



Including Disabled People

Breakthrough UK Ltd.

Policy Think Tank

Response to the Government Consultation on:

Office for Disability Issues
National Forum for Organisations of Disabled People
Piloting of Individualised Budgets

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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. On average 60-70% of Breakthrough's 40 staff are disabled people, with first hand knowledge and experience of the barriers to independence and employment. Based in the North West of England, Breakthrough UK Ltd provides training, employment and business opportunities to disabled people within the social model of disability.

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.

The Policy Think Tank: this initiative is a response to what we see as a 'policy vacuum' in relation to disability and the social model. 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 government's consultation on the Office for Disability Issues, the National Forum for Organisations of Disabled People, and Individualised Budgets has been produced collaboratively, with input from many Think Tank members, all of whom are disabled people.

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.

We welcome the opportunity to respond to the current consultation, and hope that our input is welcomed and viewed constructively. We would be delighted to expand on any of the points.

2. Context:

The Prime Minister's Strategy Unit reported in January 2005 on "Improving the Life Chances of Disabled People", outlining an ambitious 20 year vision that:

"By 2025 disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society."

This was a cross-government report and was endorsed by the Department for Work and Pensions (DWP), the Department of Health (DoH), the Department for Education and Skills (DfES) and the Office of the Deputy Prime Minister (ODPM). It contains 3 major recommendations, namely that the following should be established:

1. An Office for Disability Issues,
2. A National Forum for Organisations of Disabled People.
3. Individualised Budgets.

There have been significant advancements and achievements in relation to disability over the last 10 years, including

1. The Disability Discrimination Act (DDA) 1995 and subsequent Acts.
2. The establishment of the Disability Rights Commission.
3. Legislation which set up Direct Payments for disabled people.
4. The Special Educational Needs and Disability Act (SENDA)
5. The forthcoming Disability Equality Duty.

However, there are also real challenges and difficulties which must not be forgotten, for example,

1. The continued dominance and power of large charities in our lives.
2. The struggle that our own organisations have to survive, due to lack of local and central government support; and competition, which often comes from the large charities.
3. The difficulty we have in reaching out to all parts of the disability community, including disabled people from minority ethnic communities and people with 'significant cognitive impairments'

3. Summary Comments:

a) The Office for Disability Issues:

The ODI is not an organisation of disabled people so it cannot represent our views: instead it could commit to develop and model good practice in seeking our views. The ODI needs to play a key strategic role in taking a cross-government, cross-departmental approach to independent living. Most importantly, the ODI must not be seen as a solution, but a means to a truly holistic approach which should lead to the systematic inclusion of disability issues in *all* government departments and polices. The very real danger that other departments will simply leave disability issues to the ODI must be guarded against.

The immediate priorities should be –

- Initiating capacity building in existing disabled people's organisations during the next financial year,
- A clear **delivery** plan for **all** the policies adopted in the 'Life Chances' report:

The medium term priorities should be –

- To identify an early plan for culture change and begin its implementation.
- To address the exclusion of disabled people, and challenge the *incitement* to exclusion that exists.

b) The National Forum for Organisations of Disabled People.

Existing organisations of disabled people must be considered as central to the development of this initiative and they must be fully supported and resourced. The large traditional charities are not appropriate members of this Forum, despite their current efforts to adopt a more rights and equality based approach. An early activity would be a mapping exercise to identify those groups run by disabled people, and subscribing to the social model of disability. Capacity building, delivered by experienced disabled people, will be key to the success of the Forum.

Disabled people are diverse and it will not be possible to represent all views in one body. However a common feature is that far too often family, carers and professionals speak on behalf of disabled people. So the Forum must

avoid taking the view of carers and professionals as being anything to do with disabled people being represented – it is not.

