



Including Disabled People

Breakthrough UK Ltd.

Policy Think Tank

A response to the
Prime Minister's Strategy Unit Report:
Improving the Life Chances of Disabled People
3rd May 2005

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1. Introduction:

Breakthrough UK Ltd is a successful independent company, managed mainly by disabled people. It brings together disabled people, local businesses, and other agencies to plan and deliver projects and services to promote independence. Based in the North West of England, Breakthrough UK provides training, employment and business opportunities to disabled people within the social model of disability. On average 60-70% of Breakthrough's staff are disabled people, with first hand knowledge and experience of the barriers to independence and employment. We are proud that Breakthrough was cited in the 'Improving Life Chances' report as a good practice example of a social enterprise working in the field of employment and disability.

The Policy Think Tank: this initiative is a response to what we see as a 'policy vacuum' in relation to disability. Its membership brings together a small group of people known to subscribe to the social model, who are known for their analytical approach, and their tendency to stretch the boundaries in a variety of areas. This response to the 'Improving Life Chances' report has been produced collaboratively, with input from many Think Tank members.

The Policy Think Tank has two major aims:

- To influence government, or other strategic bodies, on matters to do with disability, from a 'social model' perspective.
- To provide briefings on current matters to do with disability for general dissemination.

The Social Model of Disability: traditionally disabled people have been seen as a problem, to be tackled by focusing interventions on the individual. Developed by disabled people themselves, the social model locates the problem with the structures and organisation of society, which take little or no account of what disabled people need to be autonomous and to live independently. We are pleased that this report recognises the social model, and urge the government to adopt this approach more widely.

The Policy Think Tank welcomes the publication of this report, and the opportunity to respond to it: we recognise that there is now a major challenge to ensure that the recommendations are turned into reality.

2. Summary Comments:

Overall this is a very positive document and the PMSU, and other contributors, are to be congratulated on an ambitious and broad ranging set of proposals. However, there are several major areas of concern which must be highlighted:

2.1. Independent living as a social and economic investment

This ambitious proposal will falter and fail if independent living is not recognised as a social and economic investment and sufficient resources made available, whether new “invest to save” monies or reallocation / reconfiguration of existing resources, or re-directing funds.

2.2. Definitions:

Clear definitions of disability, impairment and ill health are adopted, and this is to be applauded. However, the report does not always reflect these in its later use of terms and concepts and this inevitably creates a lack of clarity in its proposals, which is particularly apparent in some of the recommendations concerning employment. For example, see 7.2., below.

2.3. Infrastructure:

We recognise the ‘modernising’ agenda, and the scale of the problem. However, the intrusive and time-wasting nature of the various agencies, assessments and services that impact on disabled people’s lives needs to be streamlined and an appropriate infrastructure established. Individual budgets may be an important mechanism but the opportunity has been missed to make far-reaching changes in the way support is delivered and disabling barriers tackled.

2.4. Entitlements:

The ‘rights and responsibilities’ agenda cannot possibly be fulfilled as long as disabled peoples’ right to independent living is dictated by budget considerations.

2.5. ‘Joined up government’:

We welcome the fact that the Department for Work and Pensions, the Department of Health, the Department for Education and Skills and the Office of the Deputy Prime Minister have signed up to the ‘Life Chances’ report and anticipate that those, and other, Government Departments will take on board the ‘Life Chances’ proposals. However, this joined up approach has not been sufficiently extended, within the report’s recommendations, to the funding of independent living. This failing is also reflected in the recent DH Green Paper, “Independence, Well being and Choice”.

3. General comments

We welcome the ‘Improving Life Chances’ report, and congratulate the PMSU both on their approach and their delivery. Overall we find that the Report is very positive and represents an ambitious and broad ranging policy document. There are many welcome features, including:

- The proposal for individual budgets
- The intention that each local authority area should have a CIL-type organisation
- The focus on employers, attitude change and barrier removal
- The inclusion of job retention issues alongside job acquisition
- The support for joined up policy and programmes, particularly those concerning health and employment support
- The inclusion of skills and human capital issues
- A creative engagement with key stakeholders, too often overlooked in national disability policy (e.g the Learning and Skills Councils)
- The establishment of the Office for Disability Issues.

However, there continue to be cardinal weaknesses in the report as it stands and we fear that if these weaknesses are not addressed then implementation will falter and stall.

3.1. Resources:

This is inevitably a difficult subject, with many competing pressures and apparent priorities: at a national level decision-making can be complex and problematic, whilst local decision making can lack consistency.

