

## **Independent Living Review regional events**

### **1. Background to events**

- 1.1** The Independent Living Review was launched in July 2006 to identify imaginative and practical solutions to support independent living for disabled people. Our review takes a life course approach from young people in transition to adulthood and including older people. The Independent Living Review is a cross-government project led by the Office for Disability Issues (ODI).
- 1.2** As part of the Independent Living Review's commitment to the principle of co-production, the review team have held a series of external stakeholder events to ensure that the people whose lives are affected by policies have a chance from the outset to influence and shape what goes on.
- 1.3** Co-production means involving disabled people at all stages in the design, policy, planning and delivery of services. Whereas consultation happens at the last stages of policy development, co-production means involvement from the start.
- 1.4** The Review team held a series of stakeholder workshops on specific issues from January to April which we used to help develop policy options for the review. Each of these workshops was designed to engage with other Government departments and invited external stakeholders. The themes of the workshops were:
  - older disabled people
  - support, advocacy and brokerage
  - transition to adulthood
  - disabled parents
- 1.5** We held a series of regional events in May and June to share our emerging thinking about the Review and to discuss our emerging policy proposals.
- 1.6** These events were attended by 284 people including disabled

individuals and their organisations, as well as service providers, commissioners, regional government offices and other Government Departments. The events were held in:

- Bristol 10 May 2007
- Birmingham 15 May 2007
- London 22 May 2007
- Manchester 8 June 2007

**1.7** Key note speakers included Ivan Lewis, Minister for Care Services (Manchester), Rob Greig, National Director for Valuing People (Bristol) and Ian Loynes, Chief Executive of the Southampton Centre for Independent Living (London).

**1.8** The aims of these events were:

- To share our emerging thinking about the Independent Living Review and get feedback
- To gather views on what should be in the Independent Living Review five year strategy.

**1.9** The events involved presentations about the background to the review, the review's vision for independent living and possible delivery mechanisms for independent living. Participants worked in small groups for the remainder of the day to discuss the following three areas:

- The vision for independent living
- How to deliver independent living at a national, regional and local level
- Using a case study approach, how to deliver independent living for individuals

**1.10** Participants used pre-prepared templates to record key messages about each of these areas. Each group also had a detailed note-taker who recorded the main points from the group's discussion. This paper summarises the key messages from the completed templates and detailed notes from the group discussions.

## **2. The vision for independent living**

2.1 The review team presented their vision for independent living, and asked delegates for their views.

### **What is the vision?**

2.2 The Independent Living Review is charged with developing a cross-government five year strategy to take forward independent living for disabled adults of all ages. By 'disabled people' we mean people of any age (including older people) with mental health support needs, learning disabilities and/or physical or sensory impairments.

2.3 In order to achieve this it will be necessary to develop policy proposals which:

- give disabled people choice and control over the support they need to go about their daily lives
- take an approach to the delivery of such support which cuts across organisational responsibilities, programmes and budgets.

2.4 The review team proposed that the following needs to be in place in order to deliver independent living in 2012:

- A shared understanding of what independent living is and how to achieve it.
- Mechanisms at national, regional and local level to enable co-production of policies that affect the lives of disabled people.
- A strong evidence base for investment in independent living, enabling a cost effective use of resources.
- Effective incentives and drivers for independent living, including ways of measuring whether specific groups of disabled people can access independent living.
- A framework for meeting support needs which enables disabled people to make the decisions about how their support needs are met.
- A range of organisations providing services, housing and

equipment which are responsive to what disabled people want - enabling choice and diversity of provision and including user-led organisations.

- 2.5** We think that in order to deliver independent living by 2012 we need policies that:
- Are the result of co-production
  - Deliver choice and control
  - Enable disabled people of all ages to be equal citizens.

### **Key issues discussed**

- 2.6** At the regional events the review team asked participants for their opinions on the vision for independent living as set out above and find out views on the following questions:
- What does Independent Living mean to you?
  - Can you sign up to the vision?
  - Is Independent Living the right term?

### **Findings**

#### **1. What does independent living mean to you?**

- 2.7** Delegates came up with a range of definitions about what independent living means to them, generally centred on the principles of choice and control. Another important dimension of independent living was seen to be social inclusion and equality with non-disabled people, particularly through having equal access to mainstream services in order to participate fully in society as equal citizens. Delegates felt that ideas of empowerment and having a voice were also important dimensions of independent living.

