

## **“Improving the Life Chances of Disabled People”-a response from the British Council of Disabled People.**

The British Council of Disabled People is the only national organisation representing disabled people from across the whole of the disabled peoples community. We are entirely managed, run, organised and staffed by disabled people. Our views are taken from the experiences of other 130 member organisations, with between 300,000 and 350,000 individual member groups.

BCODP welcomes this document as one of the most positive documents to come from government, relating to disabled people, in many years. The document demonstrates that the Government was listening to what disabled people and our organisations have been saying for a long time.

BCODP particularly welcomes the proposals to :

- See independent living as the key to providing equal opportunities to disabled people.
- Introduce individualised budgets to give disabled people more choice and control over a wider range of services and coordinate the delivery of services.
- The importance of ensuring equal access for disabled children and their families to early years provision
- The goal of ensuring a smooth and supported transition to adulthood.
- The goal of increasing disabled peoples access to employment.
- The target of establishing a centre for independent living, run, managed and controlled by disabled people, in every local authority area by 2012.
- The review of spending proposed in 2006. BCODP believes this must be used as a way of making sure that there are enough resources to achieve the changes proposed in the document.

### ***Comment on introduction and summary:***

The introduction sets the tone for the document as a whole. It is positive and promotes a progressive view of how to begin changing disabled peoples lives, in language familiar to and, happily, borrowed from the independent living movement. BCODP

strongly welcomes this report as a historic step forward in government and official thinking about disabled people in society. The document contains a good example of a social model definition of disability, for the first time in official government documents. By recognising that it is the disabling barriers within society, which need to be changed, to deliver equality and freedom to disabled people, to be able to take their full and equal part, within our society, the document points Government policy in exactly the right direction

The document rightly recognises the diversity of the disabled peoples community and both how this community experiences many different forms of discrimination and how the community is continually changing and developing. The challenge will be to develop implementation and service delivery options which will reflect these essential characteristics and create an inclusive society which acknowledges and celebrates difference.

### ***Including older people.***

In this respect, it is a pity that older people are not fully included in the documents discussions and proposals. While it is stated that the changes envisaged will and can equally be applied to older people, the document doesn't specifically set out to include them. However, older people account for the majority of disabled people in our society today, following the social model definition used here. Furthermore, many of the ideas within the introduction and summary, as well as more detailed proposals later on, could equally well be applied to older people without any real difficulty. In planning for a more equal and inclusive society, it will be better if we can start by including all disabled people in the plan.

It has also been mentioned that people with Autistic Spectrum Disorders, or people with different cognitive and environmental understanding, are also among the fastest growing group of disabled people among adults as well as children and young people. Acknowledging and responding practically to the enormous diversity of the disabled peoples community is a central challenge in implementing this document.

The timescale also raises issues, acknowledged within the document itself. While it is understandable that the process of eliminating discrimination and building a fully inclusive society may

take some time, equally there are issues facing disabled people today, which need more immediate attention. Some of these issues can and should be addressed more quickly. Perhaps one of the first jobs in implementation should be to begin to identify changes which can be made more immediately to address disabled peoples condition within society today.

***New Government Office.***

The Office for Disability Issues is very welcome. The creation of such an Office will bring together the different departmental interests essential to deal with the enormous task set out in the document. Co-ordination of planning and direction for implementation that goes across governments departments is essential to the success of the project. One area of concern is the continuing link to the Prime Ministers Office. The role of the Prime Minister has, in our opinion, been central to the development of the document and it's acceptance as policy by a number of major government departments. Although the document does suggest that an annual report will be sent to that Prime Ministers Office, reporting on progress on the documents recommendations, BCODP wonders if we will need more day to day involvement from the Cabinet Office to give the new ODI the authority to drive these wide ranging changes and co-ordinate Government strategy across a number of key departments. We would prefer to see some staff from the Cabin Office seconded to the Office for Disability Issues on a long term basis, to keep the link with the Prime Ministers Office and the Cabinet Office more directly and actively in the complex work of implementing this far-sighted and challenging document.

BCODP also wonders how the new Office of Disability Issues will set about recruiting disabled people to its staff. Indications are already and rightly being made that efforts will be made to ensure that disabled people are represented among the staff in the new Office. The procedure by which this will be achieved has yet to be announced. BCODP would like to see some positions within the new unit being reserved for disabled applicants only, to guarantee a minimum representation from disabled people within the unit. Within this programme of recruitment, we would welcome attention being given to ensure that disabled people from the different and diverse sections of the disabled peoples community are well represented. For example, there may well be a case that at least two members of staff should be disabled people with learning

difficulties. Some attempt may also need to be made to ensure representation from disabled people from the black and minority ethnic communities and other underrepresented groups, such as users and survivors of the mental health system and disabled people from the lesbian and gay communities.

***Individualised budgets.***

The concept of individual budgets is introduced in general terms here and expanded on later. While the concept of individualised budgets is welcome, following the successful example of direct payments, which have proved effective in delivering flexible services which give disabled people more choice and control over their daily lives, empowering them to take a more active part in the community.

However, there are concerns about how this new concept will be introduced. For example, it will be important to be clear about which services can be purchased using this system. At one level there is the clear need to ensure such budgets are not available to purchase residential provision, if the purpose of promoting and supporting independent living is to be achieved. There is already good debate about how to manage assessment procedures and BCODP join with those who are advocating that there needs to be organisational separation between assessment and service allocation responsibilities. BCODP will very strongly advocate for the development of the idea of self assessment by disabled people as being the basis of developing this new concept and will be keen to see this tried out in the early development stages.

The assessment process is almost certainly a prime candidate for early study and development. Many of the difficulties experienced by disabled people today is associated with an assessment system which, despite all efforts to the contrary, still tends to follow financial requirements more than social and personal needs.

There is also the matter of health services and social services. Currently, there is some confusion about whether or not direct payments can be used when services are provided by the Health Service rather than Social Services. This can easily happen when part of the support required by a disabled person is directly related to their health care needs. This confusion has led to difficulties in developing direct payments and has sometimes caused individual disabled people to go through complex, difficult and stressful

procedures over a long time, before being able to get their needs met. It will be necessary to make sure that the new individualised budget system doesn't have the same problems attached.

