

MINUTES

11th September 2006

1.30 – 4.30pm

London Voluntary Sector Resource Centre (LVSRC)

Approach to the minutes

The minutes do not attempt to capture every point made, but provide a summary of the group's discussions and a record of required action points. Comments and points raised during discussion have not been attributed to individual members.

Terminology

In this paper:

- The Office for Disability Issues is referred to as “the ODI”;
- The Independent Living Review is referred to as “the review”;
- Members of the Expert Panel are referred to as “members”.

Attendees

Expert Panel members: Dame Jane Campbell (Chair), Rob Greig (Vice-chair), Saghir Alam, Ian Basnett, Nasa Begum, Zoe Carter, David Gardiner, Fazilet Hadi, Ray Johnson, Elaine Morton, Menghi Mulchadani, Jo Williams, Jean Willson, Gerry Zarb

Officials: Bruce Calderwood (ODI), Miranda Carter (Department for Transport), Mike Daly (Department for Work and Pensions), Craig Muir (Department of Health)

Project team: Pam Bennett, Helen Bowers, Sheila Evans, Mary Helson, Rosalind Hook, Jenny Morris, Steve Strong

Apologies

John Dixon, Frances Hasler, Rowen Jade, Angela Mason (Department for Communities and Local Government), Tony

Orhnia (Treasury), Chris Wells (Department for Education and Skills)

1 Introduction

- 1.1 Jane Campbell welcomed the members and suggested some working guidelines for the group. Members introduced themselves. Jane reminded members that they had been invited to join the panel in their capacity as individuals for the experience they can bring to the group, rather than as representatives of an organisation.
- 1.2 The first meeting of the Expert Panel has been marked by a written statement to Parliament by the Minister for Disabled People, and a press notice announcing Panel membership.

2 Terms of Reference (paper EP 1/1)

- 2.1 Bruce Calderwood, director of the ODI, set out the background to the review, its aims and the role of the Expert Panel.
- 2.2 The project team will need to work quickly to develop a set of proposals to feed into the Comprehensive Spending Review by November. The work of the project team will be shaped and steered by the Expert Panel, the role of which is to give expert advice to the review.
- 2.3 Members discussed whether social care and leisure services should be included in the review's aims. It was suggested that the list of issues set out for consideration is not meant to be exhaustive. The areas listed – transport, employment, housing and access to healthcare – are particularly important in developing an integrated approach to mainstream services which helps disabled people lead more independent lives.
- 2.4 It was generally felt that the Terms of Reference reflect the practical aims of the review in a concise format. It was agreed that the review will want to leave a legacy beyond its immediate aims, for example in the form of a five year strategy.

3 Project outline (paper EP 1/2)

3.1 Jenny Morris presented the review's background and aims, and asked for members' views. This discussion included the following points:

- Will the review include children and young people, and if so how do we define these groups? Although the review excludes children, it will look at young people in transition to adulthood. Formally "transition planning" takes place at age 14.
- Commenting on the review's aim to develop a "business case for investment" in independent living:
 - There is an implicit underpinning aim of supporting people to have choice and control and enabling them to make a contribution to society. The importance of the terms social inclusion and exclusion in developing a business case was firmly endorsed by the group.
 - It is as much about reallocation of existing funds and using these more efficiently as it is about new investment.
 - The case for independent living is not only an economic one; pursuing a better quality of life for people was of equal importance.
 - Putting together a "business case" is not just about money but also about public bodies achieving their objectives, e.g. the Disability Equality Duty.
 - It is important not to just regard disabled people as single units of investment, but rather to consider the domestic context as a whole e.g. other family members and partners. Independent living isn't necessarily about living alone.
 - Looking at the business case for investment should come after considering the ways in which people can be supported to live independently.

3.2 Mary Helson presented the review's initial plans and the proposed mapping exercise of policies and initiatives across

Government which support and promote independent living, in order to identify gaps and priorities. The discussion about the mapping exercise included the following points:

- It should include disabled parents, Black and Minority Ethnic groups and mental health service users and survivors.
- It should consider how initiatives impact on different groups of disabled people, as well as considering any unintended results or negative impacts of government policies.
- There are implications for social care workforces which need to be tailored to meet the needs of individuals. This may result in the creation and management of “micro-markets”, which means individuals providing their own support which could be considered as a small business. Two related suggestions to consider were the Department of Health-led work into “micro-markets” and the Coventry Centre for Independent Living.
- The project team should use networks such as the People First network and website, as well as the National Family Carers Network for gathering information and feedback. Other suggestions included the Asian People’s Disability Alliance, Equalities, NEST (the User Involvement Network for Mental Health Services in North Essex), the Disability Rights Commission Mental Health Action Group and Shaping Our Lives. The Disability Employment Advisory Committee is also aware of the review and eager to contribute.

