

IN THE MAINSTREAM OF LIFE?

People with Learning Disabilities and the National Policy Agenda

John O'Brien and David Towell

On the 9th February 2005, a group of people with both local and national leadership roles got together at the King's Fund to look over the horizon to identify positive opportunities for people with learning disabilities in the current national policy agenda, attending especially to the major policy themes which might be expected to be influential in the next Parliament and possibly beyond. This meeting was sponsored by United Response.

The group included Gordon Boxall, Debbie Brenner, David Brindle*, Simon Duffy*, Rob Greig*, Bob Grove*, Frances Hasler*, Nigel King*, Jim Mansell*, Brian McGinnis, John O'Brien, Martin Routledge, Philippa Russell*, Bob Sang*, Des Sowerby, Steve Strong, Bob Tindall and David Towell.

Those marked with an asterisk made brief presentations from their personal perspectives and everyone discussed the implications for achieving positive change. David Towell both convened the group and facilitated the discussions; John O'Brien made the record which follows this introduction as his reflection on the pattern of ideas which emerged. Not everyone present would necessarily notice the same pattern or agree with all the points. In a single day we necessarily gave more attention to some major policy areas, for example housing and employment, than others, for example health. Moreover at the level of initiatives we were looking at a rapidly moving target. We were able to look carefully at the important recent report from the Prime Minister's Strategy Unit *Improving the Life Chances of Disabled People* but not the related Adult Social Care Green Paper which was published as we started to distribute this record. Similarly in the few weeks since our meeting, Government has published a plan to replace Incapacity Benefit and announced the 2008 merger of the CSCI and the Health Commission. In this changing environment it is important to identify themes that offer continuing opportunities for positive engagement and that is what this overview attempts to do.

This meeting had two main origins. Since the publication of *Valuing People* in 2001, a group of senior leaders drawn from local authority commissioning and major independent service providing agencies has met as an action learning network to share their understanding of how best to deliver positive change consistent with *Valuing People* principles. A key focus of their work has been exploring how specialist learning disability organisations like their own can listen better to people and their families and support them in becoming fully included in the mainstream of life. In turn, this action learning network has sponsored a series of (so far) three national workshops –held at Cranfield University– where we have worked with multi-stakeholder teams to

strengthen the links between person centred planning and local strategies. (Reports from these workshops are available from David.Towell@inclusion.demon.co.uk)

In both these streams of work, participants have become increasingly interested, and increasingly skilled, at scanning the mainstream policy environment (that is, the national policies on education, health, housing, transport etc. designed to contribute to the well-being of all citizens) to identify how people with learning disabilities can clearly be 'part of the all'.

Accordingly there was strong interest in complementing the most recent Cranfield workshop on 7-8 February with a national event which aspired to 'get ahead' of the policy agenda and prepare to engage with the emerging policies which have most promise for the future. This record is the result.

What follows is in three parts. First, a map summarises a large part of our discussion of policy opportunities. The map distinguishes key themes in major policies and major initiatives through which these themes are currently being expressed, adding a strong reminder of some of the facts we know about the current situation of people and families which these policies must address. Using Acrobat Reader 6 or higher to study this map on the computer, it is possible both to enlarge this overview so as to focus on particular areas of policy opportunity (and make these more accessible for those of us who are visually challenged!) and also to follow the web links to access the full documents from which the quotes are taken. The map is thus a tool for exploring key ideas for their relevance, locating initiatives which may be helpful and identifying their connections to other policies which may need to be kept in mind in any local change strategy.

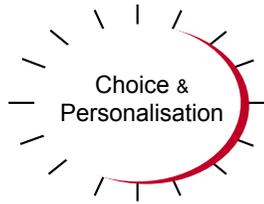
Second, we identify some key points from what we are learning about strengthening alliances and successfully engaging with this changing policy agenda.

Third, we focus on just one crucial area of life where we know there is huge scope for extending people's opportunities, that is, employment, and work through in more detail (as readers may want to do similarly in other areas of life like housing and health) both the specific initiatives which offer routes to policy implementation and the kinds of engagement most likely to deliver gains for people with learning disabilities.

Thus we offer this record as not so much a report on a day's high quality discussion (although it is) but more as a resource to local and national leaders as they 'plot' ways of strengthening relevant alliances and helping people with learning disabilities get maximum benefit from the policy agenda for 21st Century Britain.

We hope you will find it useful.