The idea of a single passport to services for disabled people has long been a subject of discussion and debate. The introduction of individualised budgets could simplify access to services for disabled people considerably and give more flexibility, freedom and choice. In choosing and developing the pilot-study areas, this will be an important area to develop.

The document rightly focuses on the issues connected with transition into adulthood, long an issue affecting disabled peoples access to the quality of service they need. A direct payments have already offered an opportunity to create a seamless service across the barrier at 18 years of age. BCODP would like to see this opportunity to introduce support services which are directly portable across the age barrier seized through the implementation of this document. The same issue applies to the age barrier at 65, possibly even more so. While the document leaves it open to consideration whether similar principles will be applied to older people, this does underline the need to specifically include services for older people within the remit of the documents implementation strategy.

The document is an exciting beginning to this challenge and opportunity.

The document begins with a very acceptable working definition of the social model of disability, giving the Government policy a firm foundation in adopting the correct philosophical approach to liberating disabled people from oppression.

It follows up with a good definition of independent living, again based securely on the work of the disabled peoples movement the years. If we can build on these sound principles, developed by the disabled peoples movement, this will become a most important and significant document.

### ***Background.***

In February 2005, the government published its vision for the next 20 years to improve the way in which disabled people take part in

society, to eradicate discrimination and ensure the full inclusion of disabled people as free and active citizens in society.

The document is introduced by the Prime Minister, who stresses that its contents are Government Policy and need to be supported across government. The paper is jointly sponsored and supported by the Department of Health, the Department for Education and Skills, the Department for Work and Pensions and the Office of the Deputy Prime Minister.

This connected thinking and working is reflected throughout the document, where joint initiatives are aimed at providing a more connected and coherent way of delivering support services to disabled people to enable them to overcome the disabling barriers which prevent them from reaching their full potential. A simpler and more accessible, person centred provision aimed at promoting independent living, with more control and choice for the individual disabled person is one of the key themes in the document.

The document also introduces the idea of individualised budgets, where disabled people can be given a single amount of money to buy a whole range of services which they may need, including personal assistance, housing adaptations, equipment, transport and so on. Together with this, the document proposes the setting up of a national network of organisations of disabled people, supported by and developed by a national organisation of disabled people, the introduction of a Task Force on Independent Living and a new government Office for Disability Issues to drive the process forwards, together with a National Forum to advise on all areas of the work involved in implementing the strategy.

The document has a number of chapters, the introduction and summary, followed by more detailed chapters on Independent Living, Early Years support, the Transition at 18, Employment and Implementation. In chapter 3, the document looks at the vision of giving disabled people full opportunities and choices by 2025. This vision is to be achieved by empowering disabled citizens, improving their life chances and real choices over their own future.

This is mainly to be achieved through promoting and developing independent living. The document uses the definition of

independent living developed by the disabled peoples movement, as expressed in a report from the Disability Rights Commission. There is a proposal to develop a network of centres for independent living across the country, one in each local authority area. To ensure a basic standard of services and to coordinate and to develop this network, the proposal envisages that a national organisation of disabled people will be given this role. The references to developing centres for independent living is a demand which the disabled peoples movement has been raising for many years and it's most welcome to see this reflected in this important document. When we are defining the role of centres for independent living, we need to reflect the diversity of work already being done across the country. We should add social activity, activity in public life and volunteering, cultural development, such as arts, music, theatre, etc. society is complex and contains many different aspects. Disabled people have something positive to contribute in every one of these areas and the right to be fully involved.

In the following section, we quote reactions from among our members, illustrating how disabled people feel about the issue of independence living.

XXX

Overall points:

There does not appear to be anything about older disabled people in this document!

How will disabled people recruit and maintain staff in an aging population where "care" work is undervalued and underpaid? This can be supported by the number of "care" agencies unable to recruit carers or PA's who can meet the relevant person spec?

It is important to appreciate that Independent Living does not mean doing everything for yourself. It should be determined by the disabled person themselves and in the case of people with learning difficulties with advocacy support. Aids and equipment have their place but people power is also important.

Many small group homes for people with learning difficulties "think" that enabling residents to get out in the community means driving them there. My experience shows me that it is not enough to dump

peopled at leisure or educational establishments without support can make them feel more isolated than living in large institutions.

Should there be something in here about the way the benefit system can make it uneconomical to work or even impossible to do unpaid work?

If this future strategy was firmly based in the social model then this would ensure that who decides what people should get is not subject to the budgets of different departments. Eg at the moment disabled people can go through many assessment processes

Yes the benefit system and the DLA which was meant to pay for the extra costs of disability is being used to offset independent living packages.

Disabled People need to be assisted into Public Appointments where relevant.

This is good but one major thing left out is that “professionals” make too many decisions on behalf of disabled people without truly involving them in meaningful consultation.

Also the contributions from disabled employers using direct payments or other sources of funding this in turn contributes to the economy of the country.

If disabled people receive the right support to become full citizens then they in turn have spending power thus contributing to the economy.

Also it should not depend on which authority you live in as to how much community care assessment you get to support your lifestyle. i.e. post code lottery. This has the adverse effect for disabled people wishing to seek another job or even for those not working to move house.

Something needed here about the need to house disabled people who have high levels of support in houses that are big enough to house equipment and PA's.

Also the lack of training by nurses and health professionals on how to “nurture” disabled people.

This is good but we need to have more status around PA's training packages run by disabled people on employment, empowerment and assertiveness skills.

For many disabled people especially those who have either lived with parents, siblings or in residential care they need to have support to understand what independent living really means.

Also better support organisations and help with legal costs if things go wrong. Providing supervision and operating disciplinary services can be impossible for dis people who find themselves employers who have often not been employed themselves.

Where needed a good way forward would be to build into the care assessment "10 hrs" for an advocate/or manager of the persons own choice (not a family member) to support the disabled employer in employment skills which include the above plus interviewing etc

It might be thought that this could be covered by the support orgs but many have not enough man power to do this nor the skills needed.

Isnt this also about suitable housing and providing support?

There is very good evidence to support the need to good assessments which can provide the right support within the home environment.

