

## **MINUTES**

**28<sup>th</sup> March 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), Jo Williams, Rowen Jade, Jean Willson, Gerry Zarb, Ian Loynes, David Gardiner, Frances Hasler, John Dixon

Officials: Bruce Calderwood (ODI), Arthur Blacklock (Department for Work and Pensions), Patience Wilson (Department of Health), Jane Everton (Communities and Local Government).

Others: Menghi Mulchandani, Pam Bennett, Sarah Kissack (ODI)

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

### **Apologies**

Saghir Alam, Zoe Carter, Raymond Johnson, Elaine Morton, Ian Basnett, Fazilet Hadi, Jenny Morris, Chris Wells (Department of

Education and Skills), Tony Orhnia (Treasury), Miranda Carter (Department for Transport).

## **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.
- 1.2 Anne McGuire, Minister for Disabled People, was unable to attend the meeting, as she was travelling to New York to sign the UN Convention on Disability Rights. Ivan Lewis, Minister for Care Services, will be attending the next meeting on 24 May, and Anne McGuire is also hoping to attend.
- 1.3 Arthur Blacklock reported that a special meeting of the Disability Employment Advisory Committee (DEAC) has been fixed for 26 April to discuss the Independent Living Review and exchange perspectives.
- 1.4 Rosalind Hook provided a brief update on the mapping work, which is looking at initiatives that are contributing to independent living. This work has been critical in informing the review's emerging proposals; the mapping work highlights the importance of drawing together initiatives across and beyond government to show a high level picture and flag up where the links and gaps are.

## **2 Independent Living Review: five year strategy – emerging policy proposals (paper EP 5/1)**

- 2.1 Mary Helson presented paper EP 5/1 and set out the review's emerging 'vision' for independent living and some of the emerging policy proposals aimed at delivering this vision. She asked the Panel what they think of the general approach to the report and the vision for independent living for 2012. The discussion included the following points:
  - It was generally felt that the vision sets the right direction for a five year strategy on independent living. Members agreed that it is important for the vision to move independent living beyond the social care arena,

to encompass other important areas that affect independent living such as transport and housing.

- Members generally felt that demonstrating a strategic high level vision through case studies was an effective way of showing how elements of the vision can be brought together to enable choice and control for the individual. However, whilst the panel felt a life course approach was important, they also cautioned a potential danger of just rehashing a service list approach to people's support requirements. They urged the review team to attempt to make the support more joined up and holistic.
- It is important to strengthen links between national policy and local implementation of policies. While presenting an inspirational high level vision is important, delivery is also crucial. The strategy needs to show how to achieve this vision, by considering practical issues such as financial and resource implications, priorities, timescales etc.
- The review report is an opportunity to connect with all disabled people, and it is therefore important to think about the language we use in order to create a strong universal message that everyone will understand. We need to be careful when using words like "framework" or "steering mechanism" as not everyone will understand this language.
- We need to think about who might not agree with or buy into this vision, and confront this head on, otherwise we risk only preaching to the converted.
- It is important to embed a sense of ownership when putting forward the review's key messages, by using external opportunities such as reports and conferences to present the review's vision and combine messages whenever possible.
- The vision espouses the principle of choice for all, but not everyone is able to choose. It is therefore important

for the message to be about equality, empowerment and human rights. We need to aim to give people as much choice as possible at any particular time in particular circumstances.

- 2.2 Mary explained that the review is taking a case study approach to developing evidence-based policy proposals so that the strategy is grounded in the lived experiences of disabled people and takes a life course approach to independent living. The paper included three examples of case studies including transition to adulthood, mental health support needs and older people.
- 2.3 Members split into groups of three to discuss an allocated case study. Mary asked members to consider the effectiveness of a case study approach, whether they agreed with the emerging proposals, and whether they had anything else to add. In general terms, it was felt that a case study approach provided an effective way of breaking out of silos and starting with the individual.
- 2.4 The groups reported back on the main points raised on each of the separate case studies:

#### Transition to adulthood (Ruth)

- Transition is a really important case study example to include in the final report, as it represents a pivotal point in life which involves many different dimensions of independent living.
- There are similarities between Ruth's situation as set out in the case study, and that of all other people. The concept of rights seems to be missing from the transition case study example. There isn't enough about the social and attitudinal dimensions of this case study.
- It is important to show circles of support - the role that Ruth's family, friends and wider social circle might play in supporting her. For young people in transition, peer support is often crucial. Ruth may need an advocate to support her in developing friendships and relationships,

in exploring what her interests actually are, as well as to help her negotiate and challenge what may be an overly protective environment.

