



**Government Response to Raising our
sights: services for adults with profound
intellectual and multiple disabilities – A
report by Professor Jim Mansell**

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Description	This is the Government's response to Raising our Sights report by Professor Jim Mansell published 19.3.10, commissioned by DH to respond to concerns raised in the consultation for Valuing People Now that adults with complex and multiple needs often do not receive the support they need to live independently.
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Cross Ref	Raising our sights: services for adults with profound intellectual and multiple disabilities
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Contact Details	MB-Disability-Briefing@dh.gsi.gov.uk
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For Recipient's Use

Foreword by Minister of State for Care Services

Raising our sights: services for adults with profound intellectual and multiple disabilities produced by Professor Jim Mansell of the Tizard Centre, Kent, is a very valuable contribution to the debate on how we can ensure that people with highly complex needs can be supported to live as independently as possible and as included and valued members of society.

Over the years, Mencap and the Profound and Multiple Learning Disability Network has done much to set this issue very firmly on the agenda and – supported by the Tizard Centre has secured commitment from key players in the public and voluntary sector as well as from Parliamentarians across all parties to improving outcomes for this often marginalised group of people. I am delighted that Mencap and the Network will continue to champion the needs and rights of people with profound and multiple learning disabilities and look forward to working with them to achieve the aims of this report.

Raising our Sights has been positively received by families who care for people with multiple and profound needs. The report and the accompanying DVD in particular emphasise the importance and value of the lives of the individuals to their families and others who also care for them. There is an important message here for society to value all its members.

We support this report and its central message that the major obstacles to wider implementation of policy for adults with profound intellectual and multiple disabilities are prejudice, discrimination and low expectations.

We are committed to improving the health and well-being of the population through a health and social care system which is provided to all those who need it. This includes those people with profound intellectual and multiple disabilities. The Government *Vision for Adult Social Care, Capable Communities and Active Citizens* made clear we were looking to councils, alongside the voluntary sector and local communities, to empower service users. We want to see a more personalised, preventative service focused on delivering the best outcomes for people who need support, enabling people to live as independently as possible.

The revised *Recognised, Valued and Supported: Next steps for Carers Strategy* outlines the priorities over the next four years to ensure carers get the support they need and to help them fulfil their ambitions be it employment or education. The *Equity and Excellence: Liberating the NHS* White Paper set out our long-term vision for the NHS. This puts people at the heart of everything the NHS does – “nothing about me without me” – and put the focus on continuously improving the outcome of their healthcare.

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I am grateful for this strong and positive approach from those who have championed the cause and situation of people with intellectual and multiple disabilities over very many years. The best practice in this report and the DVD stand as a beacon to show what can be achieved to transform lives. So particular thanks to the individuals, families and carers and all the others who have shown us what is possible and what we should aspire to.

A handwritten signature in black ink, appearing to read 'Paul Burstow'.

Paul Burstow MP
Minister of State for Care Services

Introduction

This response has been written in response to Professor Mansell's March 2010 report *Raising our sights: services for adults with profound intellectual and multiple disabilities*.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Professor Mansell was commissioned by DH following the publication of *Valuing People Now (VPN)* in 2009

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377 to undertake a review of services for adults with profound intellectual and multiple disabilities after *VPN* concluded that people with profound intellectual and multiple disabilities were not having their needs adequately met.

In his report, Professor Mansell has described elements of good service but concluded that more action is needed to deliver improved outcomes for people with profound and multiple needs. The report reaches a number of key conclusions which the Government supports. They are reproduced here for clarity:

1. Adults with profound intellectual and multiple disabilities are a relatively small, easily identified group of people with undeniable needs for care and support. Despite these needs, they and their families have often not been provided with services to adequately meet them.
2. The 'personalisation agenda' expressed in government policy does appear to provide a better quality of life for adults with profound intellectual and multiple disabilities and their families. Continued progress in widening access to these kinds of services will enable more people to benefit.
3. There are a number of obstacles to wider implementation to which government and other agencies should attend.
4. Shortage of resources may influence the speed with which the recommendations of this report can be implemented but should not change the direction of policy and practice.
5. Learning Disability Partnership Boards and voluntary bodies will have an even more important role in future in scrutinising services and giving voice to people with profound intellectual and multiple disabilities and their families. Government and regulatory bodies should take account of the likely effect of their work on the quality of life of adults with profound intellectual and multiple disabilities.

