



PMLD Network Partnership Board survey 2004

The PMLD Network published a report 'Valuing people with Profound and Multiple Learning Disabilities' in 2000. This report said that the White Paper 'Valuing People' touches on issues relevant to people with profound and multiple learning disabilities, but does not fully address them. It states that for actions on behalf of people with profound and multiple learning disabilities to be effective the principles of vision, values, rights and representation need to be agreed on. The report also sets out key actions that need to be taken to ensure 'Valuing People' initiatives substantially benefit people with profound and multiple learning disabilities.

The PMLD Network carried out a survey to find out the impact their report had had on Partnership Boards. A questionnaire was sent out to all 153 Partnership Boards to look at:-

- if the key actions in the report were being taken forward by Partnership Boards.
- what help the Partnership Boards felt they needed to ensure they were inclusive of the needs of people with profound and multiple learning disabilities.

The survey asked questions around the actions being taken and asked for examples of their work and comments. 97 Partnership Boards replied.

The survey found that whilst just over half of the Partnership Boards who replied felt they were taking forward some or all of these actions the majority were interested in receiving help to be inclusive of the needs of people with profound and multiple learning disabilities.

Main findings

49 Partnership Boards felt they had taken some actions

- 35 were finding out how many people with people with profound and multiple learning disabilities lived in their area.
- 35 were taking action to identify people with profound and multiple learning disabilities and their families as a priority for services.
- 30 were monitoring how people with profound and multiple learning disabilities were having their needs met by services.
- 29 said they were including how they will help people with people with profound and multiple learning disabilities and their families in their learning disability plans.
- 16 had appointed a champion for people with profound and multiple learning disabilities .

87 Partnership Boards replied that they needed help.

- 81 were interested in ideas to include people with profound and multiple learning disabilities in the work of the Partnership Board.
- 66 requested more information on key issues for people with people with profound and multiple learning disabilities.
- 40 were interested in key skills training.

Results

To make sure that all plans for people with a learning disability say how they will help people with profound and multiple learning disabilities help their families.

29 Partnership Boards responded yes to this question.
Examples included :

- making statements in modernisation plans such as developing additional specialist services for people who have profound physical, sensory and learning disabilities.
- one Partnership Board said there was some new respite provision specifically for people with profound and multiple learning disabilities and that the learning disability service had funded development of changing facilities.

- people with people with profound and multiple learning disabilities having person centred plans, which include a detailed communication profile.

We have organised an 'all means all' workshop attended by over a hundred professionals, service users and carers and opened by the Mayor of Leeds. We have invested in multimedia equipment to support person-centred planning. We have developed a community nursing service, which supports people to live in their own tenancies. We have invested in advocacy and user involvement. - Leeds

To find out how many people with profound and multiple learning disabilities live in the area.

35 Partnership Boards responded yes to this question. Only a few were able to give examples.

- Learning Disability Teams maintaining a register.
- through care management

To monitor how people with profound and multiple learning disabilities are getting the services they need.

30 Partnership Boards responded yes.
Examples included:

- having a functional group which ensures that the individual needs of people with profound and multiple learning disabilities are responded to by the appropriate people and that care plans are developed to express those needs.
- advocates helping in day services modernisation to find out what people with profound and multiple learning disabilities want.
- a working group who visited other services for people with profound and multiple learning disabilities.
- staff having communication training.
- using a model of CPA to monitor and review the meeting of individual needs.
- Partnership Board regularly monitoring the progress of its strategies for all, including people with profound and multiple learning disabilities.
- personal planing book.

- exploring different methods of communication.
- a consultation exercise on needs and aspirations for people with profound and multiple learning disabilities.

We undertook a review of our day services part of this process involved identifying people with profound and multiple learning disabilities and where they lived to ensure services are planned as close to their living environment as possible to avoid long coach taxi transport etc. - Bournemouth LDPB

Housing needs survey highlighted issues for people with profound and multiple learning disabilities and future needs plus recommendations about people with profound and multiple learning disabilities living with their families. - Newham

To appoint a champion for people with profound and multiple learning disabilities for the Partnership Board.

16 Partnership Boards responded yes to this question.

We are identifying someone on each of the subgroups that take forward the Valuing People agenda for the Partnership Board to champion the needs of people with people with profound and multiple learning disabilities. -Southend-on-Sea

To identify children and adults with profound and multiple learning disabilities and their parents as a priority for services.

35 Partnership Boards responded yes to this question.

Examples included:

- identifying people with profound and multiple learning disabilities as requiring particular consideration in the development of day and respite services.
- Developing meaningful day activities for people with complex or profound needs that allow them to maximise their potential.
- priorities for a Partnership Board were to provide additional staff in day services to support people with multiple and profound needs.

- prioritising people with profound and multiple learning disabilities for care plans, and person centred plans.
- people with profound and multiple learning disabilities being a key area for change groups reporting to the Partnership Boards.
- people with profound and multiple learning disabilities have been identified as a priority in an agenda for change strategy.

Identified day services as a priority for integration, established a contract for involving people with profound and complex needs in planning services, identified this group of people as a priority for person-centred plans. - Kirklees

Action plans are being revised to include specific reference to people with profound and multiple learning disabilities. Special Needs Register has detailed information re people with profound and multiple learning disabilities. Children's Register and Children's Disability Teams have identified this group as a priority. - Dudley

What help do you think your Partnership Board needs to make sure that it is inclusive of the needs of children and adults with profound and multiple learning disabilities?

Examples of suggestions:

- Information about successful inclusive planning with people with profound and multiple learning disabilities
- Information on success stories in other areas - what has worked, illustration of people's mistakes etc.
- how to enable people to increase their social networks particularly where they remain in or are about to move from locally based hospital units.
- all funding links available. Any issues for other areas by introducing social care services just based on fair access to care criteria banding critical and substantial.
- ideas about effective strategies for community involvement.

We need to continue to develop our services to ensure that we improve how we support an increasing number of service users with profound and multiple disabilities in the future in a valuing and meaningful way and any training or support in this area is very welcome. - Windsor and Maidenhead Social Services

We have an Inclusive Communication worker but this does not go far enough to include people with profound and multiple learning disabilities in the Partnership Board's work. We would welcome suggestions from those who have achieved genuine inclusion in this area. - Southend On Sea

Conclusion

This survey aimed to find out the extent of actions being taken by Partnership Boards to include the needs of people with profound and multiple learning disabilities in their work. Whilst the results show that some Partnership Boards feel they are taking forward some of the actions in 'Valuing people with profound and multiple learning disabilities', many of those who responded positively did not include examples of how they were achieving the actions.

Many of the Partnership Boards who replied were receptive to the actions in 'Valuing people with profound and multiple learning disabilities', but admit they are struggling to achieve them. Most importantly the vast majority feel they need further support in this area.

This survey has shown not only a need for this support but also a clear interest from Partnership Boards in receiving this. If the actions within 'Valuing people with profound and multiple learning disabilities' are to become a reality and 'Valuing People' is to have a real impact on people with profound and multiple learning disabilities there needs to be a commitment to providing more information and training for Partnership Boards. Without this support, information and training a huge opportunity to meaningfully include people with profound and multiple learning disabilities and their needs, will be missed.