

**Dorset Learning Disability Partnership Board**

**Complex Needs Sub-Group**

**Response to Raising our Sights Recommendations**

**September 2010**

<b>Recommendation</b>	<b>Response</b>
<b>Ensuring effective implementation</b>	
<b>Recommendation 1.</b> <i>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.</i>	Self directed support is increasing – there are now more than 1,000 packages in Dorset. Personal health budgets are being piloted. We need to ensure that people with complex needs are included in these developments.
<b>Supporting families</b>	
<b>Recommendation 2.</b> <i>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.</i>	DCC is funding the development of a user led network hub, which by design will help User Led Organisations Pan Dorset build capacity, share expertise and engage local people. One outcome is that a Centre for Independent Living is developed.
<b>Recommendation 3.</b> <i>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.</i>	Advocacy is available through Dorset People First and Dorset Advocacy.
<b>Predicting need for support</b>	
<b>Recommendation 4.</b> <i>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.</i>	The Transition Programme Board and Connexions service should be aware of these recommendations. The processes for identifying and supporting young people and their families at transition are improving, although there are capacity issues.
<b>Recommendation 5.</b> <i>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.</i>	New DCC and Health IT systems (AIS and RIO) will allow for this information to be collected and kept up to date. There will be better information sharing as a result of the CTLD review and creation of an additional CTLD as part of the campus re-provision.

<b>Recruiting and training personal assistants</b>	
<b>Recommendation 6.</b> <i>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.</i>	The issue of PA's attending DCC courses is currently under review. PA's are welcome to attend courses: the issue is who pays for the course.  Self employed PA's may have to pay the full costs of a course. This would be much higher than the fee advertised in the independent & voluntary sector brochure. These fees are highly subsidised by the Learning & Development budget.
<b>Housing</b>	
<b>Recommendation 7.</b> <i>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.</i>	The Housing sub-group needs to be aware of these recommendations (7&8)
<b>Recommendation 8.</b> <i>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.</i>	
<b>Access to community facilities</b>	
<b>Recommendation 9.</b> <i>The government should amend Part M of the Building Regulations so that all newly built major public buildings provide a Changing Places toilet.</i>	The LD Partnership Board is supporting this initiative and has asked members to signal their support for the Mencap campaign. There are currently 2 Changing Places in Dorset with more planned.
<b>Recommendation 10.</b> <i>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'.</i>	This area is being examined by the Health Action Group, (HAG) along with the need for hydrotherapy for people with profound intellectual and multiple disabilities. There is a lack of Hydrotherapy provision that needs to be addressed.
<b>Health</b>	
<b>Recommendation 11.</b> <i>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.</i>	The HAG monitors the 'Healthcare for All' action plan and the LD Self Assessment targets set by the Strategic Health Authority. There are 22 nurse champions for LD at Dorset County Hospital and a new policy for supporting people with LD.
<b>Recommendation 12.</b> <i>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</i>	The HAG invites speakers from a range of health services and makes recommendations to services for

<p><i>shape, dysphagia, epilepsy and investigation and resolution of pain and distress.</i></p>	<p>improvements. Dorset Healthcare University Foundation Trust Physiotherapy services will be reviewing the training needs of staff and carers in the field of postural support.</p>
<p><b>Recommendation 13.</b> <i>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.</i></p>	<p>Targets for improving services for this group of people are included in the LD Self Assessment. A policy is in place in Dorset County Hospital to give guidance on how to support people with LD when they attend for treatment.</p>
<p><b>Wheelchairs</b></p>	
<p><b>Recommendation 14.</b> <i>The Department of Health should reform the wheelchair service to address the problems identified in 2006.</i></p>	
<p><b>Recommendation 15.</b> <i>Powered wheelchairs should be provided where carers (whether family members, paid staff or others) need them in order to move the disabled person.</i></p>	<p>The responsibility for provision of wheelchairs for people with complex needs lies with the Dorset PCT in the shape of Dorset Wheelchair Services. They have two assessment centres based at Dorchester and St Leonards, nr. Ferndown. They have strict criteria about the types of chair they will provide which creates difficulties for people with complex needs and their carers. They will not provide an outdoor electric wheelchair if the person is able to mobilise without a power chair inside. Nor will they provide a power pack to assist the carer to push the person in a manual wheelchair, regardless of the weight of the wheelchair or the person sitting in it or the ability of the carer to push the chair. They will not provide a lightweight chair to accommodate the carer's ability to lift the chair in and out of the back of the car.</p> <p>They do offer a voucher scheme which can be applied to the last example and which works in a similar way to direct payments, giving people a basic amount of money which can then be topped up to purchase a wheelchair of their choice.</p>
<p><b>Recommendation 16.</b> <i>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</i></p>	