If resources are to be used effectively then budget allocations and financial decisions must be made with an understanding of their impact and their desired effect. We refer to resourcing issues throughout this response; however four points would seem worth highlighting:

a) Cross sector benefits: these can be positive, but there could also be negative impacts and therefore there should be no financial decisions made without considering the impact on other budgets.

b) Regulatory Impact Assessments: this could be a useful approach for financial – and also operational and qualitative – proposals and would site decisions in a systematic framework.

c) There is a cost to not investing in independent living: for example, most children living in poverty live in a household with a disabled adult, whilst the high amounts paid in Incapacity Benefit are often the economic cost of not employing disabled people.

d) Neither the Strategy Unit's report, nor the Green Paper 'Independence, Well being and Choice', promises an increase in resources. Despite the recognition of 'the costs of disadvantage' in the Strategy Unit's report (page 41), neither initiative has sufficiently acted on the economic case for expenditure on independent living. More economic analysis is required in this area.

We are disappointed that the opportunity has not been taken for a cross-governmental, cross-budget approach to expenditure on tackling disabling barriers. We believe this is the key to freeing up resources to achieve independent living.

3.2. Definitions:

Whilst the introduction to the report lays out clear definitions of disability, impairment and ill health, the report does not always reflect these on its later use of terms and concepts. This creates a lack of clarity in the interpretation of the document, meaning that the definitions and uses of disability terms remain muddled and potentially retrograde. For example: in discussing job retention (page 160) the report uses the terms impairment, sickness and 'individuals with health problems'. It is unclear what the implications of each of these are in rehabilitation terms.

Also of concern is the implication that policy should aim to enable individuals to remain in work longer when sick, or less than fully healthy (page 158) It would seem logical to make a statement on remaining longer in work when an impairment changes, but sickness (florid illness) is a different situation and we urge the government to clarify the distinction. For example, would non-disabled people who are sick be expected to be at work?

3.3. Infrastructure and timescales:

The government must get these two matters right. Firstly, disabled people have to deal with too many different systems. The explicit reference to infrastructure (page 62) is welcome, however there needs to be a stronger emphasis on the fact that the various agencies, assessments and services that impact on disabled people's lives need to be streamlined.

We also recognise that the tasks highlighted in the report are large and have huge implications: we welcome the fact that many recommendations have early deadlines but would urge the government to regularly review the possibility of bringing forward the more distant target dates.

3.4. An entitlement to independent living?

Most disabled people, especially those with a high level of impairment have a fear of being forced into residential care. The report is not strong enough on this issue.

3.5. An employment focus on the individual:

Most of the employment section is given over to 'improving the individual' with not enough emphasis on employer activation (See 7.2. below), and on removing disabling barriers.

4. Independent Living:

4.1. Centres for Independent Living (CILs):

Generally the report has many very positive ideas and an important one for the disabled peoples' movement is the suggestion that CILs are key to the improvement of opportunities for disabled people. However, there are dangers here and if this proposal is to work then it is vital that the ethos and management of CILs is accurately replicated, rather than have other organisations start calling their centres CILs in order to access any funding or contract opportunities that may result.

Existing disabled peoples' organisations could lead on the development of a national system of accreditation to confirm what constitutes a CIL; for example - run by disabled people themselves who promote a social model. This would not be about the standard of advice or services, as the Community Legal Service already have a national quality mark that such organisations can apply for, and at different levels. Neither would this just be about direct payments, but about all aspects of independent living.

It is worth noting that the recent Green Paper does not include mention of CILs. We believe CILs are crucial to the government's aim of independent living and would urge that action is taken to implement the policy of having a CIL in each local authority area.

The report does not address in any detail the need for provision to be culturally appropriate, and there is little reference to diversity. The application of independent living principles will differ among black and minority ethnic (BME) groups, for example, as well as there being gender and age implications. It is important that these groups are closely involved in developing policies and services for their own communities.

4.2. Choice:

The government's current commitment to 'choice' does not extend to giving people the choice not to have to move into residential care. Instead the Strategy Unit have proposed, and the Green Paper implemented, a consultation on:

“the merits of a ‘right to request’ not to live in a residential or nursing care setting, taking full account of the particular issues faced by the individual, and considering the financial, organisational and legal implications of both the status quo and alternative options. This ‘right to request’ would require service providers to make explicit the reasons behind their decision to recommend residential care, including cost considerations.”

