 1,2,3,4,5."'

## Revolving Doors Agency link workers' views on self-assessment

Link workers shared some of service users' ideas that the best kind of assessment is one, which is done in partnership.

'There needs to be a process, as clients know what their needs are but they don't know how to address them, they don't know what services are out there to help them. What is important is what they have had in the past and what has worked and what hasn't worked as different things work for different people. There needs to be an exploratory process between service users and somebody else who has a wider knowledge of what's out there that they can access.'

## Service users' views on sharing assessment information

Views were mixed about sharing assessment information. Some people had bad experiences of confidences being broken in the past.

'I've got experiences where I have had to go through other people and confidences are broken.'

Some participants could see the logic of assessments being shared.

'I think it should be done with agreement. It is stupid if someone is being paid by the hour to listen unnecessarily. If you've already made an agreement with, say, an agency that you're involved with, then that information can be shared. It's a personal option I'd say. They should be given a choice. Some people are prepared to repeat and don't mind repeating. But I can see after a while that if you're going through different agencies and applying with different agencies that that can wear people down a lot.'

While understanding the thinking behind the proposal other participants were still uncertain if they would be willing to take part.

'I mean [the agencies I work with] they asked me, how much information would I be happy for them to share. My response to that was, "I don't want to do that". That's just me. Others I can well understand that they don't want to keep repeating their personal history whatever it may be and they'd rather just do it once.'

Some participants felt that what was important was the kind and level of information shared.

'In some cases I think some of that [information] can be real personal. I mean [an agency I work with] can have some information about someone and it can be very detailed information about their own personal history. But then again, for the benefits people, it can just be put under a headline just depression or mental health issues – now do they really need to know what those issues they are?'

Information being shared with the Benefits Agency appeared to be the tipping point for many participants as this exchange shows.

Participant 1: 'Getting a cash-in-hand job you'd be in trouble wouldn't you, as you wouldn't want them [the Benefits Agency] to find that out?'

Participant 2: 'You could also be entitled to more benefits – it works the other way as well.'

What was important was that individuals had control over how much information about them was shared and with whom.

'That would have to be a matter of personal choice and how much information you do share with them. You would have to control over it.'

## Revolving Doors Agency link workers' views on sharing assessment information

Link workers were cautious about the idea of sharing assessments. Whether this was beneficial to clients depended on the nature of the information and the agency the data was being shared with:

'It's easier to share information that we have with other agencies to get the support that they need. Say we are sharing information with [a drugs agency] – it would work well in theory but we would be scared of sharing assessments with say benefits offices as we're coming from an advocacy position, whereas other groups are coming from a different position, which can actually be quite negative at times.'

'I would certainly not like to be assessed by someone and to know that the Benefits Agency, my housing provider, my GP and whoever else, that everyone has access to that information and knows about your mental health issues.'

A further argument against sharing information was that certain information may make it difficult for link workers to access services on clients behalf.

'For a client that is about to be evicted and contacting a housing association, obviously we're trying to present that information in the best possible light and we wouldn't necessarily want the housing association to know everything as that could affect our client's case.'

The ideal situation would be one where client and link worker agree with which agencies information can be shared.

'At the end of a page you can write all the services that are involved with [that] person and they give you consent for who and which services you can share information with. I think this kind of thing would work better.'

## Service users views' on direct payments and individual budgets

The concept of direct payments and individual budgets was totally new to the participants. Therefore the two mechanisms were discussed together. The ideas common to both instruments were described as service users having an identified

budget for social care services and having information about this budget and varying levels of access and control over how the money is spent.

### A new concept

Some people's initial responses to the idea of having a social care budget were fairly sceptical.

One set of concerns related to the additional burden of responsibility.

'I think it's their way of passing the buck. I don't think that's such a good idea.'

Another set of issues were more fundamental.

'I think it shouldn't matter how much [money] is spent but what matters is how they get better. If someone got sick, it wouldn't matter to me about [how] much money I spent at all – it would matter that they get better.'

'You can't put a price on a person's support.'

However, others could see the positive benefits that might be forthcoming.

'I start college in September and this could come in really handy.'

### Issues about having access to extra resources

For people who have issues around alcohol or substance misuse, having access to an extra income may present specific issues.

'I suffer from a drink problem and if I get up and find out I've got all this money, I would go on a drinking binge for one day and then its gone.'

'It would be useless to prefer to have it in your own bank account. They will check once every two weeks or whatever until the end of the month and they will spend it on day one on maximum accounts of cocaine and starve for two months until the next cheque. That's it.'

### The issue of exploitation

Participants felt that having access to cash or vouchers which would have tradable value may exacerbate a street culture of exploitation and bullying.

'I've known mental health patients who are targeted by people because they are on the mental health [benefit]. They wait till they get their money... and they go round with threats.'

People who are misusing drugs or alcohol may also exploit other arrangements, which involve payment of others for assistance.

'There are plenty of carers out there who are not carers who are getting paid carers' money and they are not caring... I know that happens all the time.'

### Possible solutions

Interestingly, participants, as well as being frank about the problems access to extra cash may present, were also able to offer some solutions.

'They're not just going to give you money and say, "Here you are". The government aren't daft you know to just hand out money. They aren't fools – they're going to have to take precautions.'

'I think the way, what they mean is not your own personal current account but they set up an account for you but it can only be spent on certain services and there's no way physically you'd be able to get your hands on any dough.'

'What they could do is kind of give you a direct debit card into whatever service you're using and check your statement to see where the money is going.'

### Brokers

There was general agreement that for direct payments or personalised budgets to work, some sort of brokerage would need to be in place. The idea of talking through the best package of services was welcomed.

'I'd want to talk over with somebody to find a better way of life for myself, to try and learn something but there are not many learning places.'

'I think that's a good idea of navigators holding the budget providing they don't keep it in their pocket.'

Most participants would prefer a voluntary group to look after their money rather than social services.

'I don't trust social services, I don't know them. I've not seen them.'

'[What about the] possible portability of direct payment and individual budgets?'

Some of the participants lead transitory lives – moving often. Some of them thought that one positive possibility that individual budgets might open would be increased flexibility when moving about the country.

'You're limited where you can go as well. There is separation between different public authorities if you move or go somewhere else. So there needs to be some coordination between cities if you want to move.'

Others felt that an individual budget could simplify the access to services across local authority boundaries.

'Your support depends on which borough you're in. If you're in Camden you're paid to go into Hackney and if you're in Hackney it's free, in Islington you have to apply to a charity for funding. There are boundaries in different boroughs. The inter-borough boundaries should be lessened by this procedure.'

### Fears about red tape and bureaucracy

A major barrier to homeless people accepting the concept of direct payments is that there is a perception that responsibility and the attendant red tape is being passed from statutory agencies to individuals.

'If I had enough resources [to coordinate my support] then I wouldn't be using any of these services – I wouldn't be homeless in the first place.'

'I suspect it is more trouble than it is worth, it seems initially stupid not to embrace the choice but it requires lots of thinking through beforehand during and after. It's hard enough to see how it might work for me, never mind about people as a whole.'

### Who decides if we're qualified to choose?

'I have four agencies working with me. How can they put a figure on this? It's a recipe for disaster.'

'It strikes me there's going to be loads of phenomenal running costs and where is the money coming from?'

'It's the potential for people developing [legal] liabilities, the regulations that need to be put in place.'

### Fears about needs changing over time

Some people were worried about their needs or preferences changing over time and how flexibly the system could accommodate these changes.

'Needs might vary, then they might need more money.'

'What happened if things change, does it get reviewed?'

What about having some kind of contingency plan, especially if you spend your money on something which turns out to be a mistake.

'We should be able to have a trial period with these other organisations that we may approach outside of the normal services because that money is going to be spent and they are not going to be happy if you're not happy there and they've got to go through all the paperwork to get the money back.'

### Wider implications of direct payments and individual budgets

Some participants could see the long-term implications of personalised budgets moving toward a market in social care services and had some reservations about the long-term effects of this.

'What they are trying to do, they are turning it into the free market economy, you've got the cash, and you've got the choice of two services, it's kind of 'the strongest survives'?'

However, other participants thought that competition could bring benefits.

'This brings it down to one single word. Sleep on it if you like. But the word is 'competition' as to [social care agencies] they should be more inclined to embrace competition.'

### Revolving Doors Agency link workers' views on direct payments and individual budgets

The concept of direct payments was fairly new to the link workers and the general feeling was not especially positive.

'I see it working well for people with learning and physical disabilities but for our client it leaves me with real anxieties.'

Revolving Doors Agency staff echoed the concerns of service users that if direct payments or personalised budgets resulted in clients having more access to cash they might not use the money for their social care needs.

'A client said to me, "Please make sure it [a housing benefit back payment] goes into my rent account as I'd only spend it on heroin".'

'I have seen cases where they have used the money that come in for a community care grant on alcohol, drugs and things like. At the end of day the money is coming in their name and the cheque [has] been made payable to them. All we can do is suggest and recommend what services there are but ultimately the decision is theirs. So I would say one of the areas and concerns would be how would you manage this and what kind of power would we have as workers to regulate this.'

Workers felt that a voucher system might address some of the concerns about access to cash.

'The voucher system is the best way to systematise this, but what about the services that are not part of the [voucher] system as so many interesting organisations are not in the mainstream?'

Similarly to the service users, there was also concern that access to cash or vouchers may make some clients vulnerable to exploitation by others.

'My concern is the financial view and there would be lots of exploitation if other people – friends, family carers know how much money they have coming in and know they have money there.'

To ensure that system worked well the idea of an independent body to broker arrangement was floated.

'It would be good to have an independent body that administers it because if it is held by social services, there might be a feeling they need to gate keep what the money is spent on and if it is with an independent service that they could keep and look after it.'

However, there were some reservations about how becoming a brokerage agent would effect client/staff relationships.

'I think it would change the relationship as there might be a power struggle as they might have more control of their lives.'

'Our service would change and we would not be doing what we're doing.'

However, some link workers could see that holding a budget may be empowering for clients.

'If money was held in a central place and we are able to sit down with the client and work out a package of care with them and say, "These are the services that we want to buy in", and for whoever holds the money that they could then release it – that would be really good.'

However, the amount of administrative competence needed to administer a direct payment or personalised budget might be a barrier.

'The problem is that everything has to be planned if the client wants to move on or get any service. It's the type of model where you have to be hyper-organised and they could end up with nothing if they are not organised.'

'If they are organised to begin with, they wouldn't be in the position that they are in.'

'Clients have difficulties keeping appointments and are at risk of suddenly feeling dislocated.'

'They should be able to control the finances themselves if they are able to, but for those who don't feel they are able to, they should be given lots of help. I hate the term but the idea of a navigator is a good idea that there is someone they can go to, that they can go somewhere to say what they want.'

Some link workers could see the benefits of direct payment and personalised budgets if they could offer clients more flexibility than the current arrangements. Similarly to the service users, link workers thought that one particular issue was accessibility to services that cross administrative boundaries.

'You could have a list of services in the area with a tick box, so they can mark "I want this and this and money" and they pay the day centre directly and then the transaction done. It could work another way, when actually, none of your services interests the client but they want to access the service outside the borough and payment is arranged so there is no cash handling.'

'It would be important to cross boundaries as it would force services to be more inclusive but also to think about whether they're providing adequate service, because essentially it will be like a capitalist market as clients would know where to go for the best service.'

'It is important the clients can broaden out to services in different boundaries as some people do not like to see the same faces and may like to use services in different areas to get away from familiar faces or people that know them.'

'It should be held somewhere centrally and independently because if they move around or lose touch with services they can carry on or access their money, even if they stop contact with us.'

In the long term there were concerns about direct access services becoming less common.

'The direct access would be lost for the client group here.'

## Service users' views on workforce issues

There was some scepticism about social services staff.

'I think they'll have to get rid of the stigma that's surrounded social services for God knows how many years, since they've blooming started if you ask me, to be honest. Just by changing the name from social worker to care navigator, is not going to take away, for the people who already know and experienced social services. To me its just like when companies change their logo, it doesn't really change the service.'

## Qualities of ideal social care workers

There was general agreement about the qualities that an effective social worker should have.

'For people to listen more and think and care a bit more.'

'Someone I felt was friendly and on my side.'

'Not judge and jury. They don't judge you by what you've done. The jury is that they found you guilty. It's not about what you've done in the past.'

'I'm going to get philosophical and what springs to mind is that sensitivity is the highest form of intelligence. So, someone who encourages you, puts you at ease, lets you feel you are making progress. Then you're looking forward to the next time you see them.'

However, there was some disagreement about how these qualities could be acquired. The majority felt very strongly that the best staff were people who had 'been there' themselves.

'Some people come from a completely different world don't they? I mean having a detox is not like having flu. It's nothing like flu. It's completely different.'

'Have they been kicked around by one of the parents or has their mother's head been banged against a brick wall? No. Unless they have seen it for themselves they can't say anything. They don't understand.'

'Qualifications have zero importance. What is of importance is that they are decent human beings – you can't objectify that.'

Others thought that qualifications, training and knowledge of what services are available was important.

'Good staff need to have training.'

'To have total knowledge about what is available this can come from the experience of having a job in the field.'

'Having [direct] experience [of homelessness] doesn't make you a good social worker it just allows you to communicate better.'

However, it was also acknowledged that everyone is different.

'I don't think you will find the answer, as everyone's not the same. It is all down to the actual person. As long as they are willing to help then that's brilliant.'

### Qualities of ideal social care managers

Similar views were expressed about what makes a good manager with some additional issues.

Accountability was an important concern:

'They should be different because they are the managers. They have got to know how to keep their workers in check.'

'You've got your line managers, senior managers and God knows what else, they are all passing the buck but there are specific things, which they are accountable for and which just gets passed down the line.'

The strongest view that was expressed about managers was that it was very important for them to stay in contact with service users.

'What this new top dog in social services should do is come and sit back with us behind [the local supermarket] and have a few cans. That would be an eye-opener more than any qualification. Don't say who you are just come up and sit in. Then he will understand.'

### Recruitment and retention of social care workers

It was felt that two issues were important in attracting more people to work in the social care field.

'They should be paid a bit more because I know the government's tight with their money. Because its helping isn't it? It's like care work helping other people.'

'The work has to be made more rewarding. Someone might be a good people person but they get frustrated. There aren't enough opportunities for service users to move on. I've been clean for two years but I don't feel I have made progress.'

### Revolving Doors Agency link workers' views on workforce issues

#### Qualities of ideal social care workers

Link workers views about the qualities of ideal staff reflected quite closely the views of service users.

'Very open-minded I think and not rigid in your views.'

Some link workers felt that training may be a way of acquiring the necessary skills and attitudes.

'There's something about a qualification though, because having worked in the mental health field and come across a lot of unqualified mental health workers, they don't have the same standards as qualified mental health workers. I don't know if it necessarily means going on to do a three-year social work degree, but certainly some kind of training that gets people to a certain standard of working and understanding of how the systems work.'

## Qualities of ideal managers

Link workers' views about managers also reflected the views of service users, in particular that it was important that managers maintain contact with client and front-line workers.

'With regard to managers, they should have an understanding of what it's like to do client work but be trained as managers as well and have the right management skills.'

'A danger with a lot of managers is that they sit in a separate office to do their admin. It's a good thing that some of our link workers are managers as well.'

Ensuring accountability of workers was also important as was being open to new ideas.

'For me one of the biggest things about social care work is that there is not enough accountability really as a lot of people do not want to be there and once in they are never going to be kicked out ... even if they are rubbish [at their jobs].'

'A manager should be able to encourage innovation and change.'

## Staff recruitment and retention

Link workers had clear views about what might encourage more people to work in social care and also what would make them stay in the field.