Major Policy Themes



...the state's capacity to deliver better and better services, with limited resources, will depend on it encouraging people to become more adept at self-assessing and self-managing their health, education, welfare, safety and taxes.
 -Personalisation Through Participation



Creating sustainable, inclusive communities is about everyone having a stake. Being in work and having social contacts is strongly associated with improved health and well-being.
 -Mental Health & Social Exclusion



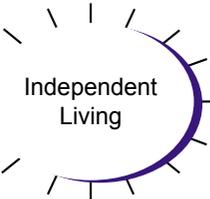
Engaging local people in the design, planning, strategic direction and evaluation of local services is the best way to ensure success in their delivery.
 -Hazel Blears, MP

Disability Policy Themes

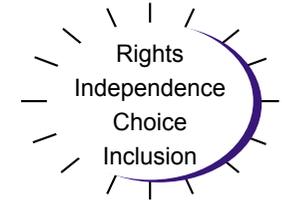
Disability is the disadvantage that comes from barriers which impact on people with impairments. These barriers mean that disabled people are often excluded from society. This exclusion of disabled people must stop.
 -Improving Life Chances



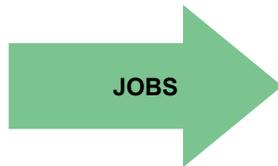
- Helping disabled people achieve independent living.
 - Improving support for families
 - Facilitating a smooth transition into adulthood.
 - Improving support & incentives for getting & staying in employment
- Improving Life Chances



The term 'independent living' refers to all disabled people having the same choice, control and freedom as any other citizen at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations and should address the practical barriers to participation that they face.
 - Disability Rights Commission



- Disabled people should have help to stay in work or get work.
 - Disabled people should be supported to increase their skills for work.
 - Disabled people should have case managers to help them find work & keep their job.
 - Employers also need advice & information about having disabled people in their workforce.
- Improving Life Chances



- The Disability Discrimination Bill will...
- Establish a duty to promote disability equality for the public sector
 - Extend the DDA to cover most functions of public authorities
 - Create new rights to transport
 - Give disabled tenants and leaseholders a right to reasonable adjustments and auxiliary aids and services
- Disability Rights Commission

Initiatives

The principle underpinning the plan is the creation of communities, not housing estates... to create and maintain places in which people want to live & to which they are proud to belong.
 - Sustainable Communities: Building for the Future



Housing quality is not just a question of basic physical standards and the amenities that houses provide. New policy issues have also emerged from a greater awareness by government of the wider importance of housing quality. These include the suitability of houses for different needs groups that are tied into community care and social inclusion agendas. So the question has also become 'decent (or fit) for whom?'
 - Evaluation of Quality & Choice: A Decent Home for All

- IN CONTROL is about self-directed support - being in charge, even if you need help. Being in control, I can...
- Decide things for myself
 - Have the money to live a good life
 - Get help that suits me
 - Have a life that is right for me.
 - Have a home of my own.
 - Be part of my community.



(Reform will) need to strike the right balance between rights and risks and to help to remove barriers to social inclusion. It will need to focus on empowering people needing social care, wherever they live, to participate as fully as any other citizen might expect in a fair society - to help them into further education, into employment, to help them support their families, to bring up their children, to be healthy and safe. And it must ensure that people are safeguarded from harm.
 -Denise Platt CSCI



The philosophical underpinning of the approach we are adopting is one which sees people as citizens. Certainly not as passive clients, nor even as consumers of service (even though where people pay in full or contribute to the costs this is not an absolute position). But the concept of citizenship has at its heart a vision of people who actively participate in all aspects of society - economically, socially, spiritually, culturally. The role of social care services therefore is to reduce the exclusion of people through promoting opportunities and independence. In short promoting peoples rights, as citizens, as human beings. We need to change the regulatory framework radically to ensure that it is focused on outcomes and what people chose.
 -David Behan CSCI

Conditions on the Ground

More than 80% of women aged between 34-54 are in paid employment and a large and rapidly growing number of people live alone. This decreases the availability of informal care and increases demand for social care among the growing population of elders.
 People with a learning disability have a 58 times greater chance of dying before the age of 50 than their fellow citizens without a learning disability.

About 50% of adults with learning disabilities live in their parent's home; many of these people have severe disabilities.
 Local surveys indicate that about 1 in 3 adults with learning disabilities want to move. This generates a need for up to 55,000 new homes. Housing associations provide 300-800 new places per year.

Many people with learning disabilities are invisible to initiatives intended to move people into work. They are not in the target group for Incapacity Benefit Reforms or picked up by LFS. Their numbers are low and the direct benefits of their employment to the public purse are not clear.

Experience shows that with the right support most people with learning disabilities can do paid work in integrated settings.
 People with learning disabilities have been net losers under the National Minimum Wage.
 25% of families caring for a disabled child or young person live on the margins of poverty

Use Acrobat Reader 6 or higher to read this map: the zoom feature allows movement from an overview to the detail and live web links connect quotations to related documents.