A mapping exercise would help because it would work to avoid the tendency to just involve the usual organisations that always put themselves forward for these kinds of fora. Reaching other people – those who might not leave home, for example, or disabled people from black and minority ethnic backgrounds – will require a dedicated outreach programme, identifying and building on existing successful initiatives. Also, fair representation can only be achieved if involvement is properly resourced: this means reimbursing any costs that individuals and organisations incur as a result of involvement.

c) Individualised Budgets

There has been a lot of emphasis in the ‘Life Chances’ report on the potential effectiveness of addressing needs at an earlier stage of people’s experience of impairment, thus preventing higher costs later on. Budgets such as DLA/AA are arguably one way of doing this, whereas the current community care system is notoriously bad at early intervention because resources are so stretched. There are many disabled people who have no contact with their local authority (LA) and don’t particularly want to have. The cash they get from DLA/AA enables them to meet their needs in the way that best suits them.

Neither DLA nor income maintenance monies should be included in individualised budgets. These benefits must not be subject to different eligibility criteria and make different charges to disabled people in different LA areas. By definition, it is not feasible to deliver an entitlement through a cash-limited budget, as has happened with the disabled facilities grant where the waiting list simply operates as a rationing system.

‘Supporting People’ funds should be added to the list of budgets considered for inclusion in individualised budgets.

4. Office for Disability Issues (ODI):

What should be the immediate priorities for an Office for Disability Issues and what should it achieve in the medium and long term?

General.

Most importantly, ODI is not a solution but a means to a truly holistic approach which should lead to the systematic inclusion of disability issues in

all government departments and polices. The very real danger that other departments will simply leave disability issues to the ODI must be guarded against.

The ODI needs to play a key strategic role in taking a cross-government, cross-department approach to independent living. In particular it needs to work with the Treasury to ensure that no decisions are made concerning expenditure on one type of need (e.g. a requirement for all new homes to be adaptable using inclusive design principles) without taking into account the consequences for other types of expenditure (e.g. social care, hospital admissions and delayed discharge). Currently, there are major inefficiencies created by the lack of transparency between different budgets and programmes – both nationally and locally. Transparency will open up opportunities to make increased expenditure in one area in order to save in other areas, and in the process promote independent living for more disabled people. This will be particularly important in the context of the difficult public expenditure decisions to be taken in the next few years. It will also be consistent with the more integrated and holistic approach which the government has said it wishes to take towards disabled (and older people's) needs.

The 'Life Chances' report committed the government to the establishment of user-led organisations, modelled on existing CILs, in each local authority area by 2010. In order to achieve this there needs to be resources put into capacity building amongst disabled people and their organisations, including resources put into developing the CIL model so that it fully represents and supports people with learning disabilities, people with mental health needs, people with sensory impairments and people of all ages, as well as people of working age with physical impairments. ODI should work with NCIL and other user-led organisations to develop a programme of work in order to fulfil the government's commitment.

Immediate priorities:

1. Top priority needs to be given to initiating capacity building in existing disabled people's organisations during the next financial year. Many of these organisations are struggling, or folding, around the country and their disabled staff are losing their jobs. Securing funding for projects and the development of disabled people to manage their organisations is proving impossible for most. Our own organisations do not have access to resources to ensure that they have the skills, knowledge and advice that they need to manage their organisations. Centres for Independent/Inclusive Living, for

example, are experiencing great difficulties because of the stress caused by lack of resources. In the meantime the traditional charities, that have been a major contributor to the exclusion of disabled people, are going from strength to strength and gain public support from high profile personalities.

The traditional charities are also at an advantage in the competitive tendering process for local authority and government commissioned services, in that they have the resources to devote to writing complex tender documents and are better able to deliver economies of scale than smaller local disability organisations. Thriving, user-led, democratically-run, local organisations are vital to many of the government's disability and wider social policies. Yet if these organisations are to exist and play their part, they need to be properly resourced and supported. The government gave a commitment in *Improving Life Chances* to ensuring that disabled people's organisations would have the capacity – locally and nationally – to play their full part (Chapter 8). The ODI should make sure that it is able to report on progress towards this commitment when making its first report to the Prime Minister next year.

2. A clear delivery plan for all the policies adopted in the 'Life Chances' report:

This should lead clearly to the implementation of the range of commitments in the '*Life Chances*' report, in particular bringing in a new system of meeting disabled people's support needs which:

- recognises expenditure on independent living as a form of social and economic investment,
- meets all aspects of disabled people's support needs, whether it is to work, to play our full role as parents, grandparents, other family members, or to participate in our local communities, and be able to access local facilities such as leisure to promote healthy living, etc
- is based on the principle of self-directed support,
- is developed in partnership with user-led organisations modelled on existing Centres of Independent Living.