'You have to have better resources, good annual leave, sick pay, supervision and good money.'

'Also career development. Where do I go from being a social worker and link worker?'

'Also to be part of contributing to reports having regular service development. It is helpful to reflect on practice in-group discussions. It is important to make workers feel more valued in what they want to do.'

## Service users' views on strategic issues

### User involvement

Participants were unanimous in their belief that user involvement was an essential component of improving services.

'They need to be open to user involvement and they aren't exactly like that are they? It might wake them up a bit.'

'There are debates on two sides between social workers and clients/service users. There should be a partnership.'

'It might be an idea to consult with homeless people to find out what they thought about the services offered. But remember – we homeless people are subject to endless “consultations” and we are quite cynical about them.'

However, social services are perceived to be less likely to implement genuine user involvement when compared with voluntary groups.

'I think it's a good thing but what I'm saying is I don't think they will be so open as [a voluntary organisation] has been. They've got a lot more government targets to reach. They've got a lot of mistakes to put right as well.'

However, some participants also had doubts about voluntary organisations' capacity for genuine user involvement.

'The difficulty with this is gaining a representative view – for example the existing organisations all have their “pet” users who would simply echo their views.'

### Spending money differently

Participants had a range of views about how local authorities could spend money differently.

'Most of the prisons are overcrowded – mostly full of drug and alcoholics who wouldn't be if there were somewhere else.'

'Put more resources into the front-line, and not to be stuck with \*\*\* council houses as I can't get the bond together to get a flat of my own.'

'Not to put it in the wrong pockets as far as I'm concerned.'

'The council should spend more money on prevention before people lose the will to do it when things get really bad. You should be able to get a detox in 24 hours as you can't get this in many cities.'

'One good service I have used is a mobile DIY outfit. They are limited in how they can help as they only work in certain areas. They will come and

do shelving, installations, gas cookers, DIY services and if you're disabled or on benefits they will come and do it for like five pounds an hour. It's very good.'

'I think I would redirect the money a little a bit more towards voluntary agencies and charities because they seem to be more 'with the people', genuine and willing to go out a bit on outreach work terms rather than a social services officer sitting in the office most of the time and making a decision from their desk.'

'It would be useful to have some money spent investigating the real reasons why people are not being housed, but languish in hostels.'

### Assessing the quality of services

Participants had varying views about how to assess the quality of services.

'I would go to ask services myself until I learnt that workers have been in the same situation what I've been in.'

'I would ask other homeless people – the best source of information about services is other homeless people.'

Got to have someone to talk through to work out the cheapest service maybe through a prospectus or paper.'

### Revolving Doors Agency link workers' views on strategic issues

#### User involvement

Link workers thought that there was a value in consulting service users.

'The best place to start is to have consultations with service users. They must know what's available and out there.'

'Spending money differently.'

Link workers would like to see more money invested in services, which provided emotional support.

'I think that acknowledging that being mentally healthy is more than just having medical treatment, its about quality of life.'

'Yes it could be spent better. A lot of us would like to provide better emotional support or counseling but we are not trained to do that.'

They also felt that alcohol services suffered from under funding.

'There is not that much support for people around alcohol as there is around drugs and dual diagnosis.'

## Conclusions

Homeless people had a great deal to say about their lives and experiences and had many useful comments and suggestions about the proposals contained in the green paper.

Homeless people are generally excluded from using community services by a number of factors including: societal prejudice, poverty, lack of information and confidence. If these issues could be addressed, there may be many positive benefits to be gained for service users through greater use of community services.

The lifestyles of this group are inherently risky. Therefore the concept of 'risk' which is centred on taking risks may have positive outcomes.

The issues of assessment, user control and genuine partnership between service users and staff were seen as more important than self assessment. The sharing of assessments and other information held by agencies was not broadly welcomed and information should only be shared by explicit consent.

Direct payments have an extremely low profile among this group. There was a range of issues which would need to be resolved before many of the group could access direct payments or individual budgets.

The qualities required by their ideal social care worker were as follows: non-judgemental, caring, client-focused, sensitive and positive. They also valued staff who had had experience of using services. It was seen as essential that senior managers maintained ongoing contact with both service users and front-line staff.

User involvement was felt to be an essential component of developing appropriate social care services. Services provided in the voluntary sector were thought to be preferable to statutory services. Investment in preventative services was widely supported.

The principles contained in *Independence, well-being and choice* were broadly welcomed by the majority of participants. However some of the proposed instruments to implement the vision will need to be worked on and adapted if the full inclusion of homeless people is to be achieved.

## Chapter 2: Black and minority ethnic people who do not have a national or other organisation that might represent their views

Facilitated, analysed and written by Nasa Begum, Principal Adviser on Participation, Social Care Institute for Excellence

## Summary of key findings

### Knowledge about social services

- Most of the Chinese elders and older Somali women had not heard of or been in contact with social services.
- Information about entitlements to services and the process of applying for them came from voluntary sector groups.

### Knowledge of green paper

- None of the black and minority ethnic service users (or potential service users) and carers interviewed were aware of the existence of the green paper or the proposals contained within it.
- Feedback on what came out of the green paper consultation was very important to people.

### Experience of accessing services

- There was a lack of knowledge about how to access services.
- People believed that if you (or a family member) know how the system works and how to present your needs then you have a distinct advantage.
- The interpretation of eligibility criteria meant services could not be received until you were in crisis or in major difficulties.
- None of the carers had had a carer's assessment.

### Self assessments

- Practical difficulties (e.g. language and literacy) of self assessments have to be ironed out before it can become a viable option.
- There were concerns about whether professionals would accept self-defined needs.
- Support is needed from the voluntary sector to complete self assessments.

## Complex assessments

- There was a lack of clarity about what constitutes complex needs.
- There was concern about whether or not there would be an entitlement to a social worker.

## Information sharing

- People were frustrated about having to provide the same information to a number of agencies.
- Principles of information sharing were welcomed but with some caveats.
- Practicalities around confidentiality and access to people's personal information raised concerns.

## Experience of using services

- Carers had very limited experience of using services – their main sources of support were carers groups.
- A great deal of dissatisfaction with home/personal care agencies was expressed. This dominated discussions with service users.

## Direct payments

- In response to difficulties with care agencies, three service users had started using direct payments.
- There was some interest expressed by elders in using direct payments but carers were sceptical about them.
- Concerns were raised about the practical difficulties of managing a direct payment, including bureaucracy and accounting arrangements.

## Independent living and risk taking

- Service users valued independent living and they did not perceive themselves at any more risk than people who did not have social care needs.
- Direct payments were seen as an important way of having control.

## Residential care

- There was an overwhelming consensus amongst Chinese elders that residential care was their preferred option for future care.

## Preventative services

- There was a belief that preventative services would have prevented deterioration.
- There was a strong perception that services were only available for people in the most desperate situations.
- People thought a more proactive approach to reaching black and minority ethnic elders should be taken.
- Accessible information, lunch clubs and other support groups were considered essential for reducing isolation and promoting well-being.

## Training and support for carers

- Arrangements must be made for supporting carers in employment.
- Carers stressed the importance of being able to have a break from their role as a carer.
- Training on lifting techniques, managing dementia and stress management were wanted.

## Barriers to using community-based resources

- Lack of accessibility, poor transport and the public environment presented considerable difficulties for service users (or potential service users) and carers.
- Cost was a deterrent to people attending community-based services.

## Aspirations

- Carers wanted to have a more fulfilling lifestyle.
- Service users felt penalised for doing voluntary work and there was a wider belief that paid employment was not an option because of support needs.

- Low expectations and lack of recognition of the skills of service users were thought to be prevailing attitudes.

## Workforce issues

- People acknowledged the pressure social workers are under.
- Qualities people wanted in a social worker included good communication, respect, improved attitudes, courtesy, empathy and the ability to follow up.

## Recruitment

- Recruitment of managers from the front-line would improve knowledge of people's needs and services required.
- Recruitment of social workers from abroad and their knowledge of processes and systems in England were identified as areas of concern.

## Social work training

- People emphasised the importance of information sharing and communication, particularly when talking to service users (or potential service users) and carers.
- Service users and carers wanted social workers to have a better knowledge of the policies, procedures and the systems within which social care is provided.

## Strategic issues

- Improved access to services was wanted.
- People were cynical about how social services manage their budgets.
- Security of funding and support for the development of voluntary sector were considered essential.
- Recognition and support of the vital role the voluntary sector plays through various support groups and activities in overcoming language barriers, offering mutual support, reducing isolation, offering advice and information and developing directly provided services (meals on wheels, home care) was needed.

## Sample

### Demographics

Fifty-five black and minority ethnic people were interviewed at six different locations. Forty-six people submitted consultation monitoring forms.

Sixteen were men and 30 were women. Seven = were between the ages of 36 and 55, 10 were between 56 and 65, and 29 were over 66.

The sample was split almost equally between service users and carers. Eight people described themselves as both service users and carers. Fourteen of the carers were over the age of 65. A majority of the carers were caring for an older relative.

Amongst the service user sample, 10 people used day services, eight people used home care agencies. Five people had a social worker, two lived in residential accommodation, 1 in a nursing home and three received direct payments. Only one person in this strand of the consultation work identified as having learning disability. Twenty-six of those who submitted consultation monitoring forms had a physical or sensory disability, six had mental health problems, 16 service users (or potential service users) were older people. One person had early onset dementia. Six of those interviewed had more than one impairment.

## Method

The approach SCIE adopted in consulting with black and minority ethnic service users and carers who may require or use social care services and who are not represented by national or other organisations, was to arrange focus groups through networks or contacts that already existed.

To identify an appropriate sample within the short time span available for the consultation, a decision was taken to target work within a London borough. Due to its very diverse population and ease of access we obtained permission from the social services department to concentrate our consultation work within Newham. A consultant working for the social services department and the Black and Minority Ethnic Community Care Forum facilitated access to black and minority ethnic service users (or potential service users) and carers. SCIE reimbursed all associated costs.

Focus groups were set up with a range of black and minority ethnic service users (or potential service users) and carers. Some focus groups were held within support groups and others were based in statutory or voluntary sector services such as luncheon clubs and an older people's resource centre (which provided day services). The criteria for inclusion were that people were not being represented by national or other organisations.

A strong emphasis was placed on reassuring potential participants about confidentiality and the fact there would not be negative repercussions as a result of their participation, particularly in terms of any services received.

The methodology used to focus the discussions was based on a semi-structured talk protocol (Appendix 3A) which covered the key areas that were relevant to black and minority ethnic service users (or potential service users) and carers. The protocol was designed around the Department of Health consultation themes and Valuing People team materials for use in green paper consultations with people with learning disabilities. The protocol does not attempt to address every aspect of the proposals contained in the green paper. Much of the success of this green paper consultation depended on the ability of the facilitator to work from a point that service users and carers could relate to. Often this was a long way from the ideas and proposals contained in the green paper.

A note taker recorded the discussions. Tape recordings were made with the consent of service users and carers. The notes and tapes were transcribed to give as accurate a record as possible of the interviews and focus groups.

The majority of the data analysis was undertaken by identifying key issues and themes to emerge, and then grouping the views and opinions expressed.

The focus group with Asian carers was mainly facilitated in Punjabi. Participants responded in a mixture of Punjabi, Urdu, Gujerati, Hindi and English. Fortunately, there are some common terms and similarities in the Asian languages spoken so the facilitator was able to understand and transcribe the tape recording.

An interpreter who knew the Chinese elders well provided an interpretation of questions and answers in Chinese.

A combination of direct quotations from service users (or potential service users) and carers, with commentary from the facilitator has been used to describe peoples' concerns within the themes and issues raised. The priority has been to hear directly the voices of the people that were spoken to. The quotations chosen are the ones that best demonstrate a point and/or illustrate the theme described.

## Findings

### Knowledge about social care services

Five of the black and minority ethnic service users and carers interviewed were in receipt of social care services. However, none of the Chinese elders interviewed had heard of or been in contact with social services although they regularly attended a lunch club provided by the local Chinese Association. One of the Chinese elders lived in a nursing home for older people but she was not aware how this was funded or how she was placed there. She was sent to the lunch club so that she had an opportunity to spend time with other Chinese elders.

When the Chinese elders were asked how they found out about the lunch club, the majority of them said they had found out through word of mouth. Networking within the community was also an important source of information dissemination for other groups of black and minority ethnic service users and carers.

The other important source of information about entitlement to services and the process for applying for them came from voluntary sector groups like a carers' support group and luncheon clubs. General practitioners (as the first point of contact for many) had an important role to play in directing people to both statutory and voluntary sector services.

### Knowledge of the green paper

None of the black and minority ethnic service users and carers interviewed were aware of the existence of the green paper or the proposals contained within it. The only information people had about the green paper was that provided by the SCIE facilitator. None of the participants were part of any other consultation on the green paper. In fact, participation in SCIE's green paper consultation was the first time participants had fed into a national consultation exercise.

The African-Caribbean carers, Asian carers, African-Caribbean elders and the group of black and minority ethnic disabled people had considerable experience of being part of local consultation exercises, but they were frustrated that they received no feedback afterwards and that there little evidence of changes being made as a result of local consultation.

'We are local people sitting here together and we can't do anything and if we go to services and give our point of view it doesn't appeal to them. They don't care.'

All the carers and black and minority ethnic disabled people insisted that they wanted feedback on what came out of this consultation exercise. One service user said:

‘I want some feedback on this. I want to make sure that what we’ve said is listened to.’

‘What I’m saying is this [problems with care agency] ... I’ve taken my time to come here... I need feedback because I take an interest in services, nothing has improved or changed... Social services don’t have to spend millions and millions of pounds to try to improve services. It’s been mentioned over and over again and something should have been done a long time ago.’

At the end of each focus group, the SCIE facilitator agreed to provide a summary of the consultation findings and where possible inform participants of the action to be taken as a result of the national consultation.

## Accessing services

One African-Caribbean elder had to rely on her son to help her bath and was very uncomfortable about this but she had never asked for help or had a community care assessment because she did not know how to go about it. She explained:

‘I have never asked because I don’t know whom to ask.’

For another African Caribbean elder, the fact her daughter worked in the social care profession made all the difference.

‘My daughter’s a social worker, she did my care plan... If I’ve got a form or something to fill in I talk to my daughter. I’m very good at doing it [filling in forms]... before you know it you phone up and they say “Oh I’ve spoken to so and so”. If I didn’t have a child in this position I would have got left behind.’

African-Caribbean carers spoke about their frustration:

‘When you need help you ask for help and when you ask for help you get refused so I don’t know any other way – what can one do?’

‘I had some problems in the past where my husband was in a nursing home. I wrote about the sickness and needed some equipment for the bathroom and was told that he didn’t fit the criteria and they didn’t even tell me what the criteria was. Nobody tells you anything until you ask them and you do not get anything unless you fit the criteria.’

'If you don't know where resources are and don't know how to get them, you're left in the dark.'

'Some people can fill in the forms and get everything they ask for. By the time I have applied they say things have changed and I have to have another assessment – it just carries on. In the end they say "No" to you so it is a waste of time.'

Asian carers spoke of the difficulties with assessments.

'A social worker came to assess my mother who can't walk, she wrote everything down. For ten months I waited, nobody got in touch. I kept ringing the council and after 10 months somebody else came and asked the same questions, eventually occupational therapy did some things like putting in rails but my mother had to suffer for 10 months.'

'It is very difficult to get services even if you and your wife are both old – the government doesn't give us anything. Our children have their own lives and can't help us. Some of us don't have children near so how are we to manage?'

'The criteria [eligibility] are so strict that it is hard for people on the borderline [of eligibility bands] to get help with services.'

'It [accessing services] depends on the person who does the assessment and how they put the case for you.'