3.3 Members asked what evaluation criteria would be used to judge the success of the review. This is part of the ODI’s work on delivering the Life Chances agenda, and involves developing a critical set of indicators to measure progress towards the long-term goal of substantive equality for disabled people. It was agreed that it is important to show explicitly how work is making a difference, either in terms of financial indicators or in terms of the difference it is making to people’s lives. The panel requested to receive an update of how this evaluation was developing and any outcomes towards the end of the Expert Panel’s 12 months work.

4 Report on work commissioned to inform the economic case for investment in independent living (paper EP 1/3)

4.1 Jenny Morris presented initial work commissioned to develop the economic case for independent living, and asked members to give initial views. Jenny explained the group that the project team needed to go ahead with this work before consulting with the Expert Panel because of the tight timetables involved in the review. However there was time to feed in comments on the work as it progressed. The findings will be presented to the Panel at the next meeting.

4.2 The discussion included the following points:

- Concerns were raised that costs of brokerage of services might come out of Individual Budgets so people in fact end up with less support. It was agreed that the costs of commissioning services as well as service provision must form part of the cost-benefit equation.
- Commissioning of services may turn out to be more like market research, with the market process developing services to meet the collective demands of individuals. In future it might be useful if end users did the market research for commissioning authorities.
- Eligibility criteria for Direct Payments / Individual Budgets and assessed needs can be problematic. A need to address the reluctance to make Direct Payments available to people considered by social care authorities as too impaired or not impaired enough. This seemed to be especially problematic for people with learning disabilities.
- It is important to consider the Community and Voluntary Sector in terms of advice and assessing support needs. This relates to one of the project aims about identifying the support, advocacy and brokerage services necessary to enable independent living for disabled people.

5 User-led organisations: report on Department of Health-led work (paper EP 1/4)

- 5.1 Craig Muir outlined the Department of Health's proposals to develop user-led organisations.
- 5.2 The two proposals that have progressed furthest are mapping existing user-led organisations and consulting with user-led organisations.
- 5.3 Members raised the following points:
- The extent to which people with learning disabilities and other service users have been involved in the mapping exercise. The project should involve Shaping Our Lives, People First and should include self-advocacy.
 - The need to clarify a precise definition of "user-led". Craig Muir explained that this was part of the consultation process with user-led organisations, to find out lessons from users, user-led organisations and family carers.
 - The importance of the Local Authority / Primary Care Trust partnership model and need to capture this in the mapping exercise. The need to capture other forms of collaborative approaches with disabled people and their organisations, and the huge variation across boroughs in extent of input into user-led organisations.
 - The need to capture examples of good practice in the mapping exercise – including not just what is available currently but exploring disability led support organisations that, for whatever reasons, have disappeared. This is important for the organisational principles that define what is meant by user-led. It was also suggested that the aspirational plans of disability organisations should be mapped, for example, partnerships between Centres for Independent Living and older people. Could the project develop such partnerships?
- 5.4 Craig asked whether one member of the Expert Panel would join the project board for the user-led work and if the project team could use the Expert Panel as a reference group. It

was agreed that the ODI and DH would explore collaborative mechanisms including working with the Expert Panel.

- There was a concern that this work is not truly user-led or user-controlled, and that one member on the board was not sufficient. Craig said he would take up the recommendation for strengthening the project board.

5.5 The Expert Panel asked to be kept informed as the project developed. The issue of the Expert Panel being involved in the Department of Health work programme on user led organisations will be taken forward by Bruce Calderwood and Craig Muir.

Action points

Project team:

- To circulate the press notice and ministerial written statement to Expert Panel members.
- To update the ODI website to give key information about the review and to give individuals and interested organisations a chance to comment.
- To make use of networks suggested by Expert Panel members in mapping existing policies and initiatives across Government that support and promote independent living.
- To present findings from the work commissioned to inform the economic case for investment in independent living at the next meeting.
- To receive an update of how the ODI evaluation of Life Chances and in particular the Independent Living work, was developing and any outcomes towards the end of this panel's 12 months work.
- To present a more detailed project plan to the Panel at the next meeting.
- To circulate contact details for Expert Panel members.

- To decide the level of expert panel involvement in the Department of Health work programme on user led organisations. Bruce Calderwood and Craig Muir to report back at the next meeting.

The next meeting will be on Monday 30 October in London.