- Cultural and systemic barriers also need to be identified and addressed in this example. Education may be a route for raising expectations and broadening opportunities.
- The recommendations might deliver independent living in a clinical way, but not in terms of challenging public perceptions. Changing societal attitudes is critical and we have to tackle this in our policies otherwise they will ultimately fail. The media may play a powerful role in shifting attitudes and changing public perception by “mainstreaming” disability.
- It is important to include transport and equipment in Ruth’s person-centred plan. We should also consider the role of youth agencies tackling social exclusion, youth workers and the internet, all of which may provide opportunities for Ruth.
- We need to think more carefully about the age at which transition starts – interdependencies start in early childhood and we may in fact be educating disabled children into dependency. We need to remember that for many parents success has come to mean winning over services, rather than enabling choice and control. We should place greater emphasis on the role of individuals as commissioners.
- If we propose creating a ‘transition service’ which cuts across children’s and adults’ health and social care, it is important to ensure that we do not inadvertently create two cliff-edges.

#### Mental health support needs

- Lee’s situation as set out in this case study example needs to be made clearer, as it was for the cost-benefit

analysis example that was presented to the panel at an earlier meeting.

- It is important to use real stories in the case studies. We need to be careful that each case study does not try to cover too many issues as it becomes confusing – the flipside of inadvertently leaving out particular people’s perspectives. There may be other ways besides the case study approach of ensuring that everyone’s voice is heard.
- The case study approach is an effective way of showing how individuals’ lives are not fragmented; however the examples of current initiatives and policies are presented in a compartmentalised way. Lee does not want to know about all the particular policies and programmes that will address particular issues in his life – he just wants an effective and holistic way of dealing with multiple barriers.
- Again, it is important to consider the importance of emotional support, families, friends and social networks in enabling greater choice and control.
- This example needs to make the role of individual programmes and advice clearer, as well as spelling out their relationship with advocacy services. We need to be clearer about what is meant by holistic advocacy services in this example – is this a network that joins up multiple agencies or is it one organisation that covers a multitude of issues?
- Support for employers is also important, but it is a difficult issue. It may be difficult to performance manage people with mental health support needs and the occupational health model doesn’t help. There is no cover for absences as for statutory maternity pay, and impairment related leave may not be seen as fair to the entire workforce. Management training should cover some of these issues.

### Older people

- As with the previous two case studies, it is important to emphasise the crucial role that family, friends and user-led organisations may play in enabling Margaret to have greater choice and control.
- Many of the independent living issues that she faces also apply to other people at different stages of the life course. These proposals should not be limited only to adult and older people's services.
- Person-centred planning is very important. There are an overwhelming number of different policy initiatives that might support Margaret. Starting with the person helps to sort out the otherwise overwhelming number of support structures available.
- The proposals set out in this case study do not consider how best to support self-funders. Even if these people can afford it, the proposals do not consider how to help them get the support they need.
- They also don't look at dual impairment and the issue that many services exist in silos with very little communication between them. The proposals need to include information about commissioning structures and Local Area Agreements, as well as more about Individual Budgets.
- Information, advice and advocacy are critical. There needs to be a way of keeping a knowledge base so that people don't get different information from different sources (through user-led organisations?). We need to think about the best way to give and receive information, who should pay for it, and who is responsible for keeping it up to date.
- The proposal on national guidance for developing local independent living strategies for older people needs to include a strong element of co-production.

2.5 Mary explained that the review is charged with leaving in place a cross-government five year strategy to deliver

independent living for disabled adults of all ages. One of the aims for the review is to propose long-term steering mechanisms for ensuring the momentum on independent living is maintained.

2.6 She asked members for their initial thoughts on how we should make sure that work on independent living carries on and that policies are effectively implemented after the review reports.

- The term “steering mechanism” is not helpful and it provides no guarantee that what is proposed is also implemented. We need to be clear exactly what the term means – is the review in a position where it is holding the government to account? Is it more about trying to progress the independent living agenda across government? Or is the review trying to influence at delivery level?
- We may be able to learn from experience of delivery and implementation in the field in order to influence policy as it evolves in the early stages.
- Our vision for independent living needs to be put at the heart of the agenda for all organisations involved in delivery. This means we will need to reconcile our agenda with existing policies such as payment by results, Individual Budgets, Pathways etc. We also need a strategy to ensure that Local Involvement Networks are signed up to what we are doing.
- Historically government has not been good at showing and collaborating. How can we use ideas learned from In Control? We may be able to learn from the strengths and weakness of the Valuing People approach.
- It is difficult to be clear about the specific steering mechanism until we are clear about what the five year strategy will entail, as this will influence what is specifically required. There needs to be an action plan with timescales for implementing practical recommendations.

