

**Strategy Unit**

**Improving the Life Chances of Disabled People**

**Annexes D-F**

**Final Draft**

**17<sup>th</sup> January 2005**

**These annexes represent the views of the Strategy  
Unit only.**

## Annex D: Focus group consultations

### Summary

This annex gives a summary of the Strategy Unit's focus group consultations with disabled people, their families, and service providers. These were undertaken during Phase Three of the project (see Section 1.6) to inform the development of specific policy options. This annex provides an overview of the rich and detailed input received from the various group discussions held. The views of these groups have been reflected in the Strategy Unit's final report, and will need to be addressed further in the future if the report's vision is to be delivered in 2025. The Strategy Unit is grateful and indebted to all those that took part.

Section D.1 of this annex outlines the focus group consultation process. Sections D.2, D.3, D.4 and D.5 summarise key findings from the consultations on independent living, early years, transition to adulthood, and employment respectively.

### D.1 Group consultations to develop policy options

The Strategy Unit is indebted to the many individuals who gave so generously of their time and expertise to participate in the programme of focus group consultations. Those involved included:

- Disabled people;
- Carers and family of disabled people;
- Representatives of organisations of disabled people;
- Representatives of national and local disability related charities; and
- People working in a range of local government organisations.

The project brought together a number of groups to discuss specific areas of policy recommendations. This annex discusses in detail the groups that contributed to the development of policy options following the publication of the Interim Analytical report in June 2004.

The groups generated a large number of suggested areas for improvement. It has not been possible to recommend in this report everything that people identified, although much of what was outlined in the groups will need to be achieved over the next 20 years if the report's vision is to be delivered.

### D.2 Consultations on Independent Living

#### **Independent Living Expert Groups**

The Strategy Unit consulted specifically on its policy proposals concerning independent living (see Annex B for a list of people involved). There were three key meetings:

- with disabled people who have significant expertise in independent living policy and practice issues;
- with people who have specific expertise concerning issues for people with mental health support needs; and
- a joint meeting of both groups to consider final proposals.

Participants were generally supportive of the Strategy Unit's policy proposals concerning independent living, and made some specific points:

- Disabled people should be entitled not to have their independence removed by, for example, being forced to move into residential care because of a lack of support and housing to enable them to live in their own home.
- Disabled people want the right to equality of opportunity, to participate on the same basis as non-disabled people.
- Many people who come under the DDA definition of a disabled person do not think of themselves as 'disabled' (especially mental health service users); and many people are disabled in a number of different ways. The important common issue is the disabling experiences they have.
- The term 'independent living' can be interpreted as living without any support, and it is important to challenge this misconception. 'Independent living' is about having choice and control; and about social inclusion – it may not always be the most appropriate term to use.
- Any system for delivering independent living must also incorporate the particular experiences and needs of people with mental health problems.
- The NHS has to play its part in enabling independent living – it is not just about social care.
- More evidence is needed about how independent living is cost effective – for individuals and for society.
- Most disabled people need independent living advisors rather than care managers.
- Grass roots organisations of disabled people are crucial to developing local responses to enable independent living. But more resources are needed to build capacity amongst such organisations.
- The key barriers to take-up of direct payments are: poor quality assessments and lack of familiarity with direct payments on the part of social workers/care managers; lack of support to take them up; unnecessary bureaucracy; and financial scrutiny imposed by social services departments.
- Direct payments take-up will not increase without the expansion of user-led Centres for Inclusive/ Independent Living which deliver outreach and peer support.

- Some of the resources spent on assessments should be moved into advocacy and support.
- People need 'portability' rather than necessarily a national system – in other words if they move, their new local authority should honour the 'package' agreed by the previous local authority.

## **Essex Coalition of Disabled People**

Key themes raised by members of this coalition were:

- Participation needs to be effective and the level of influence of disabled people needs to be maximised in decision making processes.
- Local self advocacy groups survive on limited and short term funding. This leads to a considerable drain on resources as chasing funding becomes a major part of what organisations do.
- The difference between organisations of disabled people and for disabled people is fundamental and most of the resources are tied to organisations for disabled people. Funding for the sector needs to be reconsidered if its value is to be maximised.
- Ministers and senior staff need to come to meetings with disabled people.
- Access to Work is greatly valued but a number of suggestions were made as to how it could become even more useful. Direct payments also need to be used more.
- A more unified national funding stream would be welcomed to avoid disabled people having to approach numerous organisations for money. This would be especially valued where it is not clear who should take responsibility for funding the need.
- The general public and professionals working with disabled people should have an understanding of and promote disability equality and a social model approach.
- Government needs to take a strong, coherent, and ongoing approach to disability. There needs to be continual dialogue and partnership between central government and disabled people.
- Central government should directly fund local disabled people's organisations (including funds to deliver services) and not go through local authorities.

## **Options for Independent Living, Transport and Housing**

This meeting brought together a mixture of disabled people and local government officers based in Essex. The meeting came up with a number of suggestions for improvement:

- Life time homes standards should apply to all new developments.
- The Disabled Facilities Grant process needs to be streamlined, and government co-ordination around this needs to improve.

- The parking of cars blocking disabled access needs to be rigorously and systematically addressed as a priority.
- More bus routes and easier pre-paid ticket options should be available without the current significant local variation that exists with discounted tickets.
- There needs to be a system so that disabled people who board trains are able to exit at the arranged stop reliably.
- Aviation was an area of particular concern with fear of serious injury and death being common experiences when being loaded and unloaded onto aeroplanes. This should be addressed, with the United Kingdom aspiring to lead best practice internationally.
- Road humps cause much pain and distress, stopping people from accessing their community, friends and family. Most need to be removed and should only be used as a last option. They may cause breaches of the Disability Discrimination Act 1995.
- Walking & cycling strategies need to include disabled people access.

## **Values Into Action**

This group was co-ordinated by Values into Action and included a number of people with learning difficulties. They were drawn from several self advocacy groups, including Values into Action, People First, Action Unlimited, and Advocacy Matters. Key themes raised were:

- It is important to have an independent complaints system.
- People with learning difficulties need to be supported to train all types of service providers (e.g. lawyers) how to interact with people with learning difficulties.
- People with learning difficulties need support to feel safe living independently. The accessible support of the police is important, especially when bullying is involved.
- People with learning difficulties want real jobs on equal wages, and they do not want to be in an endless cycle of training.
- Everyone needs to know their rights, not knowing them can, for example, be a barrier to using direct payments.
- Assessments should not be about what people cannot do; rather they should focus on what help people need to do things. For example, identifying the support needed to be able to manage money.
- There should be a right to advocacy and the ability to choose who that advocate is, including a family member. Advocates should have training, and there should be more advocacy funding and capacity.
- Disabled people need to have control over the funding that supports them. Group participants liked the idea of budgets being combined.
- The media should change how it portrays people with learning difficulties, helping the public to understand how they can be inclusive.

- There should be a right to independent living, and a right not to be forced into residential or group homes.

## **National Forum of People with Learning Disabilities**

The key messages from this forum were that:

- Government needs to ensure that materials are available in an accessible format and that people are given enough time to be meaningfully involved.
- Department of Work and Pensions are causing confusion by using the term Direct Payments, when the Department of Health is already using this term for something different.
- More research is needed on the barriers faced by people with learning difficulties using direct payments, especially around the issues of safety.
- Direct Payments are sometimes made too complicated by local authorities. More Service Brokers would be welcomed.
- Advocacy organisations also need more funding, so that advocates can be paid properly.
- Participants felt that the concept of individual budgets is a good one.

## **D.3 Consultations on Early Years**

### **Early Years Expert Group**

The Strategy Unit consulted specifically on its policy proposals concerning early years (see Annex B for a list of people involved). There were three key meetings:

- Disabled children are at risk of being left out of wider changes and improvements to children's services.
- There is a strong link between child poverty and disabled children.
- There is an unacceptable postcode lottery in terms of what families with disabled children can expect from services.
- There is very little data on disabled children so it is difficult to be precise about the population of disabled children and their needs.
- There is evidence on the benefits of early intervention, but more is required.
- Services need to recognise the needs of the whole family.
- Children who have severe and complex needs can be 'written off' and not provided with adequate services.
- Many services meet disabled children's needs *in theory* but not in practice.

- Key workers are very important to support families navigate through services.
- Lack of childcare hampers parents of disabled children from working.
- Minimum standards are required in service provision.
- The children's workforce is not equipped to meet disabled children's needs at present.
- A common definition of disability would enable comparable data collection and less variation in provision between areas.
- The health service needs to prioritise children's health including that of disabled children.
- Disabled children also live outside of disadvantaged areas and may not be included in programmes targeted at these areas.
- Parents need support with things like sleep training, behaviour management and emotional counselling, to enable them to meet their child's needs fully.

### **aMaze**

A group of parents of disabled young people, mostly attending residential schools, spoke about issues experienced at early years and transition (their points on transition are summarised in Section D.4). The key early years points were:

- A local "Parent friendly" information pack at diagnosis has been greatly welcomed.
- Child Development Clinics need to have key workers, who proactively support families and their children; attend meetings with an advocacy role; and chase contacts. This is in contrast to the current approach of handing out contact details and leaving parents to get on with it.
- Direct Payments are difficult due to the effort in administering, the low rate paid, and difficulties with recruiting. There should be pay roll support and parents should not have to top up the payments made to pay people themselves.
- Childcare is crucial but provision is poor. Disabled children should qualify for high levels of funding where one-to-one support is required (currently they effectively get fewer hours than non-disabled children). There needs to be a range of short break provision.
- Childcare should be available with the family to support attending normal social activities that other families enjoy, such as attending weddings.
- The Strategy Unit report needs to address the time between early years and transition.

### **Contact a Family, Ealing**

This meeting consisted of a group of parents with young disabled children and living in the London Borough of Ealing. The types of impairment the children had included autism, learning difficulties and global delay. The key points raised were:

- Printed information was wanted at diagnosis as professionals do not always communicate everything that parents need to know. There should be a follow-up appointment because information is often not absorbed well at diagnosis.
- Health visitors need to have the time to talk issues through with the parents. It is difficult for parents to manage to read information, due to the demands of their parenting role. There is high demand for a specialist health visitor/key worker.
- Support parents need more of includes: advice and information about services and benefits; respite care; good access to professionals; and help with sleep and behaviour management. Portage (home education service supporting play and communication) was felt to be very useful, but is not easily available or widely known about.
- Some parents have felt compelled to go outside the NHS, as it failed to be responsive in terms of appointment time scales and follow up. This costs families thousands of pounds.
- Living without a diagnosis can mean exclusion from services and support.
- Sometimes disabled children are not invited to other people's houses to make friends, which can lead to social isolation.
- There is a lack of advice about making a successful school entry, and in the transition between school and nursery, support is often lost. There is a need for specialist provision at school.

### **Children's Services Group**

This was a mixed group of professionals from education, social services, and health services in Suffolk. The main points were:

- Health visitors do not have the capacity or skills needed.
- Services need to be better co-ordinated. However the different perceptions and definitions held of disabled children across different services can cause barriers.
- Early years support is often based on a medical model, and focused on child protection rather than removing barriers.
- Families with fewer support needs are effectively rationed out of services. For example, there is an 18 month waiting list for occupational therapists.
- Early bird schemes and good professional support are both valued.

### **Triangle**

This meeting brought together young people with a range of impairments. The main points are described in Section D.4, below.

## D.4 Consultations on Transition to Adulthood

### **Contact a Family, Wandsworth**

This meeting brought together a group of parents with disabled young people aged mostly 12-18 and living in the London Borough of Wandsworth. Key themes raised included:

- Professionals are not always supportive and seem at times to be more concerned with managing resources than supporting disabled young people and their families. Families experience stress, and services are often disappointing in their response.
- Mainstream schools can fail young people preparing to become adults because they can:
  - make disabled young people feel like they are 'bottom of the class'; and
  - have staff who lack the skills, time, and other resources to work properly with them.
- Special schools were felt to have many positive aspects, but not if they were a long way away or combined children and young people with a wide range of very different types of impairments. Parents felt that more specialist places should be made available locally.
- The impact of caring needs to be seen in terms of the whole family, including recognising the needs of siblings. Local authority provision can focus on the disabled child or young person, ignoring and at times making worse the situation of the rest of the family.
- Attitudes held by the public and by service providers often cause distress to disabled young people and their families. Public attitude change is a priority.
- Benefits and social services do not support parents to work, although many would like to. Having a disabled child with high support needs is expensive and this isn't reflected in benefit levels.
- Parents need the support of employers so they can undertake the additional tasks required of them. In particular, lack of sleep is problematic, reducing parents' ability to cope or be employed.
- Lack of access to childcare is an important issue and gets more difficult as children get older.
- Parents with disabled children and young people often lose contact with their friend- and family-networks, which can reduce the availability of informal childcare support. Parents highlighted as their children grow into adults, there is a need to recruit and train physically strong short break providers.

## **Disabled young people group**

This meeting brought together disabled young people who are in contact with Suffolk social services. Key themes that were raised included:

- Young people need access to good work experience, but barriers to this include:
  - Risk assessments not being arranged, preventing the placement from taking place;
  - Problems with insurance coverage;
  - Lack of provision to cover transport costs; and
  - Lack of support available while on placement.
- Young people had experienced 'supported' work placements where the level of ongoing support they received was very low.
- There is very limited choice on training options, as only a few are accessible. Some 'accessible' training courses required students to travel long distances to attend. The transport transfer between the LEA and the LSC, causing confusion and problems.
- Some people really enjoyed residential college, but felt isolated when they returned home due to lost contact with local and with college friends.
- Lack of access to community and leisure activities was a major concern. The barriers were as much attitudinal as physical.
- Families can be reluctant to allow disabled young people to learn to drive. The impact this could have on household income was a concern for some families.