(Department of Health, 2005, p.32)

When disabled people and their organisations are consulted about what an entitlement to independent living would look like, the most common response is that it would involve a right to not be forced to move into residential care. Such a right is necessary because, in reality, a forced move happens by default as local authorities cap expenditure on support at home to the costs of residential care, being required to make the most cost effective use of their resources.

The increasing numbers of young people with high levels of needs are also at risk of moving into residential care as they move into adulthood, because support services and housing are often not available to meet their needs. Disabled and older people require firm legal protection if they are to avoid being forced into residential care.

4.3. Housing:

Disabled people do not have access to the same choices and opportunities in housing as non-disabled people: this is especially true for people who use wheelchairs, whether in the public or private sector. This is not taken into account in the report, which does however mention the need to develop the adoption of Lifetime Homes, which is a key area.

As part of the London Plan, all new homes will be built to Lifetime Home standards, whether built by local authorities, registered social landlords or private developers. If this was adopted nationally, it would vastly increase the amount of homes with good accessible features, and should reduce the amount of resources required for aids and adaptations. In addition, it should have a positive effect on the housing market as owners of Lifetime Homes would be able to sell their homes to a wider market.

We urge the government to adopt updated Lifetime Homes standards for all new buildings.

4.4. Disabled Facilities Grants/Aids and Adaptations:

The report suggests that giving individual budgets to disabled people and their families, to include areas such as direct payments, aids and adaptations, etc, would give disabled people more freedom and choice. This is to be welcomed, but there should be safeguards to ensure that it would be used as an investment in independent living and not be used to mask a cost cutting exercise.

Individual budgets will need to reflect the huge variety of costs from one adaptation to another: this will depend on location as well as the individuals' assessed requirements. For example, Hull City Council currently has a budget of over £1 million per year for aids and adaptations, but demand still outstrips supply. In addition, Hull is a very level city, with virtually no hills. Providing ramps and handrails in the City will inevitably be less costly than in areas with more hilly terrain which may therefore need more investment.

The real problem with the DFG system is that expenditure on adaptations is not seen as a form of investment leading to a reduction in expenditure on social care and health. The current cash-limited and means-tested system does not allow for an effective use of public resources. We urge the Treasury to take a cross-budget, cross-departmental approach to the allocation of resources for DFG. We believe this would enable an increase in expenditure on adaptations, leading to a decrease in expenditure on social care and the NHS.

The current means test for DFGs creates a disincentive to employment, particularly for families with disabled children, and leaves many low income households struggling to cope in unsuitable dwellings.

We urge the government to view DFGs as worthwhile social and economic investment and to abolish the means-test for DFGs.

4.5. Resourcing:

Independent living costs must be identified and met: the current work in progress on the cost of independent living by the Disability Rights Commission, the National Centre for Independent Living and the Social Care Institute for Excellence is to be welcomed. However:

- a) All future proposals and policies should include appropriate funding for organisations of disabled people, particularly in the process of delivery and infrastructure of direct payments. This is fundamental to independent living and should be delivered by an overarching body of disabled people. This would be a more efficient use of public resources than expenditure on the current assessment and care management system delivered by social services authorities, which creates a culture of dependency.
- b) Individual Budgets: clearly the borrowing of direct payment principles and attachment to work related choices (funding PAs etc) is a very positive development; however the commitments made in this area are not given clear timelines. Whilst benefit reforms are ongoing, direct payments already exist and are simply an issue for development. Implementation is so far downstream in practice that these ideas might be viewed as 'jam tomorrow'.
- c) "Invest to gain": neither the Strategy Unit's report, nor the Green Paper, promise an increase in resources: as a consequence neither initiative has sufficiently recognised the economic case for expenditure on independent living. Improving Life Chances referred to evidence that increased demands on health and social care budgets can result from a failure to provide housing adaptations or equipment, and that more personalised support can increase people's ability to take up paid employment and fulfil family responsibilities. Yet the implications of this have not been followed through.

In particular the opportunity has been missed to take a more holistic and transparent approach to public expenditure: if the cost implications for other budgets of not increasing expenditure to promote independent living were taken into account the economic case for such increased expenditure would be obvious.

The Green Paper is particularly disappointing in this respect. Not only is there no recognition of the additional resources which could be released by tackling disabling barriers and delivering self-directed support but the opportunity has been missed to promote the role of social care in enabling disabled and older people to fulfil their own family roles and responsibilities, and to participate and contribute as citizens.

d) 'Choice' is not sufficient: the main self determination issue for disabled people is not only about service delivery mechanisms but about whether levels of resources are sufficient to deliver. To a large extent, the promotion of choice in public services has been about models of service delivery and the belief that the private and voluntary sectors should play a bigger role in providing publicly funded services. For example, vouchers for wheelchairs were introduced some years ago but have not delivered the intended choice because of their limited value.