#### **Independent Living is:**

Choice and control	Choice about where I live
Being included	Choice about who I live with
Participating	Choosing who supports me
Having equal access	Choosing how my needs are met
Freedom	Being able to take risks

Being 'ordinary'	Being respected and having rights
Self-directed support	Being in control
Having a voice	Being an equal citizen
Equality (not segregation)	Information and support
Being in control of my whole life	Removing barriers
Power	Being adequately resourced
Flexibility	Not being "special"
Reasonable adjustments	A state of mind

**2.8** Although delegates at the regional events generally understood the principles of independent living and could communicate these clearly, they stressed that not everyone shared this understanding. Delegates felt that it was important to develop a shared understanding of independent living both across government and amongst service providers and the general public.

“What matters is building a shared understanding of what the term [independent living] means.”

**2.9** Delegates mostly felt that the term “independent living” was right, but that it is too often misinterpreted as doing things for yourself or living on your own. There were a range of other suggestions for terms that they felt would convey more clearly the underlying principles and philosophy of independent living.

<b>Other terms for “independent living” might include:</b>	
Getting a life	Empowerment
Self-determination	Equality for living
Inclusive living	Self-determined living
My right to live like you	Respect
Choice	Normal living
Having a meaningful life	<i>Interdependent living</i>

## 2. Can you sign up to the vision? Is “independent living” the right term?

**2.10** For the most part, people felt that they could sign up to the vision and felt that independent living was the right term. There was a recognition that the philosophy of independent living and much of the vision has come from disabled people themselves and user-led organisations.

2.11 However, people who attended the regional event emphasised that action is crucial. Delegates said that although the high level vision is fine, it also needs to address practical issues such as resources, costs, legislation and barriers to independent living. People made the point that 2012 is a long time away, and that there need to be clear practical steps that get us from the present situation to a point where the vision can really happen.

“Legislation is not implemented so it becomes ‘lip service’.”

“It’s time for DOING, not TALKING.”

“Government needs to stop talking about all of this and start doing it.”

“The reality needs to match the rhetoric. We need to realise the gap between reality and the vision, and clearly define priorities for action.”

2.12 There also needs to be a clear understanding of how the vision impacts on individuals and their life as a whole, and it needs to be clear that it applies to everyone regardless of their impairment or age.

“Independent living is not a phrase that is used by non-disabled people – it is taken for granted that they are able to live their own lives. Independent living is more a ‘state of mind’ than a movement. Existing support services are segregated and continue the experience of segregation. Changing wider perspectives requires that individuals demonstrate they are in control of their whole lives.”

**2.13** There were concerns about one of the components of the vision, around building a strong evidence base for investment in independent living and cost-effective use of resources. People said that the human rights case for independent living is more important than the economic case, and that independent living should not be about facts, figures, resources and statistics, as it is ultimately about individuals' lives.

**2.14** There was a feeling that the vision is not getting out to the people who need to be signed up to the vision, and that it was important to communicate the principles of independent living and actions that are needed to underpin the vision to these people and their organisations.

### **3. Delivery of independent living at local, regional and national level**

#### **Key issues discussed**

- 3.1** The review team gave a presentation about what it might take to deliver independent living at a national, regional and local level. They explained that although there are many policies and initiatives both within government and beyond, there are also a lot of stories of disabled people not being able to access independent living.
- 3.2** Delegates echoed this message, flagging up that there is too big a gap between what national policy says should happen and disabled people's actual experiences. Thinking about delivery mechanisms and how these can make independent living a reality is therefore an important part of the review's work.

#### **Findings**

- 3.3** We had group discussions on the question of what it would take to deliver independent living at national, regional and local levels. A general comment that was made is that you can't "deliver" independent living, only create the right conditions for it, because it is about empowering disabled people to have choice and control.
- 3.4** Critically, it was felt that disabled people should be closely involved in both the development and implementation of policies which affect their lives. Delegates felt that successful delivery of independent living at every level is dependent on the proper involvement of disabled people at every stage of the process, and that it is very important for disabled people to have effective channels of influence at every level. Disabled people's organisations have gathered a lot of experience, knowledge and information, and sharing this expertise and disseminating good practice is critical.
- 3.5** Another general comment was that while we need to look at delivery of independent living at every level, there needs to be a

clear system or structure in place so that the national level can communicate directly with the local level (and vice versa), through partnerships and links across different sectors and at different levels.