## **Disabled young people's services group**

This was a mixed group comprised of a parent-carer and a range of professionals from education, social services and Connexions, all based in the Suffolk area. They made a number of key points about transition:

- Professionals ask for centrally enforced definitions: to overcome the variation in definitions of who is disabled between local authority areas, between different agencies and between child and adult services.
- Central government needs to clearly define what the actual transition process/journey is – there needs to be an agreed map. It was felt that current definitions of, and guidance for, the process are too woolly. For example, Connexions guidance is interpreted by some schools as meaning that Connexions are responsible for transition, while other pieces of guidance make clear that others also have responsibility.
- Without a 'Transition PSA', disabled young people will not receive increased priority or resourcing.
- It would help local authorities if data on SEN was fed back to central government so that additional resources made available in years where there are a higher number of disabled young people moving into adulthood.

## **Triangle**

This meeting brought together young people, aged 15-22 and with a range of impairments, who work for Triangle as consultants. The young people also presented responses from two groups of younger disabled children, also affiliated with Triangle. As an organisation Triangle is based in Sussex, but the young people who took part in the group had travelled from various parts of England. The key themes raised included:

- Disabled children and young people can be more vulnerable to abuse from service providers and within families.
- A shift in attitudes is required from the public and professionals. In particular, a greater understanding of the social model of disability is important.
- Constantly having to ask for help is a negative experience; help should be there if it is needed.
- Special schools tend to be more geared up to providing care than education, and many mainstream schools are poorly set-up to provide care. This can mean disabled young people are effectively denied access to a rounded education that meets their needs.
- Often those in an allied health profession role, such as a physiotherapist or nurse, can play a key part in providing transition support. Sometimes schools fail to take an active role.
- Young people and their families can be reluctant to complain about particular service providers, in case making a complaint affects their future funding and support.
- Communication training for staff needs to be a priority, and there is a great need more skilled advocates.
- There are a number of issues with equipment, including experience of delay, lack of ownership or ability to self-repair, and failure to ask young people what equipment they actually want.
- The young people in the group felt that there was a role for using direct payments to buy the healthcare they want, when they want. Once a young person becomes an adult some types of preventative healthcare, such as physiotherapy, may only become available once ill.

## **aMaze**

A group of parents of disabled young people, mostly at residential schools, spoke about issues relating to early years and transition to adulthood (their points on early years are summarised in Section D.3). The key transition themes raised included:

- There needs to be an information pack, given to disabled young people and their families, which lists all the local contacts and options in the area.
- Person centred planning works much better than trying to squeeze people into existing provision. There needs to be greater recognition

that transition planning takes time, and that it should usually start by age 13.

- Representatives from adult social services do not always attend transition reviews, and files may not be reliably transferred between children and adult services.
- Connexions can be good for liaising with local Learning and Skills Councils to develop packages.
- There are increasing numbers of families with disabled children in the community, but support services do not seem to be reflecting this.
- Buddy services are seen as an important type of age appropriate support for transition, as disabled young people often lose existing friends around this time.
- There can be a gap between child and adult social services, with the first sometimes finishing on the 18<sup>th</sup> birthday and latter not picking up until the 19<sup>th</sup> birthday.
- There need to be improved links between mainstream and special schools. Money saved by not sending children to out of county placements is not being reinvested into local services for the child.
- Central government needs to ensure local government links with community groups. Increased central funding for local organisations would be desirable.
- Longer funding periods are also required, as too much time and effort is put into fundraising and reporting.

### **National Union of Students**

This meeting brought together a large number of disabled students in further education and disabled undergraduates and post-graduates in higher education, attending institutions around England, Scotland and Wales. The key points raised included:

- The benefits system makes it difficult for disabled students to afford to study full-time, or to financially benefit from working part-time.
- Disabled students should be entitled to housing benefit for university provided accommodation, as this is often the only accessible accommodation available.
- There need to be minimum standards in the services and facilities available to students around the country. Currently choice of institution is determined more by the reputation of the services than by the suitability of the courses on offer.
- Information about services needs to be available to students before they move to a new area. Any care package they already have should be fully transferable to where they move to.
- Students need to be reassured that declaring their impairment on applications forms will not impact on admissions or attitudes.
- There need to be more and better volunteering opportunities, and work experience needs to be practical and work based.

- There are particular issues for students from BME groups, especially as some communities have a negative view of disability.
- The Disabled Students Allowance (DSA) is insufficient to cover full interpreter costs.
- The Widening Participation programme should tackle access to post graduate opportunities.
- An individualised DSA should be available for further education students, and advice and information in the sector needs to improve.

## D.5 Consultations on Employment

### **Mind**

This meeting brought together a group of people who use mental health services to discuss the policy development of recommendations around employment. The key points raised were:

- That Jobcentre Plus staff tend to blame worklessness on disabled people's motivation, when the actual problem was employers' discrimination. This can mean that people do not want to talk to Jobcentre Plus staff, preferring someone seen as independent. Pressure applied by Jobcentre Plus staff sometimes exacerbates mental health problems.
- Some parts of the benefits systems create disincentives to try working – for example if someone has to return to benefits then there can be a long wait for them to be reinstated. The benefits system should allow a gradual and flexible return to work. Complex rules can also lead to the belief that working or looking for work would endanger benefits.
- Assessment for benefits via a one-off meeting with a stranger can damage people's health and lead them to become distressed. This can result in them giving inaccurate information, for example if they wish to leave as soon as possible.
- Many people would like to do voluntary work but are concerned this could endanger their entitlement to Incapacity Benefit.
- Many training courses are a waste of time, but job focused or IT courses are valued more highly. Older people in particular need appropriate training and good career advice.
- Mentors and local advice agencies such as Mind are regarded highly, and can be effective in getting people into work after long periods of unemployment. The New Deal for Disabled People initiative is regarded positively, however Workstep is seen as flawed due to there being only two meetings a year.
- Developing positive attitudes, and eroding stigma and negative stereotypes, are important. There should be a series of well funded publicity campaigns to address this priority.
- Occupational health units within organisations are seen as a barrier rather than an asset to people being employed. Psychiatrists need to have less power and a change of ethos.

## **Manchester Breakthrough UK Ltd.**

This meeting brought together Breakthrough staff and disabled people who have either returned to work or are not in employment. The key points raised were:

- It is difficult to move from Incapacity benefit due to uncertainty of success in a new employment role and the difficulty in returning to benefits. The Independent Living Fund and Social Services tend to reassess individuals who gain employment, which increases uncertainty and fear of moving into work.
- Many people are scared of using Jobcentre Plus for job search activities, and so prefer to do these themselves.
- Disabled people may have little idea about what sort of work they would like to do, but good advice and information - such that as provided by Breakthrough - have helped.
- Doing the job is not the only barrier to accessing work, for example transport can be a major issue for many disabled people. Some people need support on how to best manage their impairment at work. Work place attitudes can also be a real barrier, and employers need to be positive about making reasonable adjustments and involving the disabled person in this. All employers should have disability equality training.
- Access to Work was seen as a good idea but has lengthy assessment processes, is too slow to deliver, and many people do not know about it. The use by Access to Work of assessors from other organisations was questioned. Self assessment should be a favoured option to cut bureaucracy and ensure unwanted or unsuitable items are not purchased. Access to Work should be available for volunteers.
- There is too much training for the sake of training, especially for those away from the labour market.
- Schools are not good at working with disabled students to link them with appropriate work experience and employment related opportunities.
- GPs are not seen as currently adding value to the system, as they do not have employment training and give out sick notes too easily, leading to them being devalued.
- Parents are concerned about the impact on household income when a disabled child enters work.

## Annex E: Summary of responses to the Interim Analytical Report

### Summary

This annex provides a summary of responses to the Interim Analytical Report published by the Strategy Unit on 17<sup>th</sup> June 2004. Section E.1 gives an overview of the responses and describes the purpose of this summary. General issues raised in the responses received - on report format and coverage, and on cross-cutting themes and the vision - are outlined in Sections E.2 and E.3 respectively. Responses to specific key themes are briefly summarised in Sections E.4-E.7 under the following headings: independent living; early years; transition to adulthood; and employment. Section E.8 presents a table listing the names of organisations and individuals who submitted responses to the Interim Report. All responses have been published on the Strategy Unit website at [www.strategy.gov.uk](http://www.strategy.gov.uk).<sup>1</sup>

### E.1 Introduction

#### **Responses to the Interim Analytical Report**

The Strategy Unit's (SU's) Analytical Interim Analytical Report '*Improving the Life Chances of Disabled People*' (henceforth referred to as the 'Interim Report') was published for comment on 17<sup>th</sup> June 2004. An initial deadline was set for 13<sup>th</sup> August, and extended to 10<sup>th</sup> September for those who were unable to respond to the first deadline owing to the delay in making available the Word and Braille versions of the report. This annex takes into account all responses received, including those returned after the extended deadline. The SU undertook to collate and publish the responses and produce a summary of the key themes raised - continuing the practice of consultation and publication that was followed throughout the project. One respondent requested that their name and submission not be published, their response has therefore been excluded from both the SU website and the tick-list table at the end of this annex. All responses were reviewed carefully by the team and specific points were considered, even if they are not mentioned in this summary.

The SU is grateful to all those who responded to the Interim Report. The responses are relevant to the government's assessment of the report and the SU has published the responses on its website.

Whilst the responses are not a systematic evaluation of the Interim Report, they do illustrate some reactions to the report's tone, balance, analysis and coverage of the available information. The responses have also been valuable

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<sup>1</sup> The Strategy Unit has classified as a response any submission specifically prompted by the Interim Analytical Report. More general correspondence on disability issues has not been included.

in helping the SU to learn lessons about process and accessible formats that could be applied in future projects on other topics.

Overall, the SU received 111 responses from 97 different sources. Although the boundaries are not always clear, we have divided the responses according to whether they were sent from an organisation (65) or from private individuals (48). Some responses are the result of collective input, for instance the Disabled People's Forum and Inclusive Living Sheffield Ltd worked together to organise an event to enable more than 30 disabled people to discuss the report and respond to the consultation questions.

### **The purpose of this summary**

This summary is intended as a guide to the various documents and letters that were sent to us, and also as an indicator of the main themes from the range of responses we received. The summary is deliberately limited in scope and length, and readers are encouraged to view the individual submissions in full.

In an attempt to draw together the wide range of documents and comments received into a manageable package, we have generated a tick-list table to indicate the proportion of responses addressing the different key issues. Creating a tick-list to summarise such a wide-ranging set of documents is inevitably subjective, and it should be made clear that the classification is the SU's own, and represents the SU's reading of the responses received. The authors of the responses may have different views on the major themes they raised – another reason for interested parties to view the individual submissions. The SU has tried to account for as much of the written material as possible.

### **Nature of the responses**

Some respondents commented closely on the process of consultation, the content of the Interim Report, and its specific omissions and analysis. A few of these used the Strategy Unit consultation questions to structure their responses, but most fed back comments structured in different ways.

Other respondents focused on describing the specific policy proposals that they wanted to see included in the Final Report, sometimes submitting documents and pamphlets that presented their personal or organisation's views and activities.

This summary therefore combines direct responses to the Interim Report, with recommendations raised for inclusion in the Final Report.

## E.2 General comments on report format and coverage

### **Inclusion and accessibility**

Respondents welcomed the fact that the report summary was available in a number of accessible formats, including Braille, easy read, and on tape. However, some respondents felt that a BSL version of the report should have been available, and others expressed disappointment that the full report was presented in PowerPoint rather than Word (as PowerPoint is harder to convert into different font and reader formats). Some respondents felt that the use of graphics and the PowerPoint slide format made the information more accessible, and others felt that it made it less so. These comments have been taken on board in the preparation of the Final Report, which is published in Word and other formats. The SU as a whole has learnt valuable lessons through this experience for its future publications

It was pointed out that for some groups, especially those with learning disabilities, a longer period of time for commenting on the report would have been welcomed. Some respondents also felt that the report had not been circulated widely enough amongst groups of disabled people.

### **Overall approach of the Interim Report**

The most frequent response to the Interim Report was to welcome its overarching and cross-governmental approach, which many felt had been long overdue in this area. Most respondents stated that they broadly agreed with the picture drawn in the report of the current situation for disabled children and adults, and its diagnosis of the key barriers and likely areas for solutions. The fact that disability equality is being treated as a priority for government was welcomed. In particular most respondents supported:

- The identification and focus on key social, attitudinal, physical and policy barriers; and
- The report's cross-cutting approach and its focus on integrated, multi agency working; emphasis on involving disabled people and moving away from a systems-led approach; and identification of the need for wider recognition of disability issues and a coherent vision for the future.

Most respondents, however, were also able to highlight general areas of concern, either in terms of omissions or of different emphases and priorities that they would like see taken forward in the Final Report. These included perceptions that:

- The report's goal was focused on reducing costs and reducing the number of people in receipt of benefits.
- The practical implementation of recommendations would be hindered by a lack of accompanying funding.
- The report was overly based on a 'provider' led perspective.

- The emphasis was overly on physical barriers, and did not address communication barriers.
- The issues discussed had already been raised by disabled people on previous occasions, but had not yet been addressed.

### **Language, definitions and models used in the Interim Report**

Many respondents warmly welcomed an approach which they felt emphasised the removal of disabling barriers, rather than individual impairment. A few respondents, however, felt that the report overemphasised a medical model or narrow understanding of disability, which they felt was problem-based or paternalistic. It was also suggested that particular concepts, such as independent living, needed to be more clearly defined.

People highlighted the need for informed and consistent use of language. While the distinction between 'disability' and 'impairment' was welcomed, several commentators felt that the use of language needed further tightening up. Respondents objected to the use of specific words and phrases, like 'learning disabilities' and 'people with disabilities'. It was argued that language that implies disabled people are a 'burden', 'victims', or in any way negative, must be avoided. The language used in the report was also felt by some to contain too much jargon.