'You have to go and knock on the door and keep knocking if you need social services.'

One African-Caribbean service user summed up the difficulties with accessing services very well when she said:

'You've got to know where the key [to access services] is... They [service users and carers] cannot get that key to open that door to social services because they don't know which road to go to to open that door.'

None of the service users who used older people's services had heard of the Single Assessment Process. Similarly the carers interviewed were not aware of having a carer's assessment.

## Self-assessment

Both service users and carers thought that the practical difficulties with self-assessments would have to be ironed out before it would be a viable option for them.

Black and minority ethnic disabled people explained:

'I think, because of the language barrier, they can't get across what they want so it is a greater problem for us from ethnic minority backgrounds.'

'There are a lot of people who are able to do their assessment themselves and then again they're a lot of people who will not be able to do it. The reason being is partly as English is often their second language and they would have to provide translators ... who can help them with their self-assessment. Obviously once the assessment is done, I know what my needs are, but are they going to be meeting those needs? It's like X and Y – they've got their own needs, they know what they want.'

African-Caribbean carers were not very optimistic about self-assessment.

'I have been going to meetings to do with care assessment. We went all over the country to have these meetings and what are we getting? The problem is we have years of these meetings but nothing changes.'

'As far as I know I don't think I'll get nowhere with that [self-assessment] ... it's the same things going on, same avenues and squares going round and round.'

'Nobody seems to care... social services need to know that we're not getting it [services]... no matter what you do you're doing it wrong.'

Asian carers expressed a range of concerns about how self-assessments might work in practice.

'Disabled people have so many needs that it [self-assessment] couldn't be done. We want someone else like a social worker to understand and meet the needs. Otherwise it would just be another thing we would have to do.'

'Would they accept what we say? If you fill in the form saying what the problems are and the help we need, then it goes to the authority, they could just say no without even really knowing you. The problems are created when you give in the assessment.'

'I said my mother needs a seat in the shower as she can't stand. Instead they put up handrails. I know what my mother needs, I help her everyday

so why don't they listen to what I say? In the end we had to buy a stool for her to sit on but it is not very safe or very comfortable.'

'If people do their own assessments, is it by a form? Many people would find this difficult as they can't read or write. There would need to be translations and help with filling things in.'

Concerns were raised by both service users and carers that the success of self-assessments would be dependent on how well people understood the process and the gate keeping mechanisms.

'People make do – they don't know what they are entitled to or what sort of help they might be able to get to make their life easy.'

'People who know the system – who to go to and what to ask for – would be okay. Already people who know how to get help and what to say to questions get what they want, but people like us are not given help because we don't know what you have to do.'

'There are some clever people – they know they have to have a certain number on the form so they tick lots of things even if they're not true but they get high enough number (score) so that they can get services.'

There were a number of practical things that participants said would make self-assessment easier.

'Even a meeting like this [consultation focus group] for people who can't do their assessment – it would be very nice if there was this help. I can tell you, social services don't have any idea about exactly what are the problems. The meetings should be so you're going to get some support... this may be the only way people can get their problems out, especially for people who live on their own, or a spouse can come and get help with their self-assessment.'

'I think what I would need are guidelines in terms of what I'm doing – you know certain forms – what I need to do. At the moment I just do it myself. To have guidelines would help with self-assessment.'

\*\*\*\*\* (Carers group worker) could help us fill the forms in. She knows us and understands our way of life. Don't feel a burden here so easier to say we need this or that.'

'Would prefer bi-lingual people coming to help. As in this community the elderly speak only Chinese but talking to someone who is bi-lingual helps.'

'If you go to independent living schemes, they can provide support for people who are thinking of going on direct payments. Probably the key is that they [independent living schemes] can have more material about self-assessment so that people can do their own assessment. Resources need to be there so they [service users] can learn how to do it themselves.'

'When you go to direct payments you should know your needs and when they [social workers] come around, you tell them this is your need. Sometimes they do agree with you and sometimes they don't. Good to ask about self-assessment course [training], then you know how to put your needs.'

## Complex assessments

The African-Caribbean carers spoke about the lack of clarity in terms of whether or not the people would be entitled to a social worker working with them to do a complex assessment. Access to a social worker was an area of concern for the carers.

'Do you [service user] have to have more than one complaint [impairment] to get a social worker?'

'I had a social worker for my aunt, who has dementia, and when I called I was told she was off the case because she hasn't got any complication. If you want a social worker you have to ring up and ask.'

'Before we get this [assessment] we have to get the social workers because everywhere you turn they tell you they are not social workers. The system has changed so bad and not for the better. They have to put something into place. You have to have someone to go to first.'

Both service users and carers were clear about how they would like social workers to work with them.

'More contact and work more closely, more feedback, more information and resources, where are they and how to get them, lots of contact and moral support. We don't get that we just ring up and are left hanging.'

'I would like a social worker to come to the centre [older people's resource centre] and explain how it [social services] works.'

'I'd really like my social worker to sort out my carers [agency staff], as they don't even know your name— someone different all the time and they rush in and out. Social worker could make sure the carers are regular and at the time they're supposed to be.'

## Sharing information

There was frustration amongst service users and carers about having to provide the same sort of information to a number of agencies.

‘I always need to give the same information to different people.’

‘You’re going round in circles. It really depends how much you’ve got to tell and who to – it can be a doctor, housing department, social services department and benefits people. If information was shared – that saves a lot of time and energy. It would be a good idea – we are heading towards that way, are we not, with paedophiles? For example, a paedophile in Scotland moves to the south ... police and social services know what particular information is there. Sharing information will be a good idea provided it stays confidential and within the system rather than everybody else knowing about it.’

The principle of sharing information was welcomed. However, there were some caveats.

‘It depends on how much information you give them because obviously they have got to go somewhere to pass it on and before you know everybody knows your personal information.’

‘You might have somebody you know working in a particular department or friend who might not have anything about you – all this information is there and it’s open to abuse. That’s the thing that worries me.’

‘There needs to be some restrictions, data protection and all that. Nobody can just punch in your postcode and your surname and there you go, you’ve got everything in front of you.’

## Using services

Both Asian and African-Caribbean carers had very little experience of using social care services. The main source of support was the carers groups provided by a voluntary sector organisation. The carers explained the importance of such groups:

‘The carers groups – we can have social contact and talk. Sometimes outside the group you don’t talk to anyone about how things are for you.’

‘I look forward to the day trips we [carers] have and like to do more of these.’

‘Because of funding problems we don’t always know if we will continue to meet, but where else could we go to talk to other people in our situation.’

‘There is a saying “Who cares for the carers?”. For me it is coming here [carers group] that I get some care. We eat, we talk and share our problems. You are not on your own here.’

The six carers who did receive a service valued it very much for the break it offered them.

‘Someone comes to sit with my wife once a fortnight so I can go out. Without this help I wouldn’t be able to go anywhere.’ (Carer in his 80s looking after his wife.)

‘I get sit-in service twice a week which is really helpful.’

Eight of the service users used home care agencies. However, everyone who used such services expressed great dissatisfaction with the service provided. The African-Caribbean elders who took part wanted to make sure the facilitator got the message loud and clear that the quality of personal care received was their number one priority.

One of the major concerns was that service users were not even aware of the carer’s<sup>5</sup> name.

‘Overall these agencies do not even tell you the carers’ names. They do not wear a badge. Most of us here have some form of disability, whether mental or physical or something. You are nervous when Jim comes today and Jack comes tomorrow. Your poor tired brain is not working because you are focused on her voice.’

‘Sometimes I don’t even know who is coming till they arrive and she turns up “I’m the carer”. Anybody can be called a ‘carer.’ I ask, “What’s your name?” and they will say whatever it is. And I say, “I didn’t expect you”. I wasn’t told. Sometimes I am so fed up. I am really fed up, as I am dependent on these people.’

‘I am there on the bed or on the chair and somebody just comes in. I press the button and ask who it is. I can’t understand what they say so I just let them in... when she comes I would say “Who are you?”.’

The agency staff’s ability to do basic tasks was questioned.

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<sup>5</sup> In discussions about home care services the term carer is used to refer to paid agency staff.

'Once I had an experience of a carer – she was making breakfast but she doesn't know how to make toast and she doesn't make tea. I said, "Don't you drink tea?". She said she doesn't drink tea. Half of the toast is burnt and half is not cooked.'

'Simple, simple, simple things. They can't even wash a knife. They can't make a bed. They can't do anything. I am so fed up with them now.'

'When they come, they don't know their work. They must get them off the street. You say, "How are you this morning?" – no smile no nothing. They don't know what you call a 'face flannel.' They don't know a thing.'

One African-Caribbean elder throughout the focus group remained silent and then at the very end expressed his real anger and despair about the carers who were suppose to assist him.

'I don't even bother now... if they [carers] come, I appreciate it. If they don't come in I don't miss them. They can't even wash a plate, there's food left on it. Usually I have tea once in the morning, the teabags are left in the teapot. They are absolutely useless. Every single one of them.'

Reliability of care agency staff was another area that service users were very unhappy about.

'One day I was out of the bed till half past eleven and was just ringing up the agency to see if someone is going to be putting me to bed or not. Eventually they come after half past twelve.'

'In my case the carer never came in three days yet they filled out on the timesheet that they came to work so many days.'

'Now when my carers come I say remember tomorrow is Thursday and the transport comes to take me to the centre [older people's resource centre]. Again my carer hasn't turned up and I am waiting for them to come. You're not ready when the transport comes and they have to leave without me.'  
(Service user became very distressed.)

The catalogue of problems with care agencies dominated discussions with African-Caribbean elders and black and minority ethnic disabled people. However, there was one success story as two of the women explained.

'I must say in some ways I am lucky, my morning carer she treats me as if I am her mum. My morning carer I'll die for.'

## Direct payments

In response to the difficulties with care agencies, three of the black and minority ethnic disabled people had transferred to direct payments.

‘When you go to direct payment and you buy in the right helpers your life feels a lot easier.’

‘They do what you want you want them to do and what is needed to be done and then they’re gone. You’re in control, you have direct control.’

‘If the helper comes and he has one hour to spend with you, he can’t just tell you half an hour later, “I’m going, my time is over” because you are the controller... when they’re gone they don’t get paid.’

One service user said that for some people, direct payments were not a positive choice but a response to a failure of provided services to be able to meet people’s needs.

‘Today, all of a sudden I thought “Why do we have a better service just because we have to go on a direct payment?”. Some people might not want to go on a direct payment. Some people are forced to go on a direct payment. It is not right. There should be enough communication between the social services and agencies to sort out problems instead of making us go on direct payments.’

‘A lot of people would like to go on direct payments because they are not getting a good service from their agencies. What problems are you leaving for them because they can’t manage an independent living scheme either? The agency should be made to give them a better service... because if somebody can’t manage a direct payment scheme, then they are not going to be able to monitor their worker either.’

Although none of the African-Caribbean and Chinese elders had heard about direct payments, three of the African-Caribbean elders were interested in the idea of being able to use direct payments.

‘I think it would be better to have that caring money added onto your pension and then you can then buy in whom you wanted. Because now if they’re [agency carers] coming in and they’re not doing what they’re supposed to do all you can do is be truthful, and then you become a bitch. If I had money with my pension, if the carer didn’t do what I need you can get someone who will.’

‘What I would really like is that they take money from these agencies and help us get good people who know what they’re doing.’

‘Yesterday evening I had to ask a woman to help me have a bath because I’d had an accident but as soon as I opened my mouth she’s grumbling and then gone. It’s not nice. I can’t understand why. If you [facilitator] have some time hopefully you can tell me, how to stop them [social services] paying money to these horrible people so I can buy my own service that I’ll be happy with.’

‘The Chinese elders found it very difficult to conceptualise the notion of direct payments for social care needs. The priority for this group of elders was having money for clothes, food and transport.’

African-Caribbean and Asian carers were sceptical about the idea of direct payments.

‘Government won’t give us money, they are closing things and we can’t get help.’

‘I think people will have the money but still suffer in silence.’

‘There will be an issue of how much they [social services] will give and will that be how much it will cost.’

‘Have you got the people to buy the service from? If I get the money, I wouldn’t know where to get help. I am not sure whether it is a good idea for me and \*\*\*\*\* [service user].’

‘This would create a problem. I need OT [occupational therapy] and have other needs that I would like to be met. How much money is this all going to cost?’

‘I was promised a seat in the shower and didn’t get this nor a handrail. I think having the money would be extra work because you would have to go and look for what you want.’

Service users also raised practical difficulties with direct payments.

‘To get direct payments is not as easy as it should be, because you have to go through so many procedures. Why is it that you have to go through this stringent qualification sort of thing to qualify for direct payment...? Direct payments is a good idea – you have control over services that you’re getting in – but why do you have to go through the hard procedures?’

‘Don’t want it [direct payments] because of all that mess and hassle and even though I have got a lot of needs and all that, I could still get into trouble with all the papers and you don’t have any back up.’

'I think a lot of members [service users] have heard of direct payments but are scared if the carers don't turn up they're on their own, what if you don't have any back up person to come?'

'They [agencies] want about £12 or £13 an hour from you but I don't get that much for an hour on direct payment. I can't afford to give that much to the agency. So there needs to be some replacement back up type of system.'

Involving family members was an important issue for some of the service users.

'I think it is a good idea to have a family member or friend to help to make up the wage.'

'I've been told you cannot use direct payment to employ any member of the family.'

'I'd like to give the money to my son. There are times when I feel that I am asking too much from him. Even now I can't get into bed without some aid. I can try myself, but too often I have to phone him – I need the help of my son. It is not easy for me but if there was incentive for him I wouldn't feel so bad.'

## Independent living and risk taking

The black and minority ethnic disabled people interviewed all lived at home and three of them felt it was important that through the use of direct payments they had control over their own lives. Therefore, independent living was valued very much and they did not perceive themselves as being as being at risk any more than non-disabled people.

'Whoever you are you take a risk when you step into the road. You could get run over by a car but you can't stay in the house because of that.'

One service user claimed that there was a conflict between expecting family members to care for people and the move to put older people in residential care.

'The government policies, so far as I can see, especially for the ethnic minority I'm referring to – they say your elderly, your mother, father, and aunts or whatever, we've got homes for them, you don't have to look after them, and we will take care of them. But at the same time, what they're saying [in the green paper] is that your culture is such an excellent culture because you believe in expanded family and caring for your own, so what are they talking about? One minute they're saying you care for your own and on the other hand put your elderly into the home so it's a conflict.'

## Residential care

There was overwhelming consensus amongst the Chinese elders about residential care being their preferred option for the future.

‘If a residential home is being well looked after by the government then this is a good choice.’

‘It [residential care] would be a good choice because if someone who is qualified to look after [people], there is security. It is a good thing.’

‘If the family has a choice then definitely they would prefer to send the person to a voluntary sector organisation or a home or whatever rather than keeping them at home.’

One Chinese elder asked:

‘Is it possible to have an elderly centre where the elderly can live together and communicate with each other like in an elderly home?’

The Chinese elders told the facilitator of a visit they made to a ‘Birmingham Chinese elderly home.’ What they particularly liked about it was that people can cope on their own (with individual flats) and talk to others. The project visited sounded like a sheltered housing project, which enabled Chinese elders to retain their independence and retain contact with their peers.

## Preventative services

One African-Caribbean elder explained:

‘If I’d got help before I may not have deteriorated as quickly as I have done.’

The African-Caribbean elders who used the older people’s resource centre were very concerned that one of the service users had been told his place at the centre was to be withdrawn.

‘My friend has been given a letter to say at the end of this month he’s to stop coming here. I don’t know why at the end of the month – he will soon die... He wants to come here to mix with people. On his own he will soon die. Coming here helps, you mix with people and go home, you feel relaxed and feel balanced but without this you feel bad.’