Centres for Independent Living make the same case about direct payments: too often direct payments and ILF grants are not provided at a level sufficient to deliver full choice and control, and the assistance people need to use cash to buy the support required is not always available. Simply giving people 'choice' is therefore not sufficient to enable disabled people to exercise self-determination and be independent.

4.6. The nature of social care:

There is a danger that the implementation of individual budgets will lose touch with the origins of the idea: they are being piloted by the 'In Control' project as a way of changing the organisation of social care "so that people who need support can take more control over their own lives and fulfil their role as citizens" (see www.selfdirectedsupport.org). This is important for all disabled people, whether their support needs are simple or high.

The 'Improving Life Chances' report envisaged both a change in the role of professionals and an increased role for user-led organisations:

The new system would require a cultural shift so that social care professionals are working to promote self-directed support. Such a shift would be encouraged by closer working relationships between health and social care organisations and organisations of disabled people (Prime Minister's Strategy Unit, 2005, p.78)

A key part of bringing about this cultural shift was the proposal that:

"By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing Centres for Independent Living" (p.76).

However, the Green Paper on adult social care makes no such commitment. Past social policy, developed and delivered without the full involvement of disabled people and their organisations, has led to public resources being used in ways which disempower people and deny human rights. These mistakes will be repeated if the involvement of people who need support to go about their daily lives is not placed at the heart of the proposed new system.

5. Early Years:

5.1. Nursery and pre – school:

The provision of nursery or pre-school places must emphasise more strongly that inclusive provision will be expected to be the norm and that "specialist" provision will only be considered when all those involved in the child's life agree that inclusive provision is inappropriate. There should be a policy guidance presumption for inclusive provision.

5.2. "Special":

There is a worry that the term "specialist" becomes a euphemism for "segregated". The government should state clearly its opposition to segregation and its intention that, where disabled children have needs which require additional input, then these additional requirements should be met in a way which does not isolate them from their peers or separate them from the families or communities.

5.3. Inclusion:

The presumption towards inclusion will inevitably be opposed by some, even if not many, carer / parent led groups and traditional non-disabled people-led charities. Bodies such as Children's Strategic Partnerships and Sure Start Partnerships must have guaranteed places for organisations of disabled people and disability Equality expertise, ensured by DFES and DH guidance. Consultation exercises on disabled children's issues must also seek out such groups and perspectives and if, numerically, parent and carer groups outweigh such organisations, there must be weighting to balance out numbers against inequality.

5.4. Assessments:

Actions to address multiple assessment and professional intervention are welcome, as are single points of access.

5.5. Disabled parents:

There is very little discussion in this, or the subsequent chapter, on disabled parents - either with disabled children or not. This is a small but important area with implications for parenting and independent living. Disabled parents experience disadvantage: those with disabled children are often doubly disadvantaged.

6. Transition:

6.1. Inappropriate education and training

The present education system clearly does not equip young disabled people either for independent living or employment. Two recommendations from the National Employment Panel (NEP) 'Able to Work' report are significant here: recommendations 6a and 6b refer to disabled learners and post 16 special educational needs provision. We urge the government to support these recommendations.

6.2. Peer support:

It can be hard for young disabled people to meet socially, particularly in the mainstream, with other young disabled people and enjoy and offer mutual support and sharing of experiences. Innovative projects such as the GMCDP Young Disabled Peoples' project are leading the way in terms of how to tackle this problem.

We urge the government to support and encourage the setting up of such projects.

6.3. Encouraging independence:

Policies and proposals to encourage a smooth move to adulthood must take into account the, perhaps understandable, fears and worries of parents and carers which can be a major barrier to independence.

It can be especially difficult for the parents of disabled teenagers to encourage independence: many factors work to continue the dependency of young disabled people on their families. This can include

- Benefits being absorbed into the family income
- Fear of 'letting go'

Also, there are different cultural perceptions about independence. Independence is generally a very Euro-centric value based on individualism. Some reference needs to be made to the value of inter-dependence which validates a more collective approach. For example, some disabled people may choose to be less dependent because it reflects their cultural value base. An over emphasis on independence is regarded as dysfunctional in some cultures.

