

Strategy Unit
Improving the Life Chances of Disabled People
Summary of Responses to the Final Report

26th July 2005

This paper is a summary of the views received. It does not represent the views of the Strategy Unit or departments.

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Summary

This paper provides a summary of responses to the Final Report published by the Strategy Unit on 19th January 2005.

- The introduction of the summary is in section 1.
- The purpose of the summary is in section 2.
- General issues raised in the responses received are in section 3.
- Responses to specific key themes are briefly summarised in Section 4 under the following headings: independent living; early years; transition to adulthood; and employment.
- Section 5 is a table listing the names of organisations and individuals who submitted responses to the Interim Report.

All responses, with permission of the author, have been published on the Strategy Unit website at www.strategy.gov.uk.¹

1. Introduction

Responses to the Final Report

The Strategy Unit's Final Report '*Improving the Life Chances of Disabled People*' (referred to in this document as the 'Final Report') was published for comment on 19 January 2005. An initial deadline for comments to be submitted was set for 15th April, but this was extended to 6th May because of unforeseen delays printing copies of the report. This paper takes into account all responses received, including those returned after the extended deadline. The Strategy Unit is publishing the responses and produced this summary of the key themes raised to continue the practice of consultation and publication that was followed throughout the project.

The Strategy Unit has published the responses on its website. Two respondents requested that their submissions be published anonymously. All responses were reviewed carefully by the team and specific points were considered, even if they are not mentioned in this summary. All the responses have been forwarded to the Government departments responsible for taking the report forward.

The Strategy Unit is very grateful to everyone who responded to the Final Report and we would like to take this opportunity to thank again all those who sent responses either to the Interim Analytical Report or the Final Report.

¹ The Strategy Unit has classified as a response any submission specifically prompted by the Final Report. More general correspondence on disability issues has not been included.

The responses provide a valuable assessment of how a diverse audience viewed the report - the aspects which were welcomed and the areas of concern to be considered for the Final Report's implementation.

Overall, the Strategy Unit received 72 responses from 66 different sources. They have been divided according to whether they were sent from an organisation (39) or from private individuals (32). This is the Strategy Unit's interpretation of whether the response was from an individual or an organisation and the author's view may differ. Therefore we recommend that interested parties view the individual submissions on our website (www.strategy.gov.uk) to get a complete picture of the responses.

2. The purpose of this summary

To draw together the wide range of documents and comments received into a manageable package, we have created 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 Strategy Unit's own, and represents the Strategy Unit's interpretation of the responses received. The Strategy Unit has tried to account for as much of the written material as possible, but it is inevitably not possible to fully reflect all the responses that we have received in a summary.

3. General comments on the report

The report was commended by most of the respondents, many of whom welcomed the report as a vital component towards improving all aspects of disabled people's lives. Many responses also welcomed the overarching and cross-governmental approach that has been a feature of the project. A large variety of issues were addressed from the responses that we received and it is not possible to list them all in this summary document. Some of the recurring areas are noted below, but we would again like to encourage the reader to view all the submissions in full in order to get a complete picture of the issues that were raised in response to the Final Report.

Language, definitions and models used in the Final Report

Several respondents welcomed the use of the social model and urged the wider use of this approach for addressing issues associated with disability.

There were concerns that many of the departments and agencies which will be taking forward the recommendations continue to rely on the medical model. The respondents feel that without further explanation and promotion of the social model those who need to implement the report will be struggling to deal with an unfamiliar model.

It was suggested by several respondents that particular impairments were not addressed specifically enough in the Final Report. Their view is that further

work may be needed to address the needs and concerns of specific groups over and above what was detailed in the Final Report.

Vision

The 2025 vision of choice and equality for disabled people was warmly welcomed overall. However, some felt that 2025 is a too long a time frame in which to build a fully inclusive society and certain issues can and should be addressed more quickly. These should give 'quick wins' that would make a more immediate impact on disabled people's lives.