It may be useful to have something about the so call "flood gates" that are often spoken about in supporting people who need 24 x 7. Research has shown (Gerry Zarb – I think) that the number of high packages is very low.

There should also be some mention of "add on" costs for people employing PA's. Whilst not supporting residential care in any way it is important to mention that it is an all in package but employing your own staff is expensive and is in no way incl in the care assessment.

The long term effects of impairments are never looked at eg when my kitchen was adapted I suggested the two outside walls being



### ***The need for governments leadership.***

The document correctly presents the need for government intervention to achieve the objectives of the document and the need to ensure that changes happen in delivering local services to disabled people, based on the principles of independent living and inclusion, at every level. Practical differences will be the essential test of the success of this important strand in government policy development.

Clear leadership from the Government itself will be essential to driving this initiative forward and the political commitment shown at the highest level, and through key departments is extremely welcome. This commitment needs now to include, educate and commit senior officials throughout the key departments to work in partnership with disabled peoples organizations, to ensure a coherent and effective strategy is communicated.

Developing a programme where policy makers at key positions are fully involved in understanding and developing the plans for implementation at different levels will be important to gain the active commitment necessary. Similarly local and national organizations will need to develop implementation programs which involved and commit their own high level management, middle managers and front line staff, together with local organizations of disabled people to develop the strategy and push forward the implementation of these proposals.

Connecting health and social care provision is an essential ingredient to achieving independent living for disabled people. Often the barriers created by these services themselves contribute to discrimination and exclusion of disabled people from society. Some progress has been made through the establishment of Primary Care Trusts and the establishment of Partnership Boards, with active user involvement. One useful model for user involvement has been the establishment of Local Implementation Groups for areas which have benefited from the Direct Payments Development Fund. These groups involved the local authority, the organization providing direct payments support in the area, the local organization of disabled people in the area, if that's different and voluntary sector organizations working with disabled people. Where there was a proper balance between professionals and representatives from disabled peoples organizations in the structure of the groups and sufficient membership from disabled

people to make that a real decision making form, these have been very effective. Similar models could be used in other places, although simplifying the structures to make them more accessible and production will be something worth studying in the implementation and particularly in the pilot-study areas. Sometimes the range of different consultative and decision making structures are so numerous and complex that real active participation from disabled people is difficult. Resources are essential to developing the capacity of local organizations of disabled people, but structural methods of involving and making effective decisions could be looked at.

***Health and Social Services must work together.***

There is a need to resolve confusion between health service funded resources and social care funded sources. Currently the development of the direct payments scheme is being hindered by confusion about whether or not and when health services can fund direct payments. With the instruction of individualized budgets, these kinds of issues will need to be clearly resolved. BCODP knows from experience that many disabled people prefer to employ personal assistants they can train and develop themselves in how to provide specialist and sometimes intimate support, which sometimes is classified as a health need. Ironically, keeping someone socially active by providing these services through their own personal assistance programme, where the disabled person can choose who provides the service and, to a large extent, how they provide that, is often the best way to protect and improve their general health.

The delivery of this positive vision may well depend on many things, the political will to carry through the programme is essential and it's particularly welcome therefore, to see the commitment in this document. However, experience in rolling out new programmes at the local authority level show that training and involvement of senior management in planning, monitoring and evaluation the programme is also extremely valuable. In the same way local managers need to be motivated and involved in developing their own strategies for ensuring the policies are effective in their work areas. Front line workers also need to be involved and committed to the programme, so involving trade Unions needs to be part of this process. Involving users through voluntary sector networks is essential and the growing role of the voluntary sector here is vital. However to make sure disabled

peoples organizations have the resources to fully participate in this process, something which is indispensable to its success, some of the resources in “Future Funders”, initiatives like “Catch Up” for Local Strategic Partnerships, and the growth and development of Partnership Boards, must include an element specifically reserved for supporting disabled peoples organizations as a way towards achieving these welcome and desirable goals.

The structure of LPSAs is correctly identified as a possible route for achieving this. Certainly, this has some benefits and there is evidence that it does work effectively in some areas.

One question comes up in this discussion. Will the Government recommend that local authorities use the LPSA system to develop services, in conjunction with organizations of disabled people, which particularly address the issues in this document?

### ***Independent living.***

When discussing independent living and how best to promote and develop that, the document correctly refers to the definition of independent living developed by disabled people themselves, as articulated by the Disability Rights Commission. The document summarises the existing state of legislation and other government initiatives relating to developing independent living which exist so far. Although many government initiatives have been created within this area, one task for the implementation of this document could be co-ordinating and collecting together the fundamental principles within those different policy proposals and creating a single coherent, easily understandable approach which combines the strengths of these different proposals in a direct and simple process which will enable national and local groups to develop clear understanding of what they need to be doing in practical delivery to ensure the visions in this statement are translated into \*real change on the ground and measurable independent living benefits for disabled people, improving participation and inclusion, creating stronger and healthy communities and neighbourhoods.

Establishing a new set of values within service provision and community care provision is a process which is already developing through a number of existing government initiatives. There is a strong case that work still needs to be done to change the consensus within services, among professionals and planners in those service areas, that the main purpose of these services needs to be based on the ethos of supporting and developing

active and equal participation as citizens within society. The concept of believing that what we are about is promoting active citizenship is very important here. Measuring and evaluating independent living outcomes is important in delivering this programme.

Evaluating the success of introducing independent living schemes should not just be about cost-benefits. The existing system isn't supporting people well enough mainly because it lacks sufficient resources. Investing in making more resources available to wider groups of people will have long term financial and social benefits, but this cannot be a resource free solution. Supporting human rights and developing free, equal and active citizens is itself above price in its value to creating a healthy society. There's no doubt increased economic and social activity by disabled people will be financially beneficial, but this cannot be the only or main motivation in making these changes. Some assessment needs to be made about adequate resources for independent living and a cross departmental bid for the 2006 financial review.