We will ensure that these messages and those of the wider report are shared with relevant colleagues across Government, statutory and the voluntary sector and regulatory agencies.

This document sets out the Government's response to these conclusions and the report's more detailed recommendations and findings.

Recommendations and Responses

- **Ensuring effective implementation**

Recommendation 1: The government should continue to provide leadership to ensure that personalisation is extended to more people, including more adults with profound intellectual and multiple disabilities, in a way, which secures the benefits of improved quality of life and increased cost-effectiveness.

Government Response:

The Government published its *Vision for Adult Social Care, Capable Communities and Active Citizens* on 16 November 2010. This states that:

“people should get personal choice and control over their services – from supported housing through to personal care. Even those with the most complex needs can benefit from personalised services.” and
“councils should provide personal budgets for everyone eligible for ongoing social care, preferably as a direct payment, by 2013.”

The Vision is also clear that ‘people with learning disabilities, autism, disabled people and those with complex needs require person-centred planning to maximise choice and control, and appropriate help in cases where a direct payment is not chosen.’

Social Work Practices (SWPs) are one example of running mainstream social care functions differently. SWPs can be many different types of organisation but all must be social worker led. They may be social enterprises, voluntary organisations or private organisations operating independently of the council, but contracted to the council to undertake agreed delegated functions. Existing pilots currently focus on looked-after children. The Vision commits Government to invite councils and their social workers to extend this opportunity to adult services during 2011. We want to see a much more locally specialised service, with social workers combining their skills with the knowledge that local people and carers have about their own needs. This should result in greater choice and control over the services that local people purchase.

The national Learning Disability Program Board will continue to keep an interest and overview on this work.

‘*Think Local, Act Personal*, published by the adult social care sector on 4 November 2010, outlines the next steps to be taken now to take forward personalisation of adult social care. The agreement recommends how councils, health bodies and providers need to work more efficiently to personalise and integrate service delivery across health and adult social care. A number of best practice documents have been published to support Think Local, Act Personal and are available on the Putting People First website. <http://www.puttingpeoplefirst.org.uk/>

- **Supporting families**

Recommendation 2: Commissioners of health and social care services should identify mechanisms for supporting and enabling families to get advice and help in securing and running self-directed services from user-led organisations or self-help groups of other families.

Government Response:

The Government welcomes this approach, which reflects the messages in its *Vision for Adult Social Care*. Councils are encouraged to work with their local voluntary and/or community organisations and experts in user-led organisations, including care-led organisations, to provide support, advocacy and brokerage services. The new Health and Well-being Boards will have a further key role to play, drawing on Joint Strategic Needs Assessments (JSNAs) to ensure that they have good information to enable them to identify need for such support and advocacy.

Public bodies involved in supporting families have responsibilities under the Equality Act 2010. The general duty of the Act includes a requirement to enhance the involvement of disabled people, their families and carers by fostering good relations between protected groups. In meeting its responsibilities, the government encourages health and social care organisations to pay regard to this Duty by encouraging more patient and user-led involvement.

- **Advocacy**

Recommendation 3: Local health and social care commissioners should commission the development of independent advocacy arrangements suitable to represent the interests of adults with profound intellectual and multiple disabilities. They should include funding for continued advocacy in the package of self-directed services for adults with profound intellectual and multiple disabilities.

Government Response:

The Government agrees that local commissioners should look to commission such services to meet locally identified needs; in this, JSNAs will have a key role to play.

In its *Vision for Adult Social Care, Capable Communities and Active Citizens* the Government says that ‘councils should focus on improving the range, quality and accessibility of information, advice and advocacy available for all people in their communities – regardless of how their care is paid for – to support their social care choices.’

- **Planning and Predicting the need for support**

Recommendation 4: The government should continue to lead the development of more effective transition arrangements for people with learning disabilities, including those with profound intellectual and multiple disabilities, so that there is proper planning and timely provision of appropriate services as people move into adulthood.

Recommendation 5: Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected in future to enable effective planning of services.