Office for Disability Issues (ODI)

Creating an Office for Disability Issues (ODI) was seen as a vital aspect of the report and critical for ensuring the effective co-ordination of the recommendations of the report across government. However there were some concerns:

- How would staff be recruited and what proportion would be disabled?
- Would there be a diverse representation by those from across the community including disabled lesbians and gay men and disabled people from BME communities?
- Will the ODI have sufficient power to affect change in key departments?
- Why are there no new financial resources at ODI's outset?

Disabled People over 65

Several respondents felt that the exclusion of concerns facing older disabled people from the Final Report was a significant omission from the overall analysis. Particular issues brought up included:

- Retired disabled people may suddenly find they are financially a lot worse off, even if they have a pension, as they are means tested and charged for services.
- Most disabled people are elderly, a trend which will be demographically more significant by 2025.

Disabled Parents

Several of respondents felt that the report had overlooked the needs of families with one or more disabled parents.

Training and Awareness

A number of respondents suggested that training in disability awareness and Disability Equality Training was crucial across the workforce. For example, it was suggested that all those who work with children should have training on working with disabled children.

4. Comments on analysis strands

Comments on Independent Living analysis

Generally the report's recommendations on Independent Living were well received and welcomed by respondents, who agreed that Independent Living is a vital component of improving disabled people's life chances. Respondents were particularly supportive of moves towards personalised budgets to give disabled people choice of service provider. There was also much support for the proposal to establish a national network of Centres for Independent Living, one in each local authority area (recommendation 4.3). Other comments included:

- Connecting health and social care provision is an essential ingredient to achieving independent living for disabled people.
- There is currently confusion as to what services should be funded by health budgets and what services should be funded by social care budgets. This leads to unnecessarily complexity and acts as a barrier to independent living.
- The right to choose where you live is absolutely central to the concept of independent living and equality within society for disabled people.
- There is a role for good quality residential care.
- Charging for community care services by local authorities is a disincentive to disabled people learning, earning and saving because of the costs to the individual.
- User involvement if, fully implemented, will be a major step towards getting the best outcomes for disabled people from public policy.

Definition of Independent Living

A couple of respondents felt that Independent Living needed to be defined more broadly; care needs to be taken that Independent Living is interpreted as supporting disabled people to lead independent lives, and not as meaning less support for disabled people.

Independent Living as an investment

Whilst respondents agreed that expenditure on Independent Living represents an investment that will help shift disabled people out of dependency, it was argued by one respondent that there was not a strong enough 'cost/benefit' analysis in the Final Report to show the economic benefits of expenditure on Independent Living.

Independent Living and Human Rights

Although the economic case for Independent Living is compelling, one respondent argued that the human rights dimension, which cannot be quantified, is an even greater justification for Independent Living for disabled people.

Funding of Independent Living

One respondent questioned whether there will be adequate levels of funding to bring choice over services and means of support; as direct payments and

Independent Living Funds grants are not provided at a level sufficient to deliver full choice and control.

Centres for Independent Living (CILs)

CILs were seen by many respondents as being vital to improving disabled people's life chances and the target of establishing a centre for independent living, run, managed and controlled by disabled people, in every local authority area by 2010 was welcomed. Seventeen respondents unanimously agreed with the concept and detailed below are some further points of consideration which were detailed in the responses:

- The social model approach of CILs needs to be reproduced; otherwise other organisations, who do not subscribe to the social model, will start calling their centres CILs in order to access any funding or contract opportunities that may result.
- There is a need to consider how CILs can be used to disseminate information. Disabled people can only be empowered if they receive the information they need to make choices.
- The best way of ensuring the new organisations are genuinely controlled by disabled people is a high level of input from existing CILs and/or the National Centre for Independent Living (NCIL).
- Information needs to be in a form that encourages and enables its use. There should be national as well as local information available in CILs.
- There is a need to make sure there is BME and gender diversity input into service development in CILs.