### **Coverage of the Interim Report**

Respondents valued the holistic approach of the report and generally felt most key issues were covered, although a few areas were identified as under-developed such as access to leisure services, information technology, housing and transport.

Most respondents approved of the broad and inclusive definitions of disabled people used in the report. However particular sub-groups of disabled people were identified as having specific issues which were not addressed in sufficient depth. These included those:

- with particular types of impairment, including low prevalence and/or communication impairments;
- with the most significant and/or multiple impairments;
- experiencing multiple sources of discrimination or disadvantage, e.g. disabled people from BME groups;
- disabled children between early years and transition, i.e. those aged between 5 and 13; and
- people with impairments who do not self-define as disabled, such as those who are deaf or hard of hearing.

Older people are outside of the remit of the report, and some respondents queried whether this was the right decision. It was also highlighted that the

needs of carers and family members should be addressed more clearly in the Final Report.

### E.3 Cross-cutting themes and vision

#### **Vision**

The majority of respondents affirmed the need for Government to have an overall vision, which could provide a framework and strategic direction across different Government departments. Value was placed on moving towards a citizenship model, underpinned by rights and responsibilities. Some respondents suggested that this should take more of a 'civil rights' framework than was evident in the Interim Report.

#### **Attitudes and stigma**

Several respondents stressed that the low awareness and understanding of disability issues amongst the general public is a key problem that should be addressed through means such as publicity campaigns and changes to media representations and language. Some respondents felt a greater emphasis should have been given in the Interim Report to the word and concept of 'disabilism'. A few respondents felt that the report's analysis of discrimination legislation was weak and that more emphasis should have been given to the different legislative frameworks for (e.g.) special educational needs and disability.

#### **Workforce issues**

Various workforce issues were raised by respondents as crucial to the effective on-going delivery of change.

- The need for increased workforce capacity was repeatedly highlighted. The shortfall of particular types of professionals was raised, for example the lack of: speech and language therapists, British Sign Language interpreters, people qualified to undertake DDA access audits, Connexions personal advisors, occupational health workers, Social Workers, personal assistants, and others.
- Composition of the workforce was highlighted as a key issue, including the need to employ more disabled people as service providers, as well as more men and people from BME groups. The need to develop the voluntary sector and user-led service providers was also mentioned by several respondents.
- A large number of responses highlighted the need for appropriate workforce training (particularly for staff employed by the NHS). To be able to participate in a person centred process was felt to require a

significant shift in many service providers' concept of their role and of 'disability'. Disability Equality Training was cited by many respondents as crucial across the workforce, and several stressed that training should be provided by disabled people.

### **'Mainstreaming' versus specialist provision**

There were varied responses on where the balance should be between mainstream and specialist provision. Respondents did agree, however, that where there is mainstreaming, meeting the needs of disabled people must be properly resourced.

Respondents affirmed the Interim Report's conclusion that current policy development, design and delivery often addresses disability issues as a late 'add-on'. A large number of respondents agreed that *involving disabled people* was a prerequisite to their needs being mainstreamed, but stressed that this process required funding to be meaningful. Any focus on empowering individual people without also developing local organisational capacities was mentioned by a few respondents as problematic.

### **The national and the local**

Concerns were raised about how national strategies can best link with local implementation. These centred around responses relating to what are the most appropriate levers for change and how can joint working at all levels be enforced.

Respondents raised mixed concerns about balancing local flexibility with maintaining national minimum standards and avoiding postcode lotteries. Some respondents felt that there was a need for more to be dictated from the centre, stressing that without PSA targets raising the profile of disability issues change at a local level was unlikely. Other respondents, however, felt that greater local flexibility was required.

A number of respondents stressed the importance of the Final Report tying in with existing work in the area, including legislation, other Strategies and Frameworks, and forthcoming policies and pilots. The need for central government to be more joined up was referred to by a number of respondents. At a local level, respondents agreed with the barriers to joined up working identified in the Interim Report, including there being a lack of reliable data and effective data sharing, variable attendance at review meetings, and the low profile given to disability issues.

### **E.3 Comments on Independent Living analysis**

The Interim Report did not include a separate section on independent living, however a number of respondents commented on themes from across the

report which addressed this overarching topic. A general concern raised was that independent living was not given a sufficiently high profile in the Interim Report. Specific concerns included,

- The lack of coverage of housing and transport issues. Respondents suggested that the need for house and car design standards, lifetime homes, rural transport and other related issues should be addressed in the Final Report.
- Direct Payments were discussed by a large number of respondents to the Interim Report. In particular they commented on how access to Direct Payments varies by area and impairment type, that management of payroll and recruitment can be burdensome for individuals, and that the wage levels for personal assistants are often set too low.
- Access to equipment, and in particular to wheelchairs and communication aids, was cited as an important issue for the Final Report to address.
- Some respondents felt that the importance of needs-led and self-assessment approaches to service planning and delivery, and the need to separate gate keeping and budget holding, were not sufficiently highlighted in the Interim Report.
- While it was recognised that a key worker can provide vital co-ordination and system navigation, some respondents stressed that this is no replacement for access to an independent disabled advocate.
- Problems with the interface between health and social services were highlighted by a number of respondents. Specific concerns about the NHS, including around flexibility, efficiency and accessibility, were also emphasised. Having to distinguish between NHS- and LA-funded community care was also highlighted here.
- A need to focus more explicitly on access to life long learning in the Final Report was raised.
- Many respondents prioritised developing recommendations around building capacity and involving disabled people in the Final Report.
- Some people suggested improved access to Disability Living Allowance/ Attendance Allowance should be a priority for the final report.

#### E.4 Comments on Early Years analysis

Many of the themes discussed above were also raised specifically in relation to the section of the Interim Report that addressed early years' provision. The main issues raised by respondents in relation to early years included:

- Lack of research and data, inadequate information sharing, and failures of integrated working. These were often accompanied by comments on the need for common definitions of who is a 'disabled child' and for a common assessment framework.
- Insufficient funding and variation in the quality and quantity of provision.

- Poor workforce skills, training and capacity, and a failure to respond to children's changing impairment profile. Many respondents felt that issues faced by children with specific types of impairment did not get their needs addressed by a 'pan-disability' approach. These included those with the most complex needs, such as technology dependent children and some of those with an Autistic Spectrum Disorder.
- The situation for families was a recurrent theme in comments on the early years' chapter. In particular these focused on a lack of early intervention, family and pre-school support, and inaccessible homes.
- There was support from a large number of respondents for expansion of the key worker role, and several suggested local schemes that provided local good practice models for this. Some concern was expressed about how onerous the key worker or lead professional role might be if it involved responsibility for co-ordinating other agencies
- Respondents agreed that there is variation in provision across the country, and cited Sure Start as one possible vehicle for setting national standards in childcare.
- Inclusion in mainstream education was welcomed by many respondents, but many also highlighted the potential for this to fail disabled children if not properly resourced.

Most respondents felt that the Interim Report did address these key barriers, but were keen to request that these also be tackled in the recommendations in the Final Report. A few respondents felt the Interim Report should have addressed the issue of the transition into school in more depth.

## E.5 Comments on Transition to Adulthood analysis

Most respondents agreed with the identification of barriers faced at transition to adulthood included in the Interim Report. In particular:

- Respondents stressed the lack of resources currently made available for person centred planning for adulthood and emphasised that the age range for transition planning and provision needs to extend to age 25, or even 30.
- Preparation for transition was felt to need to start early, and should include work on developing decision making skills and building up confidence and high expectations. A few respondents argued that poor planning, that failed to address what young people want and how to enable them to participate, could mean increased costs to the individual and society in the longer term.
- Some respondents highlighted the need to bring together the various national guidance that has been issued on transition into a single pack.
- Most respondents commenting on issues around transition highlighted the poor level of integrated working across agencies and between child and adult services, and the lack of involvement of key partners. Some respondents highlighted a need for a statement that 'spans' transition.

Lack of preparation, understanding, support and funding for and from adult social services was also cited.

- Several respondents agreed that there is a lack of skilled advocates available to support disabled young people. In particular, they highlighted the need for independent disabled adults to be involved in mentoring disabled young people.
- Several respondents commented on how ill-equipped the Connexions Service is to work with disabled young people, and highlighted a lack of priority and resourcing within the service as responsible for this.
- Several respondents described the lack of progression options available, particularly for young people with learning difficulties. Some respondents pinned this on failures to fully mainstream the needs of disabled young people in major new legislation, programmes and services, such as Every Child Matters, Extended Schools and Connexions. In particular, the further education sector was felt to lack the skills and support needed.

Respondents generally felt that these barriers were highlighted in the Interim report and that they should also be tackled in the Final Report. Omissions in the transition chapter identified by respondents included:

- The transition between primary and secondary schools;
- Variation by local authority in use of Statements of SEN; and
- Specific issues for looked after children.

## E.6 Comments on employment analysis

There were a large number of responses relating to the Interim Report chapter focusing on employment. Comments were wide ranging and included mention of a number of examples of good practice.

- Development of vocational skills was seen by many respondents as key. A large number agreed that access to voluntary work can be a key first step and a valuable on-going role, and needs to be given a higher profile. However, a couple of responses stated that disabled volunteers should not be used as a substitute for paid employees. Routes into employment for people with learning difficulties were highlighted as of key concern.
- The benefits system was referred to by a large number of respondents as a key factor influencing disabled people's relationship with the labour market. Some stated that disincentives within the system have to be addressed, and others described how overcomplicated the system is. Respondents felt that the Personal Capability Assessment needed to be investigated due to the high proportion of refused claimants who win their cases on appeal.
- Respondents had detailed suggestions both for new services and programmes they would like introduced, and for changes and clarifications that should be made to existing programmes. These included, amongst others:

- *Access to Work*, which many respondents felt: should be better promoted amongst disabled people and employers, its application process should be streamlined, and it should be accessible to those doing voluntary work.
- *Workstep*, was felt to involve too much paperwork which is discouraging for employers and participants.
- *Disability Leave*, several respondents asked for legislation to support the introduction of Disability Leave.
- Many respondents agreed with the Interim Report's identification that changing employer attitudes and awareness should be a priority. Respondents also stressed that perceptions of who is and who is not employable, and the perceived costs of employing a disabled person, need to be challenged. A range of different respondents felt that employers need to be better supported, in particular to develop improved absence management schemes.
- A number of respondents agreed that separation of health and employment services can have a detrimental impact on how people can be supported back into work, and that there is poor recognition of the role of Occupational Health Services in facilitating employment rehabilitation by the NHS.
- Several respondents highlighted the need to include provision for people for whom full-time work will not be a realistic option, stressing that the Final Report should not overemphasise employment as the only meaningful life option.
- A few respondents felt that the employment chapter of the Interim Report did not sufficiently explore mental health conditions brought on by stress, inequalities, or harassment experienced in the work place.

## E.7 Classification of responses received

| <b>Responses from organisations</b>  |                     |             |            |             |                |
|--|---------------------|-------------|------------|-------------|----------------|
| (including organisations of/for disabled people; local authorities; housing associations; other government departments; education institutions; service provision teams; professional bodies; insurance providers; and trade unions) |                     |             |            |             |                |
|  | Independ-ent Living | Early Years | Transition | Employ-ment | General /other |
| Access Association   | ✓                   |             |            |             | ✓              |
| Access Auditors  | ✓                   | ✓           | ✓          | ✓           | ✓              |
| Action for Blind People  | ✓                   |             |            | ✓           | ✓              |
| Afasic   | ✓                   | ✓           | ✓          | ✓           | ✓              |
| Age Concern  | ✓                   |             |            |             | ✓              |
| Breakthrough   | ✓                   |             | ✓          | ✓           | ✓              |
| Bristol City Council Physical and Sensory Impairment Group   | ✓                   |             |            |             | ✓              |
| British Association of Teachers of the Deaf (BATOD)  |                     | ✓           | ✓          |             |                |
| Changing Faces and Dining with a Difference  |                     |             |            |             | ✓              |
| Children's Legal Centre  |                     | ✓           | ✓          |             | ✓              |
| Children's Services Multi Agency Strategic Implementation Group (Sheffield)  |                     | ✓           | ✓          |             |                |
| City of Sunderland Physical Disabilities Modernisation and Reform Group (MARG)   |                     |             | ✓          | ✓           | ✓              |
| Dorset People First  | ✓                   |             |            |             | ✓              |
| Downs Syndrome   | ✓                   | ✓           | ✓          | ✓           | ✓              |

|  |   |   |   |   |   |
|--|---|---|---|---|---|
| Association                                      |   |   |   |   |   |
| Essex County Council                             | ✓ | ✓ | ✓ | ✓ |   |
| Foundation for People with Learning Disabilities | ✓ | ✓ | ✓ |   |   |
| Habinteg Housing Association                     | ✓ |   |   |   |   |
| Hammersmith and Fulham Council                   | ✓ | ✓ | ✓ | ✓ | ✓ |
| Heritage Lottery Fund                            |   |   |   |   | ✓ |
| Her Majesty's Customs and Excise (HMCE)          |   |   |   | ✓ |   |
| I CAN (2 submissions)                            |   | ✓ |   |   |   |
| Inclusive Living Sheffield                       | ✓ | ✓ | ✓ | ✓ | ✓ |
| John Grooms                                      | ✓ | ✓ | ✓ |   | ✓ |
| Joseph Rowntree Foundation                       | ✓ | ✓ |   |   |   |
| Lancashire County Council                        | ✓ |   |   | ✓ |   |
| Leonard Cheshire                                 |   |   |   | ✓ | ✓ |
| Local Government Association                     |   |   | ✓ |   | ✓ |
| London College of Beauty Therapy                 |   |   |   | ✓ |   |
| MENCAP   | ✓ | ✓ | ✓ | ✓ | ✓ |
| MIND   |   |   |   | ✓ | ✓ |
| Motability                                       | ✓ |   |   | ✓ |   |
| NAICE  | ✓ |   | ✓ | ✓ | ✓ |

