

15 April 2005

Strategy Unit Disability Team
Cabinet Office
4th Floor, Admiralty Arch
The Mall,
London SW1A 2WH

RE: Improving the Life Chances of Disabled People

I am writing in response to the above consultation.

The first – and probably the most important – thing to say is how refreshing the report is. This is a heavyweight report – both in its substance and its importance – and hopefully represents a real change in the ways that policy analysis can be informed by and reflect the substance of people's lives. The partnerships with disabled people both in processes and in the perspective of the analysis represent real progress and hopefully this can be built upon and developed in the future.

For example, it would be good if parallel current policy developments (e.g. in relation to policies around older people, the Green Paper on Adult Social Care, policies about Mental Health users) are able to draw on the learning from this approach. In the past, policy developments (even while using the language of citizenship) often treated people as passive recipients of services. The approach in this document offers some helpful learning that could be taken forward more generally.

The main message in this response is a supportive one. The report is best seen as a living document, which will undoubtedly develop over time. The comments that follow are about areas that might be addressed more fully, or taken forward in developing the strategy.

COMMENTS

1. Disabled Adults in their Parenting Role

The report gives a great deal of weight to adults in employment and to the transitions of disabled children and young people into adulthood. This is entirely to be welcomed. However there are other aspects of human rights/citizenship that relate to disabled people's lives which probably also need to be brought up the agenda. For example, Disabled People can also be parents – any of us who is a parent recognises how fundamental, how central that is to our lives, often far more important than the expediencies of employment. This is mentioned in several places, but arguably a chapter on the bridges/barriers that disabled people experience in their parenting role would reflect the importance that this aspect of their lives has for many disabled people. There are general points (of raising the agenda) and specific points (in relation to current policies).

Recommendations

- i. It would be good for the report to highlight a priority for further work in this area.***
- ii. There might be a case for revising the legislation around the Independent Living Fund which currently cannot be used to meet parenting support needs at all.***
- iii. It would be good to look at Disability Living Allowance so that benefits take account of the additional costs that might be incurred through being both a disabled person AND a parent.***

2. Employment

In its balance, the chapter focuses primarily on strengthening the hand of disabled people in the labour market (in getting access to employment – ideally appropriate employment) and on the responsibilities of employers. These are really important issues and the report contains powerful messages here. However there is a danger of unintentionally giving a message to disabled people that, if you are not in employment, you are not living independently. For some disabled people a formal

position in the labour market may not be the best option and it would be good if the report had more to say about this. For example, in the launch of the Shaping Our Lives project, Stephen Ladyman noted that the tax and benefit system militated against paid work for people using their expertise and knowledge as users in “user involvement” initiatives. (particularly for those in receipt of benefits).

In addition, many of the issues that disabled people face IN employment are about their own aspirations and the difficulties that they face – not simply from the management structure, but also from their colleagues. In our projects about Independent Living we have come across bullying of people with learning difficulties in the work place (and the failure of trade union representatives to respond to their needs), a lack of understanding of well-intentioned colleagues in relation to the disabled person’s circumstances.

Recommendations

- iv. To look at the circumstances of disabled people for whom the formal labour market may not be the best option for an individual’s choice and control. This should include current inflexibilities within the present tax and benefit system.***
- v. To look at further work on bridges and barriers for disabled people in the workplace.***

3. Black and Minority Ethnic Disabled Adults

Mention is made of the importance of the issues here, but we already know a great deal about the problems, and our own approaches have been to look more at solutions. In JRF’s Race and Disability programme we have looked both at the problems Black Disabled People face, but also looked at specific solutions WITH Black & Minority Ethnic disabled people and community organisations.

Recommendations

- vi. It would be good if work were prioritised with new single Commission for Equality and Human Rights to ensure that***

multiple and complex support needs of people whose experience of exclusion cuts across “race equality”, “disability equality”, “gender equality”, “age equality” etc..

- vii. It would be good to identify appropriate and deliverable outcome measures for Black & Minority Ethnic disabled people. One task for the ODI might be to enter into a sustained dialogue with Black disabled people and their organisations.***

4. People in Residential Care

There is little mention about disabled people looking to achieve independence in a residential care setting. There is a danger in assuming, because the policy drift is towards people living in their own homes, that there is not a current policy/practice issue. There is also a danger in focusing on structural issues (and seeing these as being simply within the remit of Social Care STRUCTURES). Our Independent Living Committee recognised that more than 250,000 people were supported by local authorities in residential and nursing homes, and the Committee felt that this would be an important area to address.

