



Profound Intellectual and Multiple Disabilities Sub Group of the Lancashire Learning Disability Partnership Board

This group was established in 2011 on a North Lancashire footprint and involves family carers of people with profound intellectual and multiple disabilities (PIMD), social care providers, self-advocates who have a learning disability, health and education providers. It was established to ensure that the 'voice' of this minority group of potentially very vulnerable individuals have a say at the Partnership Board and within local social and health services. Some people use the term 'complex needs' or 'profound multiple learning disabilities'.

For the purposes of our work we use the international definition that people 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.

(taken from Raising our sights: services for adults with profound intellectual and multiple disabilities, a report by Professor Jim Mansell Report, 2010)

Total numbers of known adults identified as having as PIMD in North Lancashire

The group wanted to find out more about the needs of this population group. They sent out a questionnaire in 2012, at this point the number of adults over 18 who were known to the local authority social care services and were identified as having profound intellectual and multiple disabilities was 137. This number was split equally between Lancaster and Fylde and Wyre. We acknowledge that it is likely there are more people who have PIMD who are not known to the local authority and therefore the number might be higher. Emerson (2008), researching the numbers of people with PIMD, estimates they represent approximately 0.1 % of the population. Based on Emerson's work,

North Lancashire should have an approximate PIMD population of 322 people. Currently, we know about 137 individuals. Demonstrating the possibility that commissioners are aware of 42.5% of the PIMD population, less than half the estimated population. (See extract in appendices for more information about Emerson's work). It is acknowledged through the JSNA (Joint Strategic Needs Assessment) that this statistic will grow over the next decade.

The PIMD Group, at their recent meeting on 17 September 2015 summarized areas of concern from people with PIMD:

- Independent Living Fund and Benefits
- Accessible Health Services including having access at appointments in hospital and surgeries to wheelchairs, hoists and appropriate weighing machines.
- Community Facilities and activities
- Day services and day time activities
- Social Care Funding
- Mental health, social isolation and getting out and about are major concerns
- Carers and support to carers, including older carers who have no or very little support.
- Changing Places so that people have full access to their communities. We would like to see a Changing Place in every town in Lancashire.

The 2013 PIMD Report drawing conclusions from the questionnaires sent out in 2012 and the Mansell Report (2010) is split into ten sections and makes recommendations that:

Health

- All people with PIMD have a quality Annual Health Checks i.e. using the Cardiff model as defined by HM Government.

- All health professionals including reception staff are aware of what reasonable adjustments are and how they can support people to access good healthcare.
- Family carers are informed about Annual Health Checks, reasonable adjustments, Health Action Plans, Communication Passports, assistive technology, rights for carers and what training is available to them regarding these.
- Training should be available for any family carer or paid staff who wants to develop a communication passport.
- More people with PIMD have a Health Action Plan to ensure continuity of healthcare and improve communication between all parties to ensure quality health care for life.
- Training in how to communicate effectively with people with PIMD should be available for all; including, for example, paid staff, universal service and medical staff.
- Family carers and paid workers should be provided with information about what is available to meet health needs.
- Care pathways should be established to ensure the person's health needs are co-ordinated when they access services.
- All medical staff are given comprehensive training in the Mental Capacity Act with annual updates.
- All social care staff are given comprehensive training in the Mental Capacity Act with annual updates.
- Local experts in using the Mental Capacity Act and in making Best Interests decisions are able to offer support, expertise and advice to anyone with PIMD needing to support a decision under the Mental Capacity Act.
- The PIMD group remain in contact and engaged with NHS England regarding wheelchair services planning and reviews.
- Postural care guidelines are promoted within training for medical professionals, social care staff and other relevant individuals.
- Each individual with PIMD will have an officially recognised coordinator of care within the healthcare system, whether this is their GP, consultant or nurse. As recommended in the 'Confidential Inquiry' (2013), Recommendation 4 states:

A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions. (p108)

- The government establishes a system whereby every person with PIMD who has complex health care has access to a health care co-ordinator as essential, good person centred health practice across the UK. This coordinator would coordinate their assessment, healthcare and treatment and liaise between healthcare departments and professionals, taking a lead to follow up care coordination particularly if an individual needs screening or hospital treatment.
- The lifelong approach to health and education as laid out in the new Special Educational Needs and Disabilities green paper published in 2013 needs to be followed up with funding being available to allow the transition of equipment for school leavers, so that the equipment is bought for the individual and not the school.
- Families and supporters, as part of the transition from school, need to be educated in the importance of using the equipment and need to be trained to support the individual to continue to use it.
- Providers of services and family members need to have information and access to assistive technology and understand its relevance, alongside a funding stream which enables positive practice to be activated.