7. Employment:

7.1. The involvement of organisations of disabled people

Future policies should include appropriate funding for organisations of disabled people, which have a crucial role in supporting disabled people in employment and training, as well as independent living skills which are inextricably linked. The proposal to rollout Independent Living support

through a CIL structure should also be applied to employment support, using existing successful models such as Breakthrough.

7.2. Weighting:

Whilst the employment section of the Report is based in part on the National Employment Panel report 'Able to Work', this latter report contains much more emphasis on employer activation than the Life Chances report. Of the 33 pages allocated to employment, 26 of these pages relate to individual enhancement and only 7 to employer activity and behaviour; the strength of emphasis of the NEP report on employers has been diluted when reaching the Life Chances report. This is unfortunate, as it detracts from the social model approach which the "Life Chances" report lays out.

Most of the employment section of the 'Life Chances' report is given over to "improving" the disabled person. This is illustrated by comments on the 'problem of unemployment' and the detail of policy focus on enhancing the individual's job readiness. This model has value, but as the predominant policy approach it has proven over the years to have limited value of itself, and ultimately there is a danger that it may simply confirm the established orthodoxy that disabled people cannot work due to personal deficits.

For example the following quotes are unhelpful in this regard:

'There remain pervasive and negative cultural expectations towards working when less than fully healthy' (page 135)

'There are situations where benefit dependency is ingrained in the community or family culture' (page 139)

7.3. Pathways to Work:

Whilst most commentators view the up-skilled and more focused job-support philosophy of Pathways to Work as welcome, the NEP report makes clear the need to mainstream provision and - unlike the NDDP - to go beyond the phenomena of 'permanent' pilots, a contradictory idea in policy terms. Although the pilots have generally been regarded as an early success, data on the outflow and permanency of Pathways clients who enter work would allow a more careful appraisal of the likely success or otherwise of the Pathways pilots (page 157).

7.4. Effective Early Support - Revisions to GP and OH Practice:

GPs have a clear yet challenging role in making informed decisions as to the work potential of disabled people. Their signing of the Hippocratic Oath commits them to trying to avert further 'suffering' and this will apply where disability, impairment and sickness may inter-relate, and if not dealt with appropriately then 'suffering' will be compounded.

The report rightly points to training needs, but the issue of sufficient time and quality of GP consultations is central to any effective job retention strategy. The discussion of the health-employment interface is exciting, but also a concern in the absence of carefully fostered sensibilities about disabled peoples' rights. An unintended punitive misuse of GPs is a danger unless the highest enabling professional standards are maintained.

Whilst discussion of Occupational Health (OH) reform is to be welcomed, the report is short on detail. For example, the use of insurance based approaches to reduce long-term absence is mentioned but little concrete policy reform is suggested. Also, the OH service is viewed as essentially benevolent by the report, but may, if viewed more carefully, be seen as an active part of the problem, that it is essentially an 'occupational sickness' service which will need a fundamental repositioning if it is to support a return to, and retention in work. Questions must also be asked as to whether OH 'experts' are best placed to offer impartial employment advice, as many are far from the mainstream of modern healthcare practice and may not be leading edge practitioners, nor have access to the training required to make the 'shift'.

Finally, we must ask how radical are these proposed changes, and are all the relevant government departments really signed up? For example, if someone's employment is threatened due to an employer's perception of a health problem and by the disruption caused by having to attend health appointments; does this signal the willingness of the DWP and DH to action GPs and NHS Trusts to provide appointments outside normal working hours?

7.5. Access to Work:

This pivotal scheme rightly commands attention in the report. The scheme

has much potential in terms of enhanced working lives, job/work retention and job access. Furthermore, many disabled people cite 'Access to Work' as one of the most helpful supports towards employment.

The evidence marshalled is, however, biased and does not fully acknowledge the less positive aspects of the scheme to date - for example: Access to Work is a misnomer, most recipients are already in work when they apply for support. Moreover, many people report an overly bureaucratic approach which causes tensions at work and delays. More needs to be done to rectify this. The scheme is woefully under-advertised, some would say deliberately so in order to minimise pressure on budgets: this is unacceptable if the into-work rhetoric of policy makers is to be trusted.

We urge the government to ensure action on recommendations 5a and 5b of the NEP report 'Able to Work'.

8. Conclusion:

We have welcomed the 'Improving Life Chances' report, believing it to be a significant step towards ensuring that disabled people have the opportunities to take part in, and contribute to society. Whilst welcoming both the content and the approach of the document, we nevertheless have serious concerns which we have laid out here in what we hope is a constructive and helpful manner. We hope that this response proves useful, and look forward to feedback on our comments.