Recommendation

- viii. For further work to be done, looking at the circumstances of people in residential and nursing homes, with approaches to improve the life chances of disabled people in these settings – either by transforming solutions within these settings or finding routes out into independent living.***

5. Information, Advice and Advocacy

The report recognises (to some extent) the importance of these. It would be good if ILCoDP and LinkAge shared their thinking on this common territory. It is not enough simply to “join up” government to make it more customer friendly. One has to go back to the processes that individuals and groups experience, rather than simply thinking about structures.

The report quite properly recognises the importance of Advocacy in relation to individual lives but one needs to recognise the processes that need to be in place to make this happen. Advocacy and community organisations live at the financial margin, scrabbling for funds to survive. It also requires much more outreach to make it happen. CILs and other approaches are crucial in this regard, but they will need funding to do this outreach and will need to use community networks and groups. This is particularly true in relation to disabled people from Black and Minority Ethnic communities and to disabled people who may not be in touch with any disability organisations.

Recommendation

- ix. A policy analysis of the different types of information, advice and advocacy approaches which may be needed and a costing of the range of options – this analysis to be conducted in partnership with user-led organisations.***

6. Delivery and Sustainability

6.1 Cross Departmental

We do not have any comments on the specifics of Personalised Budgets. We will be commenting (on the Green Paper on Adult Social Care) that, although Personalised Budgets are prominently mentioned in a Green Paper whose impact will primarily be about older people – so far as we are aware – there has been no work on Personalised Budgets in relation to Older People. Although this point might not seem relevant to the present consultation, in fact it does raise issues about sustainability and the way in which the issues are owned beyond the consultation.

It will require different parts of Central Government to own the vision fully outlined within the report. It is a well-worn discussion about the difficulties of transferability and of handing on issues. The report quite rightly identifies a 20 year timescale for change, but for the report to have this impact, it will need robust structures and ownership of the initial vision to achieve its goal. It may be that there will be a joined-up handing on of the message, and the ownership of key targets should also aid in delivery, but there is probably a need for a more critical and supportive voice from Disabled People to support, challenge and counterbalance government structures. Mention is made of the role of

the National Forum of Organisations of Disabled People, but it is not clear as yet what their remit will be. It would be stronger if this was a partnership rather than purely consultative arrangement.

Recommendation

- x. To publish proposals on the role of the NFODP and other possible approaches to involving disabled people, including possible resource implications for this involvement.***

6.2 Developing a Consensus

It is likely, also, that there will be changes in political administration over the coming 20 years, and it is not clear from the report what efforts have been made to gain ownership across the political spectrum. Clearly the coincident General Election may not be the best time to develop overtly shared strategies, but it would be good to know, in taking the strategy forward, that there were attempts to build a consensus on the issues.

Recommendation

- xi. For Office for Disability Issues to consider ways of developing cross-party consensus on elements of the strategy, if not on the strategy as a whole.***

6.3. Local Delivery in Practice

Delivery and sustainability is only partly about Governments and joined up Whitehall. The Reference Group of users to the JRF Independent Living programme has commented that there is a danger of trying to graft good ideas (e.g. Direct Payments) onto problematic structures and assumptions. Their argument was not against the good idea (Direct Payments) but about the local barriers to change. Individualised Budgets will probably face some similar constraints

- xii. The Green Paper on Adult Social Care does not as yet address additional resources. There needs to be a properly costed and properly funded implementation strategy. If the underpinning assumption is that this will be at zero cost it is likely to fail.***

- xiii. Standards, regulation and ideas of good practice need to be fully owned and properly developed locally. It is still the case that many users (and some care managers!) still do not know about Direct Payments and do not know that there is an obligation on the part of services. There needs to be a mixture of support for workers (down through the hierarchical structures) to enable them to work in the best interest of users and standards that they are working to being those that are a priority for users.**
- xiv. Users also need to be key players in this and supported. The issues about standards on user involvement are very current, both in research and practice. There is a danger of tokenistic approaches being agreed or imposed upon users locally. There need to be standards which are driven by users, and this implies not just funding for involvement but also that the involvement is clear and meaningful.**

In summary, the document as a whole represents a real potential for progress and our hope is that this can be taken forward into policy and then practice.

Please do not hesitate to contact me if you would wish to follow up on any of the points raised.

Yours faithfully,

Alex O'Neil (Principal Research Manager – Independent Living)