Identifying and using appropriate resources is essential and there is little doubt that promoting independent living should lead to more effective and more delivery of services. In trying to do this, balancing different budgets and the competition which sometimes emerges between different budget holders does create additional problems and this area could potentially be an area for savings if we study it more closely and remember the basic test we want to use is to assess whether or not real independent living choices are being delivered to disabled people or not. The document identifies that, as well as health and social services, other service providers living the wider community, can also and should also, take part in providing accessible services and opportunities to disabled people. The problem of identifying resources and co-ordinating different service delivery functions has always been part of the difficulty faced in providing a coherent and accessible service to meet disabled people's needs and eliminate discrimination. Many local authorities have tried to enhance local service delivery by encouraging others, such as education and higher education authorities, leisure and sports service providers, voluntary sector organizations, etc., to provide facilities, support and resources which will support disabled people having access to these services. This is an important area. Many local authorities have tried to address financial limits on available spending for community

care services by encouraging other service providers to make their services fully accessible to disabled people, with little success. Often, the support facilities required by disabled people to fully participate in this complex range of local services simply isn't available or very difficult to access, limiting rather than enhancing independent living opportunities. The idea of individualised budgets could provide a way of co-ordinating these services together, giving easier access and ensuring the whole range of support required at every stage for a disabled person to be able to take a full part is there and available in a way that connects with and complements other support services, to genuinely offer smooth and comprehensive support systems.

Providing easy and quick access to appropriate equipment or adaptations has always been seen as part of what disabled people need to achieve independent living. In some areas, Disability Living Centres, which give disabled people the opportunity to see what equipment and adaptations are available and try out what may be appropriate for them, with advice and information available, have been successful, particularly when combined with centres for independent living. This combination provides peer support and experience to disabled people looking for information about possible equipment and other support. Developing these centres alongside CILs could be a most effective way of improving the access to these essential items, with a single reference and access point for all these to simplify the access to the services.

Accessing the correct adaptations and supporting equipment is extremely important, but shouldn't overshadow the fundamental necessity and importance of providing personal assistants based support. Getting support from another person is an essential part of developing independent living for disabled people and we need to take into account that personal assistants are required to play a very extensive range of supporting roles, working with the disabled person to achieve genuine independence and the opportunity to express themselves fully in every direction where they wish to use their talent and ability.

Communication and comprehension of information provided are both important to ensure equal access for disabled people and there are often barriers which create discrimination or some disabled people in this area. It's essential that good communication support is available to everyone who wants or

needs that. This is an area which is much undeveloped, but absolutely critical to independent living. Communication takes many different forms, from different language, including, BSL, technical support devices and personal communicator assistants. There are many disabled people with neurological conditions which effect cognitive and environmental understanding and processing, and it will be good to specifically include them in this definition.

### ***Organisations of Disabled People***

When defining the role of local organizations of disabled people, it's important to remember that Centres for independent living provide a very wide range of services to disabled people. Advice and information on welfare benefits, housing advice and information, support in accessing legal advice and other local authority services, input into the planning and development of policy and practice across the whole range of local authority provided services and services provided by other authorities, such as health, education, police, emergency services, employment practice and development, a completely holistic approach to practical involvement in planning and producing an inclusive society is one of the key objectives of any centre for independent living and they need resources to be able to play this essential and creative role.

The document recommends establishing a national network of centres for independent living, one in each local authority area, co-ordinated, supported, developed and monitored by a national organization of disabled people in the form of a National Forum, charged with these responsibilities. This is a particularly welcome recommendation and we would hope this will involve developing the role of the National Centre for Independent Living, which is already doing much of this work without direct resources being allocated, to develop, train, support capacity building, monitor, evaluate and ensure basic standards throughout the service, as well as identifying clear and precise channels through which funding can and will be provided to build strong and effective local disabled peoples organizations, building on the existing national networks and creating new groups where none yet exist.

One difficulty which is experienced by disabled people when different services are expected to contribute towards a comprehensive support plan, is that mainstream services beyond

social services don't usually contribute across the board, but tend to respond to pressure from individuals. This causes the fragmentation of services described and the intense difficulty of accessing them experienced by disabled people. If other establishments, like further education or leisure providers, or employers in a region, each committed some identified resources to supporting the participation of disabled people, the planning and availability of more inclusive and connected services would more easily become available. In providing individualized budgets, it may be necessary to investigate other legislation, like the Disability Discrimination Act 2005, to see if these organizations need to prepare Disability Equality Plans, and connected budgetary arrangements.

***Some problems in implementing this vision.***

It will be useful if individualized budgets are also part of the star rating system, similar to the way direct payments are, but with evaluation depending not just on numbers, but on measuring independence living outcomes.

Will developing local forums where the different authorities come together, with the involvement of disabled people and other voluntary sector organizations involved in working with disabled people, to plan and co-ordinate service provision?

Block contracting saves money and bureaucracy, but doesn't necessarily deliver better quality or more responsive services. Service contracts may need to include provision where users do have more decision making power over what service they are offered and how it will be provided. Already, direct payments have proved successful in offering flexibility, choice and control over essential support services. The initial legislation introducing direct payments contained a clause requiring the services received through a direct payments to be equivalent in value and quality to directly provided services, even where those services are provided by private sector and voluntary sector agencies. The question which now comes up fairly usefully is, can we now ensure those directly provided services have the same levels of flexibility, choice and control which is afforded by direct payments?

The document looks at the situation related to the information and support needed to enable disabled people to live independently. Several points are raised in this most interesting section. One

clear issue is that BCODP and other organizations of disabled people would want to press for a right to refuse residential provision. There is evidence that disabled people are often offered residential division when that is not necessarily the best option for appropriately meeting their needs. Very often, supporting people to remain within the community is much more effective. This usually enables the individual to be more socially active and remain within a more socially healthy environment, where they have better quality of support and clear opportunities to develop their own potential.

Often, particularly for older people, but essentially for all disabled people, living at home with personal assistance support is very much superior to living in an institutional setting. The right to choose where you live is absolutely central to the concept of independent living and equality within society for disabled people. A phased programme where disabled people can be actively supported to live independently within the community, rather than be concentrated into residential care units, needs to be part of the vision within this document and should be one of the central planks in the funding review in 2006.

In considering housing provision, there is an additional need to build new housing to higher standards of full wheelchair accessibility, or to full access standards, because even Lifetime Homes and the revised part M of the building regulations are still not fully reflective of all access requirements and there is a case to argue that some new building needs to be to this higher standard, to create a pool of fully accessible accommodation for disabled people.