<p><b>Recommendation 17.</b> <i>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.</i></p>	<p>Individuals with complex needs are often seen by the team at the Greenwood Centre for Independent Living when they come seeking advice and support to purchase suitable chairs for themselves.</p>
<p><b>Communication aids and assistive technology</b></p>	
<p><b>Recommendation 18.</b> <i>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.</i></p>	<p>Speech and Language Therapists carry out assessments for communication aids.</p>
<p><b>Recommendation 19.</b> <i>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.</i></p>	<p>Occupational Therapists carry out assessments for assistive technology. This area will be reviewed by the LD strategic funding panel in 2010.</p>
<p><b>Recommendation 20.</b> <i>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.</i></p>	<p>Assistive technology should not be used solely in order to reduce support costs and careful assessment should be made of the potential benefits.</p>
<p><b>Recommendation 21.</b> <i>The Department of Health should commission organisations, such as Communication Matters<sup>52</sup> and HFT<sup>53</sup>, 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.</i></p>	
<p><b>Further education</b></p>	
<p><b>Recommendation 22.</b> <i>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.</i></p>	<p>Further education needs to be included as part of Transition plans.</p>
<p><b>Recommendation 23.</b> <i>The government should ask the Young People’s Learning Agency and the Skills</i></p>	<p>As above</p>

<i>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.</i>	
<b>Recommendation 24.</b> <i>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.</i>	The Transition Programme Board need to be aware of this recommendation.
<b>Employment and day activity</b>	
<b>Recommendation 25.</b> <i>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.</i>	Dorset Day Services strategy is based on the development of local, community based services. However, some people may continue to need a building as a base - this is vital for some family carers to be able to continue their caring role.
<b>Recommendation 26.</b> <i>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.</i>	As above
<b>Short breaks</b>	
<b>Recommendation 27.</b> <i>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.</i>	DCC has reviewed short breaks provision. Additional places are being developed that will cater for people with complex needs in central and East Dorset.
<b>Training</b>	
<b>Recommendation 28.</b> <i>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.</i>	See recommendation 6.
<b>Clinical Procedures</b>	

<p><b>Recommendation 29.</b> <i>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.</i></p>	<p>Transition Programme Board.</p>
<p><b>Recommendation 30.</b> <i>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.</i></p>	<p>The development of health action plans requires that there is flexibility as to where clinical procedures are carried out. However training for support staff to carry out some clinical procedures is limited and may have the effect of preventing people from being able to attend day centres.</p>
<p><b>Recommendation 31.</b> <i>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.</i></p>	<p>As above</p>
<p><b>Funding</b></p>	
<p><b>Recommendation 32.</b> <i>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.</i></p>	<p>Joint Commissioning is in place and close partnership working will be enhanced by the review of CTLDs and the creation of an additional CTLD.</p>
<p><b>Recommendation 33.</b> <i>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.</i></p>	<p>See recommendation 1. Person Centred Planning training continues to be delivered to staff and is offered to independent providers. Personal Health Budgets are being piloted.</p>

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