

MINUTES

30th October 2006

1.30 – 4.30pm

National Council for Voluntary Organisations (NCVO)

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), Jean Willson, David Gardiner, Saghir Alam, Frances Hasler, John Dixon, Fazilet Hadi, Jo Williams, Gerry Zarb, Menghi Mulchandani, Zoe Carter, Raymond Johnson

Officials: Liz Tillett (ODI), Miranda Carter (Department for Transport), Mike Daly (Department for Work and Pensions), Patience Wilson (Department of Health), Paul Pippard (Treasury)

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

Apologies

Ian Basnett, Nasa Begum, Rowen Jade, Elaine Morton, Angela Mason (Department for Communities and Local Government), Chris Wells (Department for Education and Skills)

1 Welcome and minutes of last meeting

- 1.1 Jane Campbell welcomed the members attending the Expert Panel for the first time and reported on her meeting on 16 October with Anne McGuire, Minister for Disabled People.
- 1.2 Anne McGuire is pleased with progress so far, and is looking forward to meeting the Panel at the next meeting. We hope that Ivan Lewis, the Health Minister with responsibilities for the Life Chances agenda, will also attend.
- 1.3 The minutes from the last Expert Panel meeting were agreed.
- 1.4 Patience Wilson updated the members about the Department of Health-led work on user-led organisations. Jenny Morris has agreed to join the project board for the user-led work. They are discussing with Jane Campbell who else might be suitable to join this board. There will soon be an advert for a consultant on secondment to join the team, and the Department of Health will let the Expert Panel know when and where this advert is appearing.

2 Mapping of initiatives which impact on independent living: progress report (paper EP 2/1)

- 2.1 Rosalind Hook presented progress on the project team's mapping work to date, which has focussed on policies across Government that support and promote independent living. She explained that in the next phase of work the team will explore the potential for linking work across Government and take into account non-Government research and initiatives.
- 2.2 The discussion included the following points:
 - It is important to look at the outcomes for disabled people, not just the aims of particular initiatives. The team propose to consult with the Panel at the next meeting on what criteria should be used to assess the different initiatives in terms of whether they enable or threaten independent living.

- We need to develop a common understanding of words used in Government initiatives, for example the word “dignity” can be either empowering or patronising.
- When streamlining assessment processes you need to be careful that the exercise is not just about enabling professionals to do their job properly, rather than giving power to disabled people. The Individual Budgets pilots are very relevant to independent living, and we are learning valuable lessons about assessment from these.
- It is important to consider the impact of policies on different groups of disabled people, as what may be useful for some disabled people may not be for others. Equal access doesn't mean treating everyone the same.

2.3 On risks to independent living posed by current policies and actions, members raised the following points:

- There is a need to match the assessment process to resources on the ground. Assessment in itself may not lead to independent living if there aren't enough resources to deliver. Although there may be a sharing of objectives, there is a potential clash between policy and implementation. For example, members were concerned about the raising of adult services eligibility criteria to the critical level.
- The recent Local Government White Paper has the potential to be a risk, for example by reducing central targets that might tell us if independent living is succeeding. We need to think about which performance indicators link to independent living, such as measures of participation in communities.
- Some disabled people are sometimes portrayed as a “hard to reach group”; this is a potential barrier to independent living, because it can sometimes suggest from the outset that accommodating or finding out their needs will require intensive, therefore costly, intervention that in turn might put people off from doing anything.

- Withdrawing Supporting People money for people with learning disabilities is a potential risk, as is the decommissioning of supported living schemes.
- Compulsory registration being floated by the General Social Care Council was also raised as a risk to independent living.