Government Response: The coming Green Paper on Special Educational Needs & Disabilities will address improving transitions, including for those with profound intellectual and multiple disabilities. The Green Paper will be informed by learning from the cross-government Getting A Life programme. The Getting A Life sites have produced, and are now implementing, a pathway into paid employment and full lives for young people with severe learning disabilities. The Getting A Life cohort includes some individuals with profound intellectual and multiple disabilities.

The *Vision for Adult Social Care* says that ‘partnership working means individuals, communities, statutory organisations, the voluntary, private and community sectors, all working together. It must also mean ensuring that a joined up approach is taken within councils, including for young disabled people making the transition from children’s to adults services.’

Primary Care Trusts (PCTs) and local authorities have been under a statutory duty to undertake a JSNA since 2007.

The Health and Social Care Bill introduced to Parliament on 19 January 2011 will translate that duty onto local authorities and GP Consortia, and place them under a new duty to agree a Joint Health and Wellbeing Strategy (JHWS). The JHWS is a new requirement, through which the partners at the Health and Wellbeing Board have to agree a shared strategy for commissioning, based on their assessment of local needs.

Each commissioner then is required to have regard to the JHWS in drafting their own plans (so, the Director of Adult of Social Services or GP consortia would need to demonstrate how they have had regard to the JHWS in producing their own social care/NHS plans). There will be mechanisms for the Health and Wellbeing Board to refer to the NHS Commissioning Board if they feel that the GP consortia are not fulfilling their duties in this regard.

This all amounts to a strengthening of duties and requirements on local organisations to work together - not just on the needs assessment, but also in turning that assessment into a shared commissioning strategy, which should underpin their own plans.

The Equality Duty flowing from the Equality Act 2010 requires all health and social care commissioners to pay regard to the needs of people with learning disabilities as well as other protected groups.

The Public Health Observatory for Learning Disabilities is well placed to make the best use of current available information and share learning from those areas where registers already collect this information.

- **Recruiting and training personal assistants**

Recommendation 6: In fulfilling their responsibilities for developing and training the social care workforce, local authorities should ensure that sufficient numbers of personal assistants are available, trained in person-centred approaches to communication and support that meet the needs of adults with profound intellectual and multiple disabilities, through training that involves families and adults with profound intellectual and multiple disabilities in its delivery.

Government Response: The Government agrees that it is important that all staff in the social care workforce, including personal assistants are appropriately trained. However, it is the responsibility of individual social care employers to ensure that their staff are adequately trained for the role that they perform.

The Department of Health is working with bodies such as Skills for Care and the National Skills Academy for Social Care to improve the training and development of the social care workforce including personal assistants and is providing approximately £31m funding to Skills for Care for the training and development of the adult social care workforce this year.

The National Skills Academy for Social Care, which was launched in 2009, has been set up to focus on leadership, management and commissioning and modelling excellence in learning, in adult social care.

The Department of Health is currently working with the Department for Business, Innovation and Skills to identify barriers to growing a skilled social care workforce and to identify how these barriers can be removed.

The Government agrees that local authorities and social care employers should be looking at the availability and training of staff to meet the challenge of personalised care and are exploring options to ensure personal assistants and others directly employed by people using services are able to access local training.

The particular needs of personal assistants and their employers will be addressed in a forthcoming personal assistant strategy, to be published this year. The strategy will highlight the need to give people who use services choice and control over their care needs. It will also emphasise that with this freedom comes the responsibility to be a good employer and to train, recruit and retain staff. This strategy will be informed by a robust equality analysis.

- **Housing**

Recommendation 7: The government should revise arrangements for capital subsidy from the Homes and Communities Agency to remove the disincentive to provide adequate housing for adults with profound intellectual and multiple disabilities.

Recommendation 8: The government should resolve the apparent contradiction between social care policy and housing policy created by the Turnbull judgement to facilitate the provision of adequate housing for adults with profound intellectual and multiple disabilities.

Government Response: We recognise that there is a continuing need for new affordable housing, including supported housing. The needs and aspirations of vulnerable as well as older people and including those with profound intellectual and multiple disabilities should be considered in the provision of general needs housing, as well as in specialist provision. We expect housing associations and local authorities to work closely to identify the type of provision that will most appropriately meet the locally identified needs. They will also have the best understanding of how any new provision will fit with, and complement, existing services and supported housing locally.

