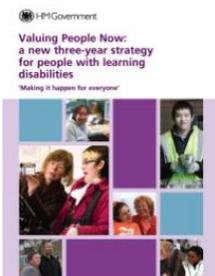




# Terms of Reference for the Profound Intellectual and Multiple Disability Sub Group



## What our group is for and how it works

The role of the board is to make sure that what 'Valuing People Now' says should be done to make things better, is happening locally for people with Profound Intellectual and Multiple Disabilities (PIMD).

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and multiple disabilities  
A report by Professor Jim Mansell

The definition of PIMD the group has chosen to use comes from the Mansell Report, (DoH, Mansell, March 2010, p4)

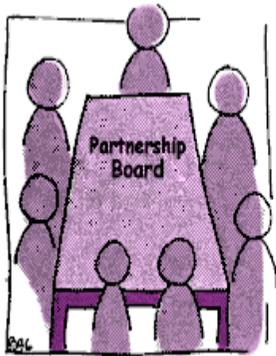


Adults with profound intellectual and multiple disabilities:

- have a profound learning disability and
- have more than one disability and

- have great difficulty communicating and
- need high levels of support with most aspects of daily life and may have additional sensory or physical disabilities, complex health needs or mental health difficulties and may have behaviours that challenge

### **Membership:**

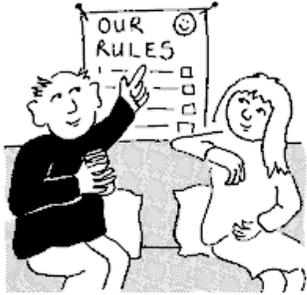


The PIMD Sub Group will be a forum for people with profound intellectual and multiple disabilities, their family and carers, professionals from health, social care, education and children's services and organisations including providers of services.

Group members from organisations will be expected to attend meetings or send a representative.

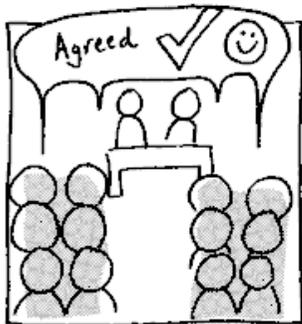
There will be no set quorum for meetings of the PIMD Sub Group so long as all parties have been appropriately notified in advance of the meeting.

Any decisions made by the PIMD Sub Group will usually be reached on the basis of a simple majority view. In the event of a 'split decision' the Chairperson will have a casting vote.



## The group will:

- hear the views of people with PIMD and represent them at all relevant forums in the community
- raise the profile of the people with PIMD
- aim to improve the life experiences of people with PIMD through its work and action
- find out how many people with PIMD live in Lancashire
- work with the Mansell Report's recommendations (see Appendix) to ensure that the lives of people with PIMD are improved
- challenge barriers to and fight for the rights, equal opportunities and social inclusion of people with PIMD
- promote good practice and knowledge which will develop the skills of paid and unpaid supporters, health workers, hospital staff and medical staff through training, awareness raising and information amongst these people and the general population and community.



## To achieve this the group will:

- feed into the partnership board and sub groups and other appropriate forums
- carry out appropriate questionnaires/audits
- have a theme for each meeting, for example, speech and language therapy, assistive technology, access, transport
- consult people with PIMD and their families or supporters to find out what is working and what is not working
- highlight gaps and barriers to improve support
- raise issues with the partnership board and commissioners
- champion the needs of people with PIMD to all task groups, networks, providers, family carers and the wider community to ensure quality support
- keep up to date with local, national and international information relating to PIMD

- ensure that the needs of people with PIMD are embedded and known about at the partnership board
- support other local and national forums that may enhance the life and wellbeing of people with PIMD



### **We will:**

- Meet six times a year
- Be accountable to the Partnership Board
- Be accountable to people with PIMD and their families through contacts generated by the PIMD sub group and the Partnership Board and make appropriate links regionally and nationally
- Write an action plan and update as appropriate (annually or bi-annually as required)
- Write a report on the action plan, as appropriate (see above), to be presented to the Partnership Board and appropriate forums within the partnership and community (for example the Physical Disability Partnership Board) and feed into the Annual Learning Disability Self-Assessment

- Make all reports, agendas and minutes as accessible as possible and post them on the Partnership Board website
- Have task groups which will meet as appropriate and which will be directed by the PIMD Sub Group
- Appoint a Chair who will oversee the group, manage the meetings, appoint minute takers at meetings, manage the distribution list, set the agenda for the PIMD Sub Group meetings, check and distribute minutes and make sure that the minutes are posted on the Partnership Board website, represent the group at external meetings and events or nominate another to attend and liaise with the Community Engagement Officer and other Sub Group Chairs or Leads on a regular basis
- Appoint at least one Co-Chair who will work with the Chair to administer meetings and assume the roles above if the Chair cannot attend to these duties
- Appoint a 'Champion' who will attend partnership board meetings with the specific remit of not allowing the board to forget people with PIMD when discussing issues, report to and from the partnership board meetings and raise issues at meetings

- Review the functions of the group and roles within the group every two years or as required
- Build and maintain links to the new Health & Wellbeing Board

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## APPENDIX



### Recommendations from 'Raising our sights: services for adults with profound intellectual and multiple disabilities' A report by Professor Jim Mansell, March 2010

#### 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.

#### 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.

## **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.

## **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.

## **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.

## **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.

## **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'.

## **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.

## **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.

## **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 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.

## **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.

## **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.

## **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.

## **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.

## **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.

## **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.