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| National Association of Paediatric Occupational Therapists (NAPOT)<br>(2 submissions) |   | ✓ | ✓ |   |   |
| National Association Supported Employment (NASE)                                      |   |   |   | ✓ | ✓ |
| National Library for the Blind  |   | ✓ | ✓ |   | ✓ |
| National Union of Teachers (NUT)  |   | ✓ | ✓ |   |   |
| Newham Disability Partnership Board   | ✓ | ✓ | ✓ | ✓ | ✓ |
| North Yorkshire County Council  |   |   |   | ✓ | ✓ |
| PACE  |   | ✓ | ✓ |   |   |
| Papworth Trust  | ✓ |   |   | ✓ | ✓ |
| Royal College of Nursing  |   |   |   | ✓ | ✓ |
| Royal National Institute for Blind People (RNIB)                                      | ✓ |   |   | ✓ | ✓ |
| Royal National Institute for Deaf People (RNID)<br>(3 submissions)                    |   | ✓ | ✓ | ✓ | ✓ |
| Shaw Trust  | ✓ | ✓ | ✓ | ✓ | ✓ |
| Skill: National Bureau for Students with Disabilities                                 | ✓ |   | ✓ | ✓ |   |
| South Central Connexions<br>(2 submissions)   |   | ✓ | ✓ |   |   |
| Speakup   | ✓ | ✓ |   | ✓ | ✓ |
| Tenants Disability Action Group   | ✓ |   |   |   |   |
| The Children's Society  |   | ✓ | ✓ |   | ✓ |

|  |   |   |   |   |   |
|--|---|---|---|---|---|
| (2 submissions)  |   |   |   |   |   |
| Transition Information Network   |   | ✓ | ✓ | ✓ |   |
| Turning Point  | ✓ | ✓ | ✓ | ✓ | ✓ |
| U Can Do IT (3 submissions)  |   |   |   | ✓ | ✓ |
| Unum Provident   |   |   |   | ✓ |   |
| WCTS   |   |   |   | ✓ |   |
| Whizz-kidz   |   | ✓ |   |   | ✓ |
| Writers Guild of Great Britain Disability Issues Committee                                     |   |   |   | ✓ | ✓ |
| Work Directions (3 submissions)  |   |   |   | ✓ |   |
| <b>Responses from individuals</b>  |   |   |   |   |   |
| (Including people in their capacity as a disabled person, academic, carer, family member etc.) |   |   |   |   |   |
| Airey, Denise  |   | ✓ | ✓ |   |   |
| Allison, Samantha  |   |   |   | ✓ | ✓ |
| Ashworth, Roy  |   |   |   |   | ✓ |
| Austen, Roy  |   |   |   |   | ✓ |
| Bailey, Peter (School of Life and Sport Sciences, University of Surrey) (2 submissions)        |   |   |   | ✓ | ✓ |
| Barton, Dr Christine   | ✓ |   | ✓ | ✓ | ✓ |
| Begley, John and Val   |   |   |   | ✓ |   |
| Cameron, Julia   |   |   |   | ✓ |   |
| Cannon, Mary   |   |   |   |   | ✓ |

|   |   |  |   |   |   |
|---|---|--|---|---|---|
|   |   |  |   | ✓ |   |
| Crawshaw, Gill<br>(Leeds City Council)            |   |  |   |   |   |
| Davis, Alison                                     |   |  |   |   |   |
| Duckworth, Stephen<br>(Disability Matters Ltd)    |   |  |   |   | ✓ |
| Ellis, Graeme                                     |   |  |   | ✓ |   |
| Filby, Grace                                      |   |  |   |   | ✓ |
| Gray, Alistair<br>(2 submissions)                 |   |  |   |   | ✓ |
| Heap, Rory  |   |  |   |   | ✓ |
| Howard, Marilyn                                   | ✓ |  |   | ✓ | ✓ |
| Hurst, Rachel (Disability<br>Awareness in Action) | ✓ |  | ✓ |   | ✓ |
| Lea, Laura  |   |  |   | ✓ | ✓ |
| Lewis, Philip                                     |   |  |   |   | ✓ |
| Llwelyn, Debra                                    |   |  |   |   | ✓ |
| Loosemore-Reppen,<br>Gerda                        |   |  |   |   | ✓ |
| Lyon, Jane  | ✓ |  |   | ✓ | ✓ |
| Lynton, Brendan                                   |   |  |   | ✓ | ✓ |
| McKinley, Stephanie                               |   |  |   | ✓ | ✓ |
| Moorjani, Padma                                   |   |  |   |   | ✓ |
| Munday, Dorcus                                    |   |  |   |   | ✓ |
| Phillips, Jan                                     |   |  |   |   | ✓ |
| Paulley, Douglas                                  | ✓ |  |   | ✓ | ✓ |
| Paulley, Stuart                                   |   |  |   | ✓ |   |
| Popkin, Marion                                    |   |  |   |   | ✓ |

|  |  |   |   |   |   |
|--|--|---|---|---|---|
|  |  |   |   |   |   |
| Rees, Raymond  |  |   |   |   | ✓ |
| Saunders, Monica<br>(SW London and St<br>Georges Mental Health<br>(NHS) Trust) |  |   |   | ✓ |   |
| Stenger, Judy<br>(Neath Mind)  |  |   |   | ✓ | ✓ |
| Stronach, Russell<br>(3 submissions)   |  |   |   |   |   |
| Sugden, David  |  | ✓ | ✓ |   | ✓ |
| Taylor, Andrew   |  |   |   | ✓ | ✓ |
| Ward, Mick   |  |   |   |   | ✓ |
| Whyatt, Adrian (DANDA)   |  |   |   |   | ✓ |
| Young, Jane<br>(2 submissions)   |  |   |   |   | ✓ |

## Annex F: Improving the Life Chances of Disabled People with the Most Complex Needs

### Summary

This review explores what some of the recent literature says about disabled people with the most complex needs<sup>2</sup>, suggesting the sorts of ways in which these needs might be met and highlights examples of progress made in improving the life chances of these groups. This subject has been explored because of the recognition that the more complex a person's needs, the wider the range of barriers they will face, and the more likely they are to fall between the gaps in the services society provides - the 'inverse care law'.

Identification of these groups is to a large extent determined by existing yet inadequate research - there are in fact other groups about whom there is no research at all. There are also gaps in terms of information on the groups identified in this paper. In cases where there are no national surveys/data available - much of the evaluative evidence has been drawn from small case studies. It should also be acknowledged that there may be alternative views as to 'what works' for each of these groups and a number of different options which could be offered in the discussion of 'practical steps'.

Groups included in this review include:

- Disabled children and adults living in **residential/secure settings**
- People with **high support needs**, a **range of impairments** and/or **multiple disadvantage**, such as disabled people who are homeless, people with learning disabilities who also have mental health problems
- People with **mental health support needs** have been identified as a group whose social exclusion particularly affects their employment prospects.
- People with **communication impairments**, excluded because of misconceptions about their interaction abilities and cognitive faculties.
- People with **low incidence/the least common impairments**, marginalised in the sense of being excluded from the debate about tackling disabling barriers.<sup>3</sup>
- Disabled people who also **experience other sources of discrimination** – such as black and minority ethnic groups; refugees and asylum seekers; gay men, lesbians and bisexuals.

<sup>2</sup> People's complex needs can have breadth (range of need) and/or depth (severity of need). Rankin, S, Regan S (2004) "Meeting Complex Needs: The Future of Social Care", Turning Point, IPPR.

<sup>3</sup> Particularly an issue for people with impairments experienced mainly by minority ethnic groups (such as sickle cell anaemia). This issue is addressed in Section 1.6.

- **Disabled parents'** needs are often marginalised by community care services and are at greater risk of losing their children into care.

All of these groups can expect to benefit from the policy recommendations made in the Strategy Unit's final report "Improving the Life Chances of Disabled People". In particular, personalised support addressing a range of barriers to independent living will enable the needs of these groups to be met. However, what these groups require in addition is for effective links to be made across different services each concerned with different sources of disadvantage – recognising that these sources of disadvantage are often concurrent.

## 1.1 Disabled children and adults in institutional/residential settings

### **1.1.1 Children in institutional / residential settings**

Disabled children are over-represented in the population of looked after children, are more likely to be placed in residential settings and stay for long periods of time in health care settings. Family stress is a key factor in requests for residential placements.

#### *Looked after disabled children*

- In March 2003, out of 94,300 children looked after at any time during the year, 12,100 or 13% were recorded as looked after because they were disabled<sup>4</sup>.
- In addition to these 12,100, an unknown number of children who are looked after by local councils will have had disabilities<sup>5</sup>.
- The vast majority of looked after disabled children are between the ages of 10-15<sup>6</sup>

#### *Children with Special Educational Needs (SEN) in residential schools<sup>7</sup>*

The following data are drawn from a DfES/DH report on disabled children in residential placements.

- In 2003 there were 6,200 pupils boarding full-time for 7 nights a week or less in 229 maintained and non-maintained special schools<sup>8</sup>
- The majority of these boarders are aged 11-15 and three quarters of these pupils are male.<sup>9</sup>

<sup>4</sup> But this will not have been recorded as being the main or principal reason for the child requiring social services. This means they cannot be identified as disabled from the data collected. ONS/DfES "Statistics of Education: Children Looked after by Local Authorities Year Ending 31 March 2003" Vol. 1: Commentary and National Tables.

<sup>5</sup> ONS/DFES (March 2003) op cit.

<sup>6</sup> DfES/DH (2004a) "Disabled children in residential placements".

<sup>7</sup> Statistics on disabled children in residential schools only count the number of children with SEN in residential schools.

<sup>8</sup> Data for maintained schools is collected through the Annual School Census.

<sup>9</sup> DfES/DH (2004a) op cit.

- Costs for residential special school places are two to three times higher than costs for providing for similar needs in day special schools.<sup>10</sup>

#### *Disabled children in Healthcare Settings*

- In the last three years 2,200 children have spent over 6 months in hospital. 245 of these children apparently spent more than 5 years in hospital.<sup>11</sup>
- The most common reason for admission of children who spend long periods in hospital is categorised as ‘mental and behavioural disorders’.

### **Key Barriers**

The research points to a number of barriers faced by disabled children in residential placements

#### *Looked After Children*

- The Safeguards Review (1997) highlighted a number of concerns about residential care including placement instability, the difficulties of recruiting properly trained staff, the high numbers of children not receiving education, as well as the tendency of children in care to lose contact with their families and communities making them more vulnerable to isolation as adults.

#### *Disabled Children in Residential Schools*

- Findings from a Nora Fry Research Centre study into disabled children and residential schools showed that parents generally did not want their children to go to a residential school (which was often many miles away from home) but felt there was no other option because of the failure of local education and social services to address their children’s needs.<sup>12</sup> The main reasons given for a disabled child going to residential school were:
  - Failure to meet a child's educational needs locally and;
  - Pressure on families.

#### *Disabled children in Health Care Settings*

- A recent Joseph Rowntree Foundation (JRF) study found that disabled children were still experiencing unnecessary negative experiences in health care establishments. The key barriers identified were:
  - **lack of support** to families;
  - **failure to listen** to children’s preferences; and

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<sup>10</sup> “Disabled Child Standard, National Service Framework for Children, Young People and Maternity Services” (2004b), DfES/DH, p31.

<sup>11</sup> DH analysis of the Hospital Episode Statistics data on age of admission to hospital in England (1998-2001).

<sup>12</sup> Abbott, D, Morris, J, Ward, L (2001) “The Best Place to Be? Policy, practice and the experiences of residential school placements for disabled children”, NFRC.

- **Inadequate co-ordination** between health, social care and educational services.<sup>13</sup>

## Practical steps

There are various strategies to overcome these barriers. The following recommendations are drawn from a DfES/DH report on disabled children in residential placements.<sup>14</sup>

- *Multi-agency working*
  - Improved multi-agency planning and service provision;
  - Multi-agency assessment for all children before a decision is made to place residentially;
  - Multi-agency guidance developed about the review, support and contact with families for children in residential placements;
  - Combined reviews of children's statement of SEN and care plan.
- *Data collection*<sup>15</sup>
  - National data on all disabled children living away from home, from health, education and social care, collated and published to provide local authorities and PCTs with a full picture;
  - Data on pupils in residential schools to be collected annually and links to pupil outcomes developed.<sup>16</sup>
- *Implications for Service Planning*
  - A regional audit of specialist provision to be carried out;
  - A record of all disabled children in residential placements - whether funded by social services, health, or education - to be held by each authority;
  - Data from individual assessments to be used to inform local and regional planning.

## Progress

Although there is still a long way to go to improve the outcomes of this group the government is making inroads in this area.

- **"Every Child Matters"** made a commitment to protecting children at risk and offering young people a joined up response from services;

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<sup>13</sup> Stalker et al (2003) "Children with complex support needs in healthcare settings for long periods", JRF.

<sup>14</sup> DfES/DH (2004a). It should be noted that these measures could also benefit children in other settings and other age groups.

<sup>15</sup> The need for improved data collection systems is identified throughout this paper. More accurate data would not only help in terms of identifying need and planning services, but may also help to highlight groups or areas which may benefit from preventative measures.

<sup>16</sup> Where pupils are in LEA residential schools this is possible as links can be made between PLASC (Pupil Level Annual Schools Census) to their attainment data – the NPD (National Pupil database). However, it is not yet possible for pupils in non-LEA maintained schools.