The recommendations in the Mansell Report regarding wheelchairs are excellent. The PIMD Group want to reiterate their support for more government support behind accomplishing these recommendations at a local and national level:

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

Recommendation 16 – People with PIMD who have used powered wheelchairs (eg 'smart' wheelchairs) at home or 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 PIMD should be provided with powered wheelchairs, suitably adapted with ‘smart technology’ where this sustains or enhances their quality of life.

- Health care staff to be trained in person centred approaches and communication with people with PIMD
- Health practitioners should be informed of good practice examples to aid their personal and educational development and PIMD training should be offered for all health care professionals, for example using protected learning time for all GPs and consultants via CCGs and health trusts
- The local NHS Health Trust should address the inequalities relating to access to specialist allied health professionals across the whole of Lancashire
- Family carers, paid staff and others to be informed about the non-instructed advocacy and advocacy services which can support individuals around health and social care needs through a variety of means and media
- The Partnership Board and health care partners take time to celebrate good practice and good news stories and share them with the wider allied healthcare professionals via trust newsletters etc and that appropriate channels of communication are set up to do this
- Family members understand the importance of Hospital Passports and Health Action Plans so that if they are not around essential information is not lost and the person can benefit from a comfortable and trouble free hospital stay or health care episode with all health staff being fully informed about the persons needs and requirements.
- Family members are encouraged and supported to complete Hospital Passports and Health Action Plans for their family member with PIMD
- All health staff are educated to understand the importance of reading and using the Hospital Passport and Health Action Plan, particularly for individuals with PIMD where communication is different.
- Nurses and GPs provide people with more advice at their Annual Health Check and consider appropriate screening, referrals and recommendations to improve the person's health, always completing the Health Action Plan for that individual
- Information is sent out to family carers to inform them about the Annual Health Check and Health Action Plan and what they are there for

- People carrying out health checks are aware of what 'reasonable adjustments' are, and to ask the supporters and family carers what they may need adjust to ensure each individual gets the most out of their health check and health service

Communication

- Training in communication methods and in developing communication passports need to be regularly available to all paid staff and families
- More information is available for family carers, professionals and social care providers about utilising assistive technology such as switches to help more people with PIMD develop and maintain communicative intention and control their home environment for example.
- Events for sharing good practice around communicating with people with PIMD are held on a regular basis to help paid staff and family carers share positive stories and to keep up to date with research into assistive technology.

Respite and Short Breaks

- Paid support workers communicate with family carers more around key essential information, for example, regarding health, meaningful daily activities, person-centred planning and finances.
- Services and social care teams are more person-centred, listen to family carers and provide accurate information about the support carers can receive including the carer's assessment. They need to ensure that the service they provide is person centred and gives a clear description of the service offer.
- Carers are kept informed and seen as 'experts by experience', that they are recognised as an invaluable part of the 'care team' and included in important decisions about the person's life.
- Family carers have the opportunity to learn about the Mental Capacity Act, capacity and best interests decision making.

Community

- The Lancashire Friends and Relationships group includes the voice and needs of people with PIMD in its action plan and aims to develop specific activities which this group will find meaningful, stimulating and engaging.
- The Lancashire Learning Disability Partnership Board co-opt the PIMD North Lancashire Group.

Within the **Raising our sights: services for adults with profound intellectual and multiple disabilities** a report by Professor Jim Mansell (2010) it talks about what are the elements of a good service:

- Good services are individualised & person centred

"When you work with an individual it has to be for that individual ... What you would do for him is different to somebody else ... (His needs are) individual to him, we do not want to know about someone else, we just learn about him & it just makes it so much easier."