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Despite tight public finances, Government is investing £4.5 billion to deliver up to 150,000 new affordable homes over the next four years. In addition, we are giving housing associations and councils real freedoms to better meet the housing needs of their local communities – freedoms they have been asking for many years.

The Department for Communities and Local Government and the Homes and Communities Agency will publish a Framework for the new Affordable Homes Programme for 2011/15, which will set out more details of the new affordable, housing delivery model and how to apply for funding. The Framework will encourage applications from a range of providers including community based and small specialist organisations.

We believe that securing good outcomes for disabled people may also mean bringing employment and housing services together to improve their well-being and meet emerging needs. 'Supporting People' provides housing related support to help individuals to live independently in their own home and avoid more costly interventions.

On 13 December 2010, the Department for Work and Pensions launched their Right to Control Trailblazers in five English local authorities. Two more Trailblazers will begin in March and April. Disabled people in the Trailblazer areas can combine money from different state funding streams, for example as a cash payment, to be spent on whatever they think most appropriate for their needs. This will allow a more personalised service, joining up housing, employment and community care.

- **Access to community facilities**

Recommendation 9: The government should amend Part M of the Building Regulations so that all newly built major public buildings provide a Changing Places toilet.

Recommendation 10: The government should invite the Local Government Association to identify and disseminate good practice in the provision of access for adults with profound intellectual and multiple disabilities to public swimming pools, as part of helping its members respond to their responsibilities for 'place-shaping'.

Government Response:

As part of the current review of Building regulations the Department for Communities and Local Government are evaluating the case to take forward consideration of Changing Places Facilities for inclusion with Part M (Access to and use of buildings) of the Building Regulations.

Department of Health officials have discussed recommendation 10 with the Local Government Association and will pursue further.

- **Health**

Recommendation 11: NHS bodies should pay particular attention to meeting the needs of adults with profound intellectual and multiple disabilities in implementing the government's response to the *Michael Report* and the report of the Local Government, Parliamentary and Health Service Ombudsmen.

Recommendation 12: NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities in each area which focus on protection of body shape, dysphasia, epilepsy and investigation and resolution of pain and distress.

Recommendation 13: The Board of each NHS Trust should consider a report specifically focused on the adequacy of health services for adults with profound intellectual and multiple disabilities and approve an action plan to ensure adequate treatment.

Government Response:

The Government is leading action to improve access to health and health outcomes for all people with learning disabilities. NHS bodies should be ensuring services meet the needs of all patients, including those with profound intellectual and multiple disabilities. The “Six Lives” Progress Report, published by the Department of Health last year (DH 14 October 2010) set out progress to improve healthcare for people with learning disabilities in line with the recommendation of the Parliamentary and Health Service Ombudsman and Local Government Ombudsman in their March 2009 investigation ‘Six Lives’. The inclusion of Learning Disabilities in the NHS Operating Framework 2011/12 further demonstrates this Government’s commitment to improving health outcomes for all people with learning disabilities.

The Confidential Inquiry into premature and avoidable deaths of people with learning disabilities and the Public Health Observatory for learning disabilities (www.improvinghealthandlives.org.uk) will provide information to support these improvements in care, including for people with profound intellectual and multiple disabilities.

Annual GP health checks for people with learning disabilities are a local way of ensuring all individuals with learning disabilities can access the right interventions for their health and well-being.

NHS Trusts – like all other public services - are responsible for ensuring they meet the needs of all the people they serve. The learning disability self assessment tool which is now used across the country is a positive way for local people to assess and hold local health organisations to account and agree with local commissioners how best to incrementally improve health and health care for people with learning disabilities.

We are clear in the *Vision on Adult Social Care, Capable Communities and Active Citizens* that many people need social care because of the effects of long-term conditions. Good partnership working between health and social care is vital for helping them to manage their condition and live independently.

All NHS bodies are required to comply with the Equality Act 2010 and from 6 April 2011 its Equality Duty that builds on the current Disability Equality Duty. NHS and social care organisations have a general duty to

- to eliminate unlawful discrimination, harassment and victimisation
- to advance equality of opportunity between different groups
- to foster good relations between different groups.

