

MINUTES

15th February 2007

1.30 – 4.30pm

Eighty9 Albert Embankment, Vauxhall

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), Ray Johnson, Zoe Carter, David Gardiner, Jean Willson, Saghir Alam, Gerry Zarb, Jo Williams, Ian Loynes, Rowen Jade

Officials: Jacinda Humphry (ODI), Nigel Dotchin (Department for Transport), Arthur Blacklock (Department for Work and Pensions), Helen Steele (Department of Health), Alison Thompson (Department for Education and Skills)

Others: Menghi Mulchandani, Neil Crowther (Disability Rights Commission)

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

Apologies

John Dixon, Ian Basnett, Elaine Morton, Fazilet Hadi, Angela Mason (Communities and Local Government), Tony Orhnial (Treasury).

1 Welcome and minutes of last meeting

- 1.1 Jane Campbell welcomed the members attending the Expert Panel for the first time.
- 1.2 The minutes and action points from the last Expert Panel meeting were agreed.
- 1.3 It was announced that Nasa Begum has left the Expert Panel, as she is taking up a secondment at DH to support their work on developing user-led organisations. The review will maintain close links with NCIL through Ian Loynes' participation.
- 1.4 The Expert Panel congratulated Jo Williams who has been made a Dame for services to learning disability in the 2007 New Year's honours list. Members also offered their congratulations to Jane Campbell, who has been made a People's Peer.
- 1.5 Anne McGuire has provisionally agreed to attend the next Expert Panel meeting on 28 March, and the review team are currently checking whether Ivan Lewis is also able to attend a future meeting.

2 Updated programme plan (paper EP 4/1)

- 2.1 Sheila Evans updated members on the programme plan and progress made on the seven main work strands, setting out the key timings for the remainder of the review and a risk log.
- 2.2 She explained that the original intention was to have completed the mapping exercise by the end of December. In practice, the number of initiatives identified and complexity of evaluating the information received has made this a much bigger project strand than originally envisaged. An update on

the mapping work will be given to members at the next meeting.

2.3 The review team asked for the Panel's views on the priorities identified for action and risks. Members had the following comments:

- It is useful to have review milestones clearly mapped in this way. In the case where mapping and research have gone on for longer than anticipated, this needs to be reflected by revised timings in the summary programme plan.
- There may be a risk that other government departments might not buy into the review's proposals.
- Engaging with disabled people at all stages of the review is really important. The review team needs to send accessible information to the next meeting of Equality 2025 to explain why it is important that they engage with the review, and to request space on the agenda to discuss the review at a future meeting.
- In making the economic case for independent living, the contribution of carers and the voluntary sector needs to be flagged up as an important part of the cost-benefit equation as well as the general context of the review.
- It is critical that hard to reach groups such as black and minority ethnic groups are included in the review, especially in work such as the mapping exercise.

2.4 The review team explained that we see engaging with the different government departments responsible for policies relating to independent living as critical. In producing the review's five year strategy, the review team aims to collaborate with other government departments in order to co-produce policy proposals through a series of workshops, discussions and meetings.

- 2.5 The review is planning a cross-government meeting in March to ensure that all government departments are engaged in developing the five year strategy.
- 2.6 We also intend to hold a roundtable discussion to consider the case for and against new legislation and our emerging conclusions will form part of our wider consultations during April and May.

3 The Disability Rights Commission's Disability Agenda (paper EP 4/4)

- 3.1 Neil Crowther from the Disability Rights Commission (DRC) presented an overview of the DRC's Disability Agenda, which was launched on 14 February and sets out the major challenges for public policy in respect of disabled people and their families and the DRC's recommendations for how to meet them.
- 3.2 He spoke in detail about the chapter on social care, but also covered issues about housing, education, communities, as well as explaining the key drivers needed in order to embed the agenda.
- 3.3 Members were asked for their views on the key aspects of the DRC's agenda that impact on the review, and which parts need to be reflected in policy proposals. The discussion included the following points:
 - As well as focussing on how to get government departments to buy into the agenda, the DRC should be looking at mobilising disabled people and disabled people's organisations. It is important to make the agenda relevant to ordinary disabled people, not just policy-makers and lobby groups. Involving disabled people from the beginning will save money in the long-term.
 - Joining issues about women, children and carers together is potentially a very powerful approach, as it brings different groups together to advocate on independent living.