Engagement for change

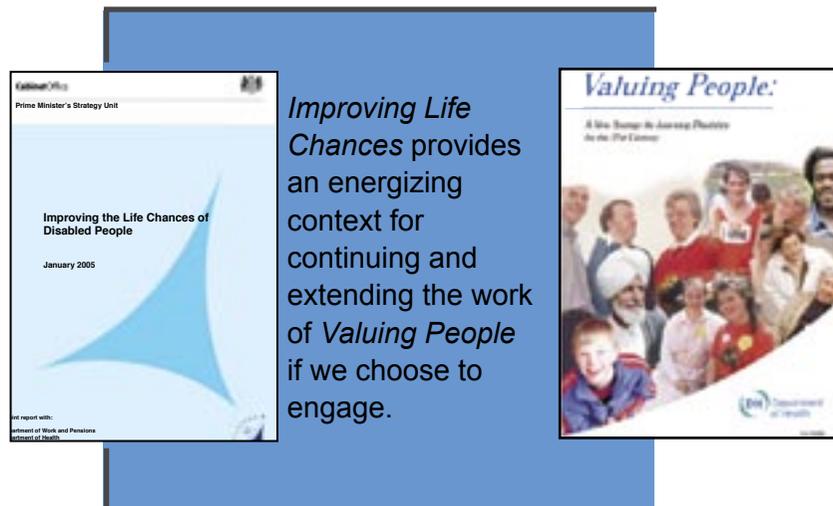
Realizing the possibilities available at this time calls for vigorous and **sustained engagement by a strong alliance** of people with learning disabilities, family members, and other allies, able to act locally and nationally in both political and implementation arenas.

- Better lives for disabled people requires attention to the opportunities for development over the life span. There is further scope for learning from action on the positive values increasingly reflected in services for people in different age bands. This means strengthening links among disabled people of all ages and their families and encouraging much higher expectations.
- Given the many boundary spanning changes required, this alliance must call government to account for joined-up action, in part by advocating for better alignment between each Department's contribution to the Government's Annual Report to Parliament on progress in Valuing People as well as in Annual Reviews by Local Authorities and Annual Reviews by Partnership Boards. This alliance must also seek to ensure these reviews are clearly informed by the lived experience of people with learning disabilities and their families.
- Continued and expanded investment in organizing and developing leadership and supporting active participation in decision making by people with learning disabilities –including children and young people with learning disabilities– and family members is necessary to extend and strengthen this alliance.

A stronger alliance will emerge from dealing with these **questions**:

- How can we build strong and effective relationships between advocates with learning disabilities, family members who advocate, and leaders of the independent living movement?

- How can we assure that the experiences of people with significant communication difficulties or substantial cognitive impairments are actively represented in decision making at every level, in discussions of social exclusion, and in the increasingly influential account of the social model of disability?
- How can we extend and highlight the positive contributions that people make when supported to assume the responsibilities of citizenship and take up socially valued roles?



- How can we encourage local action at the boundaries between service users, providers, and commissioners that both deliver real benefits to people and make clear links to evolving policies?
- How can we inform the whole system about learning from action consistent with the values and strategies set out in policy?
- How can we honor different preferences –e.g. about congregate day centres– and build momentum for significant change?
- How do people with learning disabilities and family members participate influentially in important deliberations

where they represent concerns that directly touch only a very small proportion of those affected –e.g. housing, regeneration, employment, transport?

- How do we connect with, and positively influence, reforms in services to elders?
- How do we rapidly develop local actions that test and extend policy themes like “personalisation” and “social exclusion”?
- How do we attract mainstream investment in collaborative actions around issues like employment and housing?
- How do we make best use of the public duties established by the Disability Discrimination Amendment Act?

Employment as a promising example

To image strategies for making the most of the possibilities identified on the map, consider the positive opportunities available to people with learning disabilities in only one of the life areas that both *Valuing People* and *Improving Life Chances* seek to influence. **Employment** offers a valued social role, improves social inclusion, expands

choice, and reflects the expressed desires of many people with learning disabilities. Supported employment demonstrates that many people with learning disabilities overcome negative predictions and work successfully, given proper support. Despite this, people with learning disabilities remain under-employed, even compared to other

disabled people –and they are at risk of remaining invisible in the substantial reforms envisioned by *Improving Life Chances*.