- Some progress is being made in terms of inspection - inspection of residential schools is being carried out as part of the Joint Review; OFSTED, CSCI (Commission for Social Care Inspectorate), and the Healthcare Commission<sup>17</sup> are setting up a **joint inspection framework**
- The **Children's NSF** sets standards which are aimed to help this group: where children are placed in residential settings, local protocols are in place for maintaining family contact and undertaking statutory reviews in line with the *Children Act 1989* Regulations<sup>18</sup>. Children placed away from home will have a communication plan that ensures that, whatever their level of communication, their basic needs are understood and met.<sup>19</sup>

### 1.1.2 Disabled adults living in residential settings

This section focuses primarily on the current situation for learning disabled adults living in residential settings. This group has been identified as particularly marginalised because of their segregation from the community.

- There are an estimated 622 adults with a learning disability still living in NHS long stay hospitals<sup>20</sup>. The Government made a commitment in *Valuing People* to close all the remaining long stay hospitals by April 2004 but this deadline has been missed and the hospitals have been given new deadlines<sup>21</sup>. A report by Turning Point criticised the government for not providing additional funding or additional support to NHS Trusts and social services to make changes happen locally. It argues that many areas have seen successful closures, but that this has been through the commitment and drive of local agencies<sup>22</sup>.
- A debate about long-term hospital care for learning disabled people is being reopened by the rapid expansion of units run by the private sector. Estimates suggest that there are now more than 1,000 places in such hospitals, with provision having grown 50% in the past three years<sup>23</sup>. Since *Valuing People*, a PCT can be penalised for keeping somebody long-term in an NHS facility, however, the same rules do not apply for keeping somebody in a private hospital.

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<sup>17</sup> The Healthcare Commission's legal name is the Commission for Healthcare Audit and Inspection (CHAI). It was formed by the Health and Social Care (Community Health and Standards) Act 2003 and launched on April 1st 2004.

<sup>18</sup> Department of Health (1991) "The Children Act 1989 – Guidance and Regulations", The Stationary Office.

<sup>19</sup> DH/DfES (2004b) op cit.

<sup>20</sup> Stephen Ladyman, Written Answer to Questions, 6th May, 2004, Vol 24, Part No 81. (Hansard).

<sup>21</sup> Each remaining hospital now has an individually agreed closure date between now and April 2006, Ibid.

<sup>22</sup> Turning Point (2003) "Time to move on: A hospital is not a home".

<sup>23</sup> "21st Century Asylums?" (2004), Premium Publishing cited in Brindle (04/08/04) "The ethics of care culture", cited in the Guardian.

## Key Barriers

Research highlights the risks involved in keeping learning disabled adults away from friends, family and the wider community

- There are no reliable statistics to show the prevalence of this problem. But, one study describes how local authorities place learning-disabled adults in out-of-area settings far from their original homes, and then fail to visit them regularly to check their welfare<sup>24</sup>. Key factors which increase the risk of abuse are:
  - Failure of **care managers** to visit vulnerable adults
  - Placing the adult in a setting **far from** his or her **original home**, friends and family and care manager

## Practical steps

Key recommendations from Turning Point's study into long-stay hospitals include:

- **Close** all the remaining **long-stay hospitals** and move people into appropriate accommodation in the community by no later than December 2004;
- This target should be reflected in the **priorities** of Strategic Health Authorities, NHS Trusts, social services and housing departments. It should also be one of their **performance indicators** so that they can be held to account and their progress in meeting the target can be regularly monitored and evaluated;
- The Healthcare Commission and the Commission for Social Care Inspection should **evaluate and regularly report** to government on progress made<sup>25</sup>.

### 1.1.3 The prison population

#### **There are disproportionately high rates of mental illness amongst the prison population<sup>26</sup>**

Key findings from the Survey of Psychiatric Morbidity Among Prisoners in England and Wales<sup>27</sup> showed that:

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<sup>24</sup> Learning Disability Review (2004) "The Frequency and Potential Consequences of the Failure to Visit Learning-Disabled Adults in Out-of Area Placements".

<sup>25</sup> Turning Point (2003) op cit.

<sup>26</sup> Numerous studies have also shown offenders have a significant higher likelihood of experiencing mental health problems and substance misuse and social exclusion than the general population.

<sup>27</sup> ONS (1999), <http://www.statistics.gov.uk/pdfdir/drugs0799.pdf>.

- The proportion of respondents with significant neurotic symptoms, such as anxiety, depression and phobias, in the week before interview were far higher than that found in a similar household survey and ranged from 39% of male sentenced to 75% of female remand prisoners.
- Fourteen per cent of women, 10% of men on remand and 7% of sentenced men in a follow-up clinical interview were assessed as having a functional psychosis (such as schizophrenia or manic depression) in the year prior to interview.
- Women were about twice as likely as men to report having received help for mental or emotional problems in the year before coming to prison<sup>28</sup>.
- Mental health problems can also undermine the chances of successful rehabilitation, as they can exacerbate significantly the difficulties many offenders find in coping with the demands that leaving prison places on them.<sup>29</sup>

## Key Barriers

*Key barriers identified in the Reducing Re-offending Action Plan pointed to unmet health and support needs*

- In the community, offenders are also disproportionately **without GPs**, and access to **psychiatric or psychological services** is difficult to secure.
- There is little incentive for **mainstream mental health services** to work with prisons on **assessment and resettlement** of offenders.<sup>30</sup>

## Progress

- The Correctional Services and Department of Health have a **joint target to reduce suicide and self harm** within prisons by 20% by 2010. By 2006, NHS mental health in-reach services will be available in all prisons, with health services commissioned by local primary care trusts.
- Funding has been made available from the NHS budget to introduce **multi-disciplinary teams** to provide mental health services for prisoners, along the lines of the community mental health teams. The NHS Plan calls for 300 additional NHS staff providing mental health services in prisons by the end of 2003-04, and there will be further expansion of the scheme in the period 2004-2006.

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<sup>28</sup> Women in prison tend to place greater demands on medical services, with high levels of depression and personality disorders, prevalence of self-harm, histories of drug and alcohol abuse and physical ill health generally. Home Office (2004) "Reducing Re-offending: National Action Plan".

<sup>29</sup> Home Office (2004) op cit.

<sup>30</sup> People from some ethnic minority groups can be particularly affected by the level of mental healthcare available in the criminal justice system. For example, people from black and ethnic minority communities make up 21% of the male prison population (between two and three times the proportion in the general population). SEU (2004) "Mental Health and Social Exclusion" p48. Herein referred to as "SEU report" in the main text.

## 1.2 People with high support needs, a range of impairments and/or multiple disadvantage

This section looks at adults with multiple needs and disadvantage, such as substance misuse or homelessness in addition to their mental health condition.<sup>31</sup>

### 1.2.1 The homeless population

The picture from research into the health of homeless people shows that:

- Over 75% of rough sleepers in London had used a drug and around a half of rough sleepers were dependent on a drug (excluding alcohol);<sup>32</sup>
- Around 48% of single homeless people have multiple needs, e.g. they have a mental health support need plus one or more other issue, such as alcohol or drug misuse;<sup>33</sup>
- One study indicated that homeless people with mental illness and substance dependency are five times as likely to have lost contact with caring agencies as those who were not similarly dependent;<sup>34</sup>
- Children of families who have experienced homelessness and are in temporary accommodation are at increased risk of a low birth weight<sup>35</sup> and greater likelihood of illness<sup>36</sup>, behavioural problems and delayed development;<sup>37</sup>
- Suicide accounts for one in four deaths of homeless people<sup>38</sup>. Studies have consistently shown that between 30 and 50% of rough sleepers have mental health issues<sup>39, 40</sup>;

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<sup>31</sup> There are a wider range of factors which can create complex needs than there is space to fully discuss here. These include low income, lack of English language skills, experience of discrimination and poor health (which may or may not be related to the disability in question). It should also be noted that people can experience any number of these disadvantages, and the disadvantages experienced can change over a lifetime. Transitional points in disabled people's lives can be especially problematic.

<sup>32</sup> Fountain, J., Howes, S., Marsden, J. and Strang, J. (2002) "Who uses services for homeless people? An investigation amongst people sleeping rough in London" *Journal of Community and Applied Social Psychology*, Vol 12, pp71-75.

<sup>33</sup> Homeless Link Survey (2002) "Supporting People with multiple needs"  
<http://www.homeless.org.uk/db/20021216183953>.

<sup>34</sup> Keene (2001) "Clients with Complex Needs" Blackwell Science.

<sup>35</sup> Quilgars, D. (2001) "The Incidence and Impact of Homelessness" in Bradshaw, J (ed) (2001) "Poverty the Outcomes for children", London, Family Policy Studies Centre Occasional Paper 26.

<sup>36</sup> Hutchinson, K. (1999) "Health Problems of Homeless Children" in Vostanis, P. and Cumella, S. (ed) "Homeless Children: problems and needs", London: Jessica Kingsley.

<sup>37</sup> Quilgars, D. (2001) op cit.

<sup>38</sup> Mental Health Foundation (1997) "Fundamental Facts: Suicide And Deliberate Self-Harm", Briefing No. 1. London.

<sup>39</sup> S Griffiths, (2002) "Addressing the Health Needs of Rough Sleepers", London, Office of the Deputy Prime Minister. It should be noted that causal factors work both ways (which increases likelihood of the two characteristics being present together i.e. homelessness can cause mental ill health and mental ill health can result in homelessness).

- Around nine % of applicants accepted by local housing authorities in England as being owed a main homelessness duty are considered to have a priority need for accommodation because they are vulnerable as a result of mental health problems. And 5% are considered in priority need because of a physical impairment.<sup>41</sup> This is a national average, and hides the fact that in some areas the figure can be much higher, for example in one London Borough priority need acceptances due to mental health problems is as high as 22%.<sup>42</sup>

## Key Barriers

Key barriers drawn from research highlight the inaccessibility of health services for this group.

- Despite the level of need, many homeless people experience difficulty in accessing **health services**. GPs receive no payment for people using their practice for less than three months, creating significant disincentives to register homeless people, including those in temporary accommodation. Some homeless people also have difficulty registering because of the belief that they need a permanent address or the perception by others that they may be difficult. A combination of these factors mean that:
  - homeless people are 40 times more likely than the general population not to be **registered with a GP**<sup>43</sup> relative to the rest of the population and are four times more likely than the general public to turn to Accident and Emergency services if they cannot access a GP;<sup>44</sup>
  - **primary care registration rates** vary between 24% and 92% for homeless people, the former described in a study of rough sleepers<sup>45</sup> and the latter in families in bed and breakfast accommodation.<sup>46</sup>

## Practical Steps

Many of these possible solutions are taken from the Shelter website

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<sup>40</sup> B Gill, H Meltzer, K Hinds and Mark Petticrew (1996) "Psychiatric morbidity among homeless people" London, The Stationery Office. This survey found that an estimated that 60 % of people staying in night shelters and 57% of people sleeping rough using day centres had symptoms indicative of common mental health problems and that almost a half (43) were positive on at least one of the psychosis sift criteria.

<sup>41</sup> ODPM (2004), Table 4, Homeless households in priority need accepted by local authorities, by priority need category, <http://www.odpm.gov.uk/pns/pnattach/20040136/4.xls>.

<sup>42</sup> It also important to bear in mind that the statistics record the primary reason for being accepted as in priority need, and that mental ill-health or physical disability may be a secondary factor in the other priority need categories.

<sup>43</sup> Crisis Media Brief, 2002 <http://www.crisis.org.uk/pdf/gpmediabrief.pdf>.

<sup>44</sup> Wake (1992) Homelessness and Street Drinking. London Arlington Housing Association.

<sup>45</sup> Ledington S, "Sometimes it makes you frightened to go to hospital... they treat you like dirt" Health Services Journal. 1989 11: 21-22

<sup>46</sup> Victor CR. Health and Lifestyles of homeless people; Health Educ J 1993; 52 – 79-84

- Ensure there is a **named strategic level lead** on health and homelessness in Housing Services and in the Primary Care Trust;
- Ensure that the **health, housing and support needs** of homeless people and those vulnerable to homelessness are reflected in the Local Authority **Homelessness Strategy** and in the Local **Health Delivery Plan**, and that these are reflected in service provision and front-line delivery;
- Ensure there are **PMS** (Personal Medical Services) and **NES** (Nationally Enhanced Services) for homeless people, as well as giving guidance to **GPs** on registering homeless people;
- Develop **resource packs on homelessness** services and resource packs on health services and health services for people living in temporary accommodation;
- Ensure **multi-agency teams** are established to carry out health needs and vulnerability assessments, and undertake care and resettlement planning;
- Develop protocols between **health and housing services**, on joint training/development, information collection and sharing, and on hospital admission and discharge.

## Progress

- Some progress has been made in tackling and preventing homelessness. ODPM's **Homelessness and Housing Support Directorate** (HHSD) is responsible for developing and supporting new ways to tackle and prevent homelessness, and for enabling vulnerable people to live more independently through the **Supporting People (SP) Programme**.
- The SP Programme enables vulnerable people<sup>47</sup> to move to or maintain independent living. This can include people who need to access a home as well as people at risk of losing their home through inability to manage their housing.
- HHSD has been successful in tackling the worst manifestations of homelessness by **reducing rough sleeping** and the use of B&B hotels for families with children.
- HHSD is working with the Health and Inequalities Unit and NIMHE to **raise awareness** of and address the health issues facing homeless people or those who are vulnerable to homelessness, and has issued **joint guidance** to local authorities, PCTs and other health providers on developing shared positive outcomes in health and homelessness<sup>48</sup>.

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<sup>47</sup> This can include people with physical and / or sensory disabilities, people with mental health needs and people with learning disabilities.

<sup>48</sup> "Achieving positive shared outcomes in health and homelessness" (April 2004)  
[http://www.odpm.gov.uk/stellent/groups/odpm\\_homelessness/documents/page/odpm\\_home\\_027792.hcsp](http://www.odpm.gov.uk/stellent/groups/odpm_homelessness/documents/page/odpm_home_027792.hcsp)

## 1.2.2 People with learning disabilities, high support and multiple needs<sup>49</sup>

People with severe learning disabilities often have complex and high support needs. At the same time they may be experiencing social exclusion, such as living in poor housing, with few opportunities for meaningful activity and leisure.