- The DRC's emphasis on housing is very welcome, and the agenda succeeds in joining together departments and sectors to consider real people's lives in a holistic manner. The review's policy proposals should complement and reinforce these points. It should also emphasise that sufficient space in the home is as important as accessible homes.
- The DRC's focus on employment is also very important. It may be possible to arrange a special meeting of the Disability Employment Advisory Committee (DEAC) in order to consider ODI issues generally and to discuss the Independent Living Review and exchange perspectives.
- Contributing to society in whatever way – whether economically, socially, through voluntary work etc. – is really important in terms of enhancing individuals' sense of well-being. It would be helpful to see increasing participation in civic and community life reflected in government targets.
- We need to be thinking about independent living across the lifecourse, and challenging assumptions that an ageing population necessarily means greater expense and more problems.
- Right to life appears to be missing from the agenda, but this concept is critical in terms of disabled people's identity and opportunities to practice independent living.

4 The scope and structure of the Independent Living Review's final report (paper EP 4/3)

- 4.1 Jenny introduced the paper on the scope and structure of the review's final report, which seeks members' views about whether this is the right structure for the report, and whether there are any gaps. The discussion included the following points:

- Members welcomed the inclusion of older people in the final report. However, there was a debate about whether it was necessary to have a separate chapter on older people, or whether specific issues about race, gender, age, sexuality etc. should be integrated throughout the report.
- In this case, it would be necessary to flag up all the different dimensions of difference which we would wish to include at the start of the report. We would certainly wish to assess the impact of different policies on race, gender, older people etc.
- Similarly, there was a discussion about whether the final report should flag up specific impairment groups. In the case of mental health service user groups, for example, there may be a need to emphasise specific issues relating to mental health as many mental health service users are not familiar with the language and concepts of independent living.
- The report needs to include vivid examples of different impairment groups throughout all its chapters, drawing out specific issues concerning learning disabilities, mental health, neuro-diversity etc. at every stage. However, the report could be issue-specific rather than impairment-specific, so long as it includes all impairment groups.
- The report's introduction should explain the context to the independent living movement and acknowledge what has gone before as a means of explaining the review's definition and interpretation of independent living today.
- The chapter on the role of public agencies should acknowledge the extent to which disabled people are also dependent on the commercial sector (e.g. for dentistry, optical care, banks, insurance etc.) as well as public sector for their quality of life. It is an important part of the context of independent living.

- As discussed at the last meeting of the panel, the review should look at the regulatory function of the private sector as a means of bringing about changes in public sector agencies.

4.2 A major section of the review's five year strategy will concern the social care system, and the review team is keen for the Panel to influence the content as well as the structure of the report. Members split into three smaller groups for a discussion about the recommendations they would make to government departments about the social care system. They reported back on the main points raised:

- It is important to finish redefining social care as started in the Green Paper on adult social care, to demonstrate the role of social care as promoting citizenship, relationships and interdependence. Government departments need to work together more effectively, and funding streams should be brought together to enable this.
- The Government should involve service users in developing the social care system at every level ("nothing about us without us"), both in terms moving towards a model that favours co-production of policy and in ensuring that information is accessible and available for everyone.
- There needs to be a debate about the split between private and state funding.
- There should be a national minimum set of standards, transparent allocation of resources and portability, so that everyone has the same expectations of government and what it will provide.
- In terms of cost issues, it is important to remove structural inequalities and to change the things that social care money is spent on in order to increase independent living rather than emphasise dependency.