- 3.6** However, delegates were keen to stress that this framework should not add an additional layer of bureaucracy or “reinvent the wheel”, but rather that many of the existing structures and mechanisms are adequate, they just need to be used and connected up more effectively. For example, it is important to join up all the different government departments and agencies that need to be involved. The Disability Equality Duty was also seen to be a critical lever, as this provides an opportunity at a local, regional and a national level to make demands on providers.
- 3.7** The boxes below provide a summary of the suggestions that were captured on flipcharts and in group discussions about how to deliver independent living at a national, regional and local level.

#### **National**

- Effective joining up of government departments
- The role of the Office for Disability Issues
- Effective channels for influence
- Good communication with regional and local bodies
- Local input at a national level
- The best possible legislative framework
- Legislation to give an entitlement to independent living
- Consistent interpretation of laws
- Performance indicators and targets
- Sharing good practice
- Strong leadership / champions of independent living
- More disabled people in public appointments
- Sharing lessons learned at every level
- Inspection e.g. Commission for Social Care Inspection (CSCI)’s Experts by Experience – involve more disabled people in inspection teams.  
Less emphasis on risk assessment in CSCI inspections
- National guidance, e.g. on transport

- Independent taskforce with Ministers
- Disability Equality Duty
- Change public perceptions
- Long-term commitment, both financial and social
- Listen to the voices of disabled people – more time for consultations

### **Regional**

- Use existing mechanisms – don't reinvent the wheel
- Involve key people as champions
- Separate assessment and commissioning
- Promote mechanisms for regional user-led organisations
- Promote independent brokerage / advocacy
- Support for national and local initiatives
- Disseminate best practice
- Regular forums – feed back to local councils
- Strong Centres for Independent Living – involving people in Local Strategic Partnerships (LSPs)
- Coordinate local input
- Role of Government Offices
- Guidelines for personal assistants
- Share knowledge and good practice at a regional or sub-regional level
- Guidance for personal assistants
- Develop a market – make use of regional economies of scale that don't exist at a local level

### **Local**

- Don't reinvent the wheel - involve local disabled people
- Facilitate the involvement of local organisations (capacity building)
- More community based resources (funding of User Led Organisations (ULOs) is critical)
- Take account of local situations, strategies, factors e.g. recognise rural factors
- Audits at a local level
- Disability Equality Duty
- Local Strategic Partnerships
- Local Area Agreements
- Share learning and good practice

- Customer-led services
- Ring-fenced long-term funding
- Partnership boards to become independent living partnership boards
- Stronger driver for Board level engagement
- Local forums to work with support groups of local disabled people
- Need adequate resources, training and funding to be in place

## **4. Case studies – what do we need to do to deliver independent living?**

- 4.1** The Independent Living Review is taking a case study approach to developing policy proposals so that the five year strategy to deliver independent living is based on the lived experiences of disabled people and takes a life course approach.
- 4.2** The review developed 8 case studies which were discussed in small groups at the regional events. For each of these case studies we wanted to know:
- What do we need to do to deliver independent living?
  - Do we need more policy, guidance or legislation, and if so what?
  - How do we make independent living happen for people like [x] – in other words, how do we make sure policy is implemented?
- 4.3** In thinking about what action is needed to deliver independent living for these individuals, we asked delegates to consider social care, but also housing, transport, health, employment and economic well-being.

### **Findings**

- 4.4** In general, delegates said that there is enough policy, but the issue is ensuring it is adequately implemented. There needs to be clearer guidance about entitlement to services and benefits, including information about access, and implementing policies at a local level need to be seen as a national imperative. To ensure this there needs to be sustainable funding and rigorous regulation and inspection in place.
- 4.5** It was felt that additional legislation may not help, but rather that existing legislation needs to be reinforced. In particular there needs to be clearer and stronger guidance on current rights and

the existing legislative framework, perhaps by means of a publicity campaign to raise awareness of rights. Existing legislation needs to be consistently interpreted and applied.

