

MINUTES

5th July 2007

12.30 – 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: Baroness Jane Campbell (Chair), Rob Greig (Vice-chair), Ian Loynes, Ray Johnson, Zoe Carter, David Gardiner, Saghir Alam, Frances Hasler, Rowen Jade, Fazilet Hadi, Jean Willson, Jo Williams, Ian Basnett

Officials: Craig Muir (Department of Health), Nigel Dotchin (Department for Transport), Mike Daly (Department for Work and Pensions), Jacinda Humphry (ODI), Sally Witcher (ODI).

Project team: Mary Helson, Rosalind Hook, Steve Strong, Jenny Morris, Helen Bowers, Huw Meredith, Peter Coyle, Bunmi Shodeyi, Pam Bennett

Apologies

Gerry Zarb, John Dixon, Elaine Morton, Tony Orhnial (Treasury), Hardip Begol (Department for Children, Schools and Families),

Angela Mason (Communities and Local Government), Sheila Evans (project team)

1 Welcome and minutes of last meeting

- 1.1 Jane Campbell welcomed members. The minutes and action points from the last Expert Panel meeting were agreed.

2 Interim report to Expert Panel (paper EP 7/2)

- 2.1 Mary Helson presented EP7/2, which updates members about the review's revised timetable and presents an executive summary of a progress report of the review's work to date. She explained that this report only provides a partial picture of all the work that the review team is taking forward, as the team is also working towards achieving cross-government agreement to policy proposals for the review's five year strategy.
- 2.2 Mary asked the Panel for comments about the report as a whole. Members made the following points:
 - There need to be clear action points and concrete proposals about how to deliver outcomes for independent living against each of the review's aims. Even an interim report should contain these tangible outcomes. It is particularly important to acknowledge where the blocks, obstacles and levers to change are, and to identify the process for getting to a particular outcome.
 - The report is overly long and too discursive, and it lacks clarity about where the Panel wants the world to be in five years time. Members felt that there are some positive aspects to the report, such as descriptions about what independent living means, but that these get lost because the report is so lengthy.
 - The stories about individuals' experiences and circumstances are very important and powerful in bringing this document alive and providing a reality check. We should not lose sight of the detail of

people's lives and the fact we should be focussing on enabling disabled people to live the same lives as everyone else. In doing so it is important that limited public money and resources aren't spread too thinly.

- The Panel believes that it is very important to have the confidence and bravery to make the human rights case for independent living, not just the economic case. Independent living is not about facts, figures, resources and statistics, but ultimately about individuals' lives.
- Members felt that the report doesn't adequately reflect the output from the thematic workshops and regional events that have been held, or the breadth and depth of the Panel's discussions to date. It reads more like a work-in-progress report.
- It is important that long-term thinking is balanced against urgent action. The review needs to seize this time of political opportunity and opportunities for change. It needs to consider changes in service delivery and commissioning that are taking place and take account of the implications that these will have for disabled people.
- The report should take account of the information age and the way that technology can transform lives, in order to make sure it reflects the modern world we're living in.
- It is important to capture the independent living story and to capture political interest in this report to Ministers.
- Members felt that some of the terminology employed by the report was problematic. For example, they queried the phrase "communal setting" rather than "residential care". It is important to flag up the issue of younger people of working age who are going into residential care, even if this term is not always used.

- Similarly, the phrase “older people” may not resonate with what people are talking about in the world outside. The review should provide leadership for talking about independent living in a different way.
- 2.3 Mary said that the review team will ensure that the detailed proposals for the five year strategy reflect the output from the thematic workshops and regional events, as well as the Panel’s discussions. The Panel will have a full discussion about the five year strategy at their next meeting. Mary said that the review team will also draw out key elements that the Panel liked and emphasise these in their report to Ministers, making the link to where we want to be in five years time. The review team will also report the views and comments of the Expert Panel.
- 2.4 There is a tension between what people want and existing departmental plans and resources. The review team may wish to highlight these tensions and competing priorities.
- 2.5 Jenny reminded members that this interim report is a report of the review team to Ministers, and that it reports progress against each of the review’s six aims. She stressed that this is not the detailed five year strategy, which will be discussed at the next meeting of the Expert Panel. She urged the Panel to discuss the report’s chapters in the context of what the report is rather than viewing it as indicative of the content for the detailed five year strategy, and explained that it would be helpful to receive specific feedback about each chapter.