Individual Budgets

Several respondents raised the issue of Individual Budgets. Four were supportive. One respondent expressed support for individual budgets because they would eradicate the current "postcode lottery" of entitlement. Another thought that Individual Budgets may offer an exciting and radical route to greater flexibility, transparency and creative approaches to financing housing adaptations and more progressively towards Independent Living. One respondent welcomed the recognition that people should be able to choose between cash and services.

Several other respondents mentioned some issues that they believe need to be addressed with regards to Individual Budgets:

- One respondent expressed concern that agents assisting disabled people to manage individual budgets would have to be highly trained professionals and funding would need to be set aside to pay them accordingly. This would mean less money going to disabled people. Additionally, safeguards would need to be introduced to ensure that agents were scrupulous in their management of clients' money.
- A respondent cited the fact that there is a national shortage of carers and key therapeutic staff which could threaten the feasibility of independent living for some disabled people.

- One respondent questioned whether Individual Budgets are suitable for people with complex needs.
- One respondent argued that there is currently ambiguity over Individual Budgets and therefore there needs to be further clarity about which services can be purchased using this system.
- One respondent expressed concern that young people they had spoken to felt that there wouldn't be sufficient vital support to those taking up the option.
- Another respondent felt they will only be successful if people receive the necessary level of funding to meet their needs.

Direct Payments

A couple of respondents expressed support for Direct Payments, but were concerned about the low take up by people with mental health needs. One respondent acknowledged that Direct Payments can be liberating for some people, but they can also be onerous and oppressive for others. Therefore they recommended that pilot studies are started on the ways that people with learning disabilities and their families can get support to access direct payments if they so wish.

Choice

One respondent argued that choice should include the right not to be compelled to enter into residential care

Housing

Several respondents agreed with Final Report's analysis that housing is one of the barriers to disabled people's life chances because much of the national housing stock is unsuitable for disabled people. It was agreed that economic disadvantages of many disabled people make it difficult for them to meet their housing needs either by buying or privately renting property (page 39) and that unsuitable accommodation is a particular problem for younger age groups and for families with disabled children (page 99).

Many local authorities do not know what accessible housing stock is available or the needs and characteristics of disabled people locally. As a result one respondent argued that there are thousands of disabled people who wait years before finding a house suitable for their needs.

There was support for the recommendation (page 83) that the ODPM, from 2005 onwards, should work with the Disability Rights Commission (DRC), organisations of disabled people, and the Housing Corporation to ensure that investment in initiatives such as neighbourhood renewal, housing market renewal, low-cost home ownership and key worker housing schemes improve housing opportunities for disabled people.

It was argued by one respondent that lifetime home standards have not been sufficiently adopted (page 174). Four respondents recommended that the

government adopt updated Lifetime Homes standards for all new buildings, although one other felt this did not go far enough to meet access needs.

One respondent proposed that the government should consider providing incentives to estate agents and the private housing market to retain adaptations within accessible properties.

Transport

It was agreed by those who mentioned transport issues that it is one of the main barriers for disabled people's life chances. The main points were:

- Several respondents cited that transport needs to be designed so that it is fully inclusive to enable disabled people to benefit.
- The Department of Health needs to encourage local authorities to include transport and mobility needs of disabled people in assessments within the new system of promoting independent living (page 84).
- Emphasis needs to be placed on mainstreaming, so that as wide a range of disabled people as possible have access to all public transport.

Disabled Facilities Grant (DFG)

Several respondents supported a review of the DFG. Many thought that it currently fails disabled people and acts as a barrier to independent living. Some of the reasons given by various respondents were:

- It is inadequately funded.
- It can be used as a cost cutting measure.
- It does not reflect the huge variety of cost of adaptations.
- It should be perceived more as an investment that could save money on social care and health.
- The DFG does not take account of outgoings such as mortgage repayments and expenditure on children.
- The upper limit on grants can lead to adaptations that do not adequately meet the accommodation needs of the disabled person concerned (page 67).
- Cash limits on grants mean that they cannot benefit all who need them.