Personal assistant interviewed during the research for the Mansell Report

- Good services treat the family as the expert
- Good services focus on quality of staff relationships with the disabled person
- Good services sustain the package of care
- Good services are cost effective

(pp 8-14)

Leisure & Other opportunities for involvement in the community

- The PIMD Group continue to campaign for new Changing Places to improve people's access to their community.
- There are more activities suitable for people with PIMD included in the Friends and Relationships Champions Newsletters.
- To offer disability awareness and PIMD training to bus companies for their staff and drivers.
- To work with education establishments to develop suitable opportunities for people with PIMD including employment opportunities.

Education

- Colleges offer reasonable adjustments by acknowledging that people with PIMD need continuity or may risk losing the skills they have obtained very quickly. It is recommended that colleges guarantee access for students who have regularly attended each term.
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- Educational establishments have a better and clearer enrolment and re-enrolment processes and communicate these clearly to the public to ensure continuity for progress each year to enable progression and appropriate learning.
- Educational establishments, family carers and paid staff who support people with PIMD work together to increase the number of classes available which meet the needs of individuals with PIMD across the whole of Lancashire.
- Colleges acknowledge the important role they play regarding social opportunities and well-being for both the individual and their family

carer. Carers have commented that they find accessing college important because they meet other carers.

- Colleges influence the funding decision makers to allow students with PIMD to continue their courses by communicating that for people with PIMD proving their progression will be different compared to other students. Students courses have ended because they were not able to show progression.
- Educational establishments to think about courses which aid in the transference of skills to the home environment.
- There is an acceptance within educational establishments and provision that people with PIMD can learn although this learning may be slower than other people with learning disabilities and harder to measure within the time scales that funding organisations, the government and further education establishments use to measure progress.

Transport

- The Motability scheme continues and adds greater flexibility to the ownership of cars so that house or flat mates can share the ownership and associated costs.
- All bus companies and drivers support the reasonable adjustment to people using wheelchairs on their buses and help them access the wheelchair space on buses if other passengers not using a wheelchair are using the space.
- All train and tram personnel and bus drivers are trained in disability awareness and PIMD awareness.

Housing

- Local councils and other relevant organisations provide a clear 'housing pathway' to be publically accessible to individuals and families supporting people with PIMD so that all the available suitable housing

can be considered, information is available about the process and support offered to negotiate the pathway.

- Local councils consult and engage with people with PIMD looking for housing to find out the requirements of this group. To provide specialist support to assist in the creation of relevant housing when no suitable stock is available, including advising regarding how funding can be obtained for adaptations, etc. For local councils to provide range of property that is fit for purpose to choose from.
- Families are supported to find funding for aids and adaptations to help people's lives to be easier and more comfortable.
- Consideration is given to how people with PIMD can have rights to tenancies when there are issues around capacity.
- Local housing associations and housing companies to do a housing needs assessment survey to project current and future housing needs of people with PIMD to be able to plan and build appropriate housing stock in areas of need.

Benefits and Money

- The Department for Work and Pensions improve their support to people with disabilities and their families by training their staff in disability awareness and disability benefits.
- Information about benefits is more accessible and in easy read and plain English.
- Benefits letters are to be available in easy read.
- The Local Authority makes it clear what has been put in place to support people formerly in receipt of Independent Living Fund monies.

Information and Advice

As recommended in the **Lambeth PMLD project: Understanding the lives and needs of people with profound and multiple learning disabilities in Lambeth, 2010** (p.52), it is important that Lancashire County Council makes sure their strategy around information and advice for family carers and support staff of people with PIMD includes information and advice about direct payments and individual budgets. This should include:

- awareness about what direct payments and individual budgets are
- making sure people understand the benefits of direct payments and individual budgets
- ensuring family carers can get assistance to manage, and are aware of the support available to them
- exploring which agencies are best to deliver information and advice on direct payments and individual budgets – this may be, for example, the council itself or the voluntary sector understanding how the knowledge of family carers can be utilised and shared, including treating family carers as experts by experience.