### ***Housing and transport.***

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In considering transport provision, including the role of local authorities, it's worth considering the experiment where Transport for London has successfully experimented with introducing Mobility

Forums in local authority areas, to provide a single point at which transport planning, involving all forms of transport available in a local authority area, including social services, education, health, voluntary sector, community transport schemes, door-to-door transport. This approach can produce innovative solutions and involve disabled peoples organizations and other users experiencing mobility issues within their lives. This could be a good model to follow nationally.

### **Early Years**

The document looks at the needs of families with disabled children in the critical early years. The vision of working with disabled children and their families from the very beginning is very important to the vision of the document as whole. If we can value the birth of disabled children in the same way we value the birth of any child, then a critical and important step will be taken to eradicate discrimination against disabled people later in life. Getting a new value system which sees and treats disabled people as equals in society from the very start will have tremendous benefit in establishing freedom and equality for disabled people through out society, by including them from the very beginning. In implementing this strategy, which addresses critical issues in early years experiences, some attention will need to be given to how personal assistance and other essential support is provided to young children and their families. For example, disabled children will often benefit from being able to work with the same person assistance at home as is available at the local nursery or pre-school provision, rather than having different staff carrying out those duties in the daytime and others in the evening or at home. This will release workers in these units to do the work of providing educational, social and other input to their relationships with the child and family. Often educational and local authorities don't have specific provision within planning of these services for including disabled children and their families. Hopefully this will improve with the introduction of the Disability Discrimination Act 2005, but some guidance on developing these services within this document will help that process.

The documents looks at how to support disabled children in the very early years. The vision of including disabled children in existing early years provision is a sound principle. These services will need to be connected to the child's and the families existing

support programs, so that, for example, children can bring their own personal assistants with them to these different provisions. Parents of disabled children will sometimes need support themselves. The problem often comes when parents and family members are expected to double up in the role of carers and this can be magnified when they also take on the responsibility of assisting the disabled child in managing and organizing their support programme. The principles about individualized budgets may need to take into consideration additional support which parents need to carry out their specific parenting and support roles in relationship with their children, as well as the support which the disabled child needs themselves. This is particularly important with disabled parents, where there is a disproportionate risk of family breakdown if appropriate support isn't available to both the children and the disabled parents to support the family structure.

Sure Start is a very positive and extremely welcome initiative. However the question of whether this will include provision for disabled children and their families isn't clear in the establishment of this project and it's essential that resources are available within this stream and others, to support disabled children at the early years stage.

Among other things, appropriate and effective child care will create stronger and more effective families, who can themselves be more socially and economically active within their communities, contributing great value through their additional participation.

The proposal to bring together the various essential support needed by disabled children and their families is critical to the success of this project. Housing, equipment, employment opportunities and support for employment, personal assistants and access to existing and planned new provision are all essential part of the program.

This needs co-ordinating with other sources of support for disabled children and their families, particularly through social care and personal assistance. Holistic planning is essential to the success of such a development and needs active user input.

In particular, the key workers supporting families and disabled children will need to be particularly experienced in the problems, difficulties and experiences of disabled children, their families and

particularly disabled parents. In our view, these key workers will best be placed outside the statutory sector and we recommend they be placed with local organisations of disabled people. The document already refers to setting up a national network of centres for independent living, which must be, in our view, run by disabled people themselves. If in addition to other recommendations which points to local authorities needing to provide resources to support and develop centres for independent living. There is a requirement that key workers to support disabled children, families and disabled parents, be based with those local organisations of disabled people, this will contribute towards ensuring the building of this necessary national network of CILs.

This chapter contains many positive suggestions, including co-ordinated planning and provision of services, together with the recognition that disabled families need more varied and sometimes more intensive support than is available. There are good examples about how this is being done in practice in a number of different areas around the country. Different models are used and there will be regional and local differences in how local organisations interpret these proposals. What links the proposals is central planning and a central political commitment to change and provide inclusive services.

### ***Disabled parents.***

It's particularly important that these recommendations include disabled parents and the particular need they have for parenting support as well as direct support for the disabled child. It's also essential the support for the child is centred on developing their skills in independent living and maximizing their own potential. This needs planning together with parents, disabled people, disabled children and young people, as well as the workers involved at front line level. To achieve this we may need to plan how implementation will ensure high level, middle and front line managers are going to be trained and included in promoting and developing these essential changes. The Forum envisaged is a positive step in the right direction, but ensuring real participation by everyone involved, especially disabled people and their families, is likely to be an essential ingredient to a successful process.

Interestingly enough, the "Valuing People" initiative has proved successful in some areas, although success here has been mixed

and experiences not always positive. Including people with learning difficulties has certainly taken a step forwards through this targeted initiative. This could be a useful model for funding both this initiative in early years provision and in independent living generally, by allocating specific resources to local authorities targeted at developing these developments. BCODP believes the Valuing People project is a good example of how targeted funding can have a considerable effect on improving services and supporting disabled people to be both living more independently and more active in the community and in public life. BCODP will like to see an evaluation of the Valuing People project and some learning from the benefits. This should be the basis of funding bids to the financial review in 2006, not only to promote early year services, but to promote the programme in this document as a whole.

The underlying principles behind building local structures which can support early years services must be that they support the development of independent living for the disabled child and their families, including disabled parents. We need to make sure we monitor the effectiveness of these services by measuring independent living outcomes and building that into the way the services are managed and run. This can be done by checking what actual areas of activity are being supported. In other words, what exactly is the child and the family and parents being supported to do in their lives? We also need to ask what else children, families and disabled parents want and need for future development and to check that support services are available to enable them to plan and develop their own futures.

This is particularly important in the setting up of Children's Trusts and Local Public Service Agreements. In order to make these work, we will need to make sure there is strong user input and that the children are at the centre of decision making in developing and managing the services. Even young children know what they like and don't like and have a view of what they want in the future and this voice needs to be supported and heard in the way these support structures operate.