New organisations established as part of the health and social care reform programme, for example GP Commissioning Consortia, will also be covered by this Duty offering strengthened protection for patients with learning disabilities, their families and carers. These bodies will have a specific duty to publish information on the effect that their policies and practices have had on disabled service users, carers and others from the protected groups.

- **Wheelchairs**

Recommendation 14: The Department of Health should reform the wheelchair service to address the problems identified in 2006.

Recommendation 15: Powered wheelchairs should be provided where carers (whether family members, paid staff or others) need them in order to move the disabled person.

Recommendation 16: People with profound intellectual and multiple disabilities who have used powered wheelchairs (eg 'smart' wheelchairs) at home or at school during childhood should have the option of continuing to have them provided in adult life, where this sustains or enhances their quality of life.

Recommendation 17: Other people with profound intellectual and multiple disabilities should be provided with powered wheelchairs, suitably adapted with 'smart' technology, where this sustains or enhances their quality of life.

Government Response:

The Government acknowledges that wheelchair services need to become more responsive, and is currently developing proposals to improve the commissioning approach to wheelchair services so that it facilitates the provision of efficient, personalised and responsive wheelchair and seating services. This programme of work is being taken forwards in partnership with two NHS regional pilot sites, and a multi-agency advisory group. Mencap is a member of the Advisory Group and advocates for the needs of those with profound intellectual and multiple disabilities among others. In addition, many of the users of special seating services fall into this category, and we are considering their needs specifically in terms of this vital service as well as wheelchair services.

- **Communications aids and assistive technology**

Recommendation 18: The government should decide whether funding the provision and repair of communication aids for adults with profound intellectual and multiple disabilities is the responsibility of the National Health Service or of Local Authority social care services.

Recommendation 19: The Department of Health should commission the Social Care Institute of Excellence and/or the National Institute for Health and Clinical Excellence to review and disseminate the available research and practice on the use of communication aids and assistive technology for adults with profound intellectual and multiple disabilities.

Recommendation 20: The Department of Health should fund research and demonstration projects in each region (perhaps through the Health Technology Assessment programme of the National Institute of Health Research) to identify opportunities for increasing the quality of life of adults with profound intellectual and multiple disabilities through the use of communication aids and assistive technology.

Recommendation 21: The Department of Health should commission organisations, such as Communication Matters⁵² and HFT⁵³, which have expertise in this area, to advise families and agencies about new opportunities presented by these communication and control aids; to offer opportunities for people to try out different equipment; and to train staff.

Government response:

The Government recognises the importance of communication aids and assistive technology appropriate to individuals' needs. The Department of Health is currently running the largest randomised control trial of telehealth and telecare anywhere in the world. With over 6,000 people involved across three sites, the Whole System Demonstrator programme will provide the best evidence base possible for local commissioners to make decisions about how best to use this type of technology to support locally assessed needs.

The White Paper *Equity and Excellence: Liberating the NHS* set out proposals for closer worker relationship between the NHS and Local Authorities and these issues are for local determination. The Health and Social Care Bill was introduced into Parliament on 19 January 2011 and proposals remain subject to parliamentary approval. In developing new arrangements, it is critical that the NHS and Local Authority partners work closely together from the outset to improve integration, in anticipation of proposed new statutory arrangements.

The findings from the Department of Health's Whole System Demonstrator programme will become available from spring this year. The results will be disseminated widely to support the use of assistive technology and we are confident that it will also help decisions in respect of adults with profound intellectual and multiple disabilities. The Social Care Institute for Excellence has already undertaken detailed work on the ethics of telecare for people with cognitive difficulties and they plan as part of their work programme on prevention and well-being, to review the evidence for the preventative potential of telecare and telehealth.

The National Institute for Health Research Health Technology Assessment programme is reviewing relevant recommendations through its processes for identifying and prioritising research topics. The programme produces independent research information about the effectiveness, costs and broader impact of healthcare treatments and tests for those who plan, provide or receive care in the NHS.

The *Vision on Adult Social Care, Capable Communities and Active Citizens* is clear that 'councils should commission a full range of appropriate preventative and early intervention services such as re-ablement and telecare, working in partnership with the NHS, housing authorities and others.'