*The Foundation of People with Learning Difficulties estimates that:*<sup>50</sup>

- 230,000 - 350,000 people have severe learning disabilities;
- Approximately £4.6 billion is spent each year to provide formal services for children and adults with learning disabilities in the UK;
- 25-40 % of people with learning disabilities also have mental health problems;
- It is estimated that 30% of people with severe learning difficulties are at risk of developing epilepsy, rising to 50% among those with profound learning disabilities<sup>51</sup>.

### Key barriers

The evidence suggests that people with learning disabilities are one of the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who provides their personal assistance. Particular barriers that have been cited are:

- People with learning disabilities have a high level of **unrecognised illness** and have **reduced access** to generic preventative screening and health promotion procedures;<sup>52</sup>
- Forty seven per cent of adults with learning disabilities have experienced **verbal abuse and bullying**;
- **Social isolation** remains a problem for too many people with learning disabilities. A recent study found that only 30% had a friend who was not either learning disabled, part of their family or paid to provide personal assistance for them;<sup>53</sup>
- **Employment** is a major aspiration for people with learning disabilities, but less than 10% nationally are in work, so most people remain heavily dependent on social security benefits;<sup>54</sup>
- Many people with learning disabilities have little **choice or control** over their lives. Recent research shows only 6% of people with learning

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<sup>49</sup> Section 1.1.2 dealt with a distinct group of disabled adults still living long-stay hospitals, however many of the practical solutions offered in this section could equally apply them.

<sup>50</sup> The Foundation of People with Learning Difficulties (2001) "Fundamental Facts: All The Latest Facts and Figures on Learning Disabilities".

<sup>51</sup> This compares with 0.5% for the general population and 5% for people with mild or moderate learning disabilities. Valuing People (2001) op cit. p101.

<sup>52</sup> Research has highlighted inadequate diagnosis and treatment of specific medical conditions such as heart disease, hypothyroidism and osteoporosis, Ibid p60.

<sup>53</sup> "The Quality and Costs of Residential Supports for People with Learning Disabilities, Summary & Implications" (1999), Hester Adrian Research Centre, University of Manchester.

<sup>54</sup> DH, "Valuing People: A New Strategy for Learning Disability for the 21st Century" (2001) White Paper, The Stationary Office, p19.

disabilities have control over who they lived with and 1% over a choice of personal assistant;<sup>55</sup>

- **Day services** frequently fail to provide sufficiently flexible and individual support;<sup>56</sup>
- **Inconsistency in service provision** – evidence shows that there is inconsistency and inequity for people with learning disabilities;<sup>57</sup>
- A key issue for service provision and support is the lack of information about the numbers of people with high individual support needs. The current lack of information means that their needs are not always taken into account when planning or commissioning services.

## Practical steps

The practical steps given below are derived from a Social Services Inspectorate report<sup>58</sup> and may also be highly relevant to other groups covered by this paper.

- **Integrated Services** – co-ordinating services responses/solutions across the multiplicity of agencies/professionals that are involved in the life of a person with complex disabilities;<sup>59</sup>
- **User Empowerment** – enabling people with profound intellectual impairment and limited ability to communicate, to express their views and assume as much control of their lives as possible;
- **Life Planning** – ensuring continuity of service toward agreed goals throughout the life of an individual with complex multiple disabilities;
- **Specialist support** – delivering expert services from a range of disciplines to meet a multiplicity of needs;

A more recent example is taken from Valuing People which is built around the key principles of Rights, Independence, Choice and Inclusion. It offers proposals intended to:

- Give people with learning disabilities more **choice and control** by developing advocacy, extending direct payments and including a national framework for promoting a person-centred approach to planning;
- Enable all people with learning disabilities to have access to a health facilitator and to have a **Health Action Plan**;

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<sup>55</sup> Ibid.

<sup>56</sup> Ibid.

<sup>57</sup> DH (1999) "Finding the Facts: Services for People with Learning Disabilities – A Policy Impact Study of Social Care and Health Services" surveyed 24 local authorities and found variations in social services expenditure, attendance at day centres, short break services and publicly funded education.

<sup>58</sup> SSI (1995) "Planning for Life: Developing community services for people with complex multiple disabilities", No. 2 - Good Practice in Manchester, DH.

<sup>59</sup> The Valuing People White Paper (2001) also promotes effective partnership working at all levels.

- Enable disabled young people to have **equal opportunities** for moving into adult life.

## Progress

- As mentioned above, *Valuing People* outlines a strategy for learning disability services and requires that local Partnership set up a framework for **person centred planning**.<sup>60</sup>
- The White Paper highlights the for a **highly skilled workforce**.<sup>61</sup>
- It also includes key actions in health such as the development of local specialist services for people with severe and challenging behaviour to be a priority for the capital element of **the Learning Disability Fund**.
- **In Control pilots** are part of the implementation of *Valuing People*. The main focus of In Control's work is how self-directed support can work for people with learning difficulties.

### 1.3 People with mental health support needs<sup>62</sup>

A recent Social Exclusion Unit report (2004) highlighted the extent of social exclusion experienced by people with mental health support needs:

- Although many adults with mental health problems want to work, fewer than a quarter actually do.
- Mental health problems are estimated to cost the country over £77 billion a year through the costs of care, economic losses and premature death.<sup>63</sup>
- Over 1m working age adults in GB claim incapacity benefits for mental health conditions. This group is now larger than the total number of unemployed people claiming JSA.<sup>64</sup>
- GPs spend a third of their time on mental health issues. Prescription costs for anti-depressant drugs have risen significantly in recent years<sup>65</sup>, and there are significant variations in access to talking therapies.

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<sup>60</sup> A key tool which takes on the whole person, their goals and the support needed to achieve them.

<sup>61</sup> An estimated 75% of staff are unqualified. *Valuing People* (2001) op cit.

<sup>62</sup> Black and minority ethnic groups; refugees and asylum seekers; gay men, lesbians and bisexuals with mental health support needs are discussed separately in Section 1.6 which looks at groups who also experience other sources of discrimination.

<sup>63</sup> The costs also include reduced quality of life. The costs of mental health problems in England comprise: £12.5 billion for care provided by the NHS, local authorities, privately funded services, family and friends; £23.1 billion in lost output in the economy caused by people being unable to work (paid and unpaid); £41.8 billion in the human costs of reduced quality of life, and loss of life, amongst those experiencing a mental health problem. The Sainsbury Centre for Mental Health, Policy Paper 3: "The economic and social costs of mental illness" (2003) London.

<sup>64</sup> Admin Data (May, 2004).

<sup>65</sup> Department of Health Prescription Cost Analysis System.

- Depression, anxiety and phobias can affect up to one in six of the population at any one time<sup>66</sup>, with the highest rates in deprived neighbourhoods.<sup>67</sup>
- Social isolation is an important risk factor for deteriorating mental health and suicide. Two-thirds of men under the age of 35 with mental health problems who die by suicide are unemployed.<sup>68</sup>

## Key Barriers

The SEU report identified the main reasons why mental health problems often lead to and reinforce social exclusion, the most significant of which are listed below.

- The underlying causes of social exclusion include **stigma and discrimination**. Despite a number of campaigns, there has been no significant change in attitudes.<sup>69</sup> Fewer than four in ten employers say they would recruit someone with a mental health problem.<sup>70</sup> Many people fear disclosing their condition, even to family and friends.
- **Professionals** across sectors too often have **low expectations** of what people with mental health problems can achieve.
- **Unclear responsibilities** and a **lack of co-ordination** between agencies, a narrow focus on medical symptoms, and limited support to return to work.
- **Personal Capability Assessment (PCA)** assesses an individual's ability to carry out a range of activities. The test has two parts, a physical test and a mental health test. Concerns have been raised about the mental health aspect of the PCA<sup>71</sup>.
- Mental health problems can lead to a **vicious cycle of social exclusion**, including unemployment, debt, homelessness and worsening health. With the right support this cycle can be broken.

## Practical steps

Early intervention has been shown to be particularly effective in preventing social exclusion.

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<sup>66</sup> Singleton, N, Bumpstead, R, O'Brien M, Lee, A and Meltzer, H (2001) "Psychiatric Morbidity Among Adults Living in Private Households, 2000", The Stationery Office.

<sup>67</sup> SEU (2004) op cit.

<sup>68</sup> Department of Health (2001) "Safety First: Five year report of the national confidential inquiry into suicide and homicide by people with mental illness".

<sup>69</sup> Taylor Nelson Sofres (2003) "Attitudes to Mental Illness 2003 Report", Department of Health/Office for National Statistics.

<sup>70</sup> Manning, C & White, PD (1995) "Attitudes of employers to the mentally ill" Psychiatric Bulletin, Vol 19, pp541-543.

<sup>71</sup> There is evidence that mental health issues are given insufficient or in some cases, no attention in Personal Capability Assessment interviews. A high percentage of failed Personal Capability Assessments succeed at appeal, 44% in 2002. Citizen's Advice Bureau (2004) "Response to SEU Consultation on Mental Health and Social Exclusion".

- Breaking the cycle requires a focus on **early intervention**, and fulfilling people’s aspirations and potential through **work and social participation**.
- Mental health problems do not have to trigger social exclusion. With early intervention and effective support, many more people can **retain their jobs** and **social contacts**.
- **Individual Placement and Support** programmes in the US have achieved employment rates of over 50% among people with severe mental health problems.<sup>72</sup>

## Progress

“Pathways to Work” incapacity benefits reform pilots offer a comprehensive package of return to work support. Subject to the further roll out of the Pathways Model, the specific needs of adults with mental health problems will be addressed by:

- Testing the impact of longer periods of support following return to work;
- Building strengthened partnerships between relevant agencies.<sup>73</sup>

The SEU report (2004) sets out an action plan to combat discrimination. The aim is to bring together the work of government departments and other organisations in a concerted effort to challenge attitudes, enable people to fulfil their aspirations, and significantly improve opportunities and outcomes for this excluded group.<sup>74</sup>

## 1.4 People with severe communication impairments

This section focuses primarily on children with little or no verbal speech but it is recognised that this is only a sub-group of people with severe communication impairments

- According to the DDA definition<sup>75</sup> there are an estimated 300,000 children with significant communication difficulties (through speaking, listening, reading or writing). This represents almost half (44%) of all DDA disabled children.

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<sup>72</sup> This model is also starting to be implemented in the UK for example at South West London and Maudley NHS Trust.

<sup>73</sup> Such as Jobcentre Plus and mental health services, including provision of outreach advice on employment in health settings.

<sup>74</sup> The following relevant action points are set out in the SEU report: stigma and discrimination – a sustained programme to challenge negative attitudes and promote awareness of people’s rights; the role of health and social care in tackling social exclusion – implementing evidence-based practice in vocational services and enabling reintegration into the community; employment – giving people with mental health problems a real chance of sustained paid work reflecting their skills and experience.

<sup>75</sup> The group also includes those aged 16-18 years who are unmarried, in full-time non-advanced education and living at home. Family Resources Survey, Great Britain only, 2002-2003.

- The results from the first SEN type data collection in PLASC 2004 only relates to children in maintained schools and Non maintained special schools and does not show the severity. However, as it only applies to children on School Action Plus with statements it can be assumed that they're reasonably severe. It shows that in January 2004 there were 63,890 pupils on School Action Plus or with Statements whose main SEN was classified as 'Speech, Language or Communication Needs'.
- Children with severe autism and minimal speech form one of the most communicatively disempowered groups in our society<sup>76</sup>. The issue of enabling them to communicate spontaneously is a crucial one - and one that deserves to be recognised as a key educational goal.
- Evidence from a JRF study on this group showed that the children could and did communicate spontaneously with others. They used a number of effective ways of doing so, most of which were non-verbal<sup>77</sup>.

## Key Barriers

Key barriers identified in research findings centre on a lack of understanding about this group's communication abilities

- **Common misconceptions** about the communication and interaction abilities of children with autism and little or no speech can mean that these children are not receiving the professional support they need to learn how to initiate communication.
- This is often compounded where the children's **communication environment** does not enable spontaneous communication.
- Teachers in one study<sup>78</sup> argued that the current **National Curriculum** does not recognise the central importance of teaching children with autism with minimal or no speech to communicate<sup>79</sup>.
- **Funding** - parents, education staff and speech and language therapists acknowledge that if funding from CAP (Communication Aids Project) had not been available, many of the children might not have been able to receive communication aids at all.
- The evaluation of the CAP found that the **time** taken from application to CAP for a communication aid to provision of that aid **varies** considerably, with up to a fifth of applications remaining incomplete after 12 months.

## Practical Steps

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<sup>76</sup> Potter and Whittaker (2001) op cit.

<sup>77</sup> The research involved 18 children, 16 boys and 2 girls, who had an average age of 4.5 years. All had a medical diagnosis of autism, and minimal or no speech, and were based in autism specialist classes within 5 special schools in England. Potter & Whittaker (2001) "Creating enabling communication environments for children with autism and minimal or no speech", JRF.

<sup>78</sup> Ibid.

<sup>79</sup> Yet spontaneous communication, and a conventional communication system, plays a key role in supporting children with autism to enjoy their rights as set out in the UN Convention on The Rights of the Child (1989).

- The JRF study discussed above supports the view that the key to achieving this is the creation of **communication enabling environments** within school (and other) settings, using strategies and approaches that are designed to enhance children's own role as spontaneous communicators using systems such as pointing and multi-pointing.