There was a strong perception amongst African-Caribbean and Asian carers that services were only available for the most desperate situations, and that even then it could be difficult.

‘When they [occupational therapist] did the assessment for my husband to have help with the bath, I ran the bath but they didn’t see how he gets in and out so they didn’t know how hard it is for him and how easily he could fall. If he falls and breaks his replacement knees or something else then the whole thing would collapse.’

‘I have told them that I cannot care for two people at the same time but nothing is done.’

‘Very difficult for them to put themselves in a position where they are caring for someone all day, everyday, 365 days a year, year in year out. It can be a real burden and our health can suffer badly.’

‘I am looking after my mother. At the moment I am coping but when the time comes I am going to need more help. People don’t get help even when they are really struggling.’

‘I have cared for my husband for nine years and I have now been diagnosed as disabled. I can’t get through to anyone to get any help for myself. I have cared for and saved millions of pounds caring for my husband. When I asked to get help from a social worker to help with washing I was told “No” and that I don’t fit the criteria. What do you do? You have to be crippled and dying. Why when you work and contribute to the system do you have to be dying to get help as that means you don’t need it then, you need the money to keep alive and independent. I want to live at home and be independent.’

The difficulties of accessing services early on led two of the African-Caribbean carers and one of the elders to believe it was an attempt to kill them. One woman said:

‘What I do not like is why government has to put us through all this rigmarole, which is not fair. When I was working and paying all my contributions, and now when I am old and need help they are trying to kill me, to stop paying money. This is what it is all about. They are stressing us out to just kill us. Why are they putting us through all this? It is not fair. This is one thing we should stand up for as carers and pensioners, we should go to parliament. I am ready to do this.’

For the Chinese elders, health checks and information leaflets were regarded as essential for promoting well-being and minimising the risk of people needing high levels of support later. The worker from the Chinese Association explains:

‘Need health talks. Leisure activities... elders in these communities let sickness get really bad before coming to see someone. So the way to tackle these problems is to have regular check ups as people don’t go to treat their hearts until they have problems.’

‘The preventative measure of information in Chinese is important so elders can understand what is being said. As elders do not have good levels of English.’

‘If a person is isolated in the community and he or she is unaware of activities in the community, can the government take a more proactive approach to reach them rather than expecting them [Chinese elders] coming out to see?’

‘What they [Chinese elders] are stressing because of the language barrier – they are very dependent on bilingual workers. They ask whether the social services will wholeheartedly support this lunch club?’

When asked about the role of the lunch club, Chinese elders said:

‘Happier when come here.’

‘Breaks isolation.’

‘Have a social life here. If there is no money to hire a hall then isolated.’

‘Even coming here once a week for Thai Chi class breaks isolation. It makes a difference.’

## Training and support for carers

Both service users and carers talked about carer’s needs. Service user’s explained:

‘I had a bad experience, we don’t have any children... My husband’s business went down and the only thing that mattered to him was me and me getting better... he got sick. I think he needed psychological support. To me I was getting all the care, but my husband wasn’t getting support – he had a heart attack. I think what my husband needed was a lot of moral support.’

‘Support is mandatory to show that they really are caring about people [carers] because they look after us.’

‘Well what I thought was, suppose your daughter has a full time job but she would like to assist her mother or father. I wonder if government could intervene to get in touch with the son or daughter’s employer and try to make some arrangement so that that child could leave work a little earlier but doesn’t lose any pay. Even to leave work for half hour to assist with the mother and the father. This means each side wouldn’t lose any money.’

Carers spoke about the need for a break from the caring role.

‘Social workers need to arrange a bit of a rest or a change for us [carers].’

‘My husband is on sick leave with a back problem and I also look after my daughter all the time. Sometimes I get tired and need extra support to help her tidy her room and to give me a break. I am not asking for housework or anything like that, just a little help for my daughter. I need a break as I am caring for two people.’

Both groups of carers spoke about the need for training.

‘It would be very helpful for me to understand and be trained and equipped to deal with dementia to help me care for my aunt.’

‘[I would like] training on how to lift people.’

‘Stress management would be very good because we get very stressed doing what we do.’

## Barriers to using community-based resources

Service users welcomed the idea of using community-based resources, but practical barriers prevented their participation.

‘I was locked up upstairs in one room [because of lack of access]. I could not get out. My loneliness and depression was much worse than my paralysis.’

‘They [leisure centres] do have facilities for the wheelchair user, but most of the time they’ve got the lift broken and sometimes they say we can’t get it repaired. Obviously if the lift doesn’t work you can’t go for a swim in there.’

'There are some mosques that are accessible for wheelchairs... There is one where you can take the wheelchair in but you have to stay downstairs. There is no access upstairs into the prayers room ...you have to pray downstairs with the microphones on... that is not how the case should be. We should be with the congregation and not on our own.'

'I can't ask my son to push me to church in the mornings. I am stuck because he can take me to church but can't bring me back... I'd like to go to church every week but if I can't get back from church I'm not going to go.'

Lack of transport and the public environment presented considerable difficulties.

'The roads especially when you are in a wheelchair – most of them don't have footpaths or crossings in the road. Some of the kerbs are about three inches high and there is no way you could take the wheelchair over that.'

'Sometimes the problem is the bus drivers who are so rude they don't even take the wheelchair, when you are waving your hand they just ignore you and drive away. Some of them are quite good and help you a lot. Some of the buses have ramps that don't work so you have to wait a long time.'

'Lack of transportation stops me from going out.'

'I have door to door [dial a ride] but don't know how many rides I am supposed to have before they say my tickets are done and I've used up all my rides.'

Both African-Caribbean and Asian carers talked about the difficulties of going out to use community resources.

'I struggle to go out because of having to look after my aunt and there are evening courses I would like to do.'

'If you are a carer you will need help personal care... help with transport, day trips and stimulation and integration as people [service users and carers] can just get left housebound and isolated.'

The cost of community resources was a deterrent for some carers.

'I'd like free swimming and Jacuzzi but can't afford to use them.'

'I'd like to use a sauna and steam room, as it is good for me. I could use it if I had more money.'

'Would be good to have complimentary therapy like aromatherapy once a month. It is expensive but they could come to the carers group at a lower cost.'

Asian carers stressed the need for public toilets.

'To be able to go out say to Queen's market (very popular community area) you need to be able to go to the toilet if you are old or caring for someone but the toilets are locked, even if you have a coin and can go in the toilets are dirty and there's no water.'

'We need to have good toilets so that we can go out and disabled people can go out. Some restaurants and cafés won't let you use their toilets or you can't get a wheelchair in. It is okay if you go somewhere that has a McDonalds but Green Street [a long street with lots of Asian shops, restaurants and community facilities] has only one set of toilets and they are dirty and you have to have a coin to get in.'

'Please don't forget to tell them in your report that we want toilets so that we can go out more.'

## Aspirations

One carer explained:

'I would like a more fulfilling lifestyle – maybe part time studying or a little job to get me out, but I can't leave \*\*\*\*\* [service user]. What would happen if something went wrong?'

One service user felt that he had been penalised for doing voluntary work.

'As far as work is concerned, some people are having a bad experience and I'm sure it's happening in other day centres as well. We've got a small shop [at the day centre]. I'm a volunteer ] in the shop two days until half past three. I go to the cash and carry and I always have a carer with me. I don't go on my own ... All of a sudden, I was told you don't need any help at the day centre, don't need any help at home and my services were taken away. So these are things and problems.'

'I wouldn't be able to do voluntary work unless I'm on direct payment maybe, or have a friend or carer to give me some support.'

Other service users felt there were very low expectations of them.

‘The moment you show some potential ... we live in a culture of having to degrade ourselves so that we get a helping hand.’

‘People have skills and they feel better if they’re doing something. They like to achieve things and have so much potential, and want to use skills at day centres... There’s so much to be done and a lot to be achieved.’

## Workforce issues

Two service users thought it was important to acknowledge the pressure social workers are under.

‘Basically I think that social workers are extremely under pressure and their caseload is so high so that they don’t have time to think of themselves and what they do.’

‘Social workers are inundated with cases and files. They are only given a certain amount of time to work with particular service users. Once they have done the assessment, its filed away. They are answerable to their line managers who have the final word, they haven’t seen you and they’re deciding by taking second hand information.’

## Qualities of a good social care worker

‘... I was very lucky I had a wonderful social worker for a few months – I didn’t have to ask for any help or anything. She used to tell me you need this you need that... she followed it through. I don’t want people to think that I think all social workers are bad. There are very few good ones. My old one would call me and ask me whether I am happy with this and this they all worked as a team very nicely. I was very happy. I got everything I required. Now some of the services I need I have to bang my head against a brick wall to get things done.’

‘For me the perfect social worker would be a caring person and understand the needs of the service user and follows it through with all the provisions and adaptations or whatever it is. They should go back to the service user and find out whether the service user is happy with what he or she has done so far, or has he or she missed out on anything if there is could you let them know.’

‘Getting the right attitudes for any job is important particularly in the social care industry. It can often be difficult to find the right attitude regardless of

how many skills somebody has. If they don't have the right attitude it's hard to get the quality.'

'How good a worker (social worker) is depends on the person because if they want to do the job and take it seriously as a duty then they will listen to what you say and try to understand.'

Carers described the skills in a social worker that were important to them.

'Different social workers within different teams do not have good communication between them so everything takes a lot longer... Communication between workers and with carers is very necessary.'

'Don't look down on people, be there to help, that is their duty.'

'Behave well and show respect.'

'Talk to me nicely because I am a person. She (social worker) should say things in the same way she talks at home to her family and friends.'

'Sometimes, social workers are not polite. I would like them to use different ways of saying different things to make us feel like they understand us.'

## Recruitment issues

One service user stressed the importance of recruiting the right managers.

'Instead of bringing management from outside who may or may not have experience of service users' particular needs if they were to promote from the bottom level upwards as they progress and get to the top they would know a lot more about the services and know a lot more about the needs... It would be a lot better than having a piece of paper that says they are qualified to do the job. The prime occupation of the managers now is to manage the department and nothing else, they should promote the people from the bottom level up gradually. That is what happens in London Transport.'

The recruitment of social workers from abroad was an area of concern.

'A lot of social workers coming from South Africa, Canada, Australia, Europe and other areas, they don't know the issues and they don't understand the system over here. It is a real problem.'

## Training for social care workers

The training that service users and carers identified as necessary, varied from basic social work skills to an in-depth understanding of how social care works.

‘How to be helpful.’

‘Training needs to be focused on information sharing and communication. There has to be good communication.’

‘When training they (social workers) should learn how to talk to a disabled person or an old person, especially if they are Asian.’

‘Social workers need to know how to control mood and habits so that they can speak without being angry and talk to you at your level.’

‘To be more understanding of people’s needs and then be empathetic. Put themselves in our shoes.’

‘Very important to learn how the system works and about all the rules and regulations.’

## Strategic issues

Making access to services easier was highlighted as a key issue to be addressed.

‘I say one thing and that is information. People don’t know what is there.’

‘They (council officers) send you to one office, when you get there your told no, no, no you have to go to this office, you go to the other office and they send you somewhere else. I don’t want to keep being sent here and there, I just want to be able to get help.’

Consultation and working with black and minority ethnic service users and carers was regarded as key to the effective development of social care:

‘My argument to management (of disability resource centre) is that you are providing a service to the service users yet when you employ the officers you never consult the service users, you never ask them to sit on the interview panel. Service users would be better to find out from the particular workers that they are going to employ whether they will be able to do what the needs are.’

Feedback and follow up on consultations was a source of frustration.

'They come and pick our brains basically and get ideas from all of us, but there's no follow up, they don't come back to you and say, look this is what we have done about your complaints. Nothing. Nobody.'

There was cynicism about how social services manage their budgets.

'Money should be spent fairly and equally and the money belongs to people who put it there. I would like to lead a decent life. It should spend on meeting people's needs. There are a lot of people and carers not getting money and it is not being spent wisely on the disabled who need it. I think it is being chopped up and given to whoever.'

'There are lot of people who have been waiting for years... many times when we go to meetings they talk about overspending. Why did they overspend because people are still waiting? . It must be all down to something... yet social services every year come February and March, they are spending money like water on unnecessary things like furniture in the offices, the reason is they want to spend whatever money they have this year so that the government doesn't cut it next year.'

'As you probably know with social services there's always a cut in services it affects the less unfortunate ones like us especially. The answer at the end of it would be we don't have the finance because our resources have been cut by the government.'

## Voluntary sector funding

All the carers, black and minority ethnic disabled people and Chinese elders stressed the importance of funding for community support groups like luncheon clubs and carers groups. There was a strong belief that not only did these groups overcome language barriers, offer mutual support, reduce isolation but that they were also the best sources of advice and information.

Emphasis was placed on the voluntary sector group's needs to have security of funding and support to develop other services. For example, homecare for Chinese elders was a high priority for carers and service users.

## Conclusion

The consultation exercise demonstrated (without a doubt) that black and minority ethnic service users (or potential service users) are not an homogenous group. The views and perspectives they bring are as rich and diverse as the communities they belong to.

It is impossible to draw out a consensual view on the green paper amongst black and minority ethnic service users (or potential service users) and carers although most participants agreed that eligibility criteria and gate keeping mechanisms made the current process of accessing social care services extremely difficult. Service users particularly wanted to drive home the message that home/personal care services were riddled with problems and were failing to meet their needs.

The principles of self-definition of need (with appropriate support), choice, direct payments and individual budgets (with appropriate support), participation in the community, focus on preventative services and provision of voluntary sector services were of great interest to people, although there was a degree of scepticism about how they may be implemented in practice.

Equally, there were clear ideas about how support and training for carers could be improved and workforce issues such as recruitment, social work training, promotion of front-line staff to management roles, and information sharing and communication should be addressed and improved.

Arguably, many of the issues raised are relevant to other indigenous groups of service users and carers. This may well be true, but the experience of racism, discrimination, poverty, language barriers, lack of culturally appropriate resources and limited choices severely exacerbates the difficulties faced by black and minority ethnic service users (or potential service users) and carers.

The green paper's proposals for promoting choice, independence and well-being could go a long way to providing appropriate individually tailored solutions for black and minority ethnic service users (or potential service users) and carers. The challenge for policy makers and practitioners is to hear what black and minority ethnic service users (or potential service users) and carers have said, focus on the practicalities of implementing the key proposals and ensure that this consultation is the beginning of an ongoing dialogue.

## Chapter 3: Refugees, asylum seekers and migrants

Facilitated, analysed and written by Nasa Begum, Principal Adviser on Participation,  
Social Care Institute for Excellence

## Summary of key findings

### Needs of refugees and asylum seekers

- The experience of trauma and fleeing their country of origin had a profound effect on the mental health of the refugees and asylum seekers interviewed.
- For some of the asylum seekers, the living conditions and circumstances they found themselves in exacerbated their problems. Boredom presented a major problem.

### Barriers to accessing social care services

- People didn't know how to access social care services.
- People were confused about what social care services could provide.
- Refugees and asylum seekers' social care needs were rarely acknowledged by local authorities.
- Different approaches were taken when responding to refugee and asylum seekers.
- Restrictions on entitlement to social care services for asylum seekers meant that they had to cope without social care support.
- People believed that they shouldn't rely on the state for support.

### Advice and information

- General Practitioners and other medical staff were important sources of advice and information.
- Refugee and asylum seeker networks were people's preferred routes for receiving advice and information.

### Sources of support

- Family members, including children, provided informal care and were a major source of support.
- Some refugee and asylum seekers were isolated and lacked support because they had no family or friendship networks.