Comments on Early Years analysis

Respondents agreed that working with families with disabled children at the outset was vital to ensure that the Final Report's vision will be accomplished. Many welcomed the detailed analysis of the challenges faced by parents with disabled children. Many proposals in the chapter were warmly received including:

- The benefits of early intervention and the National Centre for Early Intervention.
- Moves to promote key workers to work closely with parents.
- Inclusive provision in pre-school places.

Further barriers

Some respondents argued that there are further barriers to overcome to ensure that families with disabled children are fully included in society and have a parity of life chances. These are detailed below:

a) Barriers to mainstream schooling

A couple of respondents argued that inclusive provision should be the norm but they were concerned that there continue to be barriers to disabled children attending mainstream schools:

- The Final Report could have usefully alluded to the barriers that face children with a disability who are also highly technology dependent. Specialist community children's nurses can support children in school and enable safe medical interventions.

b) Professionals

Several respondents felt that shortages of key workers needed to be addressed to halt the social exclusion of disabled children:

- One respondent argued that whilst the report acknowledges shortages of professionals such as social workers and speech and language therapists, there are also shortages of specialist children's nurses and occupational therapists.
- Another respondent said that an ability to work with children should become a core competence for all those working with children.

c) Families with disabled children and financial hardship

- One respondent felt that the recommendations in the Early Years chapter do not address solutions to the poverty of families with disabled children.
- Another respondent mentioned that the Disabled Facilities Grant means test does not take into account outgoings such as mortgage repayments or real expenditure on children.

Other Early Years issues

The following points were mentioned by several different respondents:

- Parents may not wish to return to work and hand over the care of the child, particularly if the child faces a shortened life expectancy.
- Children's trusts could play an important role in improving local services for disabled children.
- There is a lack of joined up working in the provision of home respite care. Support in the home is often withdrawn by social services when a child is in need of medical support and often there is no nursing service to replace it.
- Individual budget pilots should also extend to families with disabled children.

- The government's childcare strategy states that every 3-4 year old will have right to free child care by 2010; whereas the Final Report recommends that disabled children will not have this right until 2015. One respondent mentioned this as discriminatory against disabled children.

Comments on Transition to Adulthood analysis

Respondents that mentioned the Transition to Adulthood analysis of the Final Report agreed with the central message of chapter 6 that the benefits of effective early years intervention will be lost if disabled young people's transition to adulthood is not managed effectively. Other transition comments were:

- The proposal to establish a single coherent and accessible service across the age barrier at 18 was welcomed.
- There is a clear need to have support services which are available in a consistent and reliable way throughout this critical transition period.
- The recommendation for extension of children's services up to the age of 25 and the need for research into meaningful day opportunities for young people with the highest level of need were welcomed by one respondent.
- Young people approaching the age of 18 should be involved in planning the services that they will receive as adults in order to ensure that adult services are genuinely responsive to their needs.
- The education system does not currently prepare young adults for employment or independent living.
- Whilst agreeing that information is needed for young disabled people, there was a concern that the Final Report sees the provision of information being directed at parents and families rather than young people themselves.
- One respondent suggested that a publication specifically for young disabled people to address their specific concerns should be made available.
- Young people can feel overprotected and this can make it difficult to become more independent.
- One respondent stated that in a consultation of disabled people, there were concerns about safety when considering a more independent lifestyle.
- The same respondent also cited problems with inter-agency responsibility for communication equipment at the point of transition to adult services.

Comments on Employment analysis

Increasing disabled people's accessibility to employment was welcomed as one of the key issues and a vital component for the achievement of

independent living for disabled people. Respondents agreed that early intervention is critical to labour market retention.

Role of employers

Several respondents stated that there should have been more about the role of employers and less about enhancing disabled people's employability. This would tally more with the use of the social model of disability whereas an emphasis on disabled people's employability was viewed as too oriented towards the medical model of disability.

One respondent argued that the Disability Discrimination Act (DDA) should be strengthened to challenge those employers who discriminate against disabled people.