It is also vital that any reforms to the benefit system, or programmes for getting people into work, are compatible with the social model approach adopted by the government in its publication of *Improving Life Chances*. We welcome the recognition in that report of the barriers which need to be tackled if disabled people are to have equal opportunities to participate fully in society, including in the labour market. The ODI has a clear role to play in ensuring that employment and social security policies have at their heart recognition of, and a desire to tackle, these disabling barriers.

Mid-term priorities:

1. Identify an early plan for culture change and begin its implementation:

The 'Life Chances' report recognises that a culture change is required, so everything that is done needs to be contributing toward that culture change that actively promotes inclusion, and whereby it is no longer acceptable to exclude disabled people. Bringing about change is not all about rules and regulations; ways of influencing what people see as right and wrong can be quite subtle. Ways of encouraging the media to show impairment as a part of the normal diversity of the population would help. (Ali Briggs as Emily Bishop's niece in Coronation Street was a good example of this). Equally, images of disabled people as tragic but brave heroes are damaging to attempts to promote equality.

2. Address the exclusion of disabled people, and challenge the *incitement* to exclusion that exists.

Plans to address both the exclusion of disabled people and stopping *incitement* to the exclusion of disabled people must be started. The too familiar promotion of the notion that disabled people are 'not normal' and cannot cope in normal society must be treated with the same degree of seriousness as the incitement to racial hatred. This includes those who promote the images and notions that disabled people, for example:

- Need pity and charity,
- Have special needs and therefore need special provision,
- Are seen as awkward, ungrateful, aggressive or militant or have the proverbial chip-on-the-shoulder, when in fact they are being assertive.

How can an ODI best represent the views of disabled people?

Perhaps 'represent' is not the right word here: it may be better to use the word 'promote', as in 'put forward the views of'. ODI is not an organisation of disabled people so it can't represent our views: instead it could commit to develop and model good practice in seeking our views. The role of the Forum will be key here, and if it truly is a Forum of Organisations of Disabled People then that is where the representativeness should be sought and channelled.

The ODI, through the Forum, will have to have meaningful consultation with a wide range of disability groups. This involves more than a "talking shop" or one-off consultation and the government has made an interesting start by not appearing to have any pre-set agenda in the recent consultations. The

meeting in Manchester emphasised that they had not made firm plans, and this approach is welcomed.

The commitment in the 'Life Chances' report for the government to develop a User Involvement Protocol is key, and perhaps it is ODI who needs to develop this - in partnership with disabled people obviously - in order to determine how ODI itself can best 'represent' (i.e. make known, or promote) disabled people's views.

5. National Forum of Organisations of Disabled People:

A major point to raise about the Forum is the consideration of how far the need for such a body is met by the existence of three major national user-led organisations, namely the British Council of Disabled People, (BCODP), the National Centre for Independent Living (NCIL) and People First. The existence of these groups must be factored into the development of the Forum, and their future survival should be considered essential to the success of the 'Life Chances' report policies.

The proposed Forum must not be populated by the traditional multi million pound national and international organisations (charities) who have a vested interest in keeping disabled people dependent, and who make their money by portraying disabled people as being needy, despite recent apparent high profile activities around 'equality' and 'rights'. Although they seem to be slowly beginning to change their practices and direction, and this must be encouraged further, nevertheless they cannot be a substitute for the views of those legitimate organisations set up, developed and controlled by disabled people which have developed the social model (reported as government policy at recent consultation meetings).

There should be provision of resources instead for organisations which are controlled by disabled people to take part. In almost all cases organisations which carry out consultations or try to involve disabled people expect that disabled people should, and will, contribute to the numerous consultations and to attend meetings using their own resources. The big charities can afford to do this, small disabled people's groups cannot. This links in with priority 1 above regarding capacity building.