### **The Transition to Adulthood**

The transition from childhood to adulthood has always been made more difficult by the divisions between the services offered to both these groups. Therefore, the proposal to establish a single

coherent and accessible service across the age barrier at 18 is very welcome. There is clear need to have support services which are available in a consistent and reliable way throughout this critical period in anyone's life, without the need to go through complex and not always responsive assessment procedure and negotiate difficult bureaucratic systems.

Direct payments already offer the opportunity to provide continuous and consistent service delivery across the age transition into adulthood. However, not all social service departments have consistent assessment and service delivery policies and practice across this divide. In areas where direct payments have developed more successfully, local authorities have a single policy and practice on direct payments across all service areas. Together with having a fairly high level officer in social services departments, responsible for everything to do with direct payments, this has increased effective service delivery and much better quality services to disabled young people. This lesson could be applied across other support services available to disabled young people.

Looking at existing legislation relating to this group, we notice that there has been mixed success in developing these so far in many local authority areas. The implementation of this documents vision will need to examine how much progress has been made and what further development is necessary to fully implement the strategy. There is also evidence that SENDA is still not fully implemented by many local education authorities. The Disability Discrimination Act 2005 will hopefully help with this, but further work is clearly essential here. Similarly, the implementation of the Disability Discrimination Act 1995 is still patchy and especially in community based provision, where services for younger people are often based. Local authorities generally haven't provided funding for the costs of converted community groups premises to allow access for disabled people and these groups, relying mostly on charitable funding, don't have additional resources to meet these needs. More co-ordination and planning as well as resources are needed. Perhaps the anticipatory duties in the new DDA 2005 will help here.

As the document says, there are already a wide range of government initiatives in this area. One of the tasks we need to set ourselves in the implementation of the document is to review these

different initiatives and see how they contribute to the overall vision of developing adults who will be well trained and supported, with their skills well developed, with real opportunities to use those skills in a range of different areas in society and the support they need to achieve their full potential. Drawing out the common areas and developing a more coherent and accessible set of services will be part of the task of establishing concepts like individualized budgets and connected service provision.

This section refers to an important principle in proposing that young people approaching adulthood need opportunities to exercise responsibility and control over their own individualized support systems. The section rightly acknowledges that children reach the age at which this becomes something they want to and are able to begin to do for themselves differs between young people. BCODP wants to see all young people as having the potential to be involved in both taking responsibility for and making decisions about their personal care and that this should always be part of personal development for every disabled child. When children approach 18, additional need is there to ensure that they have the skills knowledge and experience to manage the transition into adulthood successfully.

This transition involves principally having available appropriate support under their management and control, but also the availability of suitable opportunities. This involves looking particularly at Day service provision, which still relies extensively, in many areas, on segregated provision at Day centres or through residential care. Developing day services so they are not entirely centre based, but offer a genuine range of opportunities for education and employment, together with leisure and sports, personal development, the arts and media, but also develop services targeted principally for disabled people, but available to others in local communities who may want to use them. For example, the Open University has considered offering courses based at Day centres which would be opened to all local residents, with disabled applicants being given first choice of places. In another part of the country, disabled people run a community café, giving them the chance to learn skills connected to the catering and commercial trade, while providing a service to the local community, all of whom use the café. Integrating and including services into community provision will assist in ending the segregation of and discrimination against disabled people.

In making sure these developments do lead to real change, the role of parents and particularly disabled parents is crucial. Disabled parents will need support for themselves as disabled people. It is particularly important to make sure disabled parents have real independent living support in their own lives. If managing and running their own affairs is properly supported, they will be able to be much more effective parents. However, this does mean giving disabled parents and other parents support in carrying out their parenting role. For example, it is not much good if a disabled parent has personal assistance support to manage their own personal care and carry out domestic and other responsibilities, if they do not have support to take their child to and from school or support them in other out of school activities. This can be particularly important in the transition years, when young people are learning to become adults themselves. Strong and effective parenting can be especially important in a child's development at this age and we need to be developing support services which recognize and respond to that.

There is a clear vision in the document to offer every young person a pathway which will offer routes to employment opportunities, further education or other career development. The plan recognises the diversity of needs for young disabled people in order to be able to achieve this and the need to bring together many different providers from different services to achieve this objective. This is a very welcome approach and does address the issue that we need to be offering young people and especially young disabled people, the widest possible range of opportunities for them to choose from and all the required support and assistance they need to take full advantage of these.

Developing fully inclusive mainstream education is critical to this process and needs to be part of any local initiative. In the same way, services available to young adults need to be accessible and offer the same diversity of choice in a real sense. For example, more disabled people with learning difficulties are going to residential care when they become adults, through the lack of adequate support available to them to remain living independently in the community. Day services are also not providing the range of choice which is foreseen in this document. The development of more appropriate personal assistants support systems and a much more flexible and inclusive day service provision which works

effectively with a wide range of provides in the way this document proposes, will be an important element in achieving these goals. There is an important role for organisations of disabled people in this process. Many successful centres for independent living do have active work going on with disabled young people, much of which is directed by those young people themselves. There is evidence, for example in the work done by the Alliance for Inclusive Education with disabled young people in schools, that working together with other disabled young people and with other children of the same age, supported by disabled adults and parents, has been very affective in developing the independence and creating opportunities for young people to discover and develop their full potential.

In developing local centres for independent living this needs to be part of the work these local groups need to be enabled and supported to do. If we are going to build an inclusive society, this does mean starting with the right principles at an early age, but it must also mean carrying through these practical provisions in the transition to adulthood, so that we develop adult society which fully includes the wide diversity of the disabled peoples community.

### **Employment**

Chapter 7 concentrates on employment and employment opportunities. Disabled people have always seen access to employment opportunities as being one of the key planks in building independent living for disabled people. In fact, some of the early pioneers of the movement saw disabled peoples exclusion from the work place as being central to the discrimination against and segregation of disabled people in wider society. From this point of view, the document is correct to identify this as one of the key issues to address. At the beginning of the chapter, the document looks at the existing situation in the low levels of involvement of disabled people in employment generally and support systems available to them in overcoming the barriers to finding work, for those who want this option.