2.4 Members suggested other initiatives that the mapping work should take into account:

- Members suggested that the project team look at several other initiatives within Government. Their suggestions included work by the Department of Health on dignity in care, the Department of Health's review of the National Minimum Standards under the Care Standards Act 2000, the Local Government White Paper, the Department for Work and Pensions' reform of Incapacity Benefit, arrangements for digital switchover for older and disabled people, and policies on increasing supply of housing and raising standards of existing housing.
- It is also important to look at policies that indirectly impact on independent living, such as the Office of the Third Sector. We need to keep an eye on any structural changes that may impact on disabled people.
- Members also suggested several non-Government initiatives that the project team should consider. For example the In Control model, existing housing scheme models that focus on independent living; the General Social Care Council's role in registration of personal assistants; and the Commission for Social Care Inspection (CSCI)'s review of the Performance Assessment Framework. The project team should also contact the National Institute for Mental Health for England (NIMHE) regarding mental health service users.
- It is important to consider independent living issues in relation to Black and Minority Ethnic communities, as pilot studies don't always include these groups. There has been some preliminary work done on independent living and Black and Minority Ethnic Groups in pilot projects in York and

Humberside. The project team will also use networks such as the Asian People's Disabilities Alliance.

- Both the Disability Rights Commission and People First have programmes about independent living, and the project team will follow up these suggestions by finding out more about these. The Equalities National Council have also done some work on advocacy that is potentially relevant.

3 Proposals for the Comprehensive Spending Review 2007 (paper EP 2/2)

3.1 Jenny Morris presented the evolving proposals for the Comprehensive Spending Review which the project team is now discussing with other Government departments, and asked whether members supported the broad thrust of the proposals.

3.2 Members were generally supportive of the proposals. The discussion included the following points:

- It is important to be clear about what is meant by independent living. Independence is not just the opposite of dependence, and we should recognise that too much emphasis on independence might lead to isolation. Jenny explained that the proposals are about enabling people to have choice and control over the support they need to go about their daily lives.
- Members were concerned that some of the proposals were overly focussed on impairment-specific groups. There is a danger that focussing on particular groups of individuals mean that people see specific groups rather than the broader system as problematic. Setting targets for specific groups also means that other groups of people may get left behind.
- Jenny explained that the principles of the proposals will definitely be applied more broadly and that the project team will emphasise this. There is a possibility for influencing particular cross-cutting reviews, which is why some of the proposals deal with impairment-specific groups.

- On the proposed pilot and demonstration sites, we need to be very clear about the sort of evidence we are hoping to gain. Members asked whether we could propose substantive investment as well as pilot projects. The project team will discuss which of the proposals might be suitable for this.
- The proposal concerning transition to adulthood needs to recognise that young people with high support needs will have on-going needs for support throughout their adulthood.
- The project team could strengthen the proposals by using more detailed evidence from the work commissioned to develop the economic case for independent living. There is also a definite need for further research, although it is important to be clear that this does not mean there is not enough evidence to invest now. We should be upbeat about what evidence there is.
- Working closely with other Government departments and the cross-cutting reviews is crucial for influencing Treasury. The project team will have further discussions with Government departments to discuss how to strengthen the proposals.
- Panel members will let the project team know by email if there is any other research that could strengthen the proposals.

4 Access to mainstream services (paper EP 2/3)

- 4.1 Sheila Evans introduced the mainstream services paper, which seeks members' views on the review aim about developing options for mainstream services. She explained that this aim does not cover social care, as work on other review aims will fully address this.
- 4.2 The members split into four smaller groups for discussion and reported back on the main points raised.

- Comments on education, employment and training:
 - Work is critical and brings significant benefits to people's well-being, enabling them to contribute their skills and promoting social inclusion;
 - Developing effective information, support and advocacy will be important in enabling disabled people to gain and retain employment; we should draw parallels with initiatives to help lone parents into work
 - Recent changes in the service provided by the Learning and Skills Council could cut across the aim of integrating needs of disabled people in planning of mainstream services.