Rehabilitation and Occupational Health

Several also felt the rehabilitation obligation should fall on the employer as well as employee to help them back to work.

The expansion of Occupational Health services was seen as useful to help work retention by some respondents. However some respondents felt there were Occupational Health issues such as funding, training and mental health which need to be explored further.

Employment Service Providers

A couple of respondents mentioned that Employment Services for disabled people could be improved:

- In Job Centre Plus no-one has any real contact or commitment from employers because there is no incentive to employ disabled people who need support.
- Employment service providers fail to meet the needs of disabled people because of underlying assumptions based on stereotypes and social discrimination.

Disincentives for Disabled People to enter the labour market

Some respondents felt that there are barriers which act as a disincentive to disabled people's entry into the labour market:

- A couple of respondents expressed concern that moving into work might not work out and would result in losing benefits, which is an obstacle to those on Incapacity Benefit.
- The current welfare, tax and benefits system was seen by a couple of respondents as complex and acting as a disincentive for disabled people to return to work.

Pathways to Work

The Final Report endorsed the current DWP initiatives within the Pathways to Work pilots. A few points were raised by a couple of respondents with regards to Pathways to Work:

- Pathways to Work pilots are effective in achieving a greater rate of return to work
- A respondent welcomed the national Pathways to Work roll-out in the DWP five year plan.
- Pathways to Work needs to be carefully evaluated.

Access to Work

The proposal to restructure Access to Work so that by 2010 it can provide a new personalised system of in-work support was welcomed by one respondent. Other individual comments on Access to Work were:

- Access to Work provides critical and cost effective support to disabled people and employers.
- Access to Work support should be a statutory right for disabled people, and funding and publicity for the scheme should be increased.
- Access to Work has improved safety standards for disabled employers
- It should be extended to cover voluntary employment.
- It can be overly bureaucratic and should be more straightforward and made easier for small employers.
- There is a lack of familiarity with Access to Work and it can be inflexible. To be more effective Access to Work needs to look at how to connect Disability Employment Advisors with the experience and knowledge of disabled people and their organisations.
- It can provide inappropriate support. Access to Work can discriminate against certain impairments, for example it will not fund laptops for blind people.
- One respondent expressed a concern about the proposal to consider restricting or removing the ability of government departments to make use of Access to Work.
- One respondent mentioned that employees are usually already in work when they receive Access to Work.

GPs

The importance of the role of GPs in assessing work capability was mentioned by some respondents, particularly with regards to employment. The main points about the role of GPs were as follows:

- They have a challenging role in making informed decisions about the work potential of disabled people.
- The quality of GP consultations is central to any effective job retention strategy. Therefore, the aim to develop the role of GP's in providing advice on fitness for work was welcomed by one respondent.

- There was a concern expressed by one respondent about patient confidentiality (ref p135) when providing health information to a potential employer.
- Currently few GP's receive adequate occupational health training and the Final Report offers new training/skills opportunities to advance access to work as a component of good health.
- Whilst working to enhance the role GPs play in facilitating people who want to return to work to achieve that goal, one respondent noted that GPs don't have any control over people's workplaces.
- One respondent felt that the over-reliance on GPs to assess whether an individual is fit for work is a flaw in the current system.

Other employment issues

Other employment issues that were raised by respondents included:

- Many disabled people are employed in 'menial' work, so equal emphasis needs to be placed on disabled people already in work.
- The employment strategy should have a stronger focus on people with a learning disability.
- There needs to be recognition that work is not an option for every disabled person and that there are many other ways of making a valuable and important contribution to the community and to the economy.
- Skills development is critical to creating sustainable employment opportunities for disabled people.
- Voluntary work could provide a role for integrating disabled people into the labour market.

