'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.

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 uncertainly 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.