DH is committed to implementing the UN Convention on the Rights for Persons with Disabilities that sets out international benchmarks for the human rights of disabled people and places responsibilities on governments to ensure that disabled people have and can enjoy those same rights as non-disabled people. Article 25 of the UN Convention specifically addresses rights in health (and social care). This includes the provision of disability-related health habilitation and rehabilitation, including the use of assistive technology.

- **Further education**

Recommendation 22: The government should state as policy the goal that everyone with profound intellectual and multiple disabilities should have access to further education, in order to help funding bodies develop appropriate objectives and plans.

Recommendation 23: The government should ask the Young People’s Learning Agency and the Skills Funding Agency to monitor the volume and quality of provision they fund for people with learning disabilities, distinguishing people with profound intellectual and multiple disabilities within that population.

Recommendation 24: The Young People’s Learning Agency and the Skills Funding Agency should create incentives for specialist colleges to partner with local non-specialist further education colleges to increase the quality and amount of local provision for adults with profound intellectual and multiple disabilities.

Government response:

The Skills Funding Agency regularly publishes a statistical first release, which includes data on the number of learning aims achieved by learners with a self-declared learning difficulty or disability. This is used to help monitor take-up of provision by disabled learners.

The forthcoming Green Paper on Special Educational Needs & Disabilities will consider ways of improving the amount, quality and accessibility of local further education provision for all young people aged 16-19 (25) with learning difficulties and/or disabilities.

- **Employment and day activity**

Recommendation 25: Local authorities should ensure that adults with profound intellectual and multiple disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities.

Recommendation 26: Local authorities should ensure that they continue to provide somewhere which can be used as a base from which adults with profound intellectual and multiple disabilities can go to different activities during the day. This does not have to be restricted to people with profound intellectual and multiple disabilities – a place used by a wider range of people might be more interesting and provide more opportunities for social interaction.

Government response:

The Government has made clear its determination to improve outcomes for all people with learning disabilities, supporting people to have fulfilling lives including opportunities to work, study and enjoy social and leisure activities. We are very clear that this includes people with complex needs and people with profound intellectual and multiple disabilities. This group should be part of all plans and opportunities at a local level with appropriate support and reasonable adjustments.

Local authorities with their partner third sector organisations have responsibilities to offer services where there are assessed needs. Person centred approaches are the most positive way to ensure that individual needs are met in and across settings that are fully accessible to the individuals.

- **Short breaks**

Recommendation 27: Commissioners of health and social care services in every area should commission a range of short break services that provide staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with profound intellectual and multiple disabilities. No family supporting an adult with profound intellectual and multiple disabilities at home should be denied regular short breaks.

Government response:

We agree the importance of short breaks and support for carers. The NHS Operating framework for 2011/12 states that:

'It has not always been apparent how funding to support carers has been used in each PCT. The Spending Review has made available additional funding in PCT baselines to support the provision of breaks for carers. PCTs should pool budgets with local authorities to provide carers' breaks, as far as possible, via direct payments or personal health budgets. For 2011/12, PCTs should agree policies, plans and budgets to support carers with local authorities and local carers' organisations, and make them available to local people.'

Recognised, valued and supported: next steps for the Carers' Strategy, published on 25 November 2010, identified that £400 million was being made available for carers breaks over the next four years (2011-12 to 2014-15). This funding will be made available in Primary Care Trust (PCT) allocations (pending the introduction of GP consortia).

- **Training**

Recommendation 28: Agencies should offer subsidised or free places to families and personal assistants on any training courses they run which are relevant to adults with profound intellectual and multiple disabilities. Individual budgets should include provision for training of personal assistants.

Government response:

A Vision for Adult Social Care, Capable Communities and Active Citizens sets the context for the future direction of adult social care in England. It includes plans for a diverse workforce to deliver personalisation of adult social care. For example, commitment to provide personal budgets for all eligible people will mean Personal Assistants (PAs), directly employed by people who use care and support services, working in new, creative and person-centred ways to play an increasingly important role in providing tailored support to meet individual needs.