Chapter 1 - Introduction

- 2.6 The review team presented a brief summary of the first chapter, which introduces the report. The Panel had the following comments:
- The introduction needs to be clearer about our expectations of what we want to achieve and why changes are necessary. There is a gap between our experiences today and the point that we want to get to in the future. It is also important to acknowledge where the Independent Living Review has come from, by making reference to the Life Chances report.

- It is useful to provide multiple definitions of the concept of independent living by using the words of real people from the review's regional events, as this clearly shows that independent living means different things to different people.
- We should use the introduction to flag up that some hard-to-reach groups of people such as black and minority ethnic communities are not accessing services, often because they are not aware of the options available to them or the concept of independent living.
- This chapter fails to mention resources and disabled people's experiences of accessing resources. When we talk about resources we should emphasise that expenditure on independent living is an investment that benefits society as a whole.

Chapter 2 – current priorities and initiatives

- 2.7 The review team presented the mapping work that has been carried out, emphasising the importance of this work in flagging up where the links and gaps are in current government policies. Panel members made the point that it is difficult to keep this work up-to-date with everything that is going on across government. There will always be policy changes that need to be flagged up, as well as omissions.
- 2.8 The review team explained that this work is a snapshot of policies and initiatives taking place at a particular point in time, and that it is the process of carrying out this piece of work that has been most informative in demonstrating the importance of reaching a shared understanding of independent living across government.

Chapter 3 – economic case for independent living

- 2.9 The review team presented the chapter on building the business case and evidence base for independent living, and asked the Panel for their views. The discussion covered the following points:

- Members were not convinced that more work was needed to build the evidence base. There are lots of good examples of individuals' life stories and the difference that independent living options such as Direct Payments can make to their situations. They questioned the added value of demonstration projects and whether they provided a lever for change.
- We need to be clear about whether we are making the case for doing the same thing but cheaper, or whether we are proposing doing something new that enables disabled people to expand their lives. Qualitative evidence is crucial in making the latter case.
- We should be thinking about independent living as a whole system, and using one part of that system to unlock another part. Although there is useful evidence coming from particular areas, for example from the Individual Budgets pilot sites and the Wanless evidence around potential savings through Direct Payments, the cost-benefit analysis will never be a neat easy equation that results in clear savings to the Treasury. Other policy isn't made in this way either.
- There are additional pieces of compelling evidence that should be included in this chapter, for example the Getting to Grips evidence from Martin Cattermole in CSIP and the University of Lancaster's evaluation of the In Control pilots that show significantly better outcomes for the same or less financial resource. Five or six pieces of strong evidence that are pointing in a similar direction from different sources would be more convincing than two studies commissioned specifically for the review.
- Making the case for independent living is difficult, as the available evidence is more concerned with individual components of independent living such as housing or employment. Although we can make the economic case for investment for particular aspects of independent living, these elements don't deliver independent living on their own.

- Evidence helps to persuade Treasury but political interest does as well. We should gather more evidence but we should also ensure that we make a strong social justice case for independent living as this is more likely to capture political interest.
- Making the case is about basic human rights and social justice. Disabled people need to be valued in a way that is not measured purely by money. It is the social responsibility of government to ensure that disabled people have the right to a decent quality of life.