- 4.6** Good advocacy, information and advice were all seen as critical for enabling independent living, not only for the individual but also for the whole family and carers. Delegates felt that there need to be better support networks and independent services, particularly access to independent advocacy.
- 4.7** Delegates wanted services which are more transparent and more responsive to individuals' needs. In order to make this happen there need to be more joined up services as well as pooling of knowledge and budgets. There are various means of enabling this, such as partnership working across different agencies, use of key workers, person-centred planning, self assessments driven by the person themselves and communication support, as well as better information on the ground to overcome the issue of local variation. Delegates thought that removing divides and sharing knowledge and expertise between central government departments and social services departments such as adult and children's social care is key to ensuring a more holistic, person-centred approach to independent living.
- 4.8** In terms of resource issues, delegates felt that there need to be contingency funds as a means of dealing with unexpected issues, accepting that people's lives don't neatly follow from A to B. Additionally, delegates felt that money should be an entitlement that goes directly to disabled people – and this shouldn't be means tested. There should be no 'tax on impairment'; meaning that people should be able to keep any earned income, whether living in residential care or living in the community. Some delegates flagged up that the benefits system is overly complex and needs to be simplified (though not restricted!), so that people clearly understand how to access benefits to which they are entitled.
- 4.9** Some of the key themes that emerged from group discussions are set out according to particular themes below. Although the

group discussions were based around the whole life of individuals across the life course, and it is important not to lose sight of the importance of taking a holistic, person-centred approach, for the purposes of presenting this information it has been split into particular policy areas.

### Employment and training

- Adopt flexible work opportunities and working practices
- Acknowledge disabled people's skills and expertise
- Ensure employers have access to information, support and advice about employing disabled people
- Ensure there are suitable career development pathways
- Encourage flexibility to allow for the effects of people's impairments and personal circumstances
- Provide careers advice to enable people to make their own choices
- Promote other options e.g. voluntary work
- Adapt the Breakthrough UK model
- Develop better skills and understanding of disabled people's skills, needs and aspirations in Jobcentres – need guidance to change attitudes

### Employment support and benefits

- Put support in place to enable disabled people and carers to return to work
- Make reasonable adjustments
- Allow people to take 'career breaks' to deal with the unexpected
- Reform welfare benefits to remove disincentive to employment
- Don't be overly target-focussed. Targets to get people off Jobseekers Allowance can be unhelpful - Jobcentres should not assume that disabled people can't work and automatically refer them onto disabled benefits
- Ensure people have choice and control over any employment support they may require – employment funding streams may need to go into Individual Budgets
- Provide guidance on changing attitudes in Jobcentres
- Change residential care charging policies

### Education and training

- Conduct an education review for disabled children

- Develop person-centred transition assistance to maximise children's potential
- Develop a parent support network
- Consider young people's aspirations and give them options and pathways to achieve these
- Raise aspirations and expectations so people can make a proper informed choice – mentors can play an important role here. People leaving residential schools or parents may have limited expectations
- Accept that it is okay for people to change their needs and aspirations
- Provide help and training with general life skills and managing finances – opportunities to go on independent living courses run by Centres for Independent Living or organisations of disabled people
- The Learning and Skills Council needs to consider how older people access learning and training. Focus on accreditation can create disincentives to providing education and training for people who are interested in less formalised training or support

### Housing

- Develop more effective, stronger housing policies
- Enable disabled people to become home owners like anyone else
- Put robust systems in place that allow easier access to the property ladder
- Work with estate agents who advise owners to take out adaptations before putting their houses on the market
- Encourage accessible designs to increase choice and speed up the turnover of housing stock
- Apply Lifetime Homes Buildings Standards to all new buildings. Stronger standards should also be applied in areas of regeneration
- Legislate for private sector housing provision and building to meet the needs of disabled people
- Provide transitional funding so that people can put housing adaptations in place before taking on tenancy
- Legislate to ensure inclusive housing development, inclusive housing renewal, planning for future needs e.g. for a family with a disabled child where there will be future housing requirements

- Promote better housing design to take account of particular needs. Section 106 arrangements are too restricted
- Engage planning agencies with disability norms.
- Get housing organisations to take responsibility for repairing and maintaining housing-related equipment
- Ensure people have access to independent advocacy and the opportunity to explore different housing options (ownership, renting etc)
- Provide easyread application forms for choice-based lettings
- Assist people with bidding on the choice-based lettings system