'*Think Local, Act Personal*': *Next Steps for Transforming Adult Social Care* - , A proposed sector-wide commitment to moving forward with personalisation and community-based support published on 4 November 2010 outlines the next steps in taking forward personalisation. The particular needs of PAs and their employers will be addressed in a forthcoming PA strategy, to be published this year. The PA strategy will highlight the need to give people who use services choice and control over their care needs. It will also emphasise that, with this freedom, comes responsibility to be a good employer and to train, recruit and retain staff.

The Department of Health is currently having discussions with Her Majesty's Customs and Revenue about to encourage local authorities to ensure that people receiving direct payments who are employing PAs are made aware of employment support services and their responsibilities as employers. The latter may include plans for training staff.

- **Clinical procedures**

Recommendation 29: The Department of Health should lead an initiative to adapt policies and procedures used in children's services for use in services for adults, involving representative bodies of the relevant professions and agencies.

Recommendation 30: Local policies should be based on the principles that (i) arrangements will be designed so that they sustain and enhance the quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps.

Recommendation 31: Local policies should focus on procedures identified by families as currently problematic, including all relevant care settings, such as hospitals, community services and people's own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.

Government response:

There is currently work in children's services to develop high quality person-centred transition plans that focus on outcomes and cover health, housing, employment and community participation. New Health and Wellbeing Boards will offer an opportunity to draw these areas together. Where this works well the local health economy and local authority children's services have a joined up clear vision for this group of young people, clarity about who should attend review meetings, who should bring health information together, who should liaise with adult health services and how the young person and their family will know what will happen, how it will happen and who will do what. This is a statutory review from 14-18 for education but is widened as described to support the best outcomes for the young person and their family. Learning across systems locally from this work will ensure improvements for subsequent young people and their families and others into adult life.

The NHS White Paper, *Equity and Excellence, Liberating the NHS* made it clear that patient (and patient representative) involvement in decisions was key to better health outcomes stating emphatically there should be 'no decision about me without me'. Involvement and engagement of disabled people, children and their representatives is key to how NHS organisations meet their responsibilities and the Department of Health has reinforced this as part of the communication to the NHS on the Equality Act 2010.

- **Funding**

Recommendation 32: For adults with profound intellectual and multiple disabilities, both health and social care services should always work in close partnership both in planning and commissioning services and in providing them. Local authorities should continue to play an active part as the lead agency for learning disability services in all service development and should continue to lead individual assessment and planning, even where continuing health care funding is provided.

Recommendation 33: However funded, services for adults with profound intellectual and multiple disabilities should be developed in line with the government's personalisation agenda. They should be designed around the individual and person-centred, they should treat the family as expert, they should focus on the quality of staff relationships with the disabled person as the key to service quality and they should sustain the package of care

Government response:

Continuing healthcare guidance encourages joint arrangements between Primary Care Trusts and local authorities in respect of assessment, commissioning and case management responsibilities. It also emphasises the importance of maximising continuity of services when individuals move between NHS and local authority responsibility. Primary care trusts and local authorities are expected to pay due regard to the Equality Act 2010 and specifically the requirement to conduct equality analysis to inform and ensure learning disabled people are not disproportionately disadvantaged in their assessment and commissioning processes. All new organisation types established as part of the health and social care reform agenda will need to comply with the same duties, ensuring continuing protection for personalised services for disabled people, their families and carers.

The Government agrees and welcomes this endorsement of the importance of personalisation as a driver for real change.

A Vision for Adult Social Care: Capable Communities and Active Citizens, set the context for the future direction of adult social care in England. Our vision is to make sure everyone can get the personalised support they deserve. People should get personal choice and control over their services - from supported housing through to personal care. Even those with the most complex needs can benefit from personalised services.

On 4 November 2010, the adult social care sector published '*Think Local, Act Personal*' at the National Children and Adult Services conference, outlining next steps to be taken now to take forward personalisation of adult social care. The agreement recommends how councils, health bodies and providers need to work more efficiently to personalise and integrate service delivery across health and adult social care. A number of best practice documents have been published to support Think Local, Act Personal and are available on the Putting People First website. <http://www.puttingpeoplefirst.org.uk/>

Government Response to Raising our sights: services for adults with profound intellectual and multiple disabilities – A report by Professor Jim Mansell

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