## Progress

- The Communication Aids Project (CAP) manages a process of referral, assessment and provision of additional equipment and technology for pupils in England who have significant communication difficulties. CAP has been operational since April 2002 and is managed for the DfES by the British Educational and Communications Technology Agency (BECTA). It aims 'to help pupils who have communication difficulties by providing technology to help them access the curriculum and interact with others and support their transition to post-school provision'
- Children who had received communication aids from CAP reported positive changes in their functional abilities and quality of life. For example, some of the children reported a decrease in feelings of embarrassment, frustration, and being treated like a baby.

## 1.5 People who have low incidence or the least common impairments

This section covers only a few groups with low incidence impairments. A selection of groups (for which there are studies available) have been chosen, however, and there are common themes that run throughout this section that are applicable to a range of groups with low incidence/the least common impairments

### 1.5.1 The deafblind population

- Many of the UK's 23,000 deafblind population have some remaining hearing and vision<sup>80</sup>. Some, though, have nearly complete loss of both senses.
- Deafblindness creates special needs that cannot be met by services for people who are deaf or blind but not both. In many cases, people born deafblind also have other physical and/or learning disabilities. People with multiple impairments require specialist services geared towards each individual's combination of abilities and impairments.

## Key Barriers

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<sup>80</sup> Sense (1999) Factsheet 1, [http://www.sense.org.uk/word\\_documents/fact1.html](http://www.sense.org.uk/word_documents/fact1.html)

The findings from a Sense & Deafblind UK<sup>81</sup> report are given below. It is based on a major national survey of deafblind people's access to the specialist one-to-one support services they need to be part of society.

- 77% of those deafblind people surveyed said they did not have **specialist one-to-one support** services.
- Only 12% of deafblind people receive a one-to-one support service which meets their needs, while 7.7 % receive some kind of service but need more help or need a **better qualified worker**.
- Lack of access to one-to-one support services results in dependency, **social exclusion and depression**.
- Deafblind people feel they are treated as **second-class citizens** and want one-to-one support as of right.

### Practical steps

In the light of these findings, Sense and Deafblind UK make the following recommendations:

- The right of deafblind people to **specialist one-to-one support** with communication, access to information and mobility for daily living and access to services must be enshrined in law.
- **Intensive one-to-one work** with deafblind children helps them understand the human interaction that is the basis of communication. Deafblind people may use symbols, objects of reference, sign language, braille and other communication systems.
- **Early intervention** with continuing intensive educational support is the key to a deafblind child's future development, and continuing support may be needed throughout a person's lifetime.
- Sense's **specialist training** helps people learn to use their remaining sight and hearing as much as possible. The capacities of other senses - touch and smell particularly - must be developed to the full<sup>82</sup>.

### Progress

- DH has produced a guidance document on deafblindness for London Borough Councils. It details the actions that must be taken by Social Service Directors.<sup>83</sup>

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<sup>81</sup> Sense & Deafblind UK (1999) "Out of this world -Evidence of the systematic exclusion of deafblind people from society", A 'Yes to Access' Campaign Report.

<sup>82</sup> Ibid

<sup>83</sup> <http://www.dh.gov.uk/assetRoot/04/01/27/09/04012709.pdf>

## 1.5.2 People with a Sickle Cell Disorder (SCD) or Thalassaemia<sup>84</sup>

- In the UK groups most at risk of SCDs are people of African-Caribbean origin, who have a one in ten frequency and West Africans, who have a one in four frequency. There are estimated to be over 8000 people with a sickle cell disorder (SCD) and around 600 cases of thalassaemia in the UK<sup>85</sup>.

### Key Barriers

- Caribbean people with sickle cell anaemia have been found to feel that there is a general lack of awareness amongst **medical professionals** of their condition. This is felt to be linked to the fact that the condition generally only affects African and Caribbean people.
- In one study,<sup>86</sup> young people described many examples of **unmet need**. Particular problems include non-recognition of their needs and the support they require; a **lack of information**; and **poor quality care**.
- As a result of **ad hoc screening policies**, children were often not identified until some time afterbirth, and this was a particular problem in SCD.
- The situation was compounded for parents whose first **language** was other than English. The parent's experience also suggests that healthcare agencies do not adequately recognise or meet their **emotional needs**.

### Progress

There is little in the way of evidence in terms of progress made in supporting children, young people and their families with SCD, however the government has announced plans that should go some way towards tackling the problems of ad hoc screening policies identified above:

- In 2000, former Secretary of State for Health, Alan Milburn, announced plans to launch a comprehensive national screening programme to detect thalassaemia and sickle cell disease in pregnant women and newborn babies as well as improved quality and choice in screening programmes for all pregnant women.

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<sup>84</sup> This section has similarities with the discussion on BME groups. Unfamiliarity of the majority white population with these conditions can create difficulty. This was one of the findings in the DWP Report (2003) "Diversity in Disability - Exploring the interactions between disability, ethnicity, age, gender and sexuality".

<sup>85</sup> Atkin K, Ahmad W (2002) "Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia" Centre for Research in Primary Care, Nuffield, Institute for Health University of Leeds, Leeds, UK.

<sup>86</sup> Ibid

- This announcement should mean that by 2003-2004, the Government will be investing almost an extra £15m a year in new screening services for women and children.

### 1.5.3 Technology Dependent Children

- Because of advances in medical technology, more children with chronic conditions are surviving. Technology-dependent children are a sub-set of this group. While technology-dependent children have been grouped together in this section it should be recognised that they are a very diverse group of children in terms of their problems, the associated disabilities, whether the dependence is continuous or intermittent and whether it is permanent or temporary.<sup>87</sup>
- One commonly used estimate of technology dependence has two elements: Dependence on a technological device to sustain life or optimise health, and the need for substantial and complex nursing care for substantial parts of the day and/or night.
- There is no single basis from which to derive an estimate of the number of technology dependent children. Combining data from various sources suggest a conservative estimate of 6,000 children in the UK.<sup>88</sup>
- Major regional variations in the prevalence of technology dependent children are also indicated. These variations reflect regional differences in the incidence of condition, such as extreme prematurity which give rise to technology dependence; and the uneven development of expertise in particular regional children's hospitals.<sup>89</sup>

*Children and Young People Requiring Home Assisted Ventilation are a subset of technology dependent children.*

- It is estimated that there were 141 children in the UK in 1997 using assisted ventilation of whom 93 were living at home. It is not know the extent to which this data is reliable.<sup>90</sup>
- White (2004) *et al* found an increasing number of ventilator dependent children and young people living at home. Almost three quarters of the sample had a physical disability as a result or in addition to their primary diagnosis. There was wide variation in the amount of paid care supporting these families which appeared unrelated to the level of ventilatory dependence.

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<sup>87</sup> Quinton, D, DfES/DH (2004) "Supporting Parents – Messages from Research", Jessica Kingsley Publishers.

<sup>88</sup> National Primary Care Research and Development Centre (1999) " The community-Based Care of Technology Dependent Children in the UK: Definitions, numbers and costs".

<sup>89</sup> Ibid

<sup>90</sup> While, Cockett , Lewis S (2004) "Children and Young People Requiring Home Assisted Ventilation in the South of England: Incidence, Receipt of Care, Support and Components of the Care Package", Children and Society, Vol. 18.

## Key Barriers

The barriers and practical steps<sup>91</sup> can apply to both groups of technology dependent children discussed above:

- **Services** in the community were **not sufficiently developed** to support this group of families. Major problems were identified in the purchasing and provision of both short-term care/home support services and specialist equipment/therapies in the community.
- Service provision could be **poorly planned and co-ordinated** at an operational level and few families had a designated key worker.
- Parents felt that **professionals** did not always recognize either the **emotional costs** entailed in providing care of this nature or their expertise in caregiving.
- **Information-giving to parents** was often described as poor and participants reported that hospital professionals failed to negotiate the transfer of caregiving responsibility to parents.
- The **supply of equipment and medication** was identified as major concern of parents in a study by Quinton. Community health visitors lacked experience in supplying the range of specialist supplies and equipment the children needed. Parents were often left to organise the supplies themselves or to battle with local health agencies for them<sup>92</sup>.
- **Home support** was not always tailored to the children's needs and the availability of local **short-term care** was very much a **postcode lottery**<sup>93</sup>.

## Practical Steps

Kirk and Glendinning (1999) highlight the following recommendations for service commissioners and providers:

- **Specialist equipment** should be purchased and provided in an integrated and efficient way;
- Parents and disabled children should have access to **flexible and appropriately skilled** home care/short-term care services to provide a break in caring for parents;
- Professionals need to **work collaboratively** across health, local authority and voluntary sector services in terms of service commissioning and provision;
- Service delivery should be co-ordinated through a **key worker**;
- **Parent-professional relationships** should recognise parent's expertise in providing specialised nursing care and acknowledge the value of their active participation in their child's care. Principles of partnership should underpin the professional relationship with parents and children;

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<sup>91</sup> Identified by Kirk and Glendinning (1999) "Supporting parents caring for a technology-dependent child" Manchester, NPCRDC.

<sup>92</sup> Quinton, D, DfES/DH (2004).

<sup>93</sup> Ibid.

- There are also a number of potential opportunities for extending the information available from the **Family Fund Trust**<sup>94</sup>;
- Appropriate **professional support** can help reduce stress and facilitate coping by offering information, financial help and emotional support;
- Services need to work in partnership with families and with each other at both strategic and operational levels, to develop **integrated and co-ordinated services** that can meet the needs of this group of families.

## 1.6 Disabled people who also experience other sources of discrimination

Many disabled people experience multiple disadvantage and discrimination<sup>95</sup>

### 1.6.1 Black and minority ethnic communities

- There are 436,489 PSA disabled people who belong to black and minority ethnic groups which is equivalent to 9.6 % of the disabled population are from black and ethnic minority groups<sup>96</sup>.
- Practice guidance for managers and practitioners since the NHS and Community Care Act (1990)<sup>97</sup> and *Community Care in the Next Decade and Beyond* (DH, 1990)<sup>98</sup> contain statements emphasising the importance of sensitivity to the diverse needs of different communities, through appropriate forms of information, assessment and care planning. The reality, however, is that service provision continues to be largely “euro-centric” in nature.<sup>99</sup>

### Key Barriers

Research evidence has highlighted a number of barriers and examples of unmet need in relation to this group:

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<sup>94</sup> A survey could be carried out of those families registered on the Trust database where technology dependence has been recorded; this could cover the types of and reasons for technology dependence, the child's age at onset, duration and likely prognosis. Experience of research on families drawn from the Trust database suggests a high response rate could be anticipated, Kirk & Glendinning (1999) op cit.

<sup>95</sup> It should be noted that it is difficult to separate the effect of discrimination from other aspects of ethnic minority disadvantage.

<sup>96</sup> Annual Local Area Labour Force Survey (2001-02) run by SU on the DWP data set.

<sup>97</sup> This Act emphasised the importance of meeting the health and social care needs of disabled people and their carers in BME communities.

<sup>98</sup> Identified the need for local authorities to make assessment procedures "accessible to people from black and minority ethnic backgrounds", and flagged up the need for some "services of a special type or kind (because) services geared to the requirements of the majority may not always be appropriate" DH, (1990) p26.

<sup>99</sup> Centre for Disability Studies (2000), 'User defined outcomes of community care for disabled Asian people', <http://www.leeds.ac.uk/disability-studies/projects/asiacare.htm>.

- Ethnic minorities may feel they receive **poorer health** and hospital services due to **discrimination**. Some ethnic minority disabled people have criticised the time they had to wait for treatment, the appropriateness of the treatment received and the **attitude of staff**.
- Home support such as ‘meals on wheels’ may not always be **culturally appropriate** or sufficiently sensitive to the needs of different ethnic minority groups.
- Ethnic minorities can face **language** and **cultural barriers** to the take up services related to their disability such as respite care or disability benefits
- Ethnic minorities may feel **alienated from mainstream** (predominantly white) **mental health services**, and so tend to present late to mental health services. They are more likely to receive treatment via criminal justice system route, are more likely to disagree with their diagnosis, and can encounter discrimination on grounds of both health status and ethnicity in seeking work<sup>100</sup>;
- A Sainsbury Centre survey drew the conclusion that many black services users had a **traumatic experience** in acute centre settings and that interactions were frequently confrontational<sup>101</sup>;
- With regards to **Asian communities** in particular, one study highlights how current understanding about the ways in which disabled people and their families from Asian communities wish to have their needs met is limited<sup>102</sup>. Few studies have focused on the **particular experience** of service users from the Asian communities.

## Practical steps

The following steps, from a workshop on direct payments and black and minority ethnic disabled people, were identified as being particularly effective:<sup>103</sup>

- Recruitment of **black staff**;
- **Role models** and **peer support**;
- Race and disability **training**;
- Black **personal assistants** and carers;
- **Representation** of black disabled people;
- Availability of **culturally specific** disability groups and organisations. (One study found that this type of provision was important particularly for older people from BME groups<sup>104</sup>);

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<sup>100</sup> SEU (2004) op cit. It should be noted that The NIHME (National Institute for Mental Health in England) Black and Minority Ethnic programme aims to enhance the quality of life, challenge exclusion through improved mental health services & health outcomes.

<sup>101</sup> Sainsbury Centre for Mental Health (2002) “Breaking the Circles of Fear – A review of the relationship between mental health services and African and Caribbean communities.

<sup>102</sup> SEU (2004) op cit.

<sup>103</sup> Butt, J, Bignall, T and Stone, E.(2000) Directing Support, report from a workshop on direct payments and black and minority ethnic disabled people, York: JRF.

<sup>104</sup> DWP Report (2003) op cit.

- To ensure these steps may be more successful they should be informed by **consultation with communities** about the delivery mechanisms that best meet their needs.

## Progress

- There is work underway in DH and NIMHE (National Institute for Mental Health England) to improve mental health services for ethnic minority groups.