There are a number of points to be made. First of all, access to support in employment is something which needs to be developed. Not many disabled people and few employers are familiar with the Access to Work Scheme and this needs to be more well known and understood. Using Access to Work often needs a disabled person to have access to good quality information and advice

about using the scheme and in making applications for support. The scheme itself does need some review if it is to become effective. The scheme is sometimes quite inflexible, for example, offering taxi fares to work, but not wages for personal assistants who can drive an adapted vehicle. Disabled people using Access to Work need advocacy, information and support in managing Access to Work, in the same way disabled people using direct payments do. Often this is not available, but could be provided through a local centre for independent living, along with direct payment support services.

The emphasis in this early section of the chapter on rehabilitation does leave some areas of concern. While disabled people do want and need access to health care and health related services and support, in the same way that any member of the population would have, it is important not to stress too much the issue of rehabilitation and not to focus too much on individual impairments. The document started with a very good working definition of the social model of disability and it is of overriding importance that this is reflected throughout the recommendations in the document. This is important for a number of reasons. First of all access to existing health services are often restricted by their emphasis on rehabilitation. For example, a disabled person may have problems accessing physiotherapy services because their physical performance does not increase as the treatment is given. Yet there can be considerable health benefits for some disabled people to have access to regular physiotherapy. Rather than focusing on physical performance and individual impairments through a rehabilitation approach, we should be focusing on the disabling barriers, physical, social, environmental and others, that prevent a disabled individual from fully participating in society in the way they choose and providing solutions which overcome and remove those barriers. For example someone with limited or different physical functioning may need personal assistance, appropriate adaptations and equipment, as well as planned and structured environment in which to operate. This is the main focus of supporting independent living and applies to the area of employment equally.

The document looks at the many different ways in which the Government support disabled people to find work at the moment. While coordinating and making more accessible all of these initiatives is very important, disabled people will also need job

related skill training before being able to consider taking up work as an option and there are little opportunities for this at the moment. In addition employers will need to be active partners in this process. Local initiatives will need to include employers forums and apply the employment sections of the Disability Discrimination Act. 1995, to make work places more accessible, not just in the physical environment, but in the organisation and the management of work itself. Funding is likely to be requisite to make this program a success, and proposals will need to be submitted to the spending review in 2006, to ensure that the future development of this key part of the strategy can be achieved.

The recommendations to work with GPs, employers, occupational health provision and the Health and Safety Executive are very welcome, but need to be connected to the work of disabled peoples organisations. We should see this as a role to be played by centres for independent living and be providing them with the resources and support to develop a strong role. We also need to recognise the work of trade unions in this area and especially those which have strong self organized disabled peoples sections, such as Unison and Amicus. The role of the TUC Disability Committee and the Trade Union Disability Alliance is also central here and these organisations need to have a role in developing the strategy about supporting disabled people to find work, keep in employment and develop their skills and careers, so that disabled people can have the opportunity to progress to higher levels of employment and be well represented among senior managers as much as among the wider work force. BCODP would like to see the proposals in this document developing this wider vision of including disabled people as equals in employment.

Supporting disabled people to find employment is a positive and welcome objective. However, it needs to be recognised 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, which need to be equally valued in the concept of active citizenship. The document talks about the complexity of the benefits system and how difficult it is to access this system. The idea that we can simplify the assessment and application procedure, to create a single point of entry that can lead to the appropriate benefits needs to be part of this process more explicitly. In the same way, the benefit system itself needs

to be reviewed, to take account of both the difficulties of using the system itself and of the problems faced by disabled people who want to take up volunteering opportunities or part time work.

These principles need to be informing the changes recommended in this document, which focus on existing government initiative around the Welfare to Work Programme and the New Deal for Disabled People. BCODP recognizes and supports the need to develop and extend these services in the way envisaged, to extend the support available now to a much wider group of disabled people. However we do feel this system itself needs to become more accessible to and more responsive to individual disabled peoples needs. This can only happen if disabled people themselves are at the centre of the process. In addition to recognizing the right of individual disabled people to have choice and control over the services they receive, we believe there is an addition requirement to recognise the right of disabled people to self organize within their own structures and groups.

The development of an effective way of supporting disabled people into employment and while in employment, can only work if disabled peoples organisations, including disabled trade unionists, are involved in the planning, provision and evaluation of these services. Ensuring this is a feature of the process set out in this document, will be a most important part of creating success in the programme.

The discussion about how to make Access to Work more effective needs to look at how to connect Disability Employment Advisors with the experience and knowledge of disabled people and their organisations. Local employment forums which link together local employers, DEAs and disabled peoples organisations have had a positive effect where they exist and developing these could be part of the function of Access to Work or the DWP Employment Services. There is some evidence that the additional costs currently borne by employers when existing employees acquire disabilities can be a problem in disabled people keeping work at this critical point in their lives. Increasing the contribution of employers to the specific costs of retaining disabled employees is likely to make this situation worse, reducing security in employment for disabled people. Instead it may be worth considering increasing employers contributions to the National Insurance Scheme be increased generally, so that supporting

disabled employees is a cost shared by all employers, not just those employing disabled people.

Given that rolling out existing provision and developing it in the ways suggested here will need additional resources, this could be one way of achieving that.

In looking at the benefit system, the problems of disabled people who enter work needs to be looked at. There are two problems here that stand out. One is that the benefit system itself contains disincentives to disabled people who want to work in not establishing clear financial benefits. The other is that, when disabled people start work they will lose entitlement to some benefits which will not be available to them in the same way if they have to stop work in the future. BCODP will ask for a review of the benefits system to address this and other issues, including the complexity and difficulty of access to the benefits system.

It is also important that recognition is given to other ways of contributing to society than simply through paid work. This is not always a practical option for many disabled people and the high value of contributions made to society in a whole range of different ways needs to be acknowledged. At the same time, the opportunity to be employed in the field of arts, music, theatre and other cultural activities is not just a fundamental expression of disabled peoples identity in society, but something which needs to be equally promoted and supported through the different support systems available to disabled people.