- Comments on health:
 - There is poor access to healthcare for disabled people, and it is more difficult to have choice and control over healthcare than it is over social care;
 - The Disability Discrimination Act and effective support and advocacy both enable disabled people to access mainstream services more effectively;
 - It is important to view health from a preventative perspective e.g. through Primary Care Trusts rather than just hospitals;
 - we need to think about what creates well-being instead of just focussing on ill health; strong community links are as important to health and well-being as employment and education.

- Comments on housing:
 - Many barriers to housing will be dismantled through the Disability Equality Duty if it works effectively;
 - Home adaptations need to be matched to individual requirements to reduce money being wasted on unwanted adaptations;
 - Population pressures mean that demand for housing outstrips availability, which means you can't just leave this issue to the markets. There should be subsidies and tax breaks for social landlords;
 - Lifetime homes work well for some disabled people e.g. physically disabled people, but less so for others e.g. Black and Minority Ethnic groups. It is important to value diversity and the cultural dimensions of housing design.

- Comments on transport:
 - Transport is a means of participation in daily life and the review therefore has a role in demonstrating the difference it makes to the lives of disabled people;
 - Transport needs to be defined widely and include both public and private options;
 - The review should make links with the Disabled Persons Transport Advisory Committee (DPTAC) to develop synergies between transport and other aspects of independent living;
- Comments on other aspects of mainstream services:
 - The review should consider the Disability Rights Commission's ten priority areas as set out in "The Disability Agenda";
 - Routine availability of public toilets for disabled people with changing facilities would enable some people to be out for longer than two hours, and would radically improve their quality of life.

5 Summary programme plan (paper EP 2/4)

- 5.1 Sheila Evans introduced the summary programme plan and asked for members' views on priorities for the review. She suggested that the project team presented a paper on stakeholder strategy at the next Expert Panel meeting.
- 5.2 The discussion included the following points:
- Some members thought that social care wasn't stated explicitly enough within the programme plan. Jenny Morris explained that all the work strands of the review dealt with social care, with the exception of the mainstream services strand, but that this might be made more explicit in the plan. Jane Campbell suggested that we might discuss what is meant by social care at a future session of the Expert Panel.
 - It is important to include quality of life and the impact on an individual's well-being in the programme plan.

- It is important to remember the things that we already know, such as evaluation reports that consistently declare advocacy to be a positive thing. It is accessing and using it that could be improved.
- The 'baby boom' generation will have higher expectations of services in their old age and public services will have to take account of this. We need to recognise and highlight that if public services create dependency this also creates higher costs.
- Jane Campbell asked the members if they felt the Expert Panel had a strategic enough role. Members felt that they should have a strategic discussion on the role for public services as a whole for supporting independent living. Members agreed to have a robust strategic discussion about the review's short and long term objectives at the next meeting.

6 Any other business

- 6.1 Jane Campbell thanked Menghi Mulchandani for her contribution to the Review and wished her well in her new role in the ODI. She explained that the project team will be consulting Ministers on a new member for the Panel.
- 6.2 Jane Campbell explained that the ODI will be hosting a conference on 7 December where independent living will feature prominently. The project team will keep the Expert Panel informed about proposals for this event and all members will receive an invitation.

Action points

Project team:

- To send blank templates to members for further contributions to the mapping exercise.
- To update members about the mapping work at the next Expert Panel meeting and discuss how to evaluate this work.
- To write up the detailed group discussions on options for mainstream services and present as a paper at the next meeting of the Expert Panel.
- To make the work on social care more explicit within the programme plan, and to discuss what is meant by social care at a future session of the Expert Panel.
- To reflect quality of life and the impact on the individual's well-being in the programme structure.
- To present a paper on stakeholder strategy at the next Expert Panel meeting.
- To present a more detailed paper on strategy at the next Expert Panel meeting, and to have a robust strategic discussion about the review's short and long term aims.

Members:

- To complete mapping templates on any non-Government initiatives of which they are aware.
- To let the project team know about any other research that could strengthen the Comprehensive Spending Review proposals.

The next meeting will be on Wednesday 6 December in London.