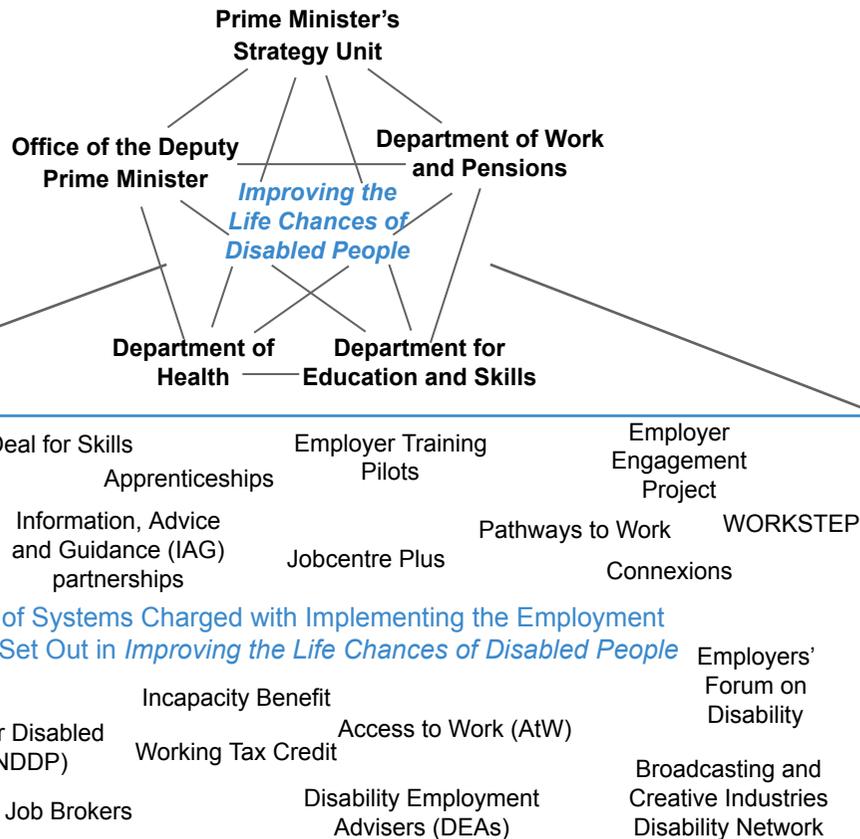
The challenge is to assure the full inclusion of most people with learning disabilities among the group of disabled people for whom employment is considered feasible by policy makers and practitioners in the area of assisting people into employment. This is certain to stretch understanding of what reasonable adjustment to disability means for people with learning and communication impairments. It also demands much expanded investment in mainstream employment services adopting practices proved effective by successful supported employment providers.

The system of systems depicted in the diagram identifies the possibilities for engagement and suggests the complexity of scanning to discover chances to promote the inclusion of people with learning disabilities. It also suggests the importance of mobilizing well-informed participants to exert influence and to guide shifts in specialist service commissioning and provision to make the most of new opportunities.

Action is necessary at every level. Those responsible for implementing *Improving Life Chances* at the centre and in key systems like Pathways to Work need the active presence of knowledgeable, and well supported advocates for the employment of people with learning disabilities.

There is a great need for working examples of strong connections between employers, mainstream employment initiatives, specialists in supported employment, and people with learning

“...any disabled person who wants a job, and needs support to get a job, should be able to do so wherever feasible.”



According to *Improving Life Chances*, a “mapping” study identified nearly 2,500 voluntary sector and local authority projects providing 6,700 pre-employment services to disabled people in Great Britain.

disabilities and their families. The capacity of many people with learning disabilities to work with skilled specialist assistance is well established. Active cross boundary collaborations are less common to date. The lessons from these collaborations must be rapidly disseminated within and across organisational and social boundaries.

The formal governance and advisory structures –as well as networks and communities of practice– emerging from the implementation of *Valuing People* offer the sort of channels and connections necessary for the exchange of intelligence, rapid problem solving, and mobilization of advocacy necessary to influence the intermediary systems charged with implementing *Improving Life Chances*.

As many individuals as possible need to engage the myriad local projects and programs which will be changing to include disabled people. To support individual action...

- Person-centred planning provides people and their families with a way to clarify their interest in employment.

- The evolving set of tools generated by **in Control** provides a way to align specialist resources around employment.
- Efforts to promote positive transitions for young people with learning disabilities offer a way to raise expectations and move toward mainstream employment initiatives to implement them.

In this effort, it is vital to maintain focus on three messages:

- People with learning disabilities are very employable given the right conditions and in the right jobs are excellent employees
- There is a human rights case for the state ensuring that the employment of all citizens with learning disabilities who want to work is economically viable and practically manageable for employers.
- The public sector should lead by example in employing a diverse workforce that includes people with learning disabilities

Energising change

This focus on employment highlights the importance of extending and strengthening the alliance of people concerned to include people with learning disabilities in the changes driven by positive policy themes. A reasonable approach will need enough people to proceed with energetic change efforts not just on employment but simultaneously in equally complex systems like housing, health, and community regeneration.

In the course of building new connections and innovative approaches it is essential to keep struggling to hold high expectations for the inclusion of people with extensive and complex support needs. Without them, new policies and programs cannot be sufficiently robust to achieve their purposes.

Passivity in the face of the opportunities offered by the current environment would be inexcusable. Expecting that benefits will flow smoothly and automatically to people with learning disabilities would be naive. What's needed is strong engagement in many new attempts at learning through action that crosses boundaries and shifts power to people with disabilities.



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