In relation to supported employment, there are problems with the existing system, which include low rates of pay and little or no opportunity to develop new work related skill or develop a career and move into main stream employment opportunities. Workers in sheltered employment often quote the fear that they may not succeed in main stream work and that they may not get appropriate support in these circumstances as reasons for not wanting to leave supported employment. This points to the need to improve the quality and flexibility of support available to disabled people in main stream work places. It also indicates that sheltered employment needs to contain more training and developing of disabled peoples skills, aimed at moving on to main stream employment within specific time limits and having a real qualification attached to support career development. Improved information and advocacy advice and assistance should be part of

this process. Connecting existing services to employers and trade unions is important, but it needs to be recognized that disabled peoples organizations also need a role in this.

### **Implementation**

In this chapter, the document looks at the implementation of the proposals and rightly suggests that we need a clear structure, with clearly defined goals, time specific targets, effective monitoring based on outcomes and accountable management. The establishment of the Office of Disability Issues and the setting up of a national forum, with strong representation from disabled peoples organisations will play a key role in providing the leadership and frame work within which a strategy for change can be developed. One of the first tasks of both the ODI and the National Forum will be to develop this process.

The implementation strategy does need to include standards and effective monitoring of these. This does mean looking at existing standards and improving them with a social model and rights based approach at the heart of the process. This process needs to involve the National Forum and go wider to local organizations of disabled people and other partners in this process to make sure that we are establishing clear and precise targets and that evaluation is based on independent living outcomes and involves local organisations of disabled people, to give a dynamic which will be connected to local communities.

In providing leadership, the ODI will have a key role and BCODP suggest that the ODI will need to have a day to day link with the Cabinet Office and the Prime Ministers Office to give it authority to drive the process and ensure cross departmental coordination. There are possible problems already here with a different government body being responsible for driving the review of social care set out in the document “Independence, Well-being and Choice” and the document on “Improving the Life Chances of Disabled People”, with the former appearing to have more of a health professional input than the latter. Strong and coordinated, coherent leadership is important and we need to make sure that the bodies directing different parts of the strategy not only have a balanced leadership, including disabled peoples organisations, but work together in a cooperative way to achieving the targets and goals within the strategy.

One suggestion made is that local authorities and other public bodies can bid for additional funds from HMT and that they should attempt to coordinate service delivery. BCODP would like to ask the question that it could be more effective if different public bodies working in the same area could coordinate funding bids, supported by joint plans for implementation. This will encourage coordination and enhance the coherence of the strategy and the delivery of services.

BCODP believes it is important to build in both incentives, in the form of additional funding opportunities and performance targets to drive forward reform. We believe that the spending review of 2006 should contain a comprehensive review of the funding of support systems for disabled people generally and that this should contain a review of the process by which government assesses the funding required by each local authority and other public bodies. The cost of the programme of change set out in this document needs to be a clear part of that review. However, the increasing use by local authorities of "Fair Access to Care" to limit entitlement to services at all and the many difficulties experienced by disabled people in accessing enough support to enable real independent living choices to be made, particularly among older disabled people, shows that a review of spending is needed to make sure funding is available to promote independent living and choice for disabled people.

The recommendations to set up a Task Force on Independent Living are very welcome, as is the recommendation of the central role to be played by organisations of disabled people. Resourcing this development will be essential. We are particularly pleased with the plans for a new Office for Disability Issues to coordinate the government's approach. Earlier on we raised the issue of the need for the new ODI to have close day to day links with the Cabinet Office and the Prime Ministers Office and suggest this could be achieved by seconding staff from the Cabinet Office to the new ODI, while retaining their links with Cabinet Office. We will also like to see the new ODI recruiting disabled people to its staff and suggest that some posts in this new office be reserved for disabled applicants only. We will also suggest that recruitment of disabled people does represent the diversity of the disabled people's community and contains a spread of experience and skills from across the disabled people's community in its make up.

As well as annual reports on progress from the ODI to the Prime Ministers Office, we suggest annual reports from every government department to the ODI on progress in the programme of change set out, to include evidence of changes made and their effect in improving the delivery of independent living to disabled people.

We suggest that the submission to the spending review includes funding to establish a national network of centres for independent living in each local authority area and a national disabled peoples organisation, based on the model of the National Centre for Independent Living, as a central part of that review.

The chapter on the implementation of the proposals focuses on the way in which the new ODI will operate and the different roles of different departments and Ministers. This is a difficult task which release on developing the partnerships and cooperation between Government Department which led to the development of these initiatives in the first place. BCODP suggests that the Task Force be based upon the model of the Task Force for Direct Payments, which proved very successful in delivering this important change in Government policy and practice. We also suggest the National Forum is heavily based on National organisations of Disabled People to give a clear majority input into the process from disabled people through their organisations. This is consistent with the aim of democratic accountability for the new program envisaged in this document. It is important disabled people feel an ownership and involvement in developing this key policy.

Altogether, this document represents one of the most positive and comprehensive contributions to the debate about how to eliminate discrimination against disabled people and create a truly inclusive society to come from any Government. BCODP wholeheartedly welcomes this report and its recommendations and we look forward to the opportunity to work closely with Government in the future to achieve the goals and objectives of full equality and rights for disabled people to live as free and active citizens in this society, in a way of their own choosing.

## **Main Recommendations**

- Support the emphasis on developing and promoting independent living including the introduction of individualised budgets
- See this as a way of coordinating the planning and provision of services to make them more accessible, more individually tailored, more flexible and better at producing independent living outcomes
- Stress that introducing individualised budgets must go hand in hand with appropriate local support services.
- See monitoring and evaluation of independent living outcomes as key to this process.
- Include disabled parents in the early years and transition arrangements.
- Recognise the growing number of disabled people with neurodiverse experiences of both information and environment.
- Include funding for a national network of organisations of disabled people to provide centres for independent living and a national organisation of disabled people to coordinate and support that network in the 2006 spending review
- Look at using the model of Valuing People as a way of providing targeted funding for the project, look at employers national insurance as a source of funding for the employment and benefits related costs, and include this in the spending review.
- Ensure the ODI has staff from a wide cross section of the disabled community.
- Use the model of the Task Force on Direct Payments for the Task Force on Independent Living, encourage joint planning and joint funding bids from different service providers in the same area to HMT
- Identify separate streams within Future Funders and funding to develop Local Strategic Partnerships which are ring fenced for supporting organisations of disabled people.
- Work with organisations of disabled people at every level to give the implementation a dynamic of real accountability.

Anne Pridmore  
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