There are groups in existence which can contribute currently – for example, this Breakthrough UK Policy Think Tank is comprised of experienced and analytical disabled people, from across England, who use the social model of disability. Other disabled people's organisations are interested mainly in

specific issues such as independent living or direct payments - and CIL's are well placed to respond, whilst issues of access to the built environment are well represented through disabled people's access groups. We suggest that an early activity could be a 'mapping exercise' of what groups of disabled people there are, which groups of people they represent and what issues they are knowledgeable about. This would then provide a good starting point for ensuring that a range of experiences and interests were represented on the Forum.

However, the planned capacity building input will also be needed to ensure that people are equipped with the skills and experience to manage their own organisations and to respond to the planned involvement in policy and service development. This means that there is a serious requirement for experienced disabled people to be resourced to develop and deliver effective capacity building.

How can we ensure fair representation of disabled adults, disabled young people, and disabled children and their families?

A mapping exercise would help to avoid the tendency to just involve the usual organisations that always put themselves forward for these kinds of fora. Also, fair representation can only be achieved if involvement is properly resourced: this means reimbursing any costs that individuals and organisations incur as a result of involvement.

As a principle the Forum has to be open ONLY to disabled people, with at least 60% coming from organisations OF disabled people. As a compromise a minority percentage (maybe 10%) could be made up of carer's groups, parents and FOR organisations, for example.

Disabled people are diverse and it will not be possible to directly represent all views. However a common feature is that far too often family, carers and professionals speak on behalf of disabled people. The Forum must avoid taking the view of carers and professionals as being anything to do with disabled people being represented – it is not.

Furthermore, many disabled people have become so institutionalised and have internalised the normalcy of someone else speaking for them, that they may not realise that this does not have to be so. This also links in with priority 1 and the need for disabled people's groups to be funded for capacity building to be delivered throughout the diversity of disabled people, and to shift the balance toward disabled people controlling representation. This will not be a

'quick fix', but must be a strategic, planned and systematic approach which may well take years to really deliver.

How can we ensure that the Forum can engage with as many disabled people as possible, especially those who, at the moment, are not given the opportunity to express their views and opinions effectively?

Firstly, the composition of the Forum will be key (see the previous section). Secondly, the Forum must go out to disabled people – for example, those in day centres are often at the bottom of the social structure and it is easy to find them. Reaching other people – those who might not leave home, for example, or disabled people from black and minority ethnic backgrounds – will require a dedicated outreach programme, identifying and building on existing successful initiatives such as the Greater Manchester Coalition of Disabled People's 'Young Disabled People's Forum'.

It is important to speak to people in a supportive and informed environment: it will be key, for example, that Day Centre staff and/or carers take a back seat. Again, capacity building (priority 1) is crucial: the Breakthrough / Liverpool City Council Independent Living Skills course is a good example of this, now mainstreamed. Funding for local organisations of disabled people to have the skills to support the consultation process with disabled people in day centres, or isolated at home, will be a crucial investment.

All consultation processes must use a wide range of formats and consultation processes including meetings, internet, with advocates, etc.

6. Piloting of 'individualised budgets':

Are there any benefits which should be left out of an individualised budget system?

No income maintenance monies should be included in individual budgets; disabled people should not be treated differently from anyone else who needs their income topped up to acceptable levels.

Similarly, Disability Living Allowance (DLA) should not be included in 'Individualised Budgets'. There have been discussions previously that the money currently spent on DLA would be transferred to local authorities, so that they could form part of the pot of money available for community care. When this was formally discussed in 1997/98, it wasn't just disability organisations that objected to this proposal but also local government

organisations and the Association of Directors of Social Services (ADSS). The fear was that any transfer of funds to LAs would, in practice, lead to cuts.

This is because under the current arrangement there is no cap on expenditure on DLA (or Attendance Allowance) (AA). If a disabled person meets the eligibility criteria they are awarded the benefit, no matter how many other disabled people there are in their locality. This is not the case with community care services. These vary with demand and political priorities. Local authorities have different eligibility criteria and make different charges to disabled people in different areas. Central government could cut the grant allocation in future years, and there might be no obligation on LAs to ring-fence the funds.