### 1.6.2 Refugees and Asylum Seekers

- In a survey for a JRF study<sup>105</sup>, 44 refugee community groups and disabled people's organisations identified 5,312 disabled refugees or asylum seekers known to them<sup>106</sup>.
- Two-thirds of refugees have experienced anxiety or depression.<sup>107</sup> They might have faced war, imprisonment, torture or oppression in their home country. In their new country, they can experience additional factors linked to poor mental health,<sup>108</sup> including social isolation, homelessness, language difficulties, and racial discrimination.<sup>109</sup>
- Migrants have higher rates of severe mental health problems. Rates of psychosis among white people migrating to predominantly white communities are twice as high as the general population, and four times as high among black people migrating to predominantly white communities.<sup>110</sup>

## Key Barriers

Key barriers identified for this group echo many of the barriers identified for BME groups listed above.

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<sup>105</sup> Roberts, K and Harris, J (2002) "Disabled people in refugee and asylum seeking communities" Published for the JRF by The Policy Press as part of the Social Care: Race and Ethnicity series, <http://www.jrf.org.uk/knowledge/findings/socialcare/962.asp>.

<sup>106</sup> There is no official source of data on the prevalence of impairments and chronic illness amongst refugees and asylum seekers in Britain.

<sup>107</sup> A Burnett and M Peel (2001) "Health Needs of Asylum Seekers and Refugees" British Medical Journal, 322: 544-547.

<sup>108</sup> BL Nicholson (1997) "The influence of pre-migration and post-emigration stressors on mental health: a study of southeast Asian refugees" Social Work Research, 21 (1): 19-32.

<sup>109</sup> N Patel and I Fatimilehin, "Racism and mental health" (1999) in G Newnes, G Holmes, C Dunn, (eds.), This is madness: a critical look at psychiatry and the future of Mental Health Services, (Ross on Wye, PCCS,).

<sup>110</sup> E Cantor Graae and JP Seltén (2004) 'Schizophrenia and Migration: A Meta-Analysis', Schizophrenia Research, 67 (1): 63. FN 38-41 cited in SEU report (2004) op cit.

- Unmet **personal care needs**, unsuitable **housing** and a lack of **aids and equipment**<sup>111</sup>;
- A lack of knowledge about their **entitlements** or how to get a community care assessment, communication difficulties and extreme **isolation**. Most workers in 'reception assistant' organisations lacked knowledge about the disability-related entitlements and needs of refugees and asylum seekers;
- The researchers identified an acute need for **improved joint working** between reception assistant organisations, local authority social services departments and the National Asylum Support Service (NASS).

### Practical steps

Based on these findings, Roberts and Harris recommend:

- **Impairment-related data** should be collected and incorporated into official demographic data sources relating to refugees and asylum seekers. All NASS staff dealing with applications for support should receive full disability and race equality training.
- There needs to be **disability equality training** for those working with refugee and asylum-seeking communities and training to increase professionals' knowledge about entitlements for disabled people in refugee and asylum-seeking communities.
- Future developments in the **asylum process and support services** for both refugees and asylum seekers should specifically address the needs of disabled and chronically ill people.

### 1.6.3 Lesbian, gay and bisexual people

Gay, lesbian or bisexual people with mental health problems, physical or sensory impairments may face double discrimination but because of lack of evidence on this group, this section focuses primarily on those with mental health needs.

In 2003, Mind published the results of the UK's largest ever survey of the mental health of lesbian, gay and bisexual people<sup>112</sup>. Key report findings include:

- Gay men and lesbians reported more **psychological distress** than heterosexual people
- There is also a wide literature exploring the vulnerability of lesbians and gay men to mental health difficulties. It is argued that the pressure to conform to heterosexual roles and values and experiences of

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<sup>111</sup> These issues were common among the 38 disabled refugees and asylum seekers interviewed.

<sup>112</sup> Sample size: 2,400. King (2003) "Mental health and social wellbeing of gay men, lesbians and bisexuals in England and Wales", Mind.

homophobia can lead to episodes of **depression, low self esteem and isolation**<sup>113</sup>.

### Key Barriers

- Many lesbian, gay and bisexual adults with mental health problems feel unable to seek help through traditional services but very **few specialist services** exist to meet their particular needs<sup>114</sup>.
- Experience of **violence and bullying** were more commonly reported by lesbians than heterosexual women.
- Up to 36% of gay men, 26% of bisexual men, 42% of lesbians and 61% cent bisexual women recounted negative or mixed reactions from **mental health professionals** when being open about their sexuality

### Practical steps

- Being able to **choose** a lesbian, gay or bisexual clinician;
- More **specialist services** should be developed to meet this group's particular needs.

An example of good practice is taken from a case study in the SEU (2004) report:

#### ***Box 1.1 PACE, London***

PACE was established in 1985 in response to a need within the lesbian and gay communities for a counselling and support agency that was genuinely responsive to their concerns. PACE is now London's largest provider of mental health and well-being services to the lesbian, gay and bisexual communities. Its range of services includes counselling, groupwork, mental health advocacy, employment, youthwork and family therapy services. All PACE services can be accessed by self-referral.

## **1.7 Disabled parents**

Disabled parents' needs are often marginalised by community care services and are at greater risk of losing their children into care.

The exact number of disabled parents in the UK is not known. According to how they are calculated, estimates range from 1.2 to 4 million parents and are thought to be increasing in number<sup>115</sup>.

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<sup>113</sup> Martin DA & Hetrick ES (1988) The Stigmatisation of the Gay and Lesbian Adolescent. *Journal of Homosexuality*, No.15. Plummer K (1989) *Lesbian and Gay Youth in England* in Herdt G (ed) *Gay and Lesbian Youth*, New York: Harrington Park.

Perry C (1999) *A Qualitative Study of the Life Experiences of Young Lesbian, Gay and Bisexual People in Warrington and Halton: Implications for Service Providers*. CPHRRU: Cheshire

<sup>114</sup> SEU Report (2004) op cit.

## Key barriers<sup>116</sup>

- Disabled parents find it difficult to access **information and advice**, advocacy and peer support;
- Disabled adults sometimes find it difficult to **access their entitlements** to support under community care legislation. This can lead to them having to rely on their children for inappropriate assistance (and their children are labelled by professionals as 'young carers'). The ILF Trust Deed precludes ILF grants being available for assistance with parenting tasks;
- Although assistance with parenting tasks should be available within the current **community care framework**, disabled people are often told that they can only access support through **children and families services**.
- Parents often find they can only get a response from services when things reach a **crisis**, at which point they are at risk of losing their children into care. Mental health policy and practice does not adequately address the fact that many people with mental health support needs are parents<sup>117</sup>.
- Uptake for **direct payments** is low - direct payments can provide the flexible support needed but much work remains to be done to increase the numbers of parents receiving direct payments, particularly those from minority ethnic communities, those with learning difficulties and those with mental health support needs
- Disabled parents experience **unequal access to health** (including maternity) and other mainstream services for parents and their children
- Disability benefits do not take account of the **additional costs of parenting** for disabled adults
- Apart from some good initiatives for sensory disabled parents, few services support disabled parents effectively<sup>118</sup>.
- The 2002 inspections found that support for disabled parents was generally **patchy and under-developed**. Few services were really effective in supporting disabled people in their parenting role and in ensuring that the disabled parent felt able to exercise choice and retain control over their own life and their child's<sup>119</sup>.

## **Practical Steps**

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<sup>115</sup> "A jigsaw of services" - Inspection Of Services to Support Disabled Adults In Their Parenting Role (2000) SSI.

<sup>116</sup> The following evidence is from Morris, J (2000) "The right support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role" JRF.

<sup>117</sup> The SEU report found that parents with mental health problems can have particular difficulties, with adult mental health services not taking their parenting roles into account. Many parents are able to carry out their parenting roles effectively, with appropriate support as necessary, yet a high proportion – 46 % of women and 28 % of men – feel that their parenting abilities have been unfairly questioned because of their mental health.

<sup>118</sup> SSI (2003) "Independence Matters: an overview of the performance of social care services for physically and sensory disabled people".

<sup>119</sup> *ibid.*, p27.

The following practical steps are drawn from a JRF study on supporting disabled adults in their parenting role:

- Clarification of the need to ensure that **parenting tasks** and roles are routinely covered within **community care assessments** and are eligible for adult services.
- Developing guidelines and **good practice materials** nationally in conjunction with disabled parents and their organisations to show how specialist adult disability services can work with children's services using both community care and children's legislation constructively to support disabled parents and their families.
- Targeting resources to support the development of work across **social services divisions** and between relevant agencies, with the intention of establishing a long-term and sustainable basis for funding services to disabled parents and their families.
- Amend the **ILF Trust Deed** to enable ILF grants to cover assistance with parenting task.
- Using **local reviews** and service audits to boost development of services to this group: e.g. by asking the number of disabled adults who have been assisted in parenting tasks and responsibilities.
- An SSI report (Social Services Inspectorate) concluded that there needs to be a **cultural and practical shift** in the approach to working with disabled parents.<sup>120</sup>

## Progress

- The government has invested heavily in recent years in improving support for parents, particularly parents of young children. **Sure Start** aims to provide co-ordinated and accessible services for pre-school children.
- The **SEU** report on mental health contains a number of **action points** to address the need for better support for parents and their children which will improve the support available to parents with mental health problems.

## 1.8 A strategy for reform

There is clearly much common ground between the groups identified in this paper in terms of the key barriers they face (such as unequal access to services, fragmentation between agencies, lack of clear and accessible information, inappropriateness of services in relation to people's needs etc). These barriers are also picked up in the main report on disabled children, young people and people of working age. However, the people identified in this paper have particularly complex, multiple and interlocking needs and will be in touch with a wider range of agencies. For example, the needs of a

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<sup>120</sup> SSI (2000) "A jigsaw of services - Inspection of Services to Support Disabled Adults In Their Parenting Role".

person with a learning disability and mental health condition in addition to substance abuse and living in a deprived area will be of a wider and more complex scope than the population group discussed in the main report. Indeed, people with multiple and interlocking problems will require a particularly personalised response and targeted intervention to meet their 'whole needs'.

Too often services fail to recognise the inter-connected nature of people's physical, social and emotional requirements and many services tend to focus on people's problems in isolation from the rest of their lives. For example, staff in drug and alcohol services may lack the skills to deal with people with mental health problems. It has recently been suggested that the Government's social exclusion policies have been most successful in helping those on the margins of poverty and social exclusion, not in its depths<sup>121</sup>.

The groups discussed in this paper will benefit from the solutions proposed in the main report. But, because of their complex needs, reform is even more important and will potentially need to encompass a wider range of issues than for the 'mainstream' disabled population.

Particularly important issues for the groups identified in this report are:

- **Whole Needs:** An approach of understanding the 'whole person' rather than a single problem should become embedded in every stage of service delivery, from assessment and treatment to aftercare;
- **Creative Whole Systems Services:** Rather than relying on average 'off the peg' methods, service providers need to be encouraged to be flexible and creative in their response to people. The emphasis here is on the flexibility of services to respond to people's needs and it also means that service providers must be willing to take more risks, with new or unconventional approaches. The voluntary sector has been at the forefront of delivering services in a flexible way and can offer a useful model;
- **User empowerment** is another guiding principle which runs through the main report. For people with complex needs the principle is still the same, however, it means that services need to break down professional boundaries to let people manage their own care. The second aspect is active participation on commissioning boards and in the delivery of services<sup>122</sup>;
- Recommendations for a **service navigator** of some sort have been made in the main report whether this is a 'key worker' for disabled children and their families or a 'case manager' for disabled adults looking for employment. However, for someone with complex needs, a service navigator would require knowledge of issues such as

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<sup>121</sup> This point is made by Rankin and Regan, IPPR (2004) op cit. p72

<sup>122</sup> Rankin and Regan (2004) op cit.

substance misuse, mental health issues, learning disability, housing benefits etc as well as an insight into different cultures and the particular problems of offenders and homeless people. Whilst professionals who interact with disabled people with the most complex needs may not be necessarily be specialists in all these fields they should at least have access to a network of people and be able help coordinate an appropriate and coherent package of support for the service user;

- Throughout the main report the importance of collecting **good data** has been emphasised to be able to plan effectively around the population's needs. For disabled people with the most complex needs data collection has to be even more sophisticated to take account of the incidence of combined need. The need for **inter-agency data and records of service overlaps and recurring service use** is even greater for this group than for those identified in Chapters 4-7. Rankin and Regan recommend a statutory duty be put on the NHS and social services departments to collect data on people who use more than one type of health and social care service. This is becoming a priority in future children's services and should be extended on a strategic level to adult services in order to obtain a clear picture of the prevalence of service use;
- The importance of a single **point of entry across health and social care services** is a fundamental part of the vision of meeting complex needs. Rankin and Regan propose that Connected Care Centres should be piloted in deprived neighbourhoods<sup>123</sup>. This would build on the Sure Start children's centres in that they could be situated in the most deprived areas and target those who are most vulnerable to experiencing social exclusion. The precise model for this service would be informed by a local needs audit.

There is no single solution to meeting complex needs. It requires a multi-faceted strategy with participation from government, commissioners, local providers and service users.<sup>124</sup> Extension of the public service reform agenda to those who are hardest to reach will deliver social inclusion for those who are hardest to help.

The Social Exclusion Unit has developed a new work programme, focused on the need to improve service delivery to the most disadvantaged groups. This reflects evidence that more severely or multiply disadvantaged people tend not to use services as much as others do, or to benefit from them as much when they do. A project on working age adults will focus on people with disabilities and long term health problems, people with poor basic skills and people from certain minority ethnic groups - and test service delivery

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<sup>123</sup> Connected care centres could act as a single point of contact in deprived communities to fill the gap between housing, employment, health, social care and area-based regeneration initiatives.

<sup>124</sup> Rankin and Regan (2004), op cit.

mechanisms in real settings. The SEU's new work programme also includes projects on vulnerable older people, frequent movers, young people, ICT and asset inequality.