5. Classification of responses received

Responses from organisations					
(including organisations of/for disabled people; local authorities; housing associations; education institutions; service provision teams; professional bodies; insurance providers; and trades unions)					
	Independ-ent Living	Early Years	Transition	Employ-ment	General /other
Association for Children with Life-threatening or Terminal Conditions and their Families (ACT) and Association of Children's Hospices (ACH)		✓	✓		✓
Action for Advocacy					✓
Age Concern					✓

				✓	✓
Association of Disabled Professionals (1)				✓	✓
Association of Disabled Professionals (2)	✓			✓	✓
Barnardo's on behalf of a coalition of 13 charities ²		✓			✓
Breakthrough UK Ltd	✓				
British Council of Disabled People (BCODP)	✓	✓	✓	✓	✓
British Medical Association Patient Liaison Group				✓	✓
Care Co-ordination Network UK		✓	✓		
Commission for Social Care Inspection (CSCI)		✓	✓		
Council for Disabled Children		✓	✓		✓
Disabled Parents Network					✓
Design Options for a Versatile Environment (D.O.V.E)	✓			✓	✓
Disabled Persons Transport Advisory Committee (DPTAC)	✓				✓
Greater Manchester Passenger Transport Authority					✓
Habinteg Housing Association					✓
Hounslow Homes					✓
John Grooms (1)	✓		✓		✓

² Mencap, Muscular Dystrophy Campaign, Scope, The Children's Society, NCH, Radar, Cbit, Contact a family, Asbah, Disability Alliance, Downs Syndrome Association, Barnardo's, Shelter

John Grooms (2)	✓				
Joint Response from Voice UK, Ann Craft Trust and Respond	✓			✓	✓
Joseph Rowntree Foundation	✓				✓
Kent County Council Social Services Department	✓				✓
Mencap	✓	✓	✓	✓	✓
Mental Health Foundation and Foundation for People with Learning Difficulties	✓	✓	✓	✓	✓
MIND	✓			✓	✓
National Advisory Council to the Thalidomide Trust	✓				✓
National Autistic Society	✓	✓	✓	✓	✓
National Centre for Independent Living	✓	✓	✓	✓	✓
National League of the Blind and Disabled				✓	
Nottingham County Council Social Services	✓		✓		✓
Pre-School Learning Alliance				✓	✓
REMPLOY				✓	
Rethink	✓	✓	✓	✓	✓
Ricability (Research Institute for Consumer Affairs)	✓		✓		✓
Royal National Institute of the Blind (RNIB)					
Scope	✓	✓	✓	✓	✓
Trade Unions Congress (TUC)				✓	
Unison				✓	
UnumProvident				✓	✓

		✓			✓
Whizz-kidz					
Responses from individuals					
(Including people in their capacity as a disabled person, academic, carer, family member etc.)					
Anonymous (1)					✓
Anonymous (2)					✓
Dr John Astbury (1)					✓
Dr John Astbury (2)				✓	✓
Pauline Broad (1)				✓	
Pauline Broad (2)				✓	
Michelle Davey		✓		✓	
Sally Dixon (Disability In Camden) (1)				✓	✓
Sally Dixon (Disability In Camden) (2)					✓
Joanne Freeman		✓			
Roy C Hayter					✓
Stephen Lee Hodgkins (DITO - Disability Information Training Opportunity)				✓	✓
Gill Houghton					✓
Mark Kendall (SRS Technology Group plc)	✓				
W R Knott					✓
G W Kohlinger (1)					✓
G W Kohlinger (2)					✓
Tom Large					✓
Mairi MacNeil					✓
Brian McGinnis –				✓	✓

(Chairman L'Arche UK)					
Rosaleen Moriarty-Simmonds (RMS Disability Issues Consultancy)					✓
William Neil (Direct Payments Scotland)	✓				
Monica Ryan	✓				
Sally Palmer					✓
Ray and Denise Rees				✓	✓
Robina Shah		✓			✓
John Shaw					✓
Maria Smith					✓
Jan Tyne					✓
John Wallace				✓	✓
Carol Wolstenholme (1)					✓
Carol Wolstenholme (2)					✓