Also, there are many disabled people who have no contact with their LA and don't particularly want to have. The cash they get from DLA/AA enables them to meet their needs in the way that best suits them. This is particularly the case for people with low to medium needs. If LAs were responsible for allocation of a limited pot of money it would inevitably go to people they were already in contact with. Over time there would be a transfer of support to those with greater needs. People with low/medium needs would gradually be excluded from any support.

Furthermore, cash benefits like DLA/AA provide choice for disabled people, who are themselves the best judges of how to spend that money and how to meet their own needs. Local authorities are quite restrictive about what services are on offer and people who use direct payments still have to account for how they spend the money and can only spend it on what's in their care assessment.

Generally local authority organisations are aware that currently they are only in touch with a small proportion of those who get DLA/AA in their LA area. They were concerned in 1997/98 at potentially being on the receiving end of a huge wave of extra demand for assessments and services. They also shared the disabled people's movement's 'in principle' objections to the removal of choice from disabled people about how they met their additional costs.

For those who qualify for community care services, the care component of DLA and AA is effectively part of the community care budget anyway because it is taken into account in LA's charging policies. A proportion of those who receive the care component are able to meet their needs from a combination of DLA/AA and their own resources, and do not look to local authority community care services. If DLA/AA was no longer available through a national system to those who have personal care needs, it is likely that, as

the LA s feared, there would be a big increase in the numbers of disabled and older people looking to their local social services for help.

The Disabled Facilities Grant (DFG) system 'mess' is an example of what happens when you have a cash limited budget to deliver an entitlement. Either central government would have to reimburse local authorities for the total cost of DLA/AA entitlement (in which case it is difficult to see what is the argument for replacing one national system of delivery with a myriad of local systems); or some form of rationing will occur. With DFGs the waiting list operates as a rationing mechanism; with community care services, assistance is limited to those with the most significant needs. If DLA/AA was rationed in this way we would lose the advantages of an administratively efficient method of meeting some of the additional costs of impairment and disabling barriers experienced by those with lower levels of needs. There has been a lot of emphasis on the potential effectiveness of addressing needs at an earlier stage of people's experience of impairment, thus preventing higher costs later on. DLA/AA is arguably one way of doing this, whereas the current community care system is notoriously bad at early intervention – because resources are so stretched.

The 'Life Chances' report said that the following budgets would be considered for inclusion in individual budgets:

- Community Care resources and Social Services expenditure on equipment and minor adaptations;
- Independent Living Funds;
- Disabled Facilities Grants;
- Family Fund; and
- Access to Work.

We would advocate the addition of 'Supporting People' funds in this list

Principles for individualised budgets:

We believe it is important to adopt a set of principles in terms of what 'individualised budgets' are intended to achieve. We believe these are

- a) Self-assessment, with support where needed.
- b) Simplification of the assessment system

b) Diligent avoidance of any cost-cutting measures, while recognising that more expenditure on one aspect of need (e.g. for adaptations) may reduce expenditure on another (e.g. social care)

c) Supporting people to make full use of the system: if individualised budgets are to work then there is a huge requirement for capacity building. Many disabled people are given direct payments by the local authority with little or no attempt to make sure they have the skills and knowledge to manage these. They are set up to fail. Disabled people's groups need to be given resources to become CIL's to provide the necessary support. This resourcing absolutely must include ensuring that those disabled people running the CIL's are given necessary skills and knowledge about managing individualised budgets and how to run an organisation (legal requirements, regulations, managing staff, conflict resolution and managing organisational finances).

d) A recognition that expenditure on enabling disabled people to live independently is a form of social and economic investment

7. Conclusion:

This response to the consultation on the proposed ODI, National Forum and Individualised Budgets has been drawn together from a group comprising *only* disabled people who are practitioners, academics, activists and people who run organisations. It draws on many years of delivery of services within the social model, years of self-organisation, and years of developing theory and analysis.

We positively welcome the 'Life Chances' report and the forward thinking government policies it contains and look forward with interest to their implementation. We are most concerned that the underlying principles of the 'Life Chances' report are observed and that disabled people – and their own organisations – should be central to the development of ways of working and the delivery of the policies.

We hope that this response/report proves useful, and look forward to feedback on our comments.

8. Further reading:

"Improving the Life Chances of Disabled People": The Prime Minister's Strategy Unit, January 2005.