- The Refugee and Asylum Seeker Social Support Group in East Suffolk (MIND and Community Refugee team project) provided an invaluable service to local refugees and asylum seekers with mental health problems.

## Self assessment

- The notion of completing a self assessment was very difficult to understand.
- The best people to identify needs were the refugee and asylum seeker networks people associated with.
- Professionals need to reach out to refugee and asylum seekers.

## Information sharing between organisations

- Opinions were divided about whether it would be helpful for organisations to share information.
- One third of refugees and asylum seekers thought it would be appropriate to share information.
- Confidentiality was seen as crucial.
- People were concerned about the potential impact on immigration status and support received if information is shared.

## Risk taking

- The idea that people might worry if refugee and asylum seekers who needed social care took risks was considered to be quite strange.
- Basic things like being able to wear traditional Muslim clothes were considered a risk.
- The risks people wanted to take were more linked to restrictions placed on them by their immigration status rather than limitations because of social care needs.

## Direct payments

- People struggled with the concept of direct payments for social care needs.
- Priorities for spending direct payments were based on basic needs such as food, transport, housing and so on.

- Views on who would be best to assist with managing a direct payment varied from wanting social workers to help, to thinking no assistance would be needed.

### Use of community-based resources

- Religious establishments were used both as a place of worship and support.
- The ability to use local amenities was limited because of language barriers, limited financial resources and feeling unsafe.

### Aspirations and interests

- There was a great deal of interest in using local resources like educational facilities, sports activities, parks and libraries.
- The opportunity to do voluntary work or to take up paid employment was important but often difficult for people.

### Workforce issues

- Various suggestions were made to improve social work training including addressing attitudes, importance of value and care, learning to really listen and changing behaviour.
- The need for a true commitment to the role of social worker was highlighted.

### Consultation in policy and service development

- Consultation in the development of policy and practice was not something the refugees and asylum seekers had done before.
- They strongly believed that professionals were not interested in the views of refugees and asylum seekers.
- Different methods of consultation were preferred – some thought group discussions were better, and others wanted face-to-face meetings.

### Priorities for service development

- For some people it was difficult to envisage having a role in service development.
- People requested a wider range of activities to do throughout the whole week.

- Secure funding and capacity building for support groups and the wider voluntary sector was identified as an issue.

### Knowledge of green paper

- None of the refugees and asylum seekers was aware of the existence of or proposals in the green paper.
- A volunteer raised concern about difficulties of being cost neutral. They argued that reorganising and restructuring services costs money in redeployment, training and redundancy payments. However, 'the concept of the green paper is a good one...'

## Sample

Thirty-two refugees and asylum seekers were involved in the consultation. Twenty-three submitted monitoring forms. The majority were from black and minority ethnic communities.

Fifteen of those who submitted monitoring forms were women and eight were men. The youngest person was 20. Twelve people were between the ages of 26 and 55, five people were between 56 and 65 and 5 people were over 65. Seventeen were service users and four were carers.

Two people used a care agency or home care and 13 had a social worker or social support service. Six were asylum seekers and 12 were refugees. Twenty used services National Asylum Seekers Support service and 19 used Refugee and Asylum Seeker Social Support group.

Two had been granted British Citizenship. Ten had a physical or sensory disability, 9 had mental health problems, 11 had experienced homelessness and only one had a drug or alcohol problem. Six people had one or more impairment.

## Method

The central issue in terms of consulting with refugees and asylum seekers who may require or use social care services was reaching them through networks or contacts that already existed. Existing networks and contacts were used partly because there would hopefully already be some form of relationship with an element of trust, also the practical difficulties of reaching service users (or potential service users) within a short period of time were enormous.

To identify an appropriate sample a number of different streams were used:

- contacts established through the Refugee Council
- direct work with the Refugee and Asylum Seeker Social Support group, a collaborative project between Suffolk Community Refugee team and East Suffolk MIND
- two refugee and asylum seekers groups already known to Newham's Black and Minority Ethnic Community Care Forum. Through this source access was obtained to a Somali women's health advocacy group.
- Source access was obtained to a Somali Women's Health Advocacy group and a local refugee and migrant project.

A strong emphasis was placed on reassuring potential participants about confidentiality and the fact there would not be negative repercussions as a result of their participation, particularly in relation to their immigration status or any support received. Nevertheless, there was a considerable degree of fear and reluctance to be involved on the part of refugee and asylum seekers approached through the Refugee Council. Seventeen people were asked to take part in face-to-face interviews or focus groups but ten people declined.

Reasons for declining to take part included:

- fear of repercussions if involved in consultation, particularly the concern that the minimal support received would be terminated
- dispersal to another location on the day of interview
- stigma around mental health problems and disability
- belief that 'it is a duty for every family to look after their own disabled people
- potential service user agreeing to participate but their carer refusing to allow this
- lack of childcare support (although SCIE would have reimbursed all costs)

- insufficient time
- confusion about what social care is and the distinction from benefit/food voucher services.

Contact was made with a Somali community worker (not in Newham), an Eritrean community work, an organisation of Latin American disabled people and a doctor who coordinates an older people's project. Unfortunately, the facilitator was unable to negotiate access to these groups for many of the same reasons outlined above. This meant it was not possible to consult with some of the newer refugee and asylum seeker communities.

A combination of face-to-face interviews and focus groups were undertaken. One of the focus groups was held with a Somali interpreter and three of the interviews with refugees and asylum seekers were conducted with an Arabic and Farsi interpreter.

The methodology used to focus the discussions was based on a semi-structured talk protocol (Appendix 3A) which covered the key areas that were relevant to refugees and asylum seekers. The protocol was designed around the Department of Health consultation themes and work done by the Valuing People team to develop materials to use in green paper consultations with people with learning disabilities. The protocol does not attempt to address every aspect of the proposals contained in the green paper. Much of the success of this green paper consultation depended on the ability of the facilitator to work from a point that service users and carers could relate with. Often this was a long way from the ideas and proposals contained in the green paper.

A note taker recorded the discussions. Tape recordings were sometimes made providing the service users (or potential service users) and carers consented. However, for some people the fear of being identified if the discussion was recorded presented a real problem, therefore detailed notes were taken. The notes and tapes were transcribed to give as accurate record as possible of the interviews and focus groups.

The majority of the data analysis was undertaken by manually identifying key issues and themes to emerge, and then grouping the views and opinions expressed.

A combination of direct quotations from service users (or potential service users) and carers, with commentary from the facilitator, has been used to describe peoples' concerns within the themes and issues raised. The priority has been to hear directly the voices of the people that were spoken to. The quotations chosen are the ones that best demonstrate a point and/or illustrate the theme described.

## Findings

### Needs of refugees and asylum seekers

The experience of trauma and fleeing their country of origin had a profound effect on the mental health of the refugees and asylum seekers interviewed:

‘I escaped because of fear in my country and had more problems (mental health problems) when I arrived here. I received news that family all killed. I don’t know what I want, don’t know what to do.’

‘When we (husband and two young children) arrived in this country I used to hope me and my husband would be killed so that our children could be looked after and be safe.’

A tearful asylum seeker said:

‘I really feel like I am in hell or prison. I fear of life. Oh my God help me I am going crazy.’

The predominant issue for the refugees and asylum seekers interviewed was that their living conditions and circumstances meant that they struggled with the basic necessities of life:

‘I need help with buying seasonal clothes. Look at me now – these are winter clothes and coat I have on, because these are the only clothes I have. I must look decent but it is very warm and uncomfortable and I have no choice.’

‘Didn’t even have money for a bus. Asked them to pay early once but they wouldn’t because my husband needed to sign something but he could not because he was in hospital. The consultant at the hospital had to write a note in the end to prove that my husband was ill.’

‘I think it would help being settled and able to access basic necessities not middle class. I am not asking to live like the Queen. For example they tell me to phone always if I want an appointment with my doctor. I have no mobile phone and even if I do have one I have no cash for the top up. People no longer use the public phones. Many are out of order and not maintained. One has to walk far in search of a public phone that is in working order to make GP appointment. Sometimes you end up fighting at the phone box because it is the only one working. I have no transport money so I feel isolated and idle.’

For some of the asylum seekers the living conditions and circumstances they found themselves in exacerbated their problems.

'I would like the cash allowance to be increased to enable me buy better quality of food. At present my choice for food is limited. I have cancer and now wear a permanent colostomy bag. If I eat wrong food I get diarrhoea and it becomes uncomfortable, as I have to change it regularly. The skin around the stomach becomes very sensitive and [I get] small wounds and infection. I have to be careful all the time.'

'I am depressed most of the time. I feel like running away because it seems nobody listens to me or give me even small money for transport. I am not a rude person but at times I can't help, things get on top of me, I appear to be rude to people because I am depressed and I am constantly asking for the basics.'

'I have so much time on my hands... when you are on your own, you create things in your own mind, it's important to have something to occupy my time.'

The Somali Women's Health group talked (through an interpreter) about the need for a good meal.

'A lunch club started about four weeks ago but what we need for the lunch club is food to eat. Social services say collect money, two pounds something but they (Somali women) are saying they haven't got enough money to pay so we are in difficulty in providing them with the food that they want to eat. The women have told us what they need for well-being is a good meal, hot food, and quality nutritious food for them to eat.'

Expectations about what support might be received were very low, this was particularly an issue for asylum seekers who felt that the messages they received was that they should not expect services.

'When you are in someone's country you are a beggar despite the circumstances you were fleeing from your own country. Also if you had a better life before you feel humiliated here by the way you are treated. Less than human. You are constantly begging, you either get or you don't, then you do not ask anymore.'

'At times when I am unwell I have not been able to go to the post office to get the weekly allowance. I end up borrowing money... tried to phone National Asylum Support Service to explain why I cannot collect money but nobody listen. They do not know how much we are suffering. Someone told me I have to be grateful for what I have got. I have been through hell. I

tell God I am going to die here... This week I should have gone to the post office but I have been unwell, so we have no food till Saturday.'

Boredom presented a major problem for the asylum seekers, it was something that interviewees were concerned about, particularly in terms of the knock on effect it had on their emotional health.

'I have a letter from the Home Office that I am not allowed to do paid or unpaid work so what can I do? There are severe restrictions on people like me ... I want to do anything to keep my mind working. To stay idle is like a torture in itself of a different form. I think this is even a human right abuse.'

'Feel stressed and alone. If I go back [to country of origin], there is nowhere I can go; my family have all been killed. I want to go back to nursing field, which was what I used to do. I feel very bored.'

## Barriers to accessing social care services

None of the Somali women (both refugees and asylum seekers) had any knowledge or experience of accessing social care services. However, they did use advocacy services and came together as a group under the auspices of health care services.

Lack of knowledge about how to access social care services and the somewhat transient lifestyle presented difficulties for some of the asylum seekers and refugees.

'I need advice and information on rights and entitlements and other sources of help. At present [due to physical impairment] I struggle to walk to the bus stop, struggle to get on and off the bus, queue at the post office until I reach my turn, it is very hard for me, I need help to cope.'

'It's not easy to do anything at present... until you get a permanent accommodation. We are constantly being moved. If you start an activity, you get moved and may have no money to travel back. It is very nomadic kind of life.'

For many of the interviewees and focus group members an acknowledgement of social care needs and service provision was extremely rare.

The different approaches taken to meet the needs of disabled asylum seekers meant that whilst living in one area \*\*\*\*\* received social services support but later when moved to a different area she lost the social care input.

'Files [social services] from where I used to live was not transferred. Had a community care assessment, needs were identified but \*\*\*\*\* social services claims they cannot provide the services.'

'I have cancer of the large bowel... I cannot be normal again. I do not get full support because I refused to travel to Newcastle. So National Asylum Support Service stopped to give me support.'

Similarly the policy of dispersing asylum seekers jeopardised the specialist input one family received. Their situation is described below.

\*\*\*\*\* and his wife came to the UK four years ago with their daughter who has profound and multiple impairments. They had been living in emergency accommodation in London for two years. On three occasions the National Asylum Support Services agreed that the family should not be dispersed because of the specialist services the daughter had linked up to, such as multidisciplinary learning disabilities team, Mencap, speech therapy, and she was on a waiting list for a specialist appointment to see a neurosurgeon.

Once again \*\*\*\*\* presented his case to the National Asylum Support Service but was told because he had failed to travel three times, he risked having the support terminated if he didn't go with his family this time. \*\*\*\*\*'s family had no option but to agree to being dispersed. Two years later the family have not had the care and specialist input transferred. Trying to negotiate with social services in the area they have been dispersed has been extraordinarily difficult and unproductive.

Restrictions on entitlement to social care services meant that for most of the asylum seekers interviewed accessing support was not an option.

'They say I am not entitled to the help because I am an asylum seeker.'

'Nobody come to see me to assess the situation. I am always going to them and telling them my about my problems but how could they believe without visit and seeing for themselves.'

'My social worker knows my problems but he is helpless. It seems there is nothing he can do although he knows what I am going through. He knows my needs. May be I need someone to check on my behalf what is happening.'

The belief that one should not rely on the state for support was the reason two of the interviewees did not seek assistance from social services.

'I am a mother and cannot give all my responsibilities to other people. I brought these children to this world.'

'My culture, we are used to looking after our own sick and old people. It is difficult to let go. For us it is like you are shifting your responsibility to others.'

'Only one of the asylum seekers had had contact with social services. Following a community care assessment, \*\*\*\*\* was provided with a home help and help with shopping. However, since then she has been moved several times and receives no assistance from social services.'

\*\*\*\*\*'s circumstances were as follows:

\*\*\*\*\* is a disabled woman with a 14-year-old daughter who goes to school and acts as her mum's carer. She is a failed asylum seeker waiting for her appeal to be heard and she is now eight months pregnant.

\*\*\*\*\* was moved to a flat with no disability access and she has to abandon her wheelchair in the flat. Her previous accommodation was accessible but she was moved because it was too expensive.

\*\*\*\*\* has no support available for when the baby arrives, although as a disabled parent she will need assistance to manage the baby. She explains:

'When the baby arrives I will need help. I cannot carry a baby. It is going to be a problem lifting, carrying and changing the baby. I cannot expect too much of my daughter...'

A failure to support this disabled parent is likely to pose significant risk to the baby, and possibly jeopardise the family unit.

Another asylum seeker with mental health problems received some support from a support worker who was provided by the Refugee and Asylum Seeker Social Support group.

Two of the refugee carers had received support from social services:

'Yes my wife and I get help from the social services because my 25-year-old daughter is disabled. As you know she has been disabled from when she was born. We had help at home – it was not a problem. When we used to live in London we were all right. We got dispersed to Liverpool nearly two years ago now. We have a house in Liverpool, which is adequate but there is no heating and hot water. My daughter is incontinent.'

For one of the carers her situation had got very desperate before she was able to get help:

'I am a single parent of two children who are autistic to different degrees. My son is 24-years old now, he has behavioural problems and he is difficult to manage. My daughter is now 14 years-old and extremely intelligent, that is also difficult to manage because whatever I do is never

keeping her busy... I asked for help but could not get any because they said I was at home so I should look after them. I agree to a certain extent but I think they do not know how difficult it is practically... my son is not patient, if he wants to go to the toilet and it is busy he will do it in the corner of the room... it is like in jail I cannot leave him unattended.

'He became violent several times and the police had to intervene and because I was an asylum seeker was told I was not entitled to help. This time he [son] threatened me so the police called an ambulance and he was taken to hospital for [psychiatric] treatment. Now I refuse to let him come home for fear of my life. He can be violent so I am afraid he might do something bad and I will not forgive myself. Social services said they did not have money to put him in special accommodation but they have taken him after a long struggle.'

## Confusion about what social services could provide

Several of the interviewees thought they had received help (particularly accommodation) from social services but they were actually referring to support from the National Asylum Support Service.

