

MINUTES

6th December 2006

2.00 – 5.00pm

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, Ian Loynes, Raymond Johnson, Zoe Carter, David Gardiner, Gerry Zarb, Elaine Morton, Frances Hasler, Rowen Jade, John Dixon, Fazilet Hadi, Jo Williams

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

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

Apologies

Ian Basnett, Saghir Alam, Nasa Begum, Angela Mason (Department for Communities and Local Government), Chris Wells (Department for Education and Skills), Tony Orhniai (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 Jane explained that unfortunately neither Anne McGuire, Minister for Disabled People, nor Ivan Lewis, Minister for Care Services, were able to attend this meeting. Jane thanked members who had sent in questions for the Ministers. We hope that Anne McGuire and Ivan Lewis will be able to attend a future meeting of the Panel.
- 1.3 The minutes and action points from the last Expert Panel meeting were agreed.
- 1.4 Craig Muir updated the members about the Department of Health-led work on user-led organisations. Sue Bott has agreed to join the project board for the user-led work. The advert for a consultant to join the team will be circulated to Expert Panel members soon.
- 1.5 Bruce Calderwood and Mary Helson updated members about the Pre-Budget Report announcement that had just taken place. Paragraph 5.30 of the report emphasises the government's commitment to ensuring disabled people have choice and control over the support they need to live their everyday lives, while paragraph 6.11 refers to the needs of older disabled people.

2 Mapping of initiatives which impact on independent living: approach to evaluation (paper EP 3/1)

- 2.1 Ros Hook presented further progress on the project team's mapping work, and explained that the team have followed up members' suggestions about other initiatives to consider that are relevant to independent living. She asked for members' views on whether the project team's suggested approach to evaluating the mapping work is the right one.
- 2.2 Members made suggestions for how the criteria for evaluating policies might be refined further:

- Promoting social inclusion is not just about participation in society, but is also about citizenship and human rights. The criteria should be defined more specifically to include these points.
- We should also consider the family context and reflect the totality of people's lives – social inclusion and human rights should extend to the family setting as well.
- Involving and engaging disabled people doesn't just involve listening to them, but it is also about the transfer of power and influence to disabled people. Initiatives should be accessible to all disabled people, and it is important to consider the extent to which they empower disabled people.
- Although it is important to note the scale and cost of different initiatives, it is important to emphasise that many projects are about investing to save later, as well as the difference that initiatives may make to an individual.
- Sustainability involves a certain amount of flexibility to be built into initiatives. Just because a policy works and is relevant now, does not mean it will continue to make its ideas and work carry on in the future. It is therefore important to ensure policies are both flexible and that they continue to be monitored.

2.3 Members also suggested further criteria to consider when evaluating the mapping work:

- One important issue to consider is that of the implementation process. It is important to consider the effectiveness of the mechanisms employed for getting from national policy level to local delivery level – policies need to be deliverable.
- There should be separate evaluation criteria around equality and diversity. Taking account of and reflecting specific issues for different people in different situations needs to be teased out further, for example taking into account disabled parents, or impairment-specific groups (e.g. mental health).

3 Strategy paper on the role of public services (paper EP 3/2)

- 3.1 Jenny Morris presented the strategy paper on the role of public services, and asked members to give their views on the strategic approach that we should take to drawing up proposals for the review's final report.
- 3.2 On the role and definition of public services, the discussion included the following points:
- How we define public services is important. This links to local authorities' responsibilities for shaping places and lowering barriers in order to increase participation in communities. This role extends beyond local authorities, and includes the National Health Service too.
 - Members saw public services as having two main roles. Firstly to support and enable full inclusion and participation in local communities. Secondly, to create an environment that enables people to live as equal citizens. Making the environment accessible is key to increasing choice and control, and public services play a crucial role in making this happen.
 - Legislation is one option to bring about change in service delivery, but it is the last resort. We need to think about what are the other levers and incentives, for example using regulatory bodies, that would bring about changes in mainstream services.
 - One suggestion was that there should be champions within local authorities that promote independent living and equality for disabled people.
 - We should think about the government as an enabler as well as a service provider; in leading on disability equality the government's influence extends beyond the public sector. Both local and central government have a role in shaping public and private services to ensure they deliver the objectives people need.

3.3 Members made a few suggestions for other things to include in the review's remit that relate to public services:

- It is important to consider economic well-being, for example access to banks, bank accounts and the Independent Living Funds. A lot of private bodies are regulated by public bodies (e.g. the Health and Safety Executive) and could perhaps be more closely regulated. The Banking Code is a voluntary code that may be weak in terms of access.
- We should also consider access to courts and legal services.
- We should consider safety in communities, as this can also be a barrier to social inclusion.

3.4 On whether the suggested principles are the right ones to use for analysing current policies, the discussion included the following points:

- As noted with the mapping paper, promoting social inclusion is not just about participation in society, but is also about citizenship and human rights.
- Involving disabled people in the design and delivery of services is important, but this is not just about involvement but also about influence and empowerment.
- The principle of empowerment goes beyond choice and control; rather it is about what initiatives such as direct payments enable individuals to do that they wouldn't otherwise be able to do. The strategy should be based on an active principle – that is, what makes a difference for individuals.
- It is also important to tease out the relevance of interdependencies and the individual's role within a family. A family's human rights may be undermined by the experience of an individual's access to public services.