Chapter 4 - legislation

2.10 The review team presented a brief summary of the review's work in this area to date, and explained that its focus has been primarily on the community care legislative framework. The review team presented a summary of a roundtable discussion and options, and asked the Panel for their comments. The discussion included the following points:

- The review will lack credibility unless it makes proposals about legislative change. Members felt that legislative change is long overdue, and expressed disappointment that Our health, our care, our say hadn't covered this area.
- Some members wanted a commitment to review legislation at the highest level, while others thought that there was already enough evidence about what needed to be done and that the Independent Living Review should be making firm recommendations about how legislation can support the human rights case for independent living.
- Community care should be viewed as a means to an end. Independent living is not about care and support, and a right to independent living should not be confused with issues about rationing.

- The Commission for Social Care Inspection's independent inspection regime is not enough to deliver a right to independent living. It is only possible to enforce the legislation that exists and the standards and policy set by the Department of Health.
- Anomalies in the legislative framework need to be ironed out. For example, legislation has not kept track with Ordinary Residence Rules, which impacts on "portability" and the ability of disabled people to take their care packages from one local authority to another. Although localism can allow for greater innovation and local empowerment, there is a need for a universal right to independent living.
- Although writing in a balanced way is important, the review needs to be clear about its position. Members failed to see how the "do nothing" option had any real advantages.
- New legislation is needed in order to create changes in attitude and what is viewed as acceptable. There has been a huge shift in societal attitudes since the 1948 National Assistance Act, and the legislative framework not only needs to reflect this change but to move it along further. Just as the Disability Discrimination Act succeeded in shifting attitudes amongst the public, so an Independent Living Bill would give individuals the right to an appropriate support package to enable them to go about their daily lives.

Chapter 5 – older people

2.11 The review team presented the chapter on older people, which sets out six priority areas for action. The Panel had the following comments:

- We need to be clear about why there is a separate chapter on older people. We also need to make the distinction between older people and older disabled people, and ensure that this is clear.

- At the moment the voices of older people are there but they are not loud, united or well-connected to the policy-making machinery. “Grey power” and “grey liberation” will become increasingly important concepts in the future as a new generation with different attitudes grows older. There are exciting opportunities for increased politicisation amongst older people, and we should be seeking to strengthen the debate.
- This chapter has lots of important elements, such as the section about older people with high support needs. The conclusion needs more detail and needs to be clearer about how we can make change happen. In particular we need to think about how existing legislation doesn’t cover private care homes, and make a clear link to the legislation chapter.

Chapter 6 – support advocacy and brokerage

2.12 The review team presented the chapter on support advocacy and brokerage and asked the Panel for their comments. Members made the following points:

- It is important to emphasise that it is becoming increasingly difficult for organisations run and controlled by disabled people, such as Centres for Independent Living, to provide services such as self-advocacy support, and that the situation is currently getting worse rather than better.
- It is important that user-led organisations are inclusive for all disabled people.
- The proposed demonstration project needs to be very clear about what it is intended to demonstrate as this will influence the timetable and scale of the project.

3 Communications Plan (EP7/1)

3.1 Rosalind Hook presented paper EP7/1, which sets out a proposed communications plan for the next stages of the review up to December. She explained that there are at least two different groups of people with whom we will want to

communicate – firstly those we wish to keep informed about the review’s progress, and secondly those we will wish to influence. Members made the following points:

- We need to influence people both internally and externally, and this process needs to start now as some people are not engaged with independent living issues and some opinion formers will be easier to reach than others. It will be important to try to influence the NHS review.
- Accessibility is very important, and the review team will make sure that any communications are available in a variety of accessible formats.
- It would be helpful to try to involve the new regional Ministers.

3.2 Members agreed to send further comments on paper EP7/1 to Ros by email.

Action points

Project team:

- To summarise the key barriers to independent living, and to make sure that the detailed proposals for the five year strategy reflect the output from thematic workshops, regional events and Panel discussions as much as possible.
- To present and discuss the five year strategy and detailed policy proposals at the next meeting.
- To report the views of the Expert Panel to Ministers.

Expert Panel:

- To send further comments on paper EP7/1 to Ros by email.

The next meeting will be in September (date tbc) in London.