'Yes I get help from the social services. I have a room in this hostel and £25 weekly allowance.'

'... I get help with this room and I share the kitchen with others. I get £25 vouchers for my food weekly. That is all.'

## Advice and information

Apart from the few people who had tried to access social services no one knew about the existence of social services, their role or how to make contact.

Four of the Somali women had acquired disabilities as part of the ageing process, although they were elderly women who were likely to be entitled to a community care assessment, throughout the green paper discussion group the women asked how they could get in contact with social services and what sort of services could be provided. The main source of advice and information for these women was the Somali Women Health Group.

The general practitioner or other medical staff were an important source of advice and information for some of the refugees and asylum seekers:

'No one was there to help us.... We really needed friendly people to talk to. We did have a doctor who was very helpful. We were both feeling very depressed and did not know what was wrong, we tried one GP but he did not understand us. When we found this doctor, he understood us and gave us anti-depressants and we felt a lot better. Told us about counseling and MIND.'

'The doctor and psychologist recommended it [MIND] to me. Very good idea.'

'I get lots of support and help but not from the social services. I get help from the Suffolk Community Refugee team and the Refugee and Asylum Seeker Social Support group. I get help from the housing association. Found out through the GP about the Suffolk Community Refugee team.'

When asked about their preferred route for receiving advice and information, the interviewees were unanimous about the refugee and asylum seeker networks as being the best source.

'The Refugee Council gives balanced advice, at least that is why I keep ringing... They will always tell you the truth even if it is bad news.'

'I get help from the Refugee and Asylum Seeker Social Support team and MIND, I ask them if I need anything.'

'Refugee and Migrant Project is doing a good job and has introduced me to many services such as Citizens Advice Bureau, physiotherapy and benefits for my health.'

'I will ask from \*\*\*\*\* Council, they are very supportive to Citizen Advice Bureau or us.'

One way of improving advice and information stressed by the Somali Women's Health group and the people from the Refugee and Migrant Project was that social workers visited the groups that they were part of:

'... come here and work in the local community... for us to get someone out (to group) to speak about all their services, then tell us about the changes and say what they can do for us which would help our needs.'

'Would like social workers to do more with Refugee and Migrant Project, come here and improve the way they work with us.'

'... Like people from social services to come here and tell us here how they can help with our problems.'

## Sources of support

One of the asylum seekers interviewed relied on her fourteen-year-old daughter for support:

‘At present I need help with shopping because I am very restricted [seven months pregnant]. I would like someone to help. I am experiencing pains, swelling in my joints. My daughter helps a lot... sometimes she rings from school to check if I am OK. When she returns from school and finds me in bed she goes straight to ask me if I am all right. Like today when she finishes her exams early she will come straight home. She is a good girl but you know she is a teenager now and she has exams.’

None of the older Somali women believed they could get help from their families. One woman explained:

‘Being a single parent has limitations. My children are still in school. And even if they finish I don’t think they want to be at home. They have their own lives.’

Most of the asylum seekers who did not have children had no informal networks of support as they had no family or friends in this country.

For those who had formed relationships, the practicalities of lack of transport, insufficient money, accommodation problems and the likelihood of being dispersed meant that sustaining links with friends became very difficult.

‘If I can go to them (friends) we talk together sometimes and share food or go places together. But I am not able to do that because they all live in the other side of London.’

‘, I cannot do anything. Very few friends know I am here. They cannot always come to me because my room is small. We cannot sit in the Kitchen because it is always busy. They do not know that I am unwell and taking medicine. You see if I take the medicine I feel sleepy, if I do not take the medicine then I feel depressed and have bad dreams.’

‘... My community here in London know us well and sometimes help us out. But in Liverpool we do not have similar community. We have to look for them and even then starting all over again takes time. We do not want people to think we are making friendship with them because we need their help. So we keep ourselves isolated.’

Six of the refugees and asylum seekers with mental health problems used a group run one day a week jointly by Suffolk Community Refugee Team and East Suffolk MIND.

This social support group was specifically designed for refugees and asylum seekers with mental health needs. A significant number of people registered at Suffolk Community Refugee Team experienced and displayed symptoms of mental distress. If these difficulties are assessed and viewed in a cultural, religious and socio-economic context, it is relatively easy to conclude that the difficulties are complex. However, these people do not usually meet the 'severe and enduring mental illness' criteria, which is the gateway into specialist mental health services. It is with this premise that Suffolk Community Refugee Team and East Suffolk MIND have focused on delivering specific, targeted primary mental health care services by developing the Refugee and Asylum Seeker Social Support group.

The support provided by the Refugee and Asylum Seeker Social Support group was something all the interviewees spoke very highly of.

'... didn't feel any better until we (both husband and wife have mental health problems) started visiting MIND and then felt like a different person. Everyone was very welcoming, felt very comfortable; let us talk about what we wanted to talk about. We found similarities with other people and my husband started to smile.'

'... the group here is a good idea. If you talk to someone who does not know you, it is hard for them to understand you, but if people know my problems, it is a lot easier. It would be good for people with the same issues to share their problems more.'

'MIND is my community, I feel comfortable and confident here.'

Two of the interviewees at the Refugee and Asylum Seeker Social Support group talked about Thursdays (the day the group meets) being the highlight of their week.

'I am very happy on Thursdays. I have made friends here and I look forward to coming every week.'

'I enjoy coming and feel sad when we go home because it is a long time before we can come again... there is nothing to do during the other days.'

'... It's good to be with people, eat and play games... you can forget problems and relax here.'

## Self-assessment

For all the refugees and asylum seekers spoken to, the notion of completing a self-assessment was very difficult to understand. Only one person had had a community

care assessment and she felt that a social worker or other professional was the best person to do it.

‘I can’t fill in forms and I don’t know what you have to say. I need help from an expert so they put things properly.’

The other refugees and asylum seekers thought the best people to help identify their needs was the groups and refugee networks they associated with. Professionals, like social workers, need to reach out to refugee and asylum seeker groups and work with them to assess people’s needs.

### Information sharing between organisations

People’s opinions were very divided between whether it would be helpful if organisations shared information about service users and carers between themselves.

A third of the refugees and asylum seekers interviewed said they did not mind if information was shared.

‘No objections to that [sharing information], it was very frustrating saying the same thing over and over to different people.’

‘I am telling people my problems. It is alright to share because I need help.’

For other refugees and asylum seekers, there were concerns about negative repercussions if information about them was shared. Confidentiality was crucial.

‘You see I am grateful for the little help I get otherwise I will be homeless. To be homeless here is very dangerous especially for me as a black person. I may get abused. So I am afraid it [sharing information] may cause problems even if you said it’s confidential, still you never know. I really want you to understand that I am grateful. This is not my country I should be thankful for what I get’,

‘I am happy to tell the doctor about my mental health problems, but there are things I wouldn’t tell other organisations about me.’

A volunteer at the Refugee and Migrant Project voiced the dilemmas for some refugees and asylum seekers when information is shared.

‘... because we’re working with people in contact with immigration control and social services have an obligation to report to the Home Office, with regards to information sharing this could affect someone’s legal right to remain and can be very damaging.’

## Risk taking

The idea that people might worry about risks service users were taking appeared to be quite strange to them, as they believed apart from family members no one would worry.

'I don't know, I don't think anyone worries about me except my daughter. She always worries about me.'

'I don't think anyone worries about me. Why should they worry about me? ... perhaps because I am depressed and rude sometimes they fear I may become violent and harm myself. Sometime I feel it is a better way out of here. I feel like that at times. What is the point of living in such a state?'

'There is only one person that worries about me, she is called \*\*\*\*\*, she is a nurse. She comes to see me often but she cannot do much because I am not entitled to many things until I receive a positive decision from the Home Office.'

'I don't have family or relatives here who will worry about me. The Government should worry about people like me but who is the Government here? It is the health and social services. They don't worry about me.'

One of the men who is an asylum seeker thought that wearing traditional Muslim clothes was a risk he could not afford to take. He said:

'I would like to wear my own traditional clothes but you have to follow the tradition of wearing the clothes of the country that you are in... [Probe why?] Because you have to fit in and if you wear your own clothes people will know you do not belong here... if someone in the street sees you they will swear.'

For another asylum seeker there was very little option but to take a risk with her children's lives, she said:

'My husband was in hospital and did not trust anyone. He wanted me to stay with him. I used to lock the girls [both under 10] in the house overnight and pray everything would be okay whilst I was at the hospital.'

The risks that refugees and asylum seekers wanted to be able to take were more linked to restrictions placed on them because of their legal status rather than being about limitations because of their social care needs.

The ability to occupy time and feel as though they were making a contribution was very important for a number of asylum seekers. Two women spoke about wanting to be able to help others.

‘I would like to start a support group for mothers in my position (carer).’

‘Interested in being a foster parent, started the assessment but found out I cannot foster because of my depression medication.’

‘I go to the Refugee Council Women’s group... we talk and share experiences also I like helping them in volunteering work.’

For other people education and employment were important.

‘Thought would have a carefree life, get education, knowledge and cultural understanding. Would like to know what education can offer me. Would like to learn English but didn’t get help from anyone.’

‘Would like to learn a profession for a job and for my future. Would like to paint. Went to college for an interview but they said that they didn't have a place, I was sent to another department and again they said that they did not have a place. Four or five people got in after me; I think they were being racist.’

‘I have completed my computer training and I would like to work.’

‘I wish I could find proper work. I worry because of my wife she looks after my daughter... She is a talented woman; if she could go out and do something different for a change it would be really helpful. We have to keep asking and asking.’

## Direct payments

Given that very few refugees and asylum seekers were receiving social care services it was not surprising that they all struggled with the concept of direct payments for social care needs.

In terms of what people’s priorities would be for spending a direct payment on, essentials like food, transport and housing were high on people’s lists.

‘Use it to help with daily needs like food and bills.’

‘I would spend it on childcare.’

'... bus pass. [Probe anything else?] No just a bus pass will be helpful. I am not well at present; if I have a bus pass I will visit some friends.'

'We need to have food instead of money.'

'Spend money on sporting activities.'

Two of the women (one a service user, the other a carer) did identify how they would like to spend a direct payment on social care.

'I would spend the money on home help, childcare and shopping. Buy a care adapted to my need so I can be independent to do my shopping, have some privacy. Oh God!'

'... use money to help my son. At present I have to go and help him, sometimes he does not eat and nobody gives him food or he doesn't want to eat. I feel he is not looked after properly. Everyone is busy [at the residential home] so I need to go there often to make sure he is clean and fed.'

Views on who would be best to assist with managing a direct payment ranged from feeling that social workers would be best placed, to others who thought that no assistance would be needed.

'Don't think I will need help I should be able to account for the money and perhaps learn the system here so I don't make mistakes.'

'I am managing finance, I think I should have no problems.'

'People's circumstances are different. I am able now – I would prefer to manage it. Sometimes family members can mismanage money, this bring a lot of trouble and split up. I would not want this to happen because of money. It will spoil relationships forever and I cannot afford to lose that because of money.'

'I would like the social worker to handle the money because sometimes he knows my daily needs and can take time to see what I need.'

'Sometimes I would prefer the social worker to look after it as I don't know about the different services that are available to me. Sometimes I would prefer to keep it myself.'

## Use of community resources

A lot of the refugees and asylum seekers used religious establishments both as a place of worship and support.

The Somali women's group explained:

'... the Christian group helps us to get help with learning language, teaching about citizenship, an access group and providing food.'

'I would like to go to church but now it is difficult because I can't walk there and have no money for transport.'

'Going to the mosque is very important. See lots of different nationalities and have good relationships with people.'

'Very religious but do not go, as I don't know if there are any places? I pray at home.'

Caution needs to be exercised about the assumption that religious establishments are helpful. One asylum seeker said:

'My family used to be very religious. I was treated badly in my country and feel that I don't want religion anymore.'

Being able to use local amenities was a barrier for some refugees and asylum seekers.

'Would like there to be more shops and a park. It's a bad area where I live and I am too frightened to let the children out.'

'Language is a problem because I cannot speak English I do not know what to say in the shops and can't take children to library or anywhere else because I do not understand.'

'I play football, go to park. Don't have anything else to do.'

## Aspirations and interests

There was a great deal of interest in using local resources.

'I like education, library, park, playing football.'

'We [family] go to the library, go to the park, walk round... it is a problem when it is raining or cold as there is nowhere to go.'

'... like to finish education and get certificate, would develop myself and would be able to pay for college fees. My hobbies are football, reading novels, going to the library, using the Internet, and watching TV. I like to keep myself busy.'

'... would like to go on holiday but cannot as haven't got any money.'

One of the asylum seekers had been training as a nurse in his home country and he was very keen to be able to continue his studies.

'Need to think about future... I do not want to deviate from nursing course but the language barrier is difficult so would be good to learn English.'

One of the refugee women who had just been granted British citizenship talked about the voluntary work she did.

'I love being with children. I am a volunteer at \*\*\*\*\*, I help with looking after the children one morning a week... I would like to do more things, maybe one day I will get a job.'

'If there's no job I would like to open up a shop but I know it's difficult because of language barriers.'

## Workforce issues

Only five of all the refugee and asylum seekers interviewed talked about improving training for social care professionals, particularly social workers. They suggested the following should be included in training:

'Would be a good idea for them to visit us to see what kind of people they are working with.'

'A change of behaviour.'

'Attitudes towards clients and how they care.'

'To teach the importance of value and care.'

'Learn to really listen and care if people need help.'

Commitment to the role of social worker was a very important issue, as one woman explained:

'I know we are not eligible for everything as asylum seekers but I want to suggest that the training of the social services staff has to be as they train

the army, to have your country and die for it. [Probe what do you mean?] I mean to have a serious commitment to work as they do in the army. And there should be a watch dog for social service work.'

## Consultation in policy and service development

Consultation and participation in the development of policy and practice was not something the refugees and asylum seekers had done before.

There was a strong belief that professionals were not interested in the views of refugees and asylum seekers.

'They don't listen they are too far away from us. Even if we say our views it is not always possible to get services. I have been like this for nearly three years. Is it right that I do not get service because I am not a refugee? The papers take so long. In the mean time I have to live in bad conditions. By the time my papers come from the Home Office I will be a dead person. Not fit for anything good in life at all, sorry.'

'At present nobody is listening, as if I am not a person, may be a foreigner and do not speak English like him or her so it is a problem putting my message across but I am a learnt person. I went to university and have skills in many things but here I cannot help myself because of my children. And of course the system is very restrictive here to refugees and asylum seekers.'

The fear of negative consequences of taking part in consultation exercises and not appearing grateful for what one has presented a major problem for some.

'Please do not mention my name... I am a refugee in this country and my right is not the same like British people. There is bad news about refugees and asylum seekers in the UK. So if you say something may be they will think I am not thankful to them, I mean social services and Refugee Council.'

Those who were more comfortable about being involved in consultation work had mixed ideas about the best way to do this.

'...if they can listen and talk face to face to us. I think they do not believe us sometimes so they could talk to Refugee Council about our condition or visit to see with their own eyes.'

'Communication is good but do not want to talk in meetings.'

'If had meetings with everyone who comes it would work. Need to feel confident enough to give a suggestion. Integration is very important. Always give respect; everyone has a right to give their opinions.'

Feedback on the findings and outcomes of consultation exercises was raised as an area of concern.

'If I give a suggestion - is it going to be listened to?'

'By asking, like now. I have been asked many times but I do not know what the outcomes of all these research survey are.'

The fact that the facilitator went to the refugees and asylum seekers rather than asking them to travel, was seen as very helpful.

'It is good to ask like now when you ask I feel you care but when nobody asks I feel on my own and that nobody cares at all. I feel frightened.'