### Health

- Ensure that the hospital discharge process is holistic, complete and subject to inspection
- Ensure that support is responsive from the beginning. Someone should not come home from hospital unless they have the necessary support at home
- NHS prescribed input such as gym, counselling etc.
- Enable better access to respite care
- Provide better, more tailored support in hospital. Support needs to be automatically triggered from the point people enter the healthcare system (as with Victim Support)
- Access to the right equipment can keep people out of hospital, while money is wasted by giving people inappropriate equipment

### Transport

- Ensure an integrated transport system – current policy needs to be better joined-up in order to lead to joined-up services
- Realistic flexibility

### Personalisation, choice and control

- Enable access to mainstream services like anyone else, including more specialist support when needed (maternity, counselling etc.)
- The process should fit the person and his or her aspirations as well as needs
- Promote person-centred interventions and planning
- Encourage direct payments and individual budgets
- Provide help and education around how to use individual budgets

- Consider the person's whole life and circumstances, including their family situation. Helping couples and families as well as individuals
- Allow people the right to take risks
- Join up children and adult social services
- Join up funding between health and social care
- Commission for outcomes rather than commissioning block contracts for bed spaces
- Enable choice about whether living in a communal setting is right for the individual – care homes often make people dependent
- Get rid of most accommodation based services and increase the amount of floating support
- Give people control over their own finances
- Adopt a healthier, more robust response to risk – we shouldn't be threatened by a risk-averse culture or be afraid to evaluate why things go wrong for fear of recrimination

### Carers

- Improve status for personal assistants so that it is seen as a viable career pathway
- Improve prospects and status for carers
- Provide support, advocacy and brokerage for carers and family as well as the disabled person
- Enable independent living and choice for carers and family
- Adopt flexible working practices to accommodation care support
- Children need support to ensure they don't become carers

### Assessment

- Use self-assessment
- Use peer-supported assessment by a local Centre for Independent Living
- Don't use Fair Access to Care criteria to control budgets. People fall outside categories. Allocate money to people rather than structures
- Support what people need and want – universal access to care rather than rationing
- Provide more guidance and specialists in multi-disciplinary teams so that agencies and bodies work together for the

- individual service user
- Don't impose artificial age limits
  - Enable people to have a choice of case workers
  - Adopt a single assessment process
  - Use joint assessment – multi-agency and professional
  - Use one key-worker to coordinate the transition process
  - Person-centred planning conflicts with the care assessment process which is dominated by the medical model of disability
  - Separate assessment from commissioning. Replace social services with a Resource Management and Assessment Body and source commissioning support externally

### Support, advocacy and brokerage

- Provide ongoing preventative support
- Use buddying, mentors and peer support
- Match support workers with people but not by looking at 'labels'
- Give people a right to independent advocacy and educate them about what their rights are
- Use someone who can see the whole picture, who knows how to navigate the system and has the power to influence the different parts of it – a keyworker who will remain in place until all the relevant parts of the system are adequately engaged
- Join up legislation and funding streams so one personal advocate can make everything happen quickly and simply
- Ensure continuity in support relationships and build up trust
- Use one personal advocate to deal with everything – equipment, benefits, emotional issues, social issues etc.
- Use circles of support – people who can help and support the whole family on a regular basis
- Ensure that advocates have a challenge as well as a support function
- Provide people with comprehensive, accessible information to enable the disabled person to make their own decisions
- Set up "one-stop shops" for information, advice and advocacy, which can be accessed in the local community and are non-stigmatising and safe
- Use local organisations to identify appropriate services and resources
- Ensure there is appropriate signposting from one service to

another

### Communities

- Use support from a faith community if required
- Ensure access to culturally and linguistically specific support as required
- Build supportive neighbourhoods and communities
- Communicate and build a different society, once which is more accepting of diversity
- Consider rural issues

## **5. Next steps**

**5.1** The discussions and evidence from the regional events have helped the review team to identify a number of factors which need to underpin delivery of independent living:

- A shared understanding of what independent living is and how to achieve it.
- Full involvement of disabled people in the development and implementation of independent living.
- Equal access to health, housing, employment, education and transport services and opportunities.
- A thriving sector of organisations controlled and managed by disabled people themselves to support people in making independent living possible.

**5.2** The review team will now be exploring with government departments and the Expert Panel proposals for a five year strategy on independent living which we will set out around the turn of the year.

**5.3** This will be followed by a formal consultation with disabled people, older people and other stakeholders to ensure we have the right direction and the right set of recommendations to deliver real change.