- Social care should be a means to an end, and commissioning should be focussed on outcomes and enabling social well-being. Assessments should be focussed on the everyday as well as what people want to do with their lives.
- There is a need to maintain the existing momentum around greater personalisation and individualisation of social care services, as well as upfront investment in preventative approaches.
- There is a need to change the language around social care, to move from concepts such as “dignity” and “respect” to “rights”, “choice” and “self-determination” and illustrate what rights and choice achieve. Advocacy and access to information are both really important here.

5 Independent Living Review stakeholder workshops (paper EP 4/2)

- 5.1 Helen introduced the paper on all the review workshops that have been held to date. The workshops have been an excellent opportunity to share key issues and explore key themes with a wide group of stakeholders, and have been immensely valuable both in terms of shaping emerging policy ideas and bringing different groups of people and organisations together to discuss issues that are common to them all. Helen explained some of the key issues and themes that emerged from the older people’s workshop on 16 January and invited the Panel’s comments.
- 5.2 Jenny spoke about the workshops on transition to adulthood and disabled parents, the latter of which was an internal government workshop involving the ODI, Department of Education and Skills and Treasury. The transition workshop was a good example of policy co-production, and involved family carers, young people, government departments and local agencies both statutory and voluntary in developing a manifesto for policy recommendations in this area.
- 5.3 The Panel’s discussion included the following points:

- Older people are not often involved in their own leadership and shaping policies that affect them. Workshops such as these are an opportunity to redress the balance.
- Members asked about the demographic analysis work that the review team is commissioning, which will be used to inform the five year strategy. The review team will update members at a later meeting of the panel about this work.
- There are similar themes emerging from all the workshops, which is encouraging as it shows continuity of messages around independent living. Different groups are using different words to talk about the same issues, and these workshops have been an excellent opportunity to bring together disparate groups and begin to develop a shared understanding of independent living.

6 Support, advocacy and brokerage (EP 4/5)

- 6.1 Steve introduced the paper on support, advocacy and brokerage. He talked about the workshop on support, advocacy and brokerage, and explained how the aims of this day were to define the key features of these concepts and suggest short and long term priorities for the review.
- 6.2 There was too little time to discuss this agenda item in detail, so Steve agreed to bring this paper back to the next meeting of the panel. In the meantime, members should send comments to him about this strand of work, in particular focusing on the following questions:
- Is any other activity needed to enable the delivery of this key component of the work of the review?
 - What should be the priority issues on support, advocacy and brokerage in the short, medium and long-term?

7 Any other business

- 7.1 The ODI has launched a consultation set up to help government departments deliver equality for disabled people by 2025. It asks disabled people what equality means to them, and gains their views on how government can best monitor progress towards equality for disabled people. Members all received a copy of the consultation document.
- 7.2 At the next meeting we will discuss support, advocacy and brokerage in more detail. We will also receive an update from the Department of Health on their work on user-led organisations, update members about the review's mapping work and discuss draft outline proposals for the review's final report.

Action points

Project team:

- To invite Ivan Lewis to a future meeting of the Expert Panel.
- To update members about the mapping exercise at the next meeting of the Expert Panel.
- To ensure that the programme chart accurately reflects revised timings for workstrands.
- To take a collaborative approach to engaging with other government departments, and to co-produce draft policy proposals for the review's five year strategy.
- To send accessible information to the next meeting of Equality 2025 to explain why it is important that they engage with the review, and to request space on the agenda to discuss the review at a future meeting of this group.
- To ensure that templates on initiatives involving black and minority ethnic groups are included in the mapping work.

- To send members the background paper from the January 16th workshop on older people.
- To discuss support, advocacy and brokerage in more detail at the next meeting.
- To arrange for the Department of Health to update members on their work on user-led organisations at the next meeting.
- To discuss draft outline proposals for the review's final report at the next meeting.

Members:

- To send comments to Steve Strong about the support advocacy and brokerage work, in particular focusing on the following questions:
 - Is any other activity needed to enable the delivery of this key component of the work of the review?
 - What should be the priority issues on support, advocacy and brokerage in the short, medium and long-term?

The next meeting will be on Wednesday 28 March in London.