The Somali interpreter explained:

'... They [Somali older women] are happy that you have come to help to solve these things, you can see from their face how happy they are that somebody's talking to them about their life.'

## Priorities for service development

A lot of the refugees and asylum seekers found it difficult to envisage having a role in developing services. However, some spoke about the services they would like to see developed further.

'... would like there to be more centres [Refugees and Asylum Seeker Social Support Group at East Suffolk MIND] like this one and work with people. It is one of the best things to be able to exchange ideas, make friends, play, and eat. I want friends as well as my family and I need money. I want to feel respected.'

'... would be good if there were more things on different days of the week... once a week is not enough.'

'... would be better if there were more games [at the Refugees and Asylum Seeker Social Support group].'

The Somali older women wanted to:

'... meet together more, go on religious tours or trips and stuff like that.'

Funding for support groups and the wider voluntary sector was raised as an issue for building their capacity to respond to the needs of refugees and asylum seekers. The volunteer at the Refugee and Migrant Project explained:

‘I think social services have such a high workload and the government has problems with funding in the voluntary sector. There needs to be an evaluation and more intervention and funding in the voluntary sector.’

If this (green paper) is to be delivered on cost neutral basis the danger is and what’s already happened is that services that are provided by non-statutory agencies have low rates of pay and long working hours and not very good working conditions. My fear is that we are going to deliver this service and what’s going to happen is vulnerable sectors of the workforce will be exploited which is bad for services. For example, families are on a long waiting list for food aid, there is no funding for more resources, it is difficult to get forward, and there is a lack of access to public funds.’

## Knowledge of green paper

None of the refugees and asylum seekers spoken to was aware of the existence or proposals in the green paper. The only information people had about the green paper were a very short summary prepared for the consultation by the facilitator.

The only person to have a view on the green paper was the volunteer at the Refugee and Migrant Project (RAMP):

‘I am a volunteer with RAMP, 53 years old and past carer and practitioner. The concept of the green paper is a good one, but I think it is about enabling people with a variety of social care needs to determine what they get from their own budget.’

‘The bit that worries me and is absurd is the cost neutrality of new concepts and development which is dangerous considering the size of the population in need of social care is growing at a potentially rapidly rate to for a much larger user population. I think the aim is to shift focus from residential to extra care but it’s not cost free. It is good to enable service users to live in own homes but people with terminal conditions will need high care residential services. If you reorganise and restructure the services that are under stress, it costs money in redeployment, training, and in redundancy payments.’

## Conclusion

The overwhelming issue to emerge from the refugee and asylum seekers consulted was that their starting position for accessing services was very different. A major concern for this group was that some of their basic human needs such as food, appropriate accommodation, social contact, transport and so on were not being met. Immigration, social policy and political discourse about refugees and asylum seekers had a profoundly detrimental effect on people's options for having their social care needs met.

The principles of independence, well-being and choice were very applicable to service users (or potential service users) and carers from refugee and asylum seeker communities. However, the reality of their lives often meant it was very difficult to envisage how self assessments, direct payments and individual budgets, independent living and opportunities to take risks and have someone who was concerned about the risks taken, was very far removed from what refugees and asylum seekers understood and experienced.

Networks and support groups for refugees and asylum seekers were a vital source of support, advice and information. However the people consulted said that it was very important that some of these were targeted at service users (or potential service users) and carers so that they did not have to worry about stigma associated with disability, mental distress or requiring social care support.

Refugees and asylum seekers may not have used the language embodied in the green paper, but they were clear about the type of assistance that would help to promote respect, dignity, safety, choice and control. The ideas put forward have implications for policy and practice. Perhaps one of the greatest challenges posed is for the Department of Health and the Home Office to work collaboratively to improve support and access to social care.

## Chapter 4: People with severe learning disabilities and/or communication impairments

### Summary of key findings

#### Exercising choice

- All of the service users had a clear idea of what they liked doing and the choices they liked to make.
- Being able to go out, particularly shopping, was very important to all the service users.
- Choice within the residential service was promoted in a range of ways from deciding which activities to do, to choosing whether or not to clean their bedroom.
- Making resources accessible enough (including using multimedia) for the individual was crucial in promoting choice.

#### Decision making

- There were a number of different ways that the residents were involved in decision-making, from using communication symbols to having their own bank account.
- One woman talked about wanting to be able to make more decisions for herself.

#### Advocacy, independence and choice

- The concept of exercising choice and having independence is just as important in a residential setting as anywhere else.
- For people with severe learning difficulties and/or communication impairments, support from advocacy services and self-advocacy training is vital.

#### Independent living and risk management

- Risk taking was a big issue for the women with severe learning disabilities.
- Staff in the residential service balanced the need for independence and risk management with a very practical approach.

## Independence and risks (chances) service users wanted to be able to take

- For some service users, the idea of doing or trying new things needed to be introduced and tried out in an experiential way.
- A desire to increase independence was expressed, although the language of independent living was not used.

## Person-centred planning

- Some service users had heard of person-centred planning and thought that they had been part of the process.
- Staff at the residential service used a variety of approaches to enable residents to take part in person-centred planning including use of multimedia and involving people who know the resident well.

## Community resources and participation

- Going out and using local amenities were top of the agenda for all the service users.
- Service users living at home were very dependent on family members to enable them to get out and be part of community activities.
- Service users who lived in the residential service had a much more active lifestyle and were very engaged in using facilities in the local community. They also retained a lot of contact with family members.
- Changes in funding regimes for support groups and the arrangements for offering college courses had a detrimental impact on the opportunities available to service users.

## Sample

Fourteen service users were involved in the consultation. Twelve submitted consultation monitoring forms.

Ten were from black and minority ethnic communities, one described themselves as Western European and one person described themselves as being White British.

There was only one person with mental health problems in the sample.

The oldest person was 46-years old and the youngest was 21. Slightly fewer than seven of those who submitted monitoring forms were aged between 36 and 45.

A third of the sample used day services (including voluntary sector provision), the majority used residential services (primarily because a residential service provider had been targeted), three were in supported living accommodation. One woman had a dual diagnosis of mental health problems and severe learning disabilities and four people had severe learning disabilities, communication impairments and what some may describe as 'behavioural problems'.

## Method

It was not possible to do one-off focus groups or interviews because of people's access needs. Therefore, an approach of doing repeated visits to build a rapport with service users was taken. The protocol used was very loosely based on the work done by the Valuing People team to develop for use in green paper consultations with people with learning disabilities. However, this green paper consultation had to be conducted on the basis that the facilitator had to work in a way that service users could relate to. This was a long way from the ideas and proposals contained in the green paper.

The group of women with severe learning difficulties met on two consecutive occasions. Discussion about the green paper or wider service development issues was very difficult for the women to engage with. However, they were very clear about the things that really mattered to them.

A provider of residential services was approached in order to try and reach a group of service users who had communication impairments and severe learning difficulties. A total of five one-hour visits were made over a period of eight days to work with four residents who had very high level support needs. It was not possible for these residents to engage with the ideas in the green paper. However, through a process of observation and communicating at an appropriate level, it was possible to obtain valuable information about the choices they liked to make, activities they enjoyed doing and their participation in the local community.

The manager and deputy manager of the residential service were also interviewed to provide information on issues such as promoting choice, residents' access requirements and community engagement.

Notes were taken from the discussion and observations. A tape recording was made of the interview with the residential service manager and deputy manager. The data was written up to give as accurate record as possible.

A combination of direct quotes from service users and staff, with commentary from the facilitator has been used to describe views and opinions expressed. The priority, wherever possible, has been to hear directly the voices of the people that were spoken to. The quotes chosen are the ones that best demonstrate a point and/or illustrate the issues raised.

## Findings

### Exercising choice

All of the service users had a clear idea of what they liked doing and the choices they liked to make.

- ‘ Games and snooker.’
- ‘ Television.’
- ‘ Coming to the group [women’s group].’
- ‘ Holidays.’
- ‘ Collecting cars [miniature].’
- ‘ Cooking potatoes.’
- ‘ Dancing.’

The one thing that service users talked about repeatedly and were obviously very enthused by was ‘shopping’ and ‘making shopping lists’. This was the main focus of both the women’s group discussions and the visits to the residential service. Being able to put things on the shopping list was a decision-making process service users could really engage with. An important part of going shopping was the opportunity to have ‘cake and coffee’, ‘lunch’ or some other refreshment activity.

Staff explained how choice could be promoted within the residential service.

‘On a day-to-day basis, we use a lot of accessible information to support choice to enable people to make informed choices around activities around meals, generally on a day-to-day basis, and around communication. People have had a relatively recent speech and language assessment so we understand what methods are useful for that individual person, rather than using a blanket approach. You need flexibility obviously. If someone doesn’t want to do something, they don’t have to obviously. With activities, people may want a taster session rather than saying, you know join this course and you are there for six months. It is more about what that person wants. It may not be right for them. Its more about experiential learning, and that can inform the choice for the individual.’

Making resources accessible enough for the individual is crucial in promoting choice.

‘Multimedia very important, using digital cameras, photographs. So this is what we are working on... person-centred access support. That is around providing the resident with enough support to participate in whatever they need. It’s working in an enabling way, rather than working in that old style model.’

## Decision making

There were a number of different ways the residents were involved in decision-making:

- menu planning: choices made through use of pictures, making shopping lists and going shopping
- one resident bought her own food
- deciding resident activities
- choosing not to take part in activities
- using communication symbols
- looking through holiday brochures to pick holidays
- having own bank accounts and signing them themselves
- one of the women from the women’s group wanted to be able to make more decisions for her self.

One woman said:

‘ ... other people make decisions, I wish I could do it myself.’

## Advocacy, independence and choice

The concept of exercising choice and having independence is just as important in a residential setting as anywhere else. For people with severe learning difficulties and/or communication impairments, support from advocacy services and self-advocacy training is vital.

One woman living in a different residential service said:

‘... don’t like other people who live here... some staff are all right, some awful, bad attitudes... I want training how to say things so people will listen.’

Within the residential service where the bulk of the consultation work was done, staff explained how they work to promote advocacy, independence and choice:

‘... around advocacy and independence and choice, there are residents’ meetings twice a month. They contribute to the agenda and also we let them know what developments there are in the house like recruitment. If there is anything they want to ask. The residents live here so they decide what happens here along with the staff. Every other month we have someone to facilitate one of the residents’ meetings from People First. We are not involved in that. That brings up lots of issues. That is really valuable to us.’

## Independent living and risk management

The discussion about risk taking (other people worrying) appeared to strike a chord with the women in the women’s group. Risk taking was a big issue for them.

‘They [family] worry if I’m safe when I’m out late and come home late by myself.’

‘ Sometimes can’t do things because other people worry.’

‘ They [supported living staff] shouldn’t be worried.’

‘ If they [people who worry] were who I am they wouldn’t worry.’

‘ We all like to try new things, make lives in different place. Should be able to take chances without people worrying.’

For the staff in the residential service, balancing the need for independence with risk management needs was tackled with a very practical approach.

‘ Making sure somebody [staff] is with them [residents]. One of the women, she makes pasta. One of the things that she had never been taught was food hygiene but teaching food hygiene and also teaching cooking is too much, she may become distracted. So it’s teaching about that responsibility. So she might need to turn the cooker off... having a teaching plan is one of the things that we have got in place at the moment. To increase her independence and competence around cooking includes talking to her about some of the skills that are involved.’

With another resident, who in addition to her learning disability and communication impairment used self harming behaviour when anxious or distressed, it was a matter of very gradually introducing the idea of doing a college course, letting her visit, and try it out so that her anxiety and self-harming behaviour reduced.

## Independence and risks (chances) service users wanted to be able to take

The service users in the residential service could not grasp the idea of doing or trying new things. The priority for them was to be able to do more of the activities that they enjoyed.

For the other women, a desire to increase their independence was expressed, although the language of independent living was not used.

For one woman who had a teenage daughter looked after by the local authority (to whom she had supervised access), living together was what she wanted.

‘ I want to stop having to be supervised with \*\*\*\*\*, want to see her on my own and get right help to have a flat with a bedroom for \*\*\*\*\* and bedroom for me’

A woman who had a learning disability and mental health problems wanted to move out of her residential home and have more privacy.

‘ ... Want to be left alone and control anger better when angry... have some help to move out... I got a letter saying I was well.’

Independence and risk taking was not just seen in terms of support to live independently, but for one woman it was about being able to travel abroad.

‘ ... like to go to different countries like the Dominican Republic where I was born. I’ve been here (England) since I was six.’

Other service users wanted to be able to go out more, particularly to the beach, holidays, dancing and out with family.

## Person-centred planning

Three of the service users in the women’s group had heard of person-centred planning and thought that they had been part of one.

One woman explained person-centred plan as:

‘ ... It’s when you are in the middle and draw a big circle, you put in it all the things you want and people [professionals] talk about the help you need.’

Another woman said:

‘ ... You go inside the room and tell your worker what should be in it [person-centred plan], then you talk about things and decide what to do.’

The staff at the residential service used a variety of approaches to enable residents to take part in person-centred planning.

‘ Again, it does vary... gathering information from the individual, one to one discussion with key workers and that. People that know them well. Also with family members, people that know them well, people at the day service. We get an informed choice. But we are also aware that we need to increase our skills around multi media. We have now got a digital video camera... we are doing a piece of work at the moment with one of the residents building cooking skills. We have got baseline assessments there to see what techniques are best. What accessible information we need to work with her to enable her to cook with minimal support. She is quite competent. We have got that on video as well so that all staff can learn from that and support her in the way that she needs to be supported to do something. So there is a lot of work around.’

## Community resources and participation

Going out and using local amenities was top of the agenda for all the service users. Some of the service users living with their families engaged in activities (like church, gudwara, weddings, birthday parties) with family members and family friends. Independent activity in the local community was not an option for service users living at home, and friendship circles beyond family contacts were unheard of. Most of these service users’ friends were established through contact with services.

Interestingly, those service users who lived in the residential service had a much more active lifestyle and they were very engaged in using facilities in the local community. For example, the residents regularly used their local pub and had done so for years – the proprietors and other customers knew the residents well and responded appropriately to their needs.

Two of the residents were regular churchgoers but on the two Sundays the facilitator visited, they had made a decision that they did not want to go. This reflected a very clear commitment within the service that taking part in activities was not a requirement or obligatory – the decision whether or not to take part in something was entirely the service users’.

In the residential service a wide range of community resources were used: from church based art groups, to voluntary sector day services, to the local park, to meetings with a user-controlled organisation called People First (and Black People First) to local cafés, aromatherapist, hairdressers, banks, shops and so on.

Changes in funding regimes and the arrangements for offering college courses did have a detrimental impact on the opportunities available to service users. Staff explained:

‘People here use the amenities in the area. Hairdressers, dentists, GPs. People have been doing that for a number of years... I have seen a difference in college places... there’s been an increase of people wanting to attend college but there aren’t enough spaces. There are more applicants for the college places but there are fewer opportunities for people to attend college. And to go on courses that they would enjoy. Like NVQ1. The other thing that has happened in the last year or so is a few of the women go to a women’s group and eat out and meet other women. They have got friends and they pop out in the evening and do other sorts of activities and have education. They [women’s group] have lost their funding so that the people here are not able to go and meet their friends and that sort of thing. I think it’s more about user groups at evenings and weekends.’

Importantly the service users who lived in the residential service retained a lot of family contact. For example, one woman regularly went to stay with her mother at weekends and others had frequent family visitors or they went to visit family members accompanied by staff.

Staff explained the involvement of family members:

‘ They (family) are very much involved. We have regular relative’s meetings. They don’t have to make an appointment. They come in and see their sons and daughters regularly. Or we go and visit them or support to visit other family members. They contribute a lot also.’