4 Transition to adulthood for young disabled people – paper for the ODI Board of Management (paper EP 3/3)

- 4.1 Jenny Morris introduced the paper of transition to adulthood for young disabled people. This issue will be considered at the next meeting of the Ministerial Group with responsibility for the *Improving Life Chances for Disabled People* agenda.
- 4.2 Jenny explained that the review team were working on a paper on transition for the ODI Board of Management meeting on 13 December. She asked members whether they felt that this draft paper captured the important issues facing disabled young people in their transition to adulthood.
- 4.3 Members saw transition to adulthood as critical in terms of influencing people's lives. They made the following general points about transition:
- Transition to adulthood can be a very difficult period for disabled people. It is a time where people form relationships and socialise in order to develop the necessary emotional maturity to grow into adults. Leisure plays an important role in this process, but many young disabled people are not able to access youth services.
 - Many disabled young people leave school with low expectations about their future, and are subject to many internalised pressures. It is therefore important to raise disabled young people's aspirations and present them with a broader menu of available opportunities.
 - Peer support, self-help and advocacy are critical in terms of encouraging personal development and providing alternatives to institutionalised care. Adults do not always know best, and user-led organisations are therefore an essential part of the transition process.
 - There are many initiatives around transition to adulthood. The important thing is connecting all the different policy initiatives and taking a holistic view.
 - There is clear evidence about what works in this area and there is no need for another scoping paper. The next useful

step would be an agreed cross-government action plan to implement what works. Person-centred planning, for example, is an effective way of ensuring a smooth transition to adulthood.

4.4 Members made the following points about specific barriers to independent living in transition to adulthood:

- Sorting out benefit entitlement and claims is difficult for 16 year olds and 18/19 year olds leaving college. The benefits system is very complex and is geared towards adults. There is a lack of awareness about access to Independent Living Funds at 16 amongst children services.
- There is a lack of support for young people to use direct payments, which contributes to low levels of direct payment take-up amongst 16 and 17 year olds.
- Preparation time is critical to smoothing the transition to adulthood and there should be ongoing work from age 14 to prepare children, their school and their family for transition to adulthood.
- The split between children and adult services is a barrier to independent living in transition to adulthood. Adult services should be expected to lead on direct payments and ensure the necessary systems are in place. Children's services should be able to draw on knowledge about direct payments from adult social services.

4.5 Members thought that a review workshop on transition to adulthood would be a good idea.

5 Outline stakeholder and communication plan (paper EP 3/4)

5.1 Sheila Evans introduced the review's outline stakeholder and communication plan and the panel's role in taking this work forward. Members agreed to send contact details for people and organisations to involve in the review direct to Sheila.

5.2 The discussion included the following points:

- Engaging with user-led organisations is critical, especially as these organisations are often impairment specific. These organisations developed the whole concept of independent living, and we need to adopt a collaborative approach that involves and engages these organisations in order to co-produce policy recommendations for the future.
- There is a risk of only speaking to those individuals and organisations that understand and are committed to the concept of independent living. The really important groups to reach and influence are the people running mainstream services, such as central and local government in their place-shaping roles, the NHS etc., and get them talking directly to disabled people.
- It is also important to influence those organisations that are most influential within government, e.g. the CBI. We should be ambitious in the groups we target.
- The concept of independent living is not always widely understood, particularly amongst certain groups such as the learning disability world, so raising awareness is essential.
- Taking the independent living message to other people's meetings and events is a useful alternative to trying to get people to engage with our agenda. We also need to consider other ways of communicating besides workshops and conferences, for example video campaigns.
- Not only will Expert Panel members act as ambassadors in taking independent living messages to other people's meetings, but they will also be ambassadors in other settings, such as commissions, task forces, etc.

5.3 Sheila explained that there will be a series of themed workshops on specific issues; these are intended to inform the development of proposals and will be held between January and April. Members agreed to contact Sheila to let her know which workshops they would be interested in attending.

6 Any other business

- 6.1 The Disability Rights Commission is launching their final Disability Agenda in February. We will consider the implications that it has for the review at the next Expert Panel meeting.
- 6.2 At the next meeting we will also consider some of the findings from the two January / February workshops on advocacy and older people, talk about strategy in more detail, and provide a programme update.

Action points

Project team:

- To invite Anne McGuire and Ivan Lewis to a future meeting of the Expert Panel.
- To refine the criteria for evaluating the mapping work as suggested and to start the analysis process. To update members at a future meeting of the Panel.
- To refocus the review's evaluation of mainstream services to include the role of public services in creating the right environment for independent living.
- To organise themed workshops on a series of issues relating to independent living between January and April.
- To update members about initial findings from the older people and advocacy workshops at the next meeting of the Panel.
- To discuss the Disability Rights Commission's Disability Agenda, the review's strategy and provide a programme update at the next meeting of the Panel

Members:

- To send contact details for people and organisations to involve in the review to the project team
- To contact the project team to let them know which workshops they would be interested in getting involved in / attending.

The next meeting will be on Thursday 15 February in London.