- We need to have a planned approach and real clarity about what the outcomes are. We need to think about what the core performance targets might be, to bear in mind short-term deliverables, and to consider making a business case.
- We need to look at the case for legislation around rights, as there are currently gaps in basic entitlement e.g. the right of someone not to live in residential care.
- Members felt that it is important to have a champion or high level steering group elsewhere in government to ensure buy-in to the review's proposals. It is also important to consider leaders in local government who might be influential around the independent living agenda.
- Moving the independent living agenda to a main political platform and mainstreaming disability was also seen as important, but there may be an educational task involved in convincing other people of the value of independent living.
- It is critical that we have a good communications and media strategy. We need to consider who is best placed to disseminate independent living messages.

### **3 Support, Advocacy and Brokerage (paper EP 5/1)**

- 3.1 Steve Strong introduced the paper on support, advocacy and brokerage, which was brought back from the last meeting of the Panel. He asked Panel members for their views on a number of issues including definitions of support, advocacy and brokerage, who pays for these services, whether they should be generic or specialist, and the extent to which they should be regulated. He asked members to email him with their detailed comments about the paper.
- 3.2 The Panel discussion included the following points:

- User-led organisations are ideally placed to provide advice around issues such as Individual Budgets. The role of peer support is important, and we need to capture good examples of this. Increasing capacity of user-led organisations is also important, and we should not try to regulate too tightly.
- It is important to keep the terms support, advocacy and brokerage separate. Tighter definitions would help people to understand that you can have independent living and brokerage at the same time.
- However, the definitions themselves are not so important as concentrating on how particular forms of support may be effective for certain situations. We also need to consider where there are potential conflicts of interest, for example Care Managers who give advice as well as controlling funding.
- It is also important to reflect on how things have changed in the past 30 years and to learn from past experience.
- We should look at the role of community matrons. There may also be scope for looking at the role of Citizen's Advice Bureaux as an example of a mainstream agency that should be fulfilling a role providing information and advice for all citizens.

#### **4 Update on the Department of Health's work on user-led organisations (paper EP 5/3)**

- 4.1 Patience Wilson introduced the paper, which asked the Panel to note progress on work led by the Department of Health to develop user-led organisations. She explained that a report will be published in April that sets out the findings of their mapping and regional conversation work. She asked the Panel what role they wished to take in relation to the user-led organisations project's next phase.
- 4.2 The Panel discussion included the following points:

- Some members said that they were happy to be involved, but stressed the work should take a bottom-up approach.
- The Budget has promised £80m for community organisations, which will be held by the Office of the Third Sector. This is an important opportunity for user-led organisations.
- The work should link with the Department of Health's work on micromarkets, which is looking at commissioning and procurement arrangements. It is important that this includes user-led representatives.
- There are also links with work that is taking place in Communities and Local Government, and it is important to connect with the empowerment agenda that was set out in their recent White Paper.
- It is important to link up with the Scope lottery-funded project to keep informed as well as informally influencing how this work moves forward. Big voluntary organisations might mentor smaller ones as a way of building capacity and expertise.
- There may be too many different messages coming from different places. It is important to link across to Equality 2025.

## **5 Equality for Disabled People: how will we know we are making progress? (paper EP 5/4)**

- 5.1 Sarah Kissack introduced a paper about the ODI's consultation on measuring progress towards equality for disabled people, which runs to 9 May 2007. She asked members how they wanted to be involved in the consultation.
- 5.2 Members felt that their role should be to audit-proof the ODI's annual report to ensure that the appropriate independent living dimensions are included. They agreed that the review team should construct a response to the

consultation on behalf of the review. Members also agreed to disseminate the consultation document to their networks and to respond as individuals if they wanted.

## **6 Any other business**

- 6.1 At the next meeting we will update members about the outcome of the regional discussions that have taken place. These will take place in Bristol (8 May), Birmingham (date to be confirmed), London (22 May) and Manchester (8 June).
- 6.2 We will also present the panel with an outline five-year strategy for discussion at the next meeting.

### **Action points**

#### **Project team:**

- To present an outline five-year strategy for discussion at the next meeting.
- To invite the Panel to regional discussion events in Bristol, Birmingham, London and Manchester
- To update the Panel about the outcome of those regional events that have taken place at the next meeting.
- To liaise with the team that is taking forward the consultation on measuring progress towards equality for disabled people, to present a submission from the independent living review as a whole.

#### **Members:**

- To send any further detailed comments on the emerging proposals to the project team.
- To email Steve with any further comments about the support, advocacy and brokerage paper.
- To let the project team know if they would like to attend any of the regional events that are taking place in May and June.

- To disseminate the ODI consultation document to their networks and to respond to the consultation as individuals by 9 May if they want.

**The next meeting will be on Thursday 24 May in London.**