## Conclusion

All the service users with severe learning disabilities, including those with communication impairments, had a lot to say about the choices they like to make, what they enjoyed doing and participation in decision making. Many (but not all) needed support to exercise choice, try new things (take risks) and use local amenities.

Accessible communication methods, support and investment of time would enable even those who may be considered to have profound and complex needs to be central to the decisions made about their lives.

In many ways it could be argued that those who lived in a residential provision had a better quality of life with much wider opportunities and very active lives. This raises questions about how sufficient support can be provided to those living with families, with supported living arrangements and living independently so that they can enjoy a similar quality of life.

The consultation did not yield answers to the specific ideas and proposals embodied in the green paper. Nevertheless, a lot of the views expressed by both service users and staff strike a chord with the themes in the green paper. The challenge remains how the philosophy of independence, well-being and choice can be put in place to improve the lives of people with severe learning disabilities and/or communication impairments.

## Appendix 1: Glossary of terms

### Hard to reach

The term 'hard to reach' can be taken to imply the individuals included in this category are of their own volition difficult to engage, rather than that their disengagement is a result of agencies' failures to proactively seek out their inclusion. In the report therefore, when the term is used, we are not implying that it is the individual who needs to change but the way they are approached by agencies. Further, many people in the disability and service-user movements favour the term 'seldom heard'. Therefore the two terms 'hard to reach' and 'seldom heard' will be used interchangeably through out the report.

### Homeless people and people with chaotic lifestyles – with multiple substance abuse and mental health problems

This is a rather cumbersome term covering a very wide and diverse range of experiences. There can be significant linkage and crossover between these various experiences. However, not everyone who is homeless misuses drugs or alcohol or indeed has mental health problems. Some people live extremely chaotic lives but nevertheless manage to remain in relatively stable accommodation. However, the terms 'homeless people' and 'people with chaotic lifestyles' will be used as shorthand to describe participants who have experienced one or more of the categories listed.

### Black and minority ethnic

The term 'black and minority ethnic' covers a diverse and very loosely related group of people. People of African Caribbean and South Asian origin are the groups that are predominant, especially the latter. Yet continued migration to the UK involves people from other parts of the world as well. As a result, the term can include residents of the UK who originate from as far apart as China and the Irish Republic. For the purpose of this discussion paper, however, it would be prudent to assume that the term 'black and minority ethnic' usually refers to African Caribbean, Chinese, and South Asian people and those who describe themselves as 'black British' and 'Asian British'. Some other smaller minority ethnic communities like Middle Eastern, Eastern European and Western European were included in the sample.

### Carers

This describes people who are providing assistance to service users but do not get paid for this. Often they are family members, partners or friends. In Chapter 2, when service users are talking about experiences of home care agencies, the term carer is used to refer to paid agency staff.

## Service users (or potential service users)

SCIE uses the phrase service users (or potential service users) as a way of describing people who receive or require social care. The term can refer to lots of different groups of people, including families, people with physical and sensory impairments, survivors and users of mental health services, older people, people with drug or alcohol misuse problems and people with learning disabilities.

It is important to note however, that not all service users like this phrase or identify themselves in this way. One reason for this is that people with problematic substance use are called 'users' (or abusers) and can also be service users. This can create a blurring of the terms and puts some people off being called service user.

## Refugees

The popular use of the words 'refugee' and 'asylum' suggest that these terms are interchangeable. This is not the case. Refugees and asylum seekers hold very different legal positions. The framework of social care and welfare entitlements of asylum seekers has changed radically in the past ten years.

A refugee is an individual to whom the UK government has offered protection. A person with humanitarian protection or discretionary leave to remain has also been offered protection but subject to review after a specified period. Recent proposals in the Government's *Five Year Plan* on asylum and immigration mean that refugee protection will automatically be reviewed after a period of five years and revoked if it is deemed safe for the refugee to return to their country of origin. If the stringent criteria of the Refugee Convention are not met but it is deemed that temporary protection is nevertheless necessary, individuals will be granted Humanitarian Protection or Exceptional Leave to Remain.

People who have refugee status have identical rights to UK citizens.

## Asylum seeker

- An asylum seeker is a person who has asked for protection but has not received a decision on their asylum claim.
- A failed asylum seeker is a person who has been unsuccessful in the asylum process and may face removal from the UK. In recent years an increasing number of people at the end of the process are unable to return to their country of origin the reasons for this are various and include illness, risk of persecution, no safe route home and lack of documentation.

- Asylum seekers are excluded from many mainstream services and benefits. If destitute, an asylum seeker can apply to the National Asylum Support Service which exists to support destitute asylum seekers with accommodation and other essential needs (this does not include social care needs).
- Additional financial support for asylum seekers with social care needs within the National Asylum Support Service system is limited. The National Asylum Support Service can make special payments to meet particular needs (eg to someone whose medical condition gives rise to special needs), in practice this power is rarely exercised.
- Local authority social services departments have a duty to assist asylum seekers in the following circumstances:
  - > Asylum seekers with needs arising other than solely through destitution under the 1948 National Assistance Act, this includes needs arising from an impairment or disability
  - > Asylum seekers who are leaving hospital after being detained for treatment under the 1983 Mental Health Act
  - > Asylum seekers who have been(as children) in local authority care
  - > Unaccompanied asylum seeking children under the provisions of the Children Act 1989.
- Thus the context for meeting the social care needs of refugees is complex both in terms of the discourse around asylum seekers and refugees and also the complex framework of entitlements to welfare and social care services.<sup>6</sup>

## Social care

Social care is defined as the provision of social work, personal care (but not nursing or medical care), protection or social support services to children in need or at risk and their families and carers, or adults at risk or with needs arising from illness, disability or old age or poverty and their families and other carers. That provision may have one or more of the following aims: to protect service users; to preserve or advance physical or mental health; to promote independence and social inclusion; to improve opportunities and life chances; to strengthen families and to protect human rights in relation to people's social needs.

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<sup>6</sup> Patel, B. (2005) *The social care needs of refugees and asylum seekers* in Race equality discussion papers, London: Social Care institute for Excellence.

## Appendix 2: Talking to you about the green paper for adult social care

### What is the green paper?

The government has produced something called a green paper. The green paper gives ideas about how to make social care better. The main ideas for doing this include:

- giving people more control over their lives.
- giving people better choices about services they get and the lives they lead.
- finding ways of knowing that social care is really making people's lives better.

The aim of the green paper is to have services that fit around a person, to help them get the life they want, rather than having to fit into services that are available.

### What is social care?

There are times in everyone's life when they need help and support. Some people need more support, because they are old, ill or have a disability, some people may look after someone who is old, ill or have a disability and they might need help with this.

'Social care' is the help people get from social services. The kind of help it could be is:

- help with day-to-day living: cooking, cleaning, shopping, personal care.
- getting a break from your family or having a rest from looking after someone else
- getting help to be part of your community.
- help to have a social life and do the things you like doing.

### What are we asking you to do?

The Social Care Institute for Excellence wants to make sure that people who need adult social care services, and don't usually have their views and ideas heard, can have their say about how to make social care better. Therefore we would like to talk to you either in a small group or in private so that you can tell us what you think.

## What will happen to the things that you tell us?

The information and ideas that you give us will be used to tell the government what people think of their new ideas and how social care could be made better. We will do this by writing a report and meeting with government officers. When the report is written and meetings are held we will not tell anyone the names of the people that we spoke to and no one will be able to tell where you live or anything like that. No information about you will be passed on to the Home Office, the Benefits Agency, Housing Departments, Social Services or any other organisation that you maybe involved with. No one will be able to give you a worse service or take anything away from you just because you have talked to us. Your identity and personal details will always be kept secret.

## Appendices 3 A & B: Consultation protocols

Appendix 3a: Protocol for consultation with black and minority ethnic service users (or potential service users) and carers, refugees and asylum seekers and people with severe learning disabilities and / or communication impairments.

### Introduction

The outline below is a framework for talking either in groups or with people individually. There are a lot of questions but there is no expectation that they will all be asked. It would be a good idea to do some prioritising. The emphasis must be starting from a point that service (or potential) users and carers can relate to. The questions need to be used flexibly so that it is appropriate and responsive to the groups or individuals being consulted with.

### Important points to make at the outset

- Thanks for agreeing to talk to us.
- Confidentiality.
- Who we are and where we are from.
- Why we're here.

### Possible questions/areas to explore

1. If you use social care services at the moment what do you think of them?  
Possible prompt questions: what is good about the services and what is bad?
2. If you don't use social care services can you tell us a little bit about why you don't?
3. What sort of help would you like to be able to live a good life?
4. What makes it hard for you to get the help you need?
5. What would help you get the help that you want?

### Questions about getting help before things get really bad

1. For some people being able to get help or equipment early on rather than having to wait until things get really bad is important. For you what difference would it have made if you got the help before things got really bad?
2. How do you think services could help people who just need a bit of support, whilst also spending money on people who need a lot of help?

### Questions about using things that are already in your local community/area

1. What sorts of things do you like doing in your local community?
2. What stops you from doing the things you want in your local community? What would help?
3. If money for your social services could be used to do stuff in the community, what would you spend it on?

### Questions about having more chances to take 'risks' and try new things, even if other people are worried about you

1. What sorts of things do you do that might make people worry about you?
2. Why do you think people worry about you?
3. What would help to make people worry less?
4. What sort of chances would you like to be able to take or what new things would you like to try?
5. What could go wrong?
6. Who would get the blame if something went wrong? Should this be different?

### Questions about finding out what you need by making sure you are at the centre of this so that you are more in control and can work out what you need?

1. If you were going to work out what support or equipment you needed, what sort of information would you need to do this? How would you want to get this information?

2. If you needed advice who would you want to get this from?
3. If you had or have needs that might be quite complicated and a social worker was going to with you on finding out what you need, how would you like that to be done?
4. Have you heard of something called person-centred planning? The Care Programme Approach? The Single Assessment Process?
5. Are there ways these could be made better?
6. How would you feel about the information from finding out what you need being passed on to other organisation so you didn't have to give the same information too many times?

### Questions about you having control over the money for your support and being able to design your support

1. Imagine that social services gave you the money so that you could buy the support you want yourself. You could either have the money in your bank account, or social services could keep it, but the money would be yours to spend on the support you wanted?
2. Which would you prefer?
3. What do you think about the idea of being able to spend the money yourself on the support you need?
4. Do you think you would need help to look after the money and spend it on the support you need, if so what sort of help would you want?
5. Who would you want to get this help from?
6. What might the difficulties be...
7. Do you think you would get a better life if you could spend the money yourself to buy the support you need?
8. In what way do you think this could make your life better?
9. If you couldn't manage the money for your support yourself, what would you think about someone else (like a member of your family) doing it for you?

### Questions about better support for family carers

1. What support would you (as a carer) or your family carer like?
2. In an ideal world what would that support be like?
3. How would you want the support to be organised?
4. How would you like social workers and other professionals to work with you?
5. Is there any training that you (as a carer) or your family carer would find useful?

### Questions about if the people who plan social care services thought about using their money differently, and they did this in a way that gave you a chance to have your say

1. Do you think that social care money could be spent differently?
2. How would you like to see it spent? What difference do you think it would make?
3. How could people who plan services make sure there are different sorts of services for people to choose from?
4. How would you like to be involved in planning services?
5. What would need to happen to make it possible for you to be able to plan services?
6. What would councils and other organisations need to do to make sure your views and ideas are included when planning services?

### Questions about getting the right support and services when you are growing up (sometimes known as transition)

1. If you were/are a young person who uses services, how would you want services to support you as you grow/grew up?
2. How do you think that things could be better for young people as they move from children's to adult services?
3. What do services need to do differently?
4. How could people who plan services make sure that young people and their families can have a say in what services look like?

### Questions about if the people who check how good services are did it in a different way

1. What would make it easier for you to decide whether a service was good or not before you chose to use it?
2. What things should social care be checking to see if services are working well for people?
3. How could they make sure that the views of people who use services are heard better?

### Questions about if social workers and other people in social care had more of the right skills and training to do their job

1. For you what would the perfect social worker or other social care staff be like?
2. What do you think should be included in their training?
3. What could people who plan services be doing to make sure there are the right staff working in social care and that they get the right training and support?

### Demographic information

- Service user or carer
- Type of client group
- Ethnic background
- Approximate age
- Gender
- Legal status. (Please note this will need to be handled very sensitively and preferably picked up during the discussion rather than being asked as a separate question. If in doubt leave it out.)

## Appendix 3B: Protocol for consulting with homeless people and people with chaotic lifestyles – with multiple substance abuse and mental health problems

- What might prevent involvement in community activities?
- Involvement with voluntary organisations
- Time bank
- Volunteering

### Taking risks

Assessments (if complex still done by social worker)

- Confidentiality of assessments/information

### Having control over money

- Bank account v social services or something else

### Direct payments

- How could these be made more accessible to people like you?
- Changing the name
- How could social care money be spent differently?
- Transition services children to adult
- Questions to ask when monitoring services
- What skills experience and qualification do social care staff need?
- Look at the values proposed by green paper

## Appendix 4: Consultation monitoring form

The information asked for on this form is only being collected so that we can make sure we talk to lots of different people. We do not need to know your name and address. Also we will not tell people personal information about you.

How old are you? \_\_\_\_\_

Are you male or female?  Male  Female

Are you a carer?  Yes  No

Are you a service user?  Yes  No

What sort of services do you use? \_\_\_\_\_

\_\_\_\_\_

How would you describe your ethnic origin? \_\_\_\_\_

\_\_\_\_\_

Are you an asylum seeker?  Yes  No

Are you a refugee?  Yes  No

Do you have a physical or sensory disability?  Yes  No

Do you have a learning disability?  Yes  No

Do you have mental health problems?  Yes  No

Are you a homeless person?  Yes  No

Do you have or have you had in the past a drug or alcohol problem?  Yes  No

## Appendix 5: Sample

Consultation monitoring form statistics for total sample	
Demographics	Totals
<b>Age</b>	
18 - 25	4
26 - 35	10
36 - 45	20
46 - 55	14
56 - 65	15
66 +	34
<b>Gender</b>	
Male	35
Female	62
<b>Carer/ service user</b>	
Carer	24
Service user	64
Both carer & service user	8
Potential service user	27
<b>Type of service used</b>	
Day service	14
Care agency / home care	10
National Asylum Support Service	21
Refugee, Asylum Seeker Social Support	20
Social worker	22
Residential	12
Supported living	3
Direct payments	3
<b>Ethnic origin</b>	
Black Caribbean	15
Black African	14
Black other / Black British	9
Somali	2
Mixed	2
Middle eastern	2
Indian	1
Pakistani	2
Bengali	2
Asian other / Asian British	12
Chinese	12
Eastern European	2

SCIE CONSULTATION RESPONSE

Western European	1
White British	16
Not specified	5
<b>Asylum</b>	
Asylum seeker	6
Refugee	12
Granted British Citizenship	2
<b>Client group</b>	
Learning disability	9
Physical or sensory disability	40
Mental health problems	25
Experience of homelessness	22
Drug or alcohol problems	10
Severe learning disability & communication impairments	4
Dementia	1
Dual impariments	17
Number of forms not submitted	20
Number of forms submitted.	97
Number of people consulted with	117
<b>Black &amp; minority ethnic people</b>	<b>46</b>
<b>Refugees &amp; asylum seekers</b>	<b>23</b>
<b>Severe learning disabilities &amp;/or communication impairments</b>	<b>12</b>
<b>Homeless people &amp; people with chaotic lifestyles</b>	<b>16</b>
<b>Total number of